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# *Medical Treatment (Prevention of Euthanasia) Bill*

**Bill 12 of 1999-2000**

Ann Winterton MP, who drew the first place in the ballot for Private Members' Bills, has brought forward a Bill which aims to prevent doctors from withholding or withdrawing treatment where the purpose of so doing is to hasten the death of a person who is not fatally ill. This paper discusses the background to Mrs. Winterton's Bill, the current legal position and some of the ethical issues involved.

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## Summary of main points

- Ann Winterton MP, who came first in the ballot for Private Members' Bills, has brought forward a Bill which would prohibit the withdrawal or withholding of medical treatment, or sustenance, if the main purpose of so doing was to cause death. The Bill will cover England, Wales and Northern Ireland.
- Euthanasia (defined by the Government as “a deliberate intervention with the express aim of ending life”) is unlawful throughout the UK. However, it may be lawful, in certain cases, to withhold or withdraw life-prolonging treatment from patients, with the result that their death is hastened.
- In 1993, as a result of the case of Tony Bland who was crushed at Hillsborough and was diagnosed as being in “permanent vegetative state”, the House of Lords considered the issue of whether it would be lawful to withdraw artificial nutrition and hydration, in the knowledge that this would lead to Bland's death. The House of Lords decided that in this case withdrawal of artificial nutrition and hydration would be lawful on the basis that it was not in Bland's interests for treatment to be continued. The Bland case was distinguished by the Law Lords from cases of euthanasia on the grounds that withdrawing or withholding life-prolonging treatment was an “omission” not an act. A doctor's omission could only be culpable in English law if they had a *duty* to act, and the House of Lords decided that no duty to continue treatment existed in this case. Mrs. Winterton has described this distinction between an “act” leading to death and an “omission”, also leading to death, as a “loop-hole” which her Bill aims to close.
- One of the main features of the *Bland* case was Tony Bland's complete lack of awareness of himself, or his environment. Other, less well-known, cases (such as *Re B* in 1981, *Re J* in 1990 and *Re R* in 1996) have considered whether it can ever be lawful to withdraw life-prolonging treatment from patients with some level of awareness. These cases have established that there are circumstances when doctors may lawfully cease to offer life-prolonging treatment, on the basis that the quality of life made possible by the treatment is intolerable to the individual patient. The British Medical Association has since published guidelines which reflect their understanding of the current case law.
- Mrs. Winterton states that her Bill does not aim to force doctors to continue life-prolonging treatment where patients are dying or in cases where the treatment would have no effect or would be “burdensome” to the patient. However, it would seek to prevent doctors or others from taking quality of life issues into account when deciding whether further treatment should be withheld.

## CONTENTS

<b>I</b>	<b>Introduction</b>	<b>7</b>
<b>II</b>	<b>Background</b>	<b>7</b>
	<b>A. The case law</b>	<b>11</b>
	<b>B. The BMA guidance</b>	<b>16</b>
	<b>C. Forthcoming legislative changes</b>	<b>18</b>
	<b>D. Ethical issues</b>	<b>22</b>
<b>III</b>	<b>The Bill</b>	<b>28</b>
<b>IV</b>	<b>Responses to the Bill</b>	<b>31</b>
<b>V</b>	<b>Appendix 1</b>	<b>34</b>
<b>VI</b>	<b>Appendix 2</b>	<b>36</b>

## I Introduction

Ann Winterton MP announced on 9 December 1999 that she would be using her first place in the Private Members' ballot to introduce a Bill "to prevent doctors intentionally bringing about the death of their patients". Her press notice went on to say that this move "comes against a background of media reports that elderly and disabled patients are dying in NHS hospitals as a result of inadequate provision of nursing and medical care".<sup>1</sup> Mrs. Winterton also specifically criticised recent guidance issued by the British Medical Association (the doctors' professional association), stating that:

Many people, particularly the disabled and the elderly, are increasingly fearful of entering hospital because the BMA, without legal authority, has issued guidelines to doctors allowing the withdrawal of medical treatment and of tubal feeding from patients who are not dying.<sup>2</sup>

This Paper will first look at the background to Mrs. Winterton's Bill, in particular the press allegations of inadequate medical and nursing care in the NHS to which she refers, the current legal position as regards taking action which is known to be likely to end in death, the BMA guidelines in this area, and some of the ethical issues surrounding the debate. It will then describe the actual provisions of the Bill, which is due to have its Second Reading on Friday 28 January, and summarise the responses to the Bill which have been received from interested organisations.

## II Background

Two main events appear to have triggered Mrs. Winterton's Bill. The first was the publication, in June 1999, of guidance by the British Medical Association on withholding and withdrawing life-prolonging medical treatment.<sup>3</sup> The second was a series of press reports in early December 1999 alleging that older patients were being literally starved to death in NHS hospitals.<sup>4</sup> Although the press reports tended to link together the BMA guidelines with the events reported, three distinct sets of allegations emerged and it may be helpful to consider them separately as they introduce separate legal and ethical issues.

Firstly, some of the case-histories cited in the press focus on poor nursing care, including dirty geriatric wards, insufficient staffing levels (leading, for example, to incontinent patients being left in wet beds or patients developing bedsores because they had not been turned often enough) and lack of basic provisions such as pillows or blankets.<sup>5</sup> In cases such as these,

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<sup>1</sup> "Prevention of Euthanasia Bill introduced", press notice from Ann Winterton MP's office, 9 December 1999

<sup>2</sup> *ibid*

<sup>3</sup> BMA, *Withholding and withdrawing life-prolonging medical treatment*, June 1999

<sup>4</sup> for example, "Elderly patients 'left starving to death in NHS'", *The Daily Telegraph*, 6 December 1999, p 1, "Charity wants inquiry into 'starving of elderly'", *The Independent*, 7 December 1999, p 11 & "Doctors call for deaths inquiry", *The Times*, 7 December 1999, p 8

<sup>5</sup> for example "People are just being written off by system", *The Daily Telegraph*, 6 December 1999, p 11

patients may end up receiving too little food, not out of any specific decision to cease feeding them, but because they are not receiving the help they need to eat and drink: meals may simply be left by the side of the bed and then removed later untouched. The reasons for such conditions may be many and varied: insufficient priority given locally to the needs of older people in hospital, and hence inadequate staffing levels and equipment; lack of training and awareness of the needs of older people, for example with eating; or incompetent or uncaring individual members of staff. While in some cases poor treatment of this kind may be the result of an attitude that “older people don’t matter”, the problem would appear to be primarily one of unacceptably low standards, not of an actual policy to hasten death.

The Government responded to similar allegations by the *Observer* newspaper in 1997<sup>6</sup> by asking the NHS Health Advisory Service (now known as HAS 2000) to investigate standards of care for older people in hospital. The subsequent report, *Not because they are old* concluded that there was clear evidence of staff shortages and consequent pressure on staff, poor physical conditions in wards, specific “skills deficits” in areas such as feeding and dealing with continence problems, and difficulties preserving dignity, both because of the physical environment and, sometimes, because of staff attitudes.<sup>7</sup> HAS 2000’s recommendations relating to these issues were endorsed by the then Health Secretary, Frank Dobson, who ordered that the report be sent to all NHS trust chief executives.<sup>8</sup> Mr. Dobson also promised that a “National Service Framework” for older people would be developed, setting out what standards older people were entitled to expect from the NHS and how care should be delivered. The Framework is due to be published in April 2000.<sup>9</sup>

The second strand of the allegations appears to be the practice of involuntary euthanasia: cases where treatment *could* be available, and there is no reason to believe the patient would refuse it, but where that treatment is not offered because the intention is that the patient should die. In cases such as these (assuming they have been reported accurately), it is not being argued that any treatment would be “futile”; treatment is just being withheld without discussion. (For a discussion of “futility” and arguments as to whether it is ever legitimate to describe treatment as “futile” see below, page 26.) The *Daily Telegraph*, for example, reported a case where a patient suffering from dehydration and under-nourishment was admitted specifically for re-hydration and re-nourishment, but received nothing to eat or drink for two weeks.<sup>10</sup> In another case, reported in the same article, an alert 84 year old woman going into hospital with an arthritic knee died 4 weeks later after allegedly being given drugs at three times the maximum dose and without treatment being provided at any time for her knee. Euthanasia, defined by the Government as “a deliberate intervention with the express aim of ending life”,<sup>11</sup> is unlawful, and police enquiries are reportedly taking place

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<sup>6</sup> eg “Join our campaign for the old”, *The Observer*, 5 October 1997, p 3

<sup>7</sup> Health Advisory Service, *Not because they are old*, 1998

<sup>8</sup> Dept of Health press notice 1998/476, 2 November 1998

<sup>9</sup> *ibid*

<sup>10</sup> “Prescribed nil by mouth unto death”, *The Daily Telegraph*, 6 December 1999, p 10

<sup>11</sup> *Who decides? Making decisions on behalf of mentally incapacitated people*, Cm 3803, December 1997, para 1.8

into some of the cases highlighted in the press. There may often, however, be problems in obtaining adequate evidence; according to the *Telegraph* article, the police investigated the case of the lady with the arthritic knee and sent a file to the Crown Prosecution Service, but there was deemed to be insufficient evidence to prosecute.

The third strand, and the most complicated both legally and emotionally, is the issue of when doctors may lawfully cease treating a patient who is not actually dying, but where treatment is believed to be “futile”. It is this issue that the BMA guidelines, referred to above, sought to address. The types of cases that might come into this category are cases where patients are in “permanent vegetative state” (ie their upper brain, and hence any capacity for consciousness, has been permanently destroyed) or where a patient has such severe disabilities that it is believed that their suffering outweighs the benefits of prolonging life. It has been argued that these cases, too, constitute “euthanasia”, just as much as those described in the preceding paragraph.<sup>12</sup> However, as the courts have made a clear distinction between the current legal understanding of euthanasia and the cases covered by the BMA guidelines, it will be helpful to keep them distinct for the purposes of this Paper. It should also be emphasised that, to be lawful, any decision to withdraw treatment from a patient in this type of condition must be made on the basis of beliefs about the *patient’s* interests. It could never be lawful, as case law stands at present, to make such a decision on the basis that the relatives have had enough, or that NHS resources would be better spent elsewhere.

Where the patient is competent to express their views (for example in cases of serious degenerative diseases where the patient decides relatively early on that they do not wish to undergo treatment), legally the situation should be comparatively straightforward: patients may accept or reject any treatment offered as they think fit. Forcing treatment on such a patient against their will could constitute the civil and criminal offence of battery. Failing to offer appropriate treatment where it has not been refused, on the other hand, could potentially constitute medical negligence. It should be emphasised, though, that patients cannot force doctors to give them treatment against their clinical judgement; where such cases have gone to court (for example in cases of very severely ill babies where their parents wish treatment to continue against medical advice) courts have traditionally been highly unwilling to direct doctors to act against their clinical judgement.<sup>13</sup> Since the Court of Appeal judgement in *Re T* in 1992, it has also been held that competent adults may refuse particular treatment in advance of loss of competence; the advance refusal would have the same power as a contemporaneous one.<sup>14</sup> A number of Law Lords approved *Re T* in the *Bland* case, but it should be noted that the comments in *Bland* were strictly *obiter*,<sup>15</sup> and that it would therefore be possible for a future House of Lords to come to a different view.<sup>16</sup> A longer summary of the current legal position on so-called “advance statements” is given below, at page 21.

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<sup>12</sup> this is implied, for example, by the Bill’s sponsors, both in the title of the Bill and in the press conference on the Bill’s publication on 18 January 2000

<sup>13</sup> *Re C (a minor) (medical treatment)* (1998) 1 FLR 384

<sup>14</sup> *Re T (adult) (refusal of medical treatment)* [1992] 4 All ER 649

<sup>15</sup> ie not essential for deciding this particular case

<sup>16</sup> *Airedale NHS Trust v Bland* [1993] 1 All ER 821 (HL)

Where a patient is not competent to make or communicate a decision, but is in the process of dying, there is a general acceptance that it may not always be appropriate to take all possible measures to prolong their life (especially if the measures would add to the patient's pain or distress). In cases such as these, the doctrine of "double-effect" (where doctors are permitted to administer powerful drugs to control pain, even if this will have the effect of shortening life) is relatively uncontroversial; many people regard it as ethically acceptable to use high dosage drugs if the primary aim is to control pain at the end of life, even if the known side-effect of these drugs would be slightly to reduce life expectancy. Whilst this doctrine of double-effect may be seen by some philosophers (particularly utilitarians who judge the morality of actions by outcome alone) as hypocritical, there have been few voices calling for pain relief to be restricted in dying patients.<sup>17</sup> Mrs. Winterton has made very clear that it is certainly not her intention to attempt to change the current legal acceptance of the doctrine of double effect.<sup>18</sup>

Where the patient is *not* competent to decide on their own treatment and is *not* dying, but their level of consciousness or interaction with the world is very low or negligible, however, there is no general consensus on what the medical profession should do and it is cases such as these that Mrs. Winterton's Bill seeks to cover. To some, it would be axiomatic that treatment should never be withdrawn if it is prolonging life, whatever the quality of that life or the level of consciousness of the individual. Others would argue that there *are* circumstances in which life should not be preserved: for example where the patient has no chance of ever regaining consciousness, where the individual is conscious but it is believed that the pain they are suffering is extreme and untreatable, or where their quality of life is so low that it is believed that *they* would choose not to continue living, were they able to express their opinion.

A point between these two positions would be the belief that it could be right to withdraw treatment if it is actually resulting in suffering, but that it can never be right to attempt to make judgements about another person's quality of life, or to decide that an unconscious person (who by definition cannot be suffering) should cease to receive treatment. Yet another approach would be that it could be right to withdraw treatment if the patient has irreversible loss of consciousness (where it is not possible to speak of the person "experiencing" life), but not in any other case. In her press conference on 18 January 2000, Mrs. Winterton stated that she was not a "vitalist" (some-one who believes that medicine should be used to prolong life whatever the circumstances), but made clear that she did not believe that doctors were ethically entitled to take quality of life issues into account when deciding to withdraw or withhold treatment.

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<sup>17</sup> Where the doctrine is criticised, the argument tends to be that voluntary euthanasia should *also* be lawful: that is, if it is lawful to give drugs which will shorten life as long as the primary aim is to relieve pain, why should it not be possible simply to give drugs which end life if that is what the patient wishes.

<sup>18</sup> Notes from Mrs Winterton's press conference, 18 January 2000



The remaining sections of this Paper consider the current legal position in this area, the BMA guidelines, and some of the possible ethical approaches before looking at the provisions of the Bill.

## A. The case law

Nothing in English statute law currently makes provision for cases where an incompetent patient could continue to live indefinitely through regular medical intervention, but where this is believed not to be in their interests, or is against their previously-expressed wishes. Indeed, as the law stands at present in England and Wales, there is no statutory provision for another person to make *any* medical decisions on behalf of an incompetent adult. “Consent” to particular treatment given by, for example, a parent or spouse of an incapacitated adult, is legally meaningless; yet any medical treatment which involves touching the patient is potentially a battery unless a valid consent is obtained. Since the landmark case of *Re F* in 1989, case law has established that in such cases doctors may lawfully act in what they believe to be the “best interests” of the incompetent patient.<sup>19</sup>

The question of what *is* in a particular patient’s best interests may not always be clear: for example the health professionals looking after a patient and the patient’s family may not be in agreement, or there may be a dispute within the family. Ultimately any decisions could be challenged in the courts. It is also possible to seek prior court approval, for example in cases involving actions which are likely to be subject to particular controversy such as the sterilisation of a mentally incompetent woman (the subject of the case *Re F*), or, as in the *Bland* case, discussed below, the withdrawal of artificial feeding from a patient in permanent vegetative state. However, even the courts cannot decide between competing possibilities for an individual’s treatment; they can only state that a particular proposed course of action is, or is not, lawful in that it does, or does not, constitute the individual’s “best interests”. Moreover, interpreting *Re F* strictly, it is not the court’s role to come to an independent conclusion as to what constitutes a patient’s best interests, but simply to ensure that the doctor’s interpretation of best interests would be backed up by a “responsible body of medical opinion”.<sup>20</sup> In practice, however, courts do appear to come to their own conclusions as to what would constitute a particular patient’s best interests, as witnessed, for example, by the lengthy consideration of this issue in *Bland*.

“Best interests” itself has been left largely undefined in case-law: such descriptions as have been offered have tended to be very wide, such as anything necessary for the “life, health or well-being” of the individual, or treatment which will “save their lives or [...] ensure improvement or prevent deterioration in their physical or mental health”.<sup>21</sup> Slightly more guidance in determining best interests was offered by the Court of Appeal in a 1990 case *Re*

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<sup>19</sup> *Re F (a mental patient: sterilisation)* [1989] 2 All ER 545 (HL)

<sup>20</sup> the so-called *Bolam* test, originally developed to judge whether or not a doctor had been negligent

<sup>21</sup> *Re F (mental patient: sterilisation)* [1990] 2 AC 1, (1989) 4 BMLR 1, per Lord Goff and Lord Brandon respectively

*J*,<sup>22</sup> although it was geared more towards decision-making on behalf of babies with an emphasis on what a “responsible parent” would do. However, other aspects of the definition could potentially be applicable to incompetent patients other than babies: the Court of Appeal stated in particular that there should be no absolute criteria, such as “life should always be prolonged”, and that one way of considering best interests was to determine “whether the child in question, if capable of exercising sound judgement, would consider this life tolerable”.

While the case of *Re F* was primarily concerned with the issue of obtaining consent to treatment, a number of cases since have looked at the opposite side of the coin: whether there were circumstances in which treatment could lawfully be withdrawn. Two sets of cases emerge: the first dealing with cases of patients in permanent vegetative state (where the patient is permanently unconscious) and the second dealing with patients with severe physical and mental disabilities which may allow them very limited interaction with others or awareness of self.

The landmark case for patients in permanent vegetative state is that of Tony Bland in 1993.<sup>23</sup> As a result of being crushed at Hillsborough, the 17 year old Bland suffered catastrophic damage to his brain and was diagnosed as being in “permanent vegetative state” or pvs. A definition of “vegetative state” prepared by a working party set up by the Royal College of Physicians in the aftermath of a report of a House of Lords Select Committee on Medical Ethics is as follows:

A clinical condition of unawareness of self and environment in which the patient breathes spontaneously, has a stable circulation and show cycles of eye closure and eye opening which may simulate sleep and waking. This may be a transient stage in the recovery from coma or it may persist until death.<sup>24</sup>

Vegetative state is defined as “continuing” when it continues for more than four weeks, but should not be regarded as “permanent” until at least 12 months following head injury or six months following other forms of brain damage. A diagnosis of pvs is therefore a diagnosis that the patient has irreversibly lost the ability to be aware of, or relate to, their environment. The working party states that the diagnosis “is not absolute but based on probabilities”; nevertheless it believes that “the diagnosis of irreversibility can be established with a high degree of clinical certainty”.<sup>25</sup>

Despite loss of consciousness, the patient in pvs is still able to breathe and digest without help. Artificial assistance, however, is needed for nutrition and hydration: the patient must be

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<sup>22</sup> *Re J (a minor) (wardship: medical treatment)* [1990] 3 All ER 930

<sup>23</sup> *Airedale NHS Trust v Bland* [1993] 1 All ER 821 (HL), [1993] 2 WLR 316

<sup>24</sup> “The permanent vegetative state”, *Journal of the Royal College of Physicians of London*, 30(2), March/April 1996. The terms “permanent” and “persistent” vegetative state tended formerly to be used interchangeably, but the working party recommended that in future “permanent” should be used to avoid confusion.

<sup>25</sup> *ibid*

fed and hydrated through a tube and needs medical assistance (through enemas and catheters) to evacuate bowels and bladder. After Tony Bland had been for several years in pvs, the Bland family and his doctors sought court permission for this artificial nutrition and hydration to be stopped, with the result that Bland would die.

There were two reasons why the Bland case came to court. The first was because, as discussed above, no-one could consent on his behalf, either to the continuation of his treatment or its withdrawal. While his doctors must have been aware, since *Re F*, that they could lawfully treat him if they believed it to be in his best interests, it was less clear what their position would be as regards the withdrawal of treatment. Although cases such as *Re J*, referred to above, had made clear the legal view that life should not automatically always be prolonged, the withdrawal of artificial nutrition and hydration (as opposed to other forms of life-sustaining care such as mechanical ventilation) was seen as a special case. The second reason was to clarify the potential role of the *criminal* law in such cases: since the doctors knew that withdrawal of artificial nutrition and hydration would automatically lead to death, the question had to be settled whether it could possibly constitute murder.

The House of Lords decided that artificial feeding and hydration *could* lawfully be withdrawn from Tony Bland. On the issue of murder, it was crucially decided that the withdrawal of feeding constituted an *omission* not an act. Were the decision to have been regarded as an “act”, it could have been argued that a charge of murder could be made out, on the grounds that both the legal “mens rea” (the intention to kill) and the “actus reus” (the action of killing) necessary for murder would have been present. However, this interpretation alone was not sufficient to remove the possibility of a murder charge, as even an omission to act may be legally culpable if the person omitting to act has a *duty* to act. While in English law a passer-by who fails to save a drowning child will not be criminally liable as they have no legal duty to save the child’s life, a parent who wilfully failed to feed their child *could* be criminally liable on the grounds that their role as a parent imposed this legal duty on them. The House of Lords therefore had to establish whether the doctors had a duty to carry on giving artificial nutrition and hydration to Tony Bland. While all five Law Lords were in agreement that the doctors in this case did not have such a duty, their reasoning was rather different.

The majority in the House of Lords decided that in cases as extreme as Tony Bland’s it could be argued that it was *not* in the patient’s best interests to carry on living: that biological life alone, with no consciousness, was not necessarily of benefit to the patient. Thus doctors not only might have no duty to continue providing medical treatment; it could even be argued that they had a duty to *stop* providing it, since their only justification for treating a patient incapable of consenting was on the grounds that the treatment was believed to be in the patient’s best interests. Their Lordships also agreed that artificial nutrition and hydration should be regarded as “medical treatment” like any other aspect of medical practice, despite arguments from the Official Solicitor that they should be regarded as a basic right which no-one could be denied.<sup>26</sup>

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<sup>26</sup> Appendix 1 to this Paper describes the medical issues involved in providing artificial nutrition and hydration

This line of argument from the majority could potentially be applied to patients *other* than those in pvs: for example those with some level of consciousness, but at such a minimal level that any kind of meaningful interaction is impossible. Lord Mustill, on the other hand, argued that when it is a question of life and death, any kind of “balancing exercise” as to whether life is a benefit or not is inappropriate: he only agreed that the doctors in Bland’s case had no duty to provide further treatment on the grounds that Tony Bland had “no interests of any kind”. It seems likely, then, that Lord Mustill might not agree that it would be lawful to cease artificial feeding and hydrating of a patient who was very severely incapacitated but not completely devoid of consciousness.

Since *Bland*, there have been a number of other similar cases taken to the High Court. In those cases which have been reported, the judge has appeared to focus primarily on establishing whether there is a medical consensus as to the diagnosis of pvs. Where this has been established, the court has then declared the proposed cessation of treatment lawful.<sup>27</sup>

In *Bland* (particularly as far as Lord Mustill was concerned), the emphasis was very much on Tony Bland’s complete lack of ability ever to feel or experience anything again. The issue was therefore not so much about the *quality* of his life as about whether purely biological life without consciousness should be prolonged or not. Another series of cases, however, where the patients involved have had some degree of awareness, have been forced to address the quality of life issue. A case in 1981, *Re B*,<sup>28</sup> established that it was not legally acceptable to deny a Down’s Syndrome child an operation for an intestinal blockage on the basis that it was better for the child to die. Templeman LJ in the Court of Appeal stated that:

There may be cases, I know not, of severe proved damage where the future is so certain and where the life of the child is so bound to be full of pain and suffering that the court might be driven to a different conclusion, but in the present case the choice which lies before this court is this: whether to allow an operation to take place which may result in the child living for 20 to 30 years as a mongoloid or whether (and I think this must be brutally the result) to terminate the life of a mongoloid child because she also has an intestinal complaint. Faced with that choice, I have no doubt that it is the duty of this court to decide that the child must live.

Thus, Templeman LJ left it open for future courts to decide that a life *could* be so “full of pain and suffering” that further treatment would not be appropriate, while putting down a clear marker that a condition such as Down’s Syndrome should certainly not come into this category. This approach was developed, nearly a decade later, in *Re J*,<sup>29</sup> a case of a very severely disabled baby who was apparently likely to feel pain normally but who would never sit up, speak, hear or possibly see. The Court of Appeal was asked to decide whether, if baby

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<sup>27</sup> for example *Swindon and Marlborough NHS Trust v S* (1995) 3 Med LR 84 & *Re G (persistent vegetative state)* [1995] 2 FLR 46

<sup>28</sup> *Re B (a minor) (wardship: medical treatment)* [1983] 1 WLR 1421 (CA)

<sup>29</sup> *Re J (a minor) (wardship: medical treatment)* [1990] 3 All ER 930

J ceased to breathe in the future, he should be artificially ventilated. In coming to the decision that re-ventilation would not be appropriate, the Court set out the following principles:

- determining best interests should be a “balancing exercise”
- there should be a strong *presumption* in favour of preserving life, but this should not be an absolute principle
- the test should be whether continued life would be intolerable *to that child*

Since *Re J*, it has therefore been clear that, in law, there are circumstances when the quality of life of an individual patient would be such that medical intervention to prolong that life would not be appropriate. However, it should be noted that the Court of Appeal in that case expressed concern about the dangers of judging the quality of another person’s life from the outside and emphasised the importance of looking at it from the *patient’s*, not an outsider’s, perspective. In practice, this may be somewhat easier to do in cases where previously competent patients have made their views known before they lost competence (or at least given some indication as to the values by which they live their lives) than in cases of babies and small children. In such cases, it may be impossible to judge whether issues such as low levels of awareness and interaction with the world are “intolerable” to the individual or not. It therefore seems likely that evidence as to the levels of *physical* pain likely to be suffered by the patient may be the factor which determines a court’s judgement.

A more recent case, *Re R*,<sup>30</sup> which was heard in 1996, forced the courts to look further at this issue. R was a very severely disabled adult, described by one of the doctors advising the Official Solicitor as having the awareness of a new-born child. His physical problems included recurrent chest infections, severe constipation, bleeding from ulceration of the oesophagus, epileptic fits, dehydration and under-nutrition. After a series of five hospital admissions in one year, the consultant responsible for his care felt that continued emergency interventions would be unethical:

To hospitalise R if he had another life-threatening crisis would, in my clinical judgement, be nothing more than striving officiously to keep him alive for no gain to him. In my opinion, this is tantamount to a failing against a basic duty of humanity. Indeed, at the last few admissions to hospital, I have had real concern as to whether it was ethical to treat him actively.<sup>31</sup>

After consultation with R’s parents, it was agreed that a “do not resuscitate” order (DNR) would be placed on his notes. This would mean that, should R suffer in future from a cardiac or respiratory arrest, “cardiopulmonary resuscitation” or CPR would not be performed. This DNR was challenged by day care staff involved in R’s care, who originally understood the order to be a more general “do not treat” order. The judge agreed that the DNR was

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<sup>30</sup> *Re R (adult: medical treatment)* [1996] 2 FLR 99

<sup>31</sup> *ibid*, at 101

appropriate, on the basis of the unanimous clinical opinion that it was highly unlikely to be successful in R's frail state. He also endorsed guidance on DNRs, produced by the British Medical Association and Royal College of Nursing, which permitted DNR orders where at least one of three criteria was met: that CPR was unlikely to be successful; that the patient, when in a mentally competent state, had made clear that they did not wish for CPR; or that CPR would only result in a quality of life unacceptable to the patient.

## **B. The BMA guidance**

The BMA guidance, *Withholding and withdrawing life-prolonging medical treatment*, was published in June 1999 after a consultation exercise among the medical profession highlighted "anxiety and uncertainty about the scope of the law and a strong desire for practical guidance which will help doctors and their colleagues take decisions which are clinically appropriate, ethically sound and legally robust".<sup>32</sup> While the guidance aims to cover all situations where the withdrawal of treatment may be considered, including the cases of competent patients, the sections which are perhaps the most relevant here are those covering the withdrawal of treatment in general from incompetent adults and children, and the particular issue of the withdrawal of artificial hydration and nutrition.

The guidance begins with some general definitions. The BMA defines the primary role of medical treatment as being:

to benefit the patient by restoring or maintaining the patient's health as far as possible, maximising benefit and minimising harm. If treatment fails, or ceases, to give a net benefit to the patient (or if the patient has competently refused the treatment) that goal cannot be realised and the justification for providing the treatment is removed. Unless some other justification can be demonstrated, treatment that does not provide net benefit to the patient may, ethically and legally, be withheld or withdrawn and the goal of medicine should shift to the palliation of symptoms.<sup>33</sup>

"Benefit" is defined as having

its ordinary meaning of an advantage or net gain for the patient but is broader than simply whether the treatment achieves a particular physiological goal. It includes both medical and other, less tangible, benefits.<sup>34</sup>

On the issue of whether life alone should always constitute a benefit, the BMA states:

Prolonging a patient's life usually, but not always, provides a health benefit to that patient. It is not an appropriate goal of medicine to prolong life at all costs, with no regard to its quality or the burdens of treatment.<sup>35</sup>

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<sup>32</sup> BMA press notice 23 June 1999

<sup>33</sup> BMA, *Withholding and withdrawing life-prolonging medical treatment*, 1998, p 1

<sup>34</sup> *ibid*, p 5

The BMA therefore clearly expresses the view that in certain circumstances, although medical treatment may be *available* which would prolong life, it would not be appropriate to offer it. This general principle is in line with the case-law cited earlier, although it is obviously impossible to state whether in any particular case a court would find that continuing life would be “so intolerable”<sup>36</sup> to the patient that the life-prolonging treatment should not be provided.

The guidance goes on to suggest how its principles should be expressed in practice, including the following:

- any decision to withdraw life-prolonging treatment should be based on the best available clinical evidence, and doctors therefore have an obligation to keep their skills and knowledge up to date;
- where there are locally or nationally agreed guidelines, these should be consulted;
- where the patient’s condition results from a sudden or unexpected medical event and the diagnosis is uncertain, initial efforts should be focused on stabilising the patient so that a proper assessment can be made;
- where there is reasonable doubt about a patient’s ability to benefit from a treatment, it should be provided for a trial period so that its effectiveness may be properly judged;
- before any decision to withdraw treatment is taken, time should be taken to make a thorough assessment of the patient’s condition by a multi-disciplinary team;
- treatment should never be withheld on the grounds that it is easier to withhold treatment than to offer it and later withdraw it;
- all treatment decisions should be regularly reviewed;
- both legally and ethically, all treatment decisions must promote the patient’s “best interests”. The type of factors which would determine the patient’s best interests would include: the patient’s own wishes and values, where known; clinical judgement as to the effectiveness of proposed treatment; the likelihood of the patient suffering unmanageable pain; the level of awareness the patient has of their existence as evidenced, for example, by ability to interact with others (however expressed) or their capacity for self-directed action; the likelihood of any improvement in their condition; whether the invasiveness of the treatment is justified in the circumstances; the views of the parents if the patient is a child; and the views of those close to the patient as to what the *patient* would see as beneficial.

On the particular issue of the cessation of artificial nutrition and hydration, the guidance restates the view of the House of Lords in *Bland* that artificial nutrition and hydration constitutes “medical treatment”. It can therefore be withheld from patients in certain circumstances, in the same way as other forms of medical treatment deemed not to “benefit” the patient may be withheld, without the courts necessarily regarding the patient as having been “starved to death” by the doctors involved. The BMA welcomes the categorisation of artificial nutrition and hydration as medical treatment, but states that it recognises that many

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<sup>35</sup> *ibid*, p 2

<sup>36</sup> the term used in *Re J*, see above, note 26

people *do* see a big difference between medical treatment and nutrition, regardless of how "medicalised" the process of feeding the patient may be, and that therefore further safeguards are necessary.

Where death is imminent, and continuing to feed the patient artificially (eg through a syringe in the throat or through a tube) may be unnecessarily intrusive and prolong the dying process, then such feeding may be withdrawn, although "basic care" (including the offer of *oral* nutrition/hydration and any procedures such as pain relief needed to keep the patient comfortable) should be provided. Where death is *not* imminent, any proposal to withdraw artificial nutrition and hydration should be subject to formal clinical review by a senior clinician who has experience of the condition from which the patient is suffering and who is not part of the team currently treating that patient. Details of all cases where such a decision is made should be available for clinical review so that it can later be confirmed that proper procedures were followed, and anonymised information should also be available to the Secretary of State for Health and the Commission for Health Improvement, so that it is possible to achieve an overview of such decisions.

In a recent Question in the House of Lords, the Health Minister Lord Hunt of Kings Heath described the guidelines as "a thoughtful and useful contribution"<sup>37</sup> When questioned specifically on the issue of elderly patients in hospital being asked whether they wished to be resuscitated, should they have a heart attack during their stay, he went on to say:

Delicate issues surround this area which have to be dealt with sensitively. That is why the BMA guidelines on the withholding of treatment are an important contribution to that debate. It is right also that every adult with the mental capacity to make their own treatment decisions should have the right to refuse medical treatment if they so wish. However, the question as to how they discuss that with clinicians must be handled with sensitivity and care.<sup>38</sup>

### C. Forthcoming legislative changes

*Re F* and the *Bland* case still represent the current state of the law on the treatment of incompetent patients and the withdrawal of artificial nutrition and hydration. However, the Government has been consulting for some time on possible changes to the law in this area, following the publication of proposals by the Law Commission in 1995.<sup>39</sup> The Lord Chancellor's Department published a consultation document, *Who decides?*, in December 1997.<sup>40</sup> Subsequently, in October 1999, the Government issued firm proposals for legislation in the document *Making decisions*.<sup>41</sup> These proposals would change considerably the legal

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<sup>37</sup> HL Deb 19 January 2000 c 1116

<sup>38</sup> HL Deb 19 January 2000 c 1117

<sup>39</sup> Law Commission, *Mental incapacity*, HC 189 1994-95

<sup>40</sup> *Who decides*, Cm 3803, December 1997

<sup>41</sup> *Making decisions*, Cm 4465, October 1999



framework in which decisions about the withholding or withdrawal of treatment would take place.

The Law Commission proposed that there should be a new “general authority to act reasonably”, so that it would be lawful for anyone to do anything for the health or welfare of an individual “if it is reasonable for it to be done by the person who does it” and if it is in the person’s “best interests”. This would effectively enshrine in statute law the current position that medical practitioners may treat incapacitated patients if it is in their best interests, but also widens it beyond the purely medical, and provides a definition of best interests. Other suggestions by the Law Commission included: creating a new test of capacity; enshrining the validity of “advance statements” in statute law; allowing people to appoint “attorneys” to make proxy decisions for them, should they ever lose capacity; allowing a new Court of Protection to appoint “managers” to make such decisions when the individual had not appointed an attorney; making new statutory provision to ensure the independent supervision of serious medical decisions, such as sterilisation or the withdrawal of artificial feeding and hydration; and making new statutory rules to regulate research.

In *Who decides?*, the Government invited comments from the public on these proposals, indicating that they were “minded to accept” a number of the Commission’s recommendations, including a statutory definition of incapacity, the general authority to act reasonably and the appointment of attorneys. On other issues, particularly advance directives and controls on research, the White Paper took a neutral stance, inviting views on whether the proposals should move forward at all, as well as on the practicalities as to the possible form of such legislation.

*Making decisions* sets out the Government’s firm proposals, after consideration of the response to *Who decides?* The following proposals have been accepted, although it is not yet known how soon legislation will be brought forward to implement them:

- a new test for capacity, based on a functional approach: that is on an individual’s *ability* to make decisions about their medical treatment, not on the *content* of those decisions (in other words, an individual cannot be deemed incapable just for making what seems to others to be a very rash or strange decision). There will be a presumption that an individual has capacity unless proved otherwise.
- a general authority to act reasonably, where any act carried out for an incapacitated person will be lawful “if it is in all the circumstances reasonable for it to be done by the person who does it”, and where the decision-maker reasonably believes that the action is in the patient’s best interests. The intention is that this authority would be sufficient to cover day-to-day decisions and actions, such as giving medication and providing help with dressing or feeding. The White Paper does not spell out clearly whether accepting or refusing less routine medical treatment could be included within the general authority, but given the more specific arrangements for such decisions (see below), it seems unlikely that this would be usual.

- statutory guidance on how “best interests” are to be determined. Factors to be considered should include: the ascertainable past and present wishes and feelings of the patient concerned; the need to encourage them to participate as fully as possible in any decision affecting them; the views of people close to the patient as to the patient’s wishes and feelings; and whether the desired action or outcome could be achieved by less restrictive means.
- provisions that the general authority will not apply if the action in question would be contrary to a decision made by a court-appointed manager or by the “donee” of a continuing power of attorney (see below). However, this would not prevent a challenge in the courts in cases where there are serious disagreements about the best course of action.
- provisions to enable individuals with capacity to appoint others to take health and welfare decisions for them, should they lose capacity in the future, under a “continuing power of attorney” (CPA). This will replace the existing “enduring power of attorney” which only permits the delegation of financial decision-making. In order to provide safeguards, legislation will specify the form and manner of the execution of the CPA, make procedural requirements and restrict who may become an attorney. The attorney acting under the powers of a CPA will not be able to take healthcare decisions until the donor is incapacitated, and will not be able to authorise the withdrawal of artificial nutrition or hydration unless explicitly permitted to do so by the CPA. Someone who makes a CPA will be able to revoke it at any time while they still have capacity.
- new powers for the Court of Protection, to be exercised either directly by the Court or through Court-appointed “managers”. Managers will be able to make healthcare decisions on behalf of the incapacitated person in the same way as attorneys, but they will be subject to tighter controls. Similarly, the Court of Protection will be able to make decisions itself on behalf of an incapacitated individual, and will have the power to make declarations as to an individual’s capacity. The Court’s powers in healthcare matters will include approving or refusing particular treatment, requiring the person responsible for the patient’s healthcare to transfer responsibility to some-one else, and obtaining access to medical records. Very serious healthcare decisions, such as the withdrawal of artificial nutrition and hydration from a patient in permanent vegetative state cannot be delegated to a manager and will remain for the Court to decide. It is envisaged that usually it would be appropriate for the Court, not a manager, to take decisions that involve the *refusal* of medical treatment, but it would be open to the Court to decide to give such a power to a manager if it thought fit.

The Government has, however, decided that a number of the Law Commission’s other proposals “should not be taken forward at this time”. These include enshrining the current case law on advance statements in statute, and setting up new rules on research involving incapacitated individuals. According to *Making decisions*, the responses on the issue of advance statements reflected a wide range of firmly held views: respondents variously believed that advance statements were morally wrong and that giving them legislative force

would prevent doctors from saving patients' lives; that existing case law (which establishes that an advance *refusal* is binding on doctors, if applicable to the circumstances in question) was quite clear enough already; and that the case law was not properly understood and that enshrining it in statute would clarify the position satisfactorily. Reflecting this diversity of opinion, the Government has decided not to legislate in this area, but took the opportunity in the White Paper to set out "a clear statement of the present legal position" as follows:

It is a general principle of law and medical practice that all adults have the right to consent to or refuse medical treatment. Advance statements are a means for patients to exercise that right by anticipating a time when they may lose the capacity to make or communicate a decision.

An advance statement contains a person's instructions as to which medical treatment that person would or would not be prepared to accept if he or she should subsequently lose the capacity to decide for himself or herself. An advance statement can request specific treatments. It is an important principle that health professionals are not legally bound to provide that treatment if it conflicts with their professional judgement about the most appropriate treatment to give to a patient just as they would not be bound to give a treatment requested by a patient with capacity. However, the health professional may take the person's wishes into account when deciding the course of action.

Advance statements are sometimes concerned with the refusal of life sustaining procedures in the event of terminal illness. They have nothing to do with euthanasia or suicide. They cannot authorise a doctor to do anything which is illegal or which a person with capacity could not request a doctor to do. Nor can they ask for treatment which is clinically inappropriate. Advance statements are simply a method whereby a person can exercise his or her right to accept or reject medical treatment. The Government wishes to make absolutely clear its complete opposition to euthanasia, which is and will remain illegal.

Adults with capacity have the right to refuse or withdraw their consent to medical treatment. We do not accept that the decision has either to be reasonable or has to be justified to anyone apart from the individual who is making the decision. It follows that the Government respects the right of people with capacity to be able to define, in advance, which medical procedures they will and will not consent to at a time when that individual has become incapable of making or communicating that decision. The courts have approved this principle and have determined that certain forms of advance statements already have full effect at common law. The judgements in *Re T*,<sup>42</sup> together with those in *Airedale NHS Trust v Bland*<sup>43</sup> in both the Court of Appeal and the House of Lords, indicate that an advance refusal of treatment which is 'clearly established' and 'applicable in all the circumstances' is as effective as the decision of a capable adult. The case of *Re C*<sup>44</sup> provided further clarification. In that

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<sup>42</sup> *Re T (Adult: Refusal of Treatment)* [1992] WLR 782

<sup>43</sup> *Airedale NHS Trust v Bland* [1993] AC 789

<sup>44</sup> *Re C (Adult: Refusal of Treatment)* [1994] 1 WLR 290

case, the High Court held that a refusal of treatment by a patient who had capacity to make that refusal was binding on his doctors for the present and the future until it was revoked. The Government accepts those decisions.<sup>45</sup>

The Government has therefore clearly indicated that it has no intention of changing the current case-law (for example by setting out in statute that advance refusals are *not* valid), but nor, at present, does it intend to “fix the statutory position once and for all” by enshrining the current case law in statute. The issue will be kept under consideration “in the light of future medical and legal developments”.

## D. Ethical issues

The above sections have discussed the current case law which affects the withholding or withdrawing of treatment, the guidance issued by the BMA, and the Government’s intentions as to future law reform. However, ethical approaches to these issues vary widely, and the fact that a particular approach has been enshrined in case-law does not necessarily mean that it is therefore in accordance with all ethical codes. This section of the Paper will attempt to summarise some of the possible ethical approaches to the issue of withholding treatment and discuss the extent to which current case-law is in sympathy with them. Inevitably it will be very brief; suggestions for further reading are included in Appendix 2.

**Utilitarian** approaches to ethics focus on the *outcomes* of moral decisions. The *intentions* behind certain decisions are therefore deemed to be morally irrelevant. Put very simply, an action is ethically right under a utilitarian system of ethics if the result is a net increase in “utility” (measured in a variety of ways, such as the total amount of happiness, or prosperity, or lack of unhappiness, in a particular society). Thus, if the measure of utility is the happiness of the population, then end-of-life decisions will be ethical, or not, depending on the extent to which they increase, or decrease, that happiness. If it could be demonstrated that the current legal position causes a significant level of anxiety in the older population, fearing that they will not receive the treatment they need or want, then utilitarians would regard it as unethical since it decreases utility. If, on the other hand, people have a greater fear of being subject to treatment that they believe they will *not* want at the end of their lives, then the current legal position would be regarded as ethical. One significant feature of utilitarian philosophy is that it takes no account of the individual, except in so far as this affects the utility of the whole. It could therefore be argued that if withdrawing treatment from patients in pvs would release large cost savings which could treat others more conscious of the benefit, then it would be ethical from this perspective to do so.

Very few people, apart from philosophers, adhere to a purely utilitarian approach to ethics. However, the idea that, other things being equal, it is right to maximise the total good is widespread; for example in the approach to healthcare spending that argues that funding should be allocated in such a way as to create the greatest possible increase in population

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<sup>45</sup> *Making decisions*, Cm 4465, p 4

health status, even if this means that particular individuals do not benefit at all. Another aspect of utilitarianism which is relatively common is the belief that it is the results of actions which have moral value, not the intentions which lie behind them. Thus, for example, the claim that there is a moral difference between an act and an omission, where both the intention and the actual outcome is the same (which was crucial in the *ratio*<sup>46</sup> of the *Bland* case), would be regarded as hypocrisy.

A very different approach would be a **rights-based** approach, according to which human beings, by their very nature as human beings, possess certain rights, such as the right to receive what medical treatment they need, to have their autonomy respected, or (perhaps the most basic right of all) the right not to be killed. The widespread nature of this approach is demonstrated by the existence of international organisations and treaties upholding human rights, such as the European Convention on Human Rights. Two problems which tend to arise in connection with rights-based theories are firstly the fact that there is no clear consensus on what exactly constitutes a “right” or who may claim entitlement to one, and secondly the difficulty with dealing with situations where rights appear to conflict. While, in the latter case, it may often be possible to argue that some rights come higher in a pecking order than others and will take priority in any conflict, again there is no necessary consensus over this pecking order. The debate over the morality of abortion, for example, is often phrased in terms of a woman’s “right” to determine what happens in her own body versus the “right” of an unborn child not to be killed. The opposing sides on that argument may not even agree over the very existence of the “right” claimed by the other, and will certainly be in conflict about which should take precedence. Nevertheless, despite the theoretical arguments about how rights can be “proved” or how conflicts between different rights can be dealt with, most “rights” do reflect widespread and fundamental beliefs about the nature of human beings and how they ought to behave towards each other.

A third approach to ethics, and one which underpins the approach of most **religions**, is a “**deontological**” (duty-based) one. Deontological ethics start from the premise that human beings have duties and obligations; in “revealed religions” such as Christianity, Judaism and Islam, these duties and obligations may be made manifest through prophets, through sacred texts, and, in Christianity, through the incarnation of God as a human being. The ten commandments and the sermon on the mount are famous examples of deontological codes by which Christians are urged to live their lives. Another, rather less well known, example of a deontological code is the “categorical imperative” of Immanuel Kant (according to which we should only undertake an action if we could will it to become a universal law – in other words if we would think it right for anybody else to take exactly the same action). Unlike rights-based theories, which do not tell us *how* to behave, except by respecting the rights of others, deontological theories tend to include moral absolutes: certain actions are regarded as *intrinsically* immoral, even if one could argue that no-one is harmed by them, or even that in a particular case people will benefit.

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<sup>46</sup> ie the legal principles on which the case is decided

One of the ethical arguments surrounding the withdrawal of medical treatment falls very clearly into the deontological and religious category: the principle of respecting the “sanctity of life”. This principle is obviously of crucial importance, although again it is interpreted very differently by various groups, with quite different meanings attached to both “sanctity” and “life”. Thus in one interpretation, the principle of the sanctity of life is taken to mean that human life must always be preserved if the means to do so exist, if necessary against the will of the individual whose life it is. Life in this definition might be seen as a gift from God which we are not at liberty to refuse. Under another interpretation, the principle is taken to refer to the intrinsic value of human life: the belief that human life is valuable by its very nature, even if the person involved does not value it, or is not aware of it (for example because of severe learning disabilities or unconsciousness). However, this interpretation need not make the same clear absolute claim as the first, that life must always be preserved if humanly possible. It could be argued, for example, that bare existence, with no possibility of future consciousness, should not be included in “life”: that the life we are holding to be sacred must include at least some of the aspects which, taken together, appear to make human life distinctly different from that of other species, such as the ability to relate to other human beings, to experience joy and sadness, to reason, to have aesthetic responses and so on. Moreover, stating that life is intrinsically valuable does not automatically “trump” any competing factors, such as an individual’s own wish not to be treated (whether expressed contemporaneously or previously through an advance statement). The first interpretation of “sanctity of life”, on the other hand, does not admit of any “balancing” of this principle against another.

The principle that is most often set against the sanctity of life by those who argue that it can, in certain circumstances, be permissible to cease life-prolonging medical treatment, is the principle of “respect for autonomy”, or the more limited “right to bodily integrity”. These principles state that human beings have the right to determine what happens to their own bodies, and ultimately to determine when they no longer desire medical assistance in prolonging their life. The legal principle that it would be a battery to treat a competent patient against their will, or an incompetent patient where they have made an advance statement refusing treatment in these circumstances, appears to depend heavily on the ethical principle of respect for autonomy.

As discussed above, in the context of rights-based theories of ethics, there is no simple resolution between those who uphold the more “absolutist” definition of the sanctity of life and those who would give primacy to autonomy: the two principles derive from separate value systems which, in the case of life-sustaining treatment refused by the patient, are simply incompatible (although they may produce the same answer in many other cases). An adherent of the primacy of autonomy might argue that the two principles are *not* in conflict: that the ability to exercise autonomous decision-making is a basic part of one’s human nature and that to be denied it by others is to be denied what makes life “sacred” in the first place. However, such an argument would be quite unconvincing to those holding the belief that it is “life” itself that is sacred, not what particular individuals choose to define as the most important aspects of that life. The Church of England House of Bishops and the Roman Catholic Bishops Conference of England and Wales addressed the potential conflict between

sanctity of life and autonomy as follows, in a joint submission to the House of Lords Committee on Medical Ethics in 1993 on the subject of euthanasia:

**The sanctity of life and the right to personal autonomy**

7. Attention is often drawn to the apparent conflict between the importance placed by Christians on the special character of human life as God-given and thus deserving of special protection, and the insistence by some on their right to determine when their lives should end.

8. This contrast can be falsely presented. Neither of our Churches insists that a dying or seriously ill person should be kept alive by all possible means for as long as possible. On the other hand we do not believe that the right to personal autonomy is absolute. It is valid only when it recognises other moral values, especially the respect due to human life as such, whether someone else's or one's own.

9. We do not accept that the right to personal autonomy requires any change in the law in order to allow euthanasia.

10. The exercise of personal autonomy necessarily has to be limited in order that human beings may live together in reasonable harmony. Such limitation may have to be defined by law. While at present people may exercise their right to refuse treatment (although this may be overridden in special but strictly limited circumstances), the law forbids a right to die at a time of their own choosing. The consequences which could flow from a change in the law on voluntary euthanasia would outweigh the benefits to be gained from more rigid adherence to the notion of personal autonomy. But in any case we believe that respect for the life of a vulnerable person is the overriding principle.<sup>47</sup>

Moreover, those who challenge a “balancing” between autonomy and the sanctity of life could argue that there are also serious *practical* dangers involved in an approach which allows one to pick and choose what aspects of life are to be held sacred. In the case of advance refusals of treatment, for example, individuals might guess quite wrongly how they might react in the future if faced with very serious illness or disability, or how they might value that life when it was the only life open to them. Similarly, it could be argued that there is no way of knowing if people have changed their minds since refusing particular treatments in an advance statement, or whether a refusal reflects a temporary depression rather than a deeply-held view.

The relative weights to be given to respect for autonomy and respect for the sanctity of life, and indeed how respect for the sanctity of life is to be defined, become crucial when considering some of the central terms used in debates over the withdrawal of life-prolonging treatment such as “best interests”, “burdensome” and “futility”. This is especially the case where the patient in question is not competent to accept or refuse treatment, for reasons such

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<sup>47</sup> reproduced on the Church of England's website: <http://www.cofe.anglican.org/view/medical.html>

as very severe learning disability or stroke. As discussed in earlier parts of this Paper, the legal position is that such patients may be treated in their “best interests”, with the current case-law leaving the determination of “best interests” very much to doctors. An approach that placed great emphasis on autonomy might query why such a decision should be a matter for doctors at all: while medical assistance is certainly needed either to continue or withdraw treatment, and for diagnosis and prognosis, it could be argued that the actual issue of whether life should continue is one that only the person involved (or, in default of the patient being able to express a view, those who know them best) can take.

If, on the other hand, it is believed that sanctity of life must ultimately “trump” autonomy, then it could be argued that a person’s “best interests” must always lie in remaining alive, or in remaining alive unless their pain is unendurable and uncontrollable, and hence there would be no real decision for either doctors or others to take. The doctors’ role under either of these latter approaches would be limited to determining the most appropriate treatment (for example active treatment to prolong life or palliative care where the patient is in such pain that active treatment is believed too burdensome) to achieve these aims. Recent attempts to define how best interests should be determined (for example by the Law Commission and the British Medical Association: see above, page 20 & page 17 respectively) have tended to give greater weight to the autonomous approach.

Similarly, the term “burdensome” is used in a variety of ways. An approach emphasising the role of individual autonomy might describe treatment as “burdensome” if, for that particular patient, the pain or discomfort inherent in the treatment was not outweighed by the benefits the treatment brought (for example if the quality of continued life made possible by the treatment was not valued by the patient). On this understanding of “burdensome”, treatment which some patients might regard as burdensome, might be accepted with gratitude by others in an identical position. Alternatively, “burdensome” could be understood to have a more objective meaning of causing an unacceptable degree of pain or distress to the patient.

One of the most contentious terms of all is perhaps “futility”. Medical treatment could be deemed to be “futile” if it is not achieving its aim: but this begs the much bigger question as to what *is* the aim of medicine in cases such as these. Again, the range of answers would depend on one’s views on the meaning and importance of the sanctity of life and the importance to be given to autonomy. If life in *any* form, including permanent unconsciousness, is sacred, then treatment cannot be futile as long as it is still assisting the patient to live. If sanctity of life is understood as the principle of accepting life as a “gift” which one cannot refuse, but which one is not required to prolong at absolutely all costs, then treatment may not be futile, unless the patient is actually dying, or the treatment is causing unacceptable pain or distress. If, on the other hand, what is believed to be sacred about life is more than physical existence, then treatment might be regarded as futile if it cannot help return the patient to a state in which they can enjoy what *they* would regard as an acceptable quality of life.

Finally, it may be helpful to raise the issue of the principle of **justice**. As with many other principles, there is no consensus on how it should be defined: definitions offered by philosophers include making decisions based on people’s *needs*, on their *entitlements* or their



*deserts*. Other approaches would be to argue justice requires us to give equal consideration to people's interests or to satisfy claims in proportion to their relative strengths. Given that the NHS will always have a finite budget, the way justice is interpreted could have a major impact on decisions on the withholding or withdrawing of treatment. An approach based on "need" or equal consideration of interests might suggest that treatment to preserve life should always take priority over treatment to improve the quality of life, on the basis that the need in the former case will always be greater. Alternatively, it could be argued that patients in pvs are not aware of any benefit from the treatment they are receiving, and hence could not be said to "need" it. An argument based on "entitlement" might be developed in quite different directions: either that everyone is entitled to the same amount of healthcare resource (and hence spending large amounts treating very incapacitated patients could not be justified if this would reduce the amount left over for everyone else), or that life itself is such a basic "entitlement" that it should always be given priority. An emphasis on "desert" might bring in factors such as whether patients have themselves contributed to their own state of ill health. Finally, an approach which emphasised satisfying claims in proportion to their strength would lead to a greater proportion of healthcare resources being devoted to those with greatest need for treatment, but would always have to give *some* consideration to weaker claims.

### III The Bill

The *Medical Treatment (Prevention of Euthanasia) Bill*<sup>48</sup> had its formal First Reading on 15 December 1999 and is due to have its Second Reading on 28 January 2000. The Bill itself is very short and is reproduced in full below.

A  
**B I L L**

TO

Prohibit the withdrawal or withholding of medical treatment, or the withdrawal or withholding of sustenance, with the intention of causing the death of a patient; and for connected purposes.

**B**E IT ENACTED by the Queen's most Excellent Majesty, by and with the advice and consent of the Lords Spiritual and Temporal, and Commons, in this present Parliament assembled, and by the authority of the same, as follows:-

Withdrawal or withholding of medical treatment.

**1.** It shall be unlawful for any person responsible for the care of a patient to withdraw or withhold from the patient medical treatment or sustenance if his purpose or one of his purposes in doing so is to hasten or otherwise cause the death of the patient.

Interpretation.

**2.** In this Act-

"medical treatment" means any medical or surgical treatment, including the administration of drugs or the use of any mechanical or other apparatus for the provision or support of ventilation or of any other bodily function;

"patient" means a person suffering from mental or physical illness or debility;

"sustenance" means the provision of nutrition or hydration, howsoever delivered.

Short title, commencement and extent.

**3.** - (1) This Act may be cited as the Medical Treatment (Prevention of Euthanasia) Act 2000.

(2) This Act shall come into force at the end of one month beginning with the day on which this Act is passed.

(3) This Act extends to England, Wales and Northern Ireland only.

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<sup>48</sup> Bill 12 of 1999-2000

In her press conference on 18 January 2000, Mrs. Winterton stated that the aim of those drafting the Bill was to “bring to an end the efforts of the euthanasia lobby (and of the British Medical Association) to widen the ‘loophole’ created by the *Bland* judgement which allowed doctors deliberately to end patients’ lives because those lives were thought to be of no value rather than the treatment being of no value”. One of the central features of the *Bland* judgement, as discussed on page 13 of this Paper, was the definition of the withdrawal of treatment as an omission, not an act. Such an omission could only attract criminal liability if there was a *duty* to act – and in *Bland*, the Law Lords decided that in that case such a duty did not exist. This Bill, if passed, would in certain cases make the withdrawal of treatment unlawful, without needing to establish a legal duty to continue treating.

Mrs. Winterton has emphasised what the Bill does *not* aim to do:

The Bill will not require doctors to strive officiously to keep alive patients who are dying, but in accordance with good medical practice they will need to ensure that appropriate care is given to such patients.

The Bill will not prevent doctors from ceasing tubal feeding and hydration of patients, where, for example, its provision has become too burdensome to the patient or where its continuation would not be of benefit to the health of the patient; but the Bill will prevent them from ceasing tubal feeding for the purpose of killing patients.

The Bill will not prevent mentally competent adults from making decisions relating to their own healthcare (for example refusing surgery or blood transfusions); but it will slow down the development of legally binding advance directives which compel doctors to take action making them complicit in the assisted suicide of mentally incapable patients; and

The Bill will not prevent doctors providing palliative care or other medical treatment for patients provided that such treatment is appropriate to their condition and necessary to reduce pain and discomfort even if this has an unwelcome side effect of reducing life expectancy.<sup>49</sup>

The Bill itself contains no penalty, and it would therefore appear that the intention is to link this definition of an “unlawful act” with the existing law on murder. The definition of murder is found in case law and states that:

Subject to three exceptions, the crime of murder is committed where a person of sound mind and discretion unlawfully kills any reasonable creature in being and under the Queen’s peace with intent to kill or cause grievous bodily harm.<sup>50</sup>

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<sup>49</sup> notes from Mrs. Winterton’s press conference, 18 January 2000

<sup>50</sup> as cited in *Archbold: criminal pleading, evidence and practice 1999*, p 1560

In order to prove murder, courts must find that the defendant both committed the *actus reus* of murder (the act of unlawful killing) and had the *mens rea* (the intention to kill or cause grievous bodily harm). The intention of the Bill appears to be to establish that withdrawing or withholding medical treatment with the purpose of hastening the death of the patient would automatically constitute the *actus reus* of murder. It could, however, be argued that the legal debate in *Bland* focused not on the meaning of “lawful” in the common law definition of murder, but rather on whether the omission to treat could be regarded as “killing”. On this interpretation, conduct made unlawful by this Bill might not be sufficient alone to establish the *actus reus* of murder.

The effectiveness of the Bill in practice, if it becomes an Act, will also depend a great deal both on how any future courts define both “purpose”, as used in clause 1, and also on how courts might interpret doctors’ “intentions” in cases where a decision to withdraw treatment or artificial nutrition or hydration is considered. Although the Bill deliberately avoids the word “intention” in its main clause, the intention to kill or cause grievous bodily harm is still integral to the common law definition of murder.

It might be argued that, in the type of cases which the BMA guidelines seek to address (such as cases where patients are in pvs or have a minimal awareness of themselves or their surroundings) doctors do not have the “purpose” of killing their patients when they withdraw treatment, but rather believe that life-prolonging treatment is not providing a “benefit”. (See page 16 for the BMA’s definition of “benefit” and page 26 for a discussion of the term “futility”.) On such an interpretation, the Bill would not appear to change the current legal position. The opposite view would be that if it is *known* that the inevitable effect of withdrawing treatment will be death in a patient who is not fatally ill, then death *must* be the “purpose” of that conduct.

On the question of legal “intention”, to decide whether the *mens rea* of murder was present, again this would be a matter for judicial interpretation. The Law Lords in *Bland* were not forced to come to a conclusion on the intentions of the doctors in that case, because they had already decided that withdrawal of artificial feeding from Tony Bland would be a non-culpable omission. There is, however, some support in *Bland* for the interpretation that his doctors did “intend” his death. Lord Mustill, for example, suggested that the crucial distinction between unlawful “mercy-killing” and the lawful withdrawal of artificial feeding in this case was the distinction between acts and omissions, with the implication that “intention” was present in both cases.<sup>51</sup> Lord Browne-Wilkinson was even clearer, stating that “as to the element of intention or *mens rea*, in my judgement there can be no real doubt that it is present in this case; the whole purpose of stopping artificial feeding is to bring about the death of Anthony Bland”.<sup>52</sup> Lord Goff, on the other hand, stated that it was crucial that the central question be “correctly formulated”:

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<sup>51</sup> *Airedale NHS Trust v Bland* [1993] 2 WLR at 388

<sup>52</sup> *ibid* at 383

The question is not whether the doctor should take a course which will kill his patient, or even take a course which has the effect of accelerating his death. The question is whether the doctor should or should not continue to provide his patient with medical treatment or care which, if continued, will prolong his patient's life.<sup>53</sup>

## IV Responses to the Bill

The Bill has generated strong reactions, both in favour and against its provisions. The Chief Rabbi and the Catholic Bishops Conference of England and Wales firmly support it, as does the voluntary organisation Alert – Information on Euthanasia. The Church of England “wholeheartedly supports the underlying motive” of the Bill, but expresses concern as to whether the effect will be to force doctors into the practice of defensive medicine. The Down's Syndrome Association sees the Bill as a safeguard for people with Down's syndrome, for example in cases where children with Down's syndrome are denied heart surgery or places on the waiting list for heart or lung transplants. The British Medical Association, on the other hand, is firmly opposed to the Bill, as are the voluntary organisations Age Concern and the Alzheimer's Society. The responses received from all these organisations are summarised below.<sup>54</sup>

The **Catholic Bishops' Conference of England and Wales** states that the Bill “fully accords with the Catholic Church's ethical teaching on euthanasia” and argues that the Bill is “timely and necessary” in the light of the vague but widely-held opinion that “it is perfectly all right to ‘let some-one die’ as long as you don't ‘do’ anything to them”. The response states the Catholic view that a “pattern of care should never be adopted with the intention, purpose or aim of terminating the life, or bringing about the death of a patient” and highlights the difference between patients who are chronically ill (for example in a coma) and those who are dying. It is argued that this approach does not mean that life must be preserved at all costs, as treatment may at times be withheld on the basis that it is “disproportionate” to the results to be expected. However such decisions should not be premised on “quality of life” judgements, which could be seen to imply that a person's life has no value. On the question of a doctor's “purpose”, the response highlights cases where a “pro-euthanasia” and “anti-euthanasia” doctor might, in the same case, both decide that treatment should be withdrawn: the first on the basis that the kindest thing to do would be to terminate the patient's life, and the second on the basis that the treatment is causing discomfort and exacerbating other aspects of the patient's condition. However, it is argued that, although the outcome might be the same, there is both a moral and legal difference between the two doctors' actions, and that the Bill would prevent pro-euthanasia doctors from acting surreptitiously.

The **Office of the Chief Rabbi** supports the Bill, arguing that “the mandate of the doctor is to heal, and, where that is impossible, to ameliorate suffering and anguish. Only the Author of life himself may reclaim the life of man”. On the question of “death with dignity”, it is stated

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<sup>53</sup> *ibid* at 371

<sup>54</sup> Copies of the full text of responses can be made available to Members for consultation on request.

that “ultimately, the test of our humanity is our ability to face our fate and that of those close to us with courage, humility and dedication; not to hasten death because dying has become burdensome”.

The **Board for Social Responsibility of the Church of England** supports the motive of the Bill, emphasising that, like the Catholic Church, it believes that “a pattern of care should never be adopted with the intention, purpose or aim of terminating the life or bringing about the death of a patient.” The response goes on to highlight the difficulties involved in certain cases in determining whether the cause of death is the underlying medical condition or the withholding of treatment. An example is given of a case where a doctor may believe it to be right to withdraw treatment because he believes it is disproportionately burdensome to his patient: if he knows perfectly well that death will follow the withdrawal of certain kinds of treatment, “on what objective grounds can he protest his innocence of motive?” The Board expresses the concern that the Bill might have the effect of encouraging doctors to practise “defensive medicine”, and that it might be better “to encourage purity of motive in all healthcare practitioners, and then leave them free to make the decisions at the work face, where they belong”.

**Alert – information on euthanasia** argues that “there can of course be no ethical difference between intentional killing by commission or by omission, and there should be no legal difference”. It is suggested that permitting doctors to decide that some lives do not deserve care is “not only immoral but highly dangerous” and that it will lead to the trust between patients and their doctors being eroded. Mrs. Winterton’s Bill is seen as “timely” and deserving of full support.

The **Down’s Syndrome Association** describes the Bill as a “safeguard” for patients with Down’s syndrome, given the number of cases where people with Down’s syndrome have been denied the medical or surgical treatment they need, which in some cases may have hastened their deaths. The particular case of heart and lung transplants is highlighted: “In the UK people with Down’s syndrome are denied this treatment because it is felt that their lives are of less value”.

The **British Medical Association** states that it is unable to support the Bill as it believes it will “confuse an already complex process, result in poor quality patient care and remove patient autonomy”. Describing the Bill as “superficially reassuring”, the BMA argues that its emphasis on the “purpose” of the doctor in withdrawing treatment would diminish consideration of an individual’s own moral values, religious or cultural beliefs and views as to how they wish to live their lives. In order to illustrate what it sees as the “inherent fault” in the Bill, the BMA describes two circumstances in which the Bill would change the current decision-making process. In the first, a patient undergoing dialysis for chronic kidney disease develops a rapidly progressive and terminal cancer and requests the withdrawal of dialysis; it is argued that the Bill would prevent the doctors from agreeing to this request, because they would be acquiescing to the patient’s purpose of hastening death. In the second, a patient with progressive breast cancer decides in advance what treatment should be given, withheld or withdrawn, in case the cancer spreads to other organs and she is unable to express a view. It is argued that following the patient’s wishes might be interpreted as having the

purpose of bringing about her death. The BMA reiterates that it is “firmly opposed” to euthanasia and that its guidelines on withdrawing treatment are not about euthanasia. It also emphasises that those guidelines have been supported by a variety of organisations, including the Royal College of Nursing, the Association of Palliative Medicine and the Alzheimer’s Society.

The organisation **Age Concern** states that it does not support the Bill “as we do not believe it will improve the care of older people towards the end of their lives”. It emphasises that, of course, old and vulnerable people need to be reassured that when they go into hospital they will get the nursing care and medical treatment they need and “their lives will not be forfeit because of bed shortages”. However, it is argued that this is a quite different matter from withdrawing treatment which is no longer of benefit to the patient. Concern is expressed that the attempt to prevent doctors from “intentionally bringing about the deaths of their patients either by action or omission” will not necessarily coincide with the best interests of patients. “An understanding of the views of the patient is paramount.”

The organisation **Alzheimers Society** has also expressed opposition to the Bill, fearing that it has the potential to diminish the quality of care given to people with dementia, rather than improve it. It highlights the fact that the Society receives many calls through its national helpline from the families of people with dementia who are distressed by “the inappropriate and often brutal use of tube feeding in health care settings”. The Society supports the definition of artificial nutrition and hydration as “medical treatment”, not “basic care”, and emphasises that in no circumstances should “basic care” be withheld. The Society particularly emphasises its belief in the importance of decision-making being based on a consensus between patient, family and healthcare professionals, as suggested in the BMA guidelines. It expresses concern that the Bill could lead to the patients’ wishes being overridden, both in cases where they are still mentally competent and in cases where they have clearly indicated their wishes in advance through an advance directive.

## V Appendix 1<sup>55</sup>

### Artificial nutrition and hydration: medical issues

The House of Lords in *Bland* decided that artificial nutrition and hydration constituted “medical treatment”. This view is supported by the BMA, but is not universally accepted. A recent article in the *Catholic Medical Quarterly*, for example, argued that while *placing* feeding tubes might constitute medical treatment, the provision of nutrition through such tubes should constitute ordinary or basic care.<sup>56</sup> This Appendix describes the various forms that artificial feeding can take.

Previously well nourished patients can tolerate 5 to 7 days without nutritional support. In patients who are malnourished or stressed, tolerance is reduced to 3 to 5 days.<sup>57</sup> Nutritional support can be provided through two routes, enteral and parenteral. Enteral support (employing the gastrointestinal tract) is the preferred route as it is the more natural, less invasive, and less inclined to complications – primarily the septic complications of introducing catheters into veins are avoided. Parenteral support (employing a method other than the gastrointestinal tract) is used only when the gastrointestinal tract is not functional, accessible, or safe to use. The exact route of administration will depend on the length of therapy, nutritional requirements, goal of nutritional therapy, availability of intravenous access, severity of illness and fluid status. As a long-term method of providing nutrition, even the less hazardous method of enteral tube feeding has limitations and difficulties. However, these will vary considerably from patient to patient and tube-feeding, once successfully established, can be relatively trouble-free.

#### a. *Enteral support – tube feeding*

Tube feeding involves continuous or intermittent administration of nutrients into the gastrointestinal tract, and the fluid requirements of the patient can in many cases be accommodated simultaneously. There are a number of situations in which tube feeding cannot be used. These include:

- obstruction in the gastrointestinal tract that cannot be bypassed with a feeding tube
- protracted vomiting or diarrhoea
- ileus (paralysis of the bowel muscle)
- acute bowel ischaemia (insufficient blood supply to a part of the bowel)
- gastrointestinal inflammation

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<sup>55</sup> by Alex Sleator

<sup>56</sup> “Tube feeding: medical treatment or basic care?”, *Catholic Medical Quarterly*, August 1998, pp 5-7

<sup>57</sup> Blackwell Science Inc, *Medical nutrition and disease*, 1999 p 325



For short term tube feeding - perhaps several weeks duration - a flexible nasogastric tube is passed through the nose and down the throat to rest in the stomach or in some cases the small bowel. Patients who require long-term tube feeding may be given a tube which feeds directly into the stomach or small bowel through the skin. This involves a surgical procedure. When functioning well this method of tube feeding is more comfortable for the patient but it carries risks such as peritonitis, infection where the tube leaves the bowel and passes through the skin, and tube displacement.

The most common complication of tube feeding in the hospital setting is diarrhoea, but constipation is a more common symptom in patients receiving long-term tube feeding and those who are immobile. In spite of fibre and adequate water in the feeding formula, enemas may be required on a regular basis to treat the constipation.

Monitoring is necessary to avert a range of complications associated with tube feeding, which can include metabolic complications such as overhydration and chemical imbalance, gastrointestinal complications such as vomiting or constipation and mechanical complications such as clogged and displaced feeding tubes. Patients may pull out feeding tubes either intentionally or inadvertently.

***b. Parenteral support***

Because of the potential for serious complications parenteral nutrition is reserved for those in whom tube feeding is not appropriate. Providing nutrition via a catheter inserted into a peripheral vein is appropriate only for short term use. If long-term parenteral nutrition is needed a catheter is set up which provides access to a large central vein. This can be directly into a central vein, such as the jugular in the neck, or via a peripherally inserted catheter which is fed up into a central vein. Mechanical complications of catheter insertion can include pneumothorax (or air within the chest cavity) and injury to blood vessels.

Sepsis is a constant danger where there is an indwelling venous catheter and meticulous catheter insertion techniques must be followed by vigilant nursing.

It can be difficult to achieve a fluid balance which avoids the opposing risks of dehydration and fluid overload. In addition, complications such as hyperglycaemia (high blood sugar) can occur.

Where a patient is being adequately hydrated, urine will be produced and many patients who are sufficiently ill to need artificial hydration will also need an indwelling catheter to provide for removal of urine.

## VI Appendix 2

The section in this Paper on the possible ethical approaches to end of life issues is necessarily very short. If Members wish to pursue these issues further, the following texts might be of interest.

- D Brock, *Life and death*, 1993
- Gerald Dworkin, *The theory and practice of autonomy*, 1988
- Ronald Dworkin, *Life's dominion: an argument about abortion and euthanasia*, 1993
- Ian Kennedy, *Treat me right: essays in medical law and ethics*, 1991 (paperback edition with additional essays)
- John Keown, ed, *Euthanasia examined: ethical, clinical and legal perspectives*, 1995
- A MacIntyre, *After virtue*, 1991
- James Rachels, *The elements of moral philosophy*, 1993
- B Steinbock, ed, *Killing and letting die*, 1980
- J Waldron, ed, *Theories of rights*, 1984