Chapter 4
Food and Fluids: Human Law, Human Rights and Human Interests

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4.1 Introduction

Academic discussion about nutrition and hydration tends to concentrate on conceptual matters intrinsic to the ethics of removing food and fluids in individual cases. It is, for example, undoubtedly important to distinguish between vitalistic and utilitarian excesses in understanding the rights and wrongs of withdrawing food and fluids delivered by tube or by spoon from mentally incapable patients. Vitalism wrongly insists that *all* must be done to save the life of the incapacitated patient irrespective of the legitimate wishes of the patient, and the cost, effectiveness and physical burden on the patient of the intervention in question. Utilitarian accounts wrongly sacrifice the principle of the inherent dignity of every human being however disabled to a "quality of life" principle insisting that some people lack personhood or have disabilities that suggest that their very lives (as distinct from their treatment) should be regarded as undignified, futile or even over-burdensome.

In the context of changing positive law, however, it is important to understand the considerable financial, scientific and medical interests there are in controlling death. These interests need not be illicit in themselves. The interests of hospital and state efficiency, freedom from unnecessary compensation claims, scientific research and increased supplies of organs for transplant are not in themselves wrongful. When understood in the context of law that invites bureaucratised homicide and serious mutilation of the non-consenting or ill-informed vulnerable, these interests introduce new extrinsic concerns. There is every reason to believe that a proper analysis of this ethico-legal terrain demands a comprehensive inquiry into wider matters sometimes wrongly rejected as consequentialist. Failure to identify these broader interests and their moral limits might well lead one to a conceptual failure to see the wood for the trees.

England and Wales has seen radical alteration of the law of homicide and assault. The *Mental Capacity Act 2005* (which comes into force in 2007) will soon

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C. Tollefsen (ed.), *Artificial Nutrition and Hydration: The New Catholic Debate*, 77–100.

govern the removal of "treatment" which, after *Airedale NHS Trust v Bland* [1993] AC 789, includes food and fluids delivered by tube, and in certain cases also, by spoon. It does so by introducing binding advance decisions, attorneys empowered to make certain treatment decisions on behalf of the patient and a new version of the Court of Protection which will replace the jurisdiction of the ordinary courts. It also consolidates and extends recent case law permitting sterilisation and abortion on those considered incapacitated. It permits non-therapeutic research on non-consenting mentally incompetent adults. By recognising the binding nature of the advance decision, it sets up the conceptual apparatus for introduction of routine administration of the lethal injection. It introduces the notion of an attorney newly empowered to make certain "treatment" decisions on behalf of the patient. Given the abuse and homicide it arguably invites, it is possible to see the legislation as a responsibility-shifting exercise designed to foster new socially useful but fundamentally unjustly won ends.

The UK has also passed the *Human Rights Act 1998* which introduces into English law the *Convention for the Protection of Human Rights and Fundamental Freedoms* (hereafter *European Convention on Human Rights*, the Convention or ECHR). Whatever one's reservations about the actual application of the Convention in particular cases and its role in European domestic legislatures, the *Human Rights Act 1998* is now undoubtedly a part of the positive law of the UK. The conceptual apparatus of the Convention is far from antithetical to a genuinely natural law bio-ethic. The language of the Convention recognises, at least on its surface, the intrinsic dignity of human beings and, properly understood, permits a genuinely natural law ethic of dying. It is therefore instructive to visit the positive law of England and Wales on withholding and withdrawing food and fluids, examining it against the demands of the *European Convention on Human Rights* and against the background of financial and scientific interests in controlling death, dying and the human body itself. In what follows, tensions between the 2005 Act and the *European Convention on Human Rights* are examined. I argue that theoreticians and lay folk alike are being persuaded of the need for this legislative reform on the basis of unsustainable readings of personal autonomy and the social good, on an improper understanding of the ethical principles governing human intervention in death and dying, and in ignorance of the substantial financial and scientific interests behind the legislation. Far from promoting autonomy and the social good, the legislation undermines human rights and threatens human dignity.

4.2 The Mental Capacity Act 2005

The *Mental Capacity Act 2005* (hereafter, the 2005 Act) has significant implications for mentally incapacitated patients in England and Wales.[1] It constitutes the culmination of efforts by successive governments proceeding from the Law Commission *Draft Bill on Mental Incapacity 1995*, to enact legislation in respect of the

care and treatment of the mentally incapacitated. Read in the light of existing case law, certain sections of the *2005 Mental Capacity Act* have profound consequences. Most notably they give a catalogue of new actors power to withhold and withdraw "treatment" including artificial nutrition and hydration from patients who, it should be highlighted, may not be dying. These new decision-makers include donees under lasting powers of attorney (attorneys) and those purporting to bear the advance decisions of mentally incapacitated patients. In addition, wide-ranging powers are established in respect of a virtually unrecognisable Court of Protection now empowered to make life and death decisions governing removal of "treatment" as well as decisions to perform research on, remove tissue from, sterilise and abort the young of mentally incapacitated patients.

The *Mental Capacity Act 2005* needs to be read in conjunction with other legislation that has appeared recently. The *Human Tissue Act 2004* (which came into force in 2006) permits *inter alia* use of tissue from non-consenting patients. The *Medicines for Human Use (Clinical Trials) Regulations 2004* (S.I. 2004/1031) allows for clinical drug trials on non-consenting patients on the authority of novel representatives. The *Mental Capacity Act 2005* also expressly permits non-therapeutic research on the non-consenting on the authority of novel third parties. As we shall see, these proposals exist against an intellectual background that can be described as broadly utilitarian. In successive volumes of *The Lancet*, senior medico-legal figures (Hoffenberg et al., 1997, pp. 1320–1321) representing the International Forum for Transplant Ethics make the case for removal of organs from non-consenting patients in permanent vegetative state for use in transplantation. They also recommend societal opt-out organ "donation" as a way of increasing the stock of organs available for transplant (Kennedy et al., 1998, pp. 1650–1652). For non-utilitarian bio-ethicists these suggestions might highlight the aims, driving interests and moral limits of the legislation.

It is also worth remembering too that some twenty years earlier in 1984, at the 5th Biennial Conference of the World Federation of Right to Die Societies held in Nice, Australian bioethicist Dr. Helga Kuhse suggested a strategy for the implementation of euthanasia by lethal injection: "If we can get people to accept the removal of all treatment and care—especially the removal of food and fluids—they will see what a painful way this is to die and then, in the patient's best interest, they will accept the lethal injection" (Marker, 1993, pp. 94, 267).

It is widely argued that this law reform is progressive, fosters patient autonomy and clears the way for necessary scientific research. An alternative, more realistic reading is that these radical alterations in the law of assault and homicide create contradictory and unworkable obligations for health professionals and fundamentally compromise the human rights and bodily integrity of the vulnerable.

4.3 The Background to the 2005 Act

The 2005 Act allows new agents to require doctors to withdraw or withhold treatment from mentally incapacitated patients. Ever since the controversial and highly

criticised House of Lords decision in *Airedale NHS Trust v Bland* (1993) AC 789, treatment has included tube feeding and even feeding by hand in cases where this is possible. So what the proposed legislation logically authorises is the removal of food and fluids with consequent dehydration to death of patients.

When *Bland* was decided, the case attracted much criticism not least because three out of five Law Lords stated that the aim of stopping feeding was to bring about Tony Bland's death. *Bland* was understood, by both supporters and critics of the decision, to mark a *volte face* in English law. Well-known euthanasia advocates like Peter Singer (1994, p. 1), for example, noted that the case marked the collapse of the Judeo-Christian principle of the inviolability or sanctity of human life. Critics regarded the apparent rationale behind the decision defective (for example, Finnis, 1993, p. 329), and argued that the doctrine of the sanctity of life had been "misrepresented, misunderstood and mistakenly rejected" (Keown, 1997, p. 481). The majority's reasoning involved three important propositions. The first was that tube feeding was "treatment" not ordinary care (Lord Keith, *Bland*, p. 858). For the first time tube feeding was regarded as treatment. The second and most important proposition in the majority's reasoning was that Tony Bland had no "best interest" because he had *no meaningful life* (Lord Mustill, *Bland*, p. 897). The third proposition was that while it would have been unlawful to kill Tony Bland with a lethal injection, removal of his feeding tube would constitute a permissible omission (Lord Goff, *Bland*, p. 868).

4.3.1 "Treatment" or Ordinary Care?

So in the UK now, *Bland* has come to stand for the proposition that tube feeding is not ordinary care but "treatment" which, in certain circumstances, may be withdrawn even from people who would not otherwise die.[2] The result of withdrawing tube feeding from a patient and then refraining from feeding the patient by hand (this is often possible even with patients diagnosed in a persistent vegetative state, or PVS) is that the patient dies some days later of hunger and thirst. It is well known that feeding by tube is a simple matter. It makes life easier for nurses and other health professionals who might otherwise have to spend some hours feeding by hand. The tube can either be placed in the abdomen or inserted by a capable patient himself or herself through the nose. Its point is to ease feeding, a natural function of the body. It is not costly. It is simple basic care, a non-technical extension of the every-day activity of feeding by hand. Above all, it is not an attempt to stabilize, treat or cure a patient, as is something like ventilation.

That tube feeding should be regarded as effective ordinary care is emphasized by Keith Andrews of the Royal Hospital for Neurodisability in South London. Keith Andrews is particularly well placed to comment. He was a witness in *Bland* and it was he who later documented 17 out of 40 misdiagnoses of PVS some three years after *Bland* was decided (Andrews et al., 1996, pp. 13–16).[3] He has been reported as saying that: "the only reason that tube feeding has been identified as 'treatment' is so that it can be withdrawn . . . I would argue that tube feeding is extremely ef-

fective since it achieves all the things we intend it to. What is really being argued is whether the patient's life is futile—hence the need to find some way of ending that life" (1995, p. 1437). His analysis highlights a most important feature of the *Bland* decision. After the enactment of the 2005 Act this part of the *Bland* majority judgement has profound implications.

A fact worth mentioning about the aftermath of the *Bland* case is that nearly a decade after the initial injury another survivor of the Hillsborough disaster woke up. Like Bland, he was diagnosed as in PVS. Andrew Devine was apparently in a "permanent" vegetative state for eight years before communicating with his parents.[4] Stanley and Hilary Devine, the parents of Andrew, had never sought to prevent their son's being fed. In 1996, the solicitor for the Devines reported a massive improvement and expressed the family's wish for privacy. In fact, there are a number of examples of patients awaking[5] from a "permanent" vegetative state.[6] So frequently have diagnoses of "permanent vegetative" state been falsified by the patient's subsequent recovery or further scientific revelations, that the very terminology used has been altered. "Permanent" is now "persistent" vegetative state. The word "vegetative" is still common parlance despite the pejorative connotations. I adopt the prevailing terminology to avoid misunderstanding and despite its dehumanising overtones. Once a person is regarded a vegetable or an animal, it become less difficult to permit the bringing about of his death.

4.3.2 "Worthless Lives" and "No Best Interests"

Recent first instance cases have taken the *Bland* decision as authority for the idea that some people have no meaningful lives and therefore no "best interests." Since *Bland* the courts have been at liberty to make this determination before withdrawing tube feeding. In *Re D (Adult: Medical Treatment)* [1998] 1 FLR 411 the patient was able to respond to ice water, was able to track moving objects and evinced a "menace" response. It was held, applying *Bland*, that notwithstanding the fact that the criteria for PVS were not fulfilled, the patient showed no evidence of a meaningful life and that it was not in D's interest to be "kept alive."

Again in *Re H (A patient)* [1998] 2 FLR 36, the patient could focus on an object and could be aroused by clapping. There was evidence of visual tracking as well. It was held that H was in PVS and that cessation of "treatment" was in her best interests. What is particularly disturbing is that the patients involved were not dying. They died finally of dehydration once tube feeding was withdrawn.[7]

This new approach to the mentally incapacitated derives from certain majority judgements in *Bland*. Lord Hoffmann described Tony Bland thus: "His body is alive, but he has no life in the sense that even the most pitifully handicapped but conscious human being has a life". He went on to describe Tony Bland's existence as a humiliation. He was, he said, "grotesquely alive" (Lord Hoffmann, *Bland* p. 863). Lord Keith referred to Tony Bland's "existence in a vegetative state with no prospect of recovery [as considered by responsible medical opinion] as not being a benefit . . ."

(Lord Keith, *Bland*, p. 858–859) Lord Mustill asserted that Tony Bland "had no best interests of any kind" (Lord Mustill, *Bland*, p. 897).

At the time of the decision it was pointed out that these kinds of statement suggested a new drive, one which sought to determine whether a person's life is of a sufficiently high *quality* to warrant the protection of the law. This idea of a "worthless life" and the companion question "whether it is in the best interests of a patient to survive" is a new one and arguably runs contrary to the criminal law as traditionally understood. It has, until recently, been an assumption of the law that all human beings share the same fundamental worth simply in virtue of their humanity irrespective of their physical or mental abilities or disabilities. The law has steadfastly refused to discriminate between those thought to have worthwhile lives and those pronounced worthless.

A central problem with the notion of a "worthless life" (for the purposes of permitting some rather than other intentional homicides), is that the notion, upon analysis, is fraught with difficulty.[8] Above all the concept involves *unjust discrimination* against the severely disabled precisely on the basis of the severity of their disability. Furthermore, the notion of a "worthless life" is highly subjective and fraught with arbitrariness. This, in itself, invites abuse. Health professionals and observers are faced with laws that are neither stated nor promulgated. They cannot know in advance whether they are obeying the law or are in breach of it. Without clear and public criteria for deciding these matters, the law itself becomes an instrument of injustice operating on an entirely unpredictable basis. I have addressed the inherent discrimination against the disabled implicit in the concept of the "worthless life." The concept has a certain verisimilitude to the Nazi notion of the "*lebensunwerten Lebens*" in any case. The principal objection is that we all suffer and are vulnerable at one time or another. Attempts to stipulate criteria like "rationality, self-consciousness and autonomy" as the necessary conceptual test, have the unhappy and counterintuitive consequence of suggesting that the sleeping, the drunk and the unconscious lack the technical status of "personhood" (Laing, 1996, pp. 196–225). Even the judge and professor must sleep and countless people find themselves, at some point in their lives, unconscious. Who is to say that the non-responsive patient (or those otherwise incapacitated) is living the life of the non-person, or the life unworthy of life? At the very least, if there is to be a general concept of a "worthless life" or "non-person" the criteria for the application of the notion had better be clear and identifiable. No such criteria were made plain in *Bland*. As we shall see in what follows, the technical concepts of "lives unworthy of life" and non-personhood are arguably ones that are antithetical to the concerns for equal dignity, human life and just treatment contained in the European Convention on Human Rights, and other international instruments.

4.3.3 Intentional Killing by Omission

The third revolutionary aspect of the *Bland* decision was its approach to intentional killing by omission. Traditionally, intentional killing by omission was prohibited. The authors of a standard and authoritative British textbook of criminal law, Smith

and Hogan, now describe the decision in *Bland* thus: "There was no doubt about the intention to kill. The object of the exercise was to terminate B's life. It was accepted that to kill by administering lethal injection or any similar act would be murder; but what was proposed was held to be not an act but an omission" (Smith and Hogan, 1999, p. 50).

It is indeed a long-established principle of the common law that there is no duty to save a person from death. If you or I see someone drowning in the sea, there is no obligation to dive in and save the victim. It is this idea that the majority in *Bland* relied upon in granting the declaration to withdraw tube feeding. Since Tony Bland had no right to "treatment" (here, tube feeding), he was not being deprived of anything to which he had a right when it was removed, with whatever purpose. This, at least, was the majority's rationale.

But, as was pointed out at the time (Finnis, 1995, p. 329; Keown, 1997, p. 481), intentional killing by omission is still murder provided the intention is there. If I intend to kill my baby at home by omitting to feed it, it is the fact that I intend to kill that is important in determining whether this omission should be regarded as murder.[9] The fact that the method used to kill is an omission will not save me from a murder conviction if the intention can be proved. It might be difficult to prove intention, as it is in many other kinds of case, but evidential problems are not substantial ones. It is a long established principle that murder can be committed by intentional omission as well as by intentional act.[10] It is also well-known that manslaughter can be committed by omission where there is an assumption of care of the victim or where there is a special relationship or a special duty to act created by statute or contract or public office. There can be no doubt at all that the doctor-patient relationship involves, in the most intimate way, this duty of care.

So the majority's decision to permit intentional killing by omission by health professionals in circumstances where the patient was not dying marked a major break with the English criminal law. If *Bland* indicated willingness by the English courts to break with existing English law, the *Mental Capacity Act 2005* goes much further. It permits various third parties, attorneys and those claiming to know the advance decisions of the patient, to authorise what the courts alone after *Bland* were authorised to order.

4.4 Human Rights and the 2005 Act

The notion of equal dignity informs Article 2 of the *European Convention for the Protection of Human Rights and Fundamental Freedoms* which provides that:

> Everyone's right to life shall be protected by law. No-one shall be deprived of his life intentionally save in the execution of the sentence of a court following his conviction of a crime for which this penalty is provided by law.

Given that dehydration is a particularly nasty way to die the principle is also borne out by Article 3 which states that: "No one shall be subjected to . . . inhuman or

degrading treatment or punishment." Article 8 states that: "Everyone has the right to respect for his private and family life, his home and his correspondence."

It is also made explicit in Article 14 which stipulates that:

> The enjoyment of the rights and freedoms set forth in this Convention shall be secured *without discrimination* on any ground such as sex, race, colour, language, religion, political or other opinion, national or social origin, association with a national minority, property, birth or other status.

The fact that a person is disabled, even severely disabled, is no grounds to discriminate against his right to life and to freedom from inhuman and degrading treatment. Notwithstanding these articulations recent human rights cases suggest the position in relation to artificial nutrition and hydration is far from settled.

On 30 July 2004, shortly after the *Mental Capacity Bill* received its first reading, the High Court handed down an important judgment analysing the General Medical Council's guidelines on withdrawing and withholding food and fluids. In that case Leslie Burke, a man with a progressive neurological condition, perceiving the combined effects of the Bland case and the effects of the GMC guidance which permitted the removal of food and fluids on quality-of-life grounds, sought a declaration that the guidance failed to protect against human rights abuses. Mr Justice Munby found that the GMC guidance was indeed defective because it allowed artificial food and fluids to be withdrawn from patients in circumstances that failed to protect against breaches of Article 2 (right to life), Article 3 (freedom from inhuman treatment), Article 8 (right to family and private life) and Article 14 (non-discrimination) of the European Convention.

No sooner had judgement been handed down, but the government announced its intention to appeal. The Court of Appeal duly overturned the decision of the High Court and, finally, on appeal to the European Court of Human Rights, the Court considered that Mr Burke had failed to establish that UK law was such that he faced a real or imminent risk that tube-feeding would be withdrawn in circumstances that implied a painful death by thirst. The Court stated that it was satisfied that the presumption of UK law was in favour of "prolonging" life wherever possible. The Strasbourg Court agreed with the Court of Appeal that the GMC Guidelines which Leslie Burke sought to challenge simply set out good practice for doctors and did not alter the law. They approved the Court of Appeal's judgment and confirmed that if a doctor withdrew tube-feeding from a *competent* patient who desired tube-feeding to continue then it would be murder. Where a patient was *incompetent*, however, then as a general rule they considered tube-feeding should continue for as long as it prolonged life. There were, however, circumstances where a doctor might find that ANH in fact hastened death and thus it was impossible to lay down any absolute rule as to what the best interests of a patient would require.

The unwillingess of the Strasbourg Court to enter into a debate about UK law was perhaps only to be expected given that the newly enacted *Mental Capacity Act 2005*, with its then unpublished *Code of Practice*, had yet to come into force. Had the challenge been successful the *Burke* Case would have pre-empted the 2005 Act and trumped parasitic instruments still in a draft stage.

There was considerable opposition to the *Mental Capacity Bill,* not merely to the worrying dehydration questions raised by the Bill but also to other matters. Novel third parties (such as attorneys, those claiming to have legally binding advance directives refusing treatment, and, in the early stages of the Bill's passage too, court appointed deputies) were authorised to require doctors on pain of an assault charge, to remove and withhold "treatment" (which after *Bland* includes ANH and in certain cases spoon feeding too). Not only this but controversial procedures like non-voluntary sterilisation and non-voluntary abortion (then questionably permitted but only on a High Court order *Re F (Mental Patient: Sterilisation)* [1990] 2 AC 1; *Re SG* [1991] 2 FLR 329 respectively) were, at that stage, potentially in the hands of these newly empowered agents.

A profoundly different Court of Protection was emerging, one that no longer merely dealt with the financial welfare of the incompetent but overseeing his very medical treatment, life and death. Importantly, the Bill allowed non-therapeutic research to be performed on certain mentally incapacitated patients without their consent. It abolished the High Court's jurisdiction to hear applications on the above-mentioned matters with the substitution of (and even then only in certain cases) the Court of Protection, an institution that then afforded very little of the transparency, requirement of representation, ordinary appeal and procedural form demanded by a genuine court. Indeed the 23rd Report of the Joint Committee on Human Rights confirmed these and a number of other concerns. The Bill, it argued, would also involve arbitrary deprivations of liberty occasioned by insufficient procedural safeguards as outlined in *Winterwerp v Netherlands* (1979) 2 EHRR 387 and *HL v United Kingdom* (Application No 45508/99) (unreported) 5 October 2004, and use of easily alterable Codes of Practice to specify matters that affect the law of homicide and assault thus suggesting an absence of procedural safeguards against abuse of fundamental human rights.

Although welcomed by numerous parties such as the Making Decisions Alliance, the Law Society, as well as the Voluntary Euthanasia Society, the Bill was opposed root and branch by other disability rights groups such as Disability Awareness in Action, People First, the British Council of Disabled People, the Coalition of Organizations of Disabled Peoples and I Decide. Numerous religiously affiliated organisations such the Evangelical Alliance, CARE, the Christian Medical Fellowship, the Lawyers Christian Fellowship, anti-euthanasia organisations such as ALERT, the Society for the Protection of Unborn Children, the British Section of the World Federation of Doctors Who Respect Human Life and anti-eugenics organisations also opposed the Bill (Laing, 2005b, pp. 137–143). Strangely, the Catholic Bishops Conference of England and Wales did not oppose the legislation root and branch but sought amendments only,[11] making no mention of the potential for numerous human rights abuse of the kind outlined.

4.5 The Apparatus: Advance Decisions, Attorneys, Deputies and a New Court of Protection

The Act permits for the first time in English law a variety of new agents to bind a doctor on pain of an assault charge, to remove "treatment" from the mentally incapacitated. Binding advance decisions, donees under lasting powers of attorney and a new Court of Protection are among the novel third parties empowered to require this state of affairs.

4.5.1 Advance Decisions

The trouble with binding advance decisions is precisely that they are made in advance either verbally or in writing. This refusal of treatment might occur when a person is not suffering from a particular condition, is not being offered any particular treatment, and has no idea what the condition requires or how he or she would feel in this particular situation. The patient may be speculating years in advance of the treatment. The advance decision legally *binds* the doctor. In the absence of complex inquiries into whether the statement constitutes a patient's up-to-date wishes, the decision determines the patient's fate and health professionals are legally indemnified for their lethal actions and omissions. An advance directive might be entirely nonsensical, medically speaking. The doctor would be bound by this document, often made long ago and in ignorance of the circumstances in which the patient finds himself.

It should be remembered that after *Bland* "treatment" means tube feeding (and in certain cases too, spoon-feeding). Many people simply do not know that an advance refusal of treatment may mean death by dehydration *at a time triggered and determined by the health team* who would be legally indemnified against homicide by virtue of the patient's advance decision. The Code specifies that a person *may* help himself to legal and medical advice in making his advance decision but does not require him to do so. For those who do not understand the law, the consequences are likely to be grave. Section 26(3) states that:

> A person does not incur liability for the consequences of withholding or withdrawing a treatment from P, if at the time, he reasonably believes that advance decision exists which is valid and applicable to the treatment (2007 Code, Clause 26 (3)).

What this means is that the health service is legally indemnified against prosecution, claims of negligence or disciplinary proceedings once the advance decision is triggered. The advance decision-maker may make a decision in ignorance of the implications of *Bland*, or of what cures will become available, or of how he will feel at the time in question. He would be bound, in the absence of complex investigations into the decision itself, by that refusal of life-sustaining treatment. The only safeguard, if such it can be called, is that an advance decision to refuse ANH must be in writing.

The binding advance decision envisaged by the 2005 Act reverses important presumptions in favour of saving life with the threat of litigation. This seriously undermines medical professionalism and the core ethic of the medical profession. The practical implication of being able to prosecute and sue a doctor for administering

"treatment" in the face of an ill-informed advance decision, where it would have the effect of saving the patient from death or chronic disability, is that medical teams will be highly unlikely to undertake further investigation in emergency situations (as are often undertaken in respect of suspect wills with the benefit of time and cool consideration) into whether a person's refusal of treatment was properly informed and genuine rather than fraudulent, unconscionably obtained, or undertaken in ignorance. Since they would be indemnified against liability by triggering an advance decision, the medical system would be loaded against saving life even by relatively simple means. This creates a climate fundamentally hostile to the practice of medicine.[12]

If perchance the doctor *were* to act on his own initiative to give the patient the best, most up-to-date treatment thereby attempting to save the patient from long-term disability, he would be open to a charge of assault. And if he were to withhold treatment from his patient in accordance with the directive, he might yet find himself faced with a suffering, disabled patient properly anxious for damages for his disability. After all, how was the patient to know that his advance decision was going to leave him chronically disabled? The doctor, as we have seen, would be indemnified by section 26(3) against liability for the long-term disability occasioned by the existence of the directive. Thus, the binding advance decision threatens the vulnerable by undermining the position of patients who are left permanently or chronically disabled by the failure to receive treatment that they might otherwise have received were it not for the ill-informed advance directive. It also acts as the preventative for cure. Because bad clinical practice becomes binding on the doctor, the patient would have no straightforward recourse to the law of negligence.

This possibility in turn supplies a further cause for concern. The effect of the advance decision is to *shift responsibility* for significant clinical decisions to the decision-maker himself. There are substantial conflicts of interest involved in the business of shifting legal responsibility for lethal decisions since the health service and medical professionals themselves are no longer bound by a duty to act in the best clinical interests of the patient once the decision was triggered. These are undoubtedly pressures associated with compensation claims for bad treatment. Secondly, there are pressures on beds and resources. The Western world has a growing costly, non-productive ageing population thanks, in part, to its unwillingness to reproduce. Accordingly, top-down bureaucratic pressures to clear beds and increase hospital efficiency are bound to constitute an operating factor in the determination of whether a decision to withdraw "treatment" should be pursued. Thirdly, as we shall see, there are numerous other scientific and medical interests in controlling death. These possibilities might be deprecated as alarmist and over-pessimistic about medical good-will, but a brief consideration of the bureaucratic, financial, medical and research pressures on health professionals working in a fundamentally altered moral climate must give us pause.

In reality, binding advance decisions, made long in advance of known situations, introduce all manner of conflict and contradiction for the well-meaning health professional. There remains existing domestic law prohibiting assisting in suicide (*Suicide Act 1961*), recently confirmed as compatible with the Convention in *Pretty v. United Kingdom* [2002] 2 FLR 45. Accordingly, if the doctor permanently removed

tube feeding from a patient whose *aim* it was to die by starvation, there would be the further possibility that he would be faced with a charge of assisting suicide. So he would be in breach of the law prohibiting assisting suicide if he acted on the advance directive. Damned if he did and damned if he did not, there would, in other words, be a straightforward conflict of obligations: i.e. to remove the food and fluids and participate in the patient's suicidal intent and to refrain from removing food and fluids on pain of an assault charge (Laing, 1990, pp. 106–116). Such would be the logical effect of enacting legislation allowing advance directives given the *Bland* decision. That this is not as fanciful as it might first appear is supported by the new Kelly Taylor[13] test case in which a patient wishes to require doctors to sedate her and then dehydrate her to death in a bid to hasten her death by a year. Cynics will doubtless see the case as one that is designed to further the aims of advocates of state sanctioned medical killing. Once it is admitted that intentional killing may be performed by omission a year in advance of natural death at the behest of the patient, the question of the lethal injection is the next logical step.

Much could be said about the contradictions raised by this new legislation. It is perhaps these grave deficiencies that prompted the warnings of the 23rd Report of the Joint Committee on Human Rights highlighting the failure of the legislation to supply adequate safeguards against Articles 2, 3 and 8 incompatibilities. Further, the fact that it is the mentally incapacitated as a class that are thought ripe for these and other kinds of intervention, highlights the Article 14 discrimination inherent in this and related legislation. For our purposes what remains of importance are the financial, medical and research interests that underpin the legislation and, in this context, the responsibility shifting exercise envisaged by section 26(3).

4.5.2 Attorneys

If the binding advance decision undermines personal autonomy in unexpected ways, the attorney deciding for the mentally incapacitated explodes it altogether. As I have suggested already, it is this responsibility shifting aspect of the Act that is perhaps its most dangerous feature. Substituted consent is not an expression of the personal autonomy of the patient. On the contrary, it is an expression of the autonomy of the attorney.

The 2005 Act introduces the concept of the "lasting power of attorney." We are familiar with the need for enduring (or durable) powers of attorney allowing certain people to deal with the property and *financial* affairs of the incompetent patient. The Act extends the ambit of existing powers to include medical and indeed life-and-death decision-making. Section 11(8) of the Act states that a lasting power of attorney extends to refusing consent to the carrying out or continuation of *life-sustaining treatment* where the lasting power of attorney contains express provision to that effect (section 11(7)(c)). Once again the accepted definition of "treatment" in *Bland* logically implies that the donee of a lasting power of attorney has the power to decide whether a patient should be dehydrated to death by the refusal of tube-feeding qua "treatment". It should be remembered that on occasion patients

who are not dying at all will need ANH. They may be sedated or in a coma or unconscious. To allow a third party to substitute his consent for that of the patient is to invite abuse. This need not be malicious, though it may be. It may be simply undertaken in ignorance on the advice of those with a conflict of interest.

Again, it should be remembered that after *Bland* "treatment" means tube feeding (and in certain cases too, spoon-feeding). Many people simply do not know that an advance refusal of treatment may mean death by dehydration at a time triggered and determined by the attorney. Further there is no requirement that people filling in these new powers of attorney forms be advised of the legal implications of their decision. This again invites appalling abuse and shifts responsibility for profound decisions to those who will often be the least informed.

Now, where the lasting power of attorney authorises the attorney to make decisions about the patient's personal welfare, the authority by section 11(7) (c) extends to giving or refusing consent to the carrying out or continuation of a treatment by a person providing health care for the patient. Certain recent cases are authority for the proposition that non-voluntary sterilisation and non-voluntary abortion (*Re F (Mental Patient: Sterilisation*) [1990] 2 AC 1; *Re SG* [1991] 2 FLR 329 respectively) are "treatment" that can be in a mentally incapacitated, often mentally disabled, patient's "best interests." So the logical upshot is that the attorney can now authorise these profoundly questionable procedures and indeed the law sets up the apparatus for this new regime. The most worrying aspect of this novel responsibility-shifting initiative is that enormous burdens are placed upon the attorney as well as permitting hitherto unknown power to substitute his consent for that of the patient. The attorney bears a duty of care, good faith, and confidentiality as well as duties to comply with the directions of the Court of Protection. Thus, if the patient is left chronically disabled for refusal or authorisation of treatment, it will no longer be the health service to whom the patient must turn for legal redress, it will be his own attorney, often a loved one placed in this invidious position. There is, of course, the possibility that an attorney will be acting in bad faith.

Abuse is prohibited by the Act and the Code. Of greater concern, is precisely that the new attorney will often be acting on the advice of health professionals. When a health professional can be sued for his actions there is far greater likelihood that he will act in the best interests of the patient. Given that health professionals no longer bear primary responsibility for authorising controversial procedures like refusal of treatment (including food and fluids), abortion, sterilisation, research and other procedures, the question of the soundness of the advice being given will be pivotal. In short, once again far from promoting personal autonomy, the device of the substitute decision-maker often acting on bad medical advice (possibly driven by a conflict of interest) suggests the legislation invites Articles 2, 3 and 8 abuse. Once the context and interests in shifting responsibility for lethal decisions are understood, we might be less ready to regard these changes in positive law as promoting personal autonomy or advancing the interests of vulnerable patients.

The Code outlines the requirement that the patient expressly authorise consent to or refusal of life-sustaining treatment. But this does little to safeguard the patient against abuse and homicide of the kind outlined. This is because a patient will rarely

know the legal ramifications of the term "treatment" nor indeed the implications of new law in permitting non-therapeutic research and, as we shall see, clinical drug trials too. There is the further requirement that certain serious healthcare and treatment decisions be brought before the Court of Protection. Those envisaged include, for example non-consensual PVS dehydration cases, organ and bone marrow "donation" cases, non-therapeutic sterilisation, abortion and research cases and other cases in which there is some dispute about whether treatment is in a particular person's best interests (paras. 6.18–6.19 Code). The very fact that cases in which there is *dispute* about whether treatment is in a person's best interests are set out as one of the kinds of case that would need to go to the Court of Protection highlights the vulnerability of patients surrounded by compliant attorneys acting on the advice of professionals.

4.5.3 Court Appointed Deputies

Court appointed deputies too may be involved in making healthcare decisions where "important and necessary actions cannot be carried out without the court's authority, or there is no other way of settling the matter in the best interests of the person who lacks capacity to make particular welfare decisions" (para. 8.38 Code). This will extend to "best interests" sterilisation and abortion decisions. Whether it extends to dehydration orders remains to be seen. It is explicitly recognised that deputies will often be at loggerheads with the family and that "[t]here may even be a need for an additional court order prohibiting those family members from having contact with the person" (para. 8.39 Code).

4.6 Other Interests: Non-Therapeutic Research, Clinical Trials, Sterilisation and Abortion on the Non-Consenting Mentally Incapacitated

Section 30 of the Act permits intrusive research to be carried out on a person who lacks capacity to consent if it is carried out—"(a) as part of a research project which is for the time being approved by the appropriate body . . ." section 31(4) (b) permits non-therapeutic research that has no potential to benefit P without P's consent provided that the research is "intended to provide knowledge of the *causes or treatment of, or of the care of persons affected by the same or a similar condition*" (the emphasis is mine).

At the same time, the *Medicines for Human Use (Clinical Trials) Regulations 2004*[14] Schedule 1 Part 5 Regulation 12 makes express provision for clinical trials on non-consenting mentally incapacitated patients upon the consent of a "legal representative". In such a case: "[i]nformed consent given by a legal representative to an incapacitated adult in a clinical trial shall represent that adult's presumed will."[15] Attorneys, advance decisions and court appointed deputies are all mechanisms by

which research on the non-consenting might be achieved. The Regulations do however require that: "[t]here are grounds for expecting that administering the medicinal product to be tested in the trial will produce a benefit to the subject outweighing the risks or produce no risk at all."[16] This requirement of "benefit to the subject" is only stated in the alternative in the *Mental Capacity Act 2005*. So the 2005 Act goes much further on this point than do the *Clinical Trials Regulations*. There are, however, concerns about the way the regulations define the legal representative of an adult lacking capacity. If no satisfactory personal representative is available either the doctor responsible for the patient's care, if not involved in the clinical trial, may be the legal representative, or indeed anyone nominated by the health service body providing care for the patient. The potential for conflicts of interest and the risks to the patient presented by this possibility have been commented upon.[17]

Further, the *Medicines for Human Use (Clinical Trials) Amendment (No. 2) Regulations* 2006/2984 came into force on 12 December 2006. These Regulations amend the *Clinical Trials Regulations (2004/1031)* to allow that an incapacitated adult be included in a clinical trial if certain conditions are met notwithstanding the fact that the ordinary condition that the incapacitated adult's legal representative have given informed consent (para. 4) is absent. Regulation 2 applies where: (i) treatment is required urgently; (ii) the nature of the trial requires urgent action; (iii) it is not reasonably practicable to meet the conditions specified; and (iv) the procedure adopted has been approved by an ethics committee. The Amendment Regulations therefore allow clinical trials in emergency situations on incapacitated adults *without consent*.

If this is not enough, the background to the 2005 Act suggests a patient's very organs are at risk given the new moral and legal climate. After all, influential English-speaking philosophers have endorsed the idea of organ removal without explicit consent.[18] In 1995 there was public outcry to the draft Mental Incapacity Bill because it envisaged the removal of tissue and thus organs from the non consenting vulnerable (Clause 10 *Mental Incapacity Bill 1995*). The defence of this non-therapeutic intervention on the non-consenting mentally incapacitated may be regarded as a broadly utilitarian one. On this view, the mentally incapacitated patient, perhaps in PVS and perhaps not, is regarded a potential source of benefit to third parties and, as outlined in previous paragraphs, a "non-person"[19], one having "no meaningful life" and therefore "no best interests" morally speaking. Once the patient is regarded in this way, there can be little reason to object to use of his body for the benefit of others and indeed, in 1997 Hoffenberg et al. (pp. 1320–1321) made certain proposals in *The Lancet* in an article entitled "Should organs from patients in permanent vegetative state be used for transplantation?" The authors implied that the only reason against removing organs from PVS patients without their consent was that there was as yet no consensus in support of the activity. Accordingly, it was concluded that: "For religious, cultural and other traditional reasons, it is likely that the proposal would be rejected, nevertheless, the arguments in favour are sufficiently compelling to justify serious debate" (Hoffenberg et al., 1997, p. 1321).

But why stop at PVS patients? As a matter of fact, on the small matter of the 40% misdiagnosis of PVS outlined earlier in this paper they had this to say:

> We are aware of the difficulty involved in making a correct diagnosis of PVS, and, particularly, of distinguishing the locked-in syndrome. However, in this paper we discuss the possible use of organs from those patients *in whom a decision has already been taken to withdraw treatment and allow them to die.* The actual cause of their unresponsive condition is not in this sense relevant (Hoffenberg et al., 1997, p. 1321).

They go on to claim that "if patients in PVS are thought to be sentient or capable of experiencing pain, discomfort, or distress either before or after a decision has been taken to withdraw food and fluids, a strong case could be made on humane grounds for routine administration of palliative analgesic or psychotropic therapy" (Hoffenberg et al., 1997, p. 1321). This statement simply highlights how the further end of maximising organs can often obscure a patient's very life and humanity. It also emphasises the possibility of operating with a reckless disregard for human life. It also underlines the argument against causing either death or distress to the non-consenting incapacitated. It is not an argument in favour of killing him.

I have argued elsewhere that once tests like those of "rationality, autonomy and self consciousness" are used to determine who is a "*Person" (a technical term designed by utilitarians to achieve their greater ends), the sleeping, the comatose and the drunk are indeed properly regarded "non-persons." Indeed we all go in and out of "personhood" every evening. A fuller analysis of the moral implications of personism is beyond the scope of this paper but they are signal to an understanding of the principle of equal dignity. That the non-therapeutic intervention being suggested by Hoffenberg et al., was not merely minor intervention in which the patient may have a vested interest, but serious lethal intervention in which he had no possible interest whatsoever, was nowhere discussed.

There are, to be sure, hard cases when it comes to intervention on the mentally incapacitated. A person might need a blood transfusion or bone marrow transplant and her mentally incapacitated twin might be best placed to supply this regenerable tissue. Recently, it has been recognized that an incompetent can indeed have *vested interests* in certain non-therapeutic intervention. One useful case in this area is that of *Re Y.*[20] To say that a person has vested interests in the survival of a family member is very different to the possibility of wholesale organ harvesting from the incompetent favoured by Hoffenberg et al. First and foremost the "vested interest" analysis recognizes the needs and interests of the incompetent without first stipulating that the patient has "no best interests," "no meaningful life" or is some other form of "non-person." This after all, is one of the troubling features of the personism implicit in certain judgements of the *Bland* decision and the cases that apply *Bland*. Equally, it need not be thought impermissible to undertake medical procedures (that would assist medical research in licit ways) on non-consenting adults so long as those procedures were likely to be beneficial to the patient. This would avoid the discriminatory "no best interests," "no meaningful life" personist tests advocated by the maximising theories of Hoffenberg et al. Much could be said about this possibility but for the purposes of this paper, the discussion must be limited.

To argue in favour of non-therapeutic intervention on the non-consenting mentally incapacitated as Hoffenberg et al. have done, advocating removal of vital organs in the name of social utility, highlights the commercial, scientific and other

interests involved in this area. It also suggests the kinds of limiting case one ought to keep in mind when examining matters of principle.

There is explicit reference in para. 6.18 of the recently published 2007 Code of Practice (attaching to the *Mental Capacity Act 2005*) to the need to take certain cases to the Court of Protection, unless there is an advance decision or attorney to make such decisions. The possibility of removal of organs from non-consenting patients and much more is explicitly mentioned in the Code.

Paragraph 6.18 states that:

> 6.18 Some treatment decisions are so serious that the court has to make them – *unless the person has previously made a Lasting Power of Attorney appointing an attorney to make such healthcare decisions for them or they have made a valid advance decision* to refuse the proposed treatment. The Court of Protection must be asked to make decisions relating to:
>
> - the proposed withholding or withdrawal of artificial nutrition and hydration from a patient in permanent vegetative state
> - cases where it is proposed that a person who lacks capacity to consent should donate *an organ* or bone marrow to another person
> - the proposed non-therapeutic sterilisation of a person who lacks capacity to consent (for example for contraceptive purposes)
> - cases where there is a dispute about whether a particular treatment will be in a person's best interests (Code 2007, para. 6.18 p. 99).

Paragraph 6.19 states that:

> 6.19 This last category may include . . . untested and innovative treatments . . . where it is not known if the treatment will be effective, or certain cases involving a termination of pregnancy. It may also include cases where there is a conflict . . . between professionals and family members which cannot be resolved in any other way (Code 2007, para. 6.19 p. 99)

Read in conjunction with the 2005 Act, its Code and the Clinical Trials Regulations the *Human Tissue Act 2004* also allows novel representatives to authorise grave decisions thereby inviting abuse, mutilation and homicide of the vulnerable often, we can assume, in ignorance and upon poor advice. (See especially *Human Tissue Act 2004 (Persons who Lack Capacity to Consent and Transplants) Regulations 2006/1659.*)

Given that decisions regarding dehydration, clinical trials, non-therapeutic research, sterilisation and abortion upon the non-consenting are, for the first time, in the hands of entirely novel parties, and often interested advisers rendered unaccountable, there is ground to believe that the interests of science and society are being permitted systematically to take precedence over the rights and dignity of the vulnerable incapacitated patient.

Repairing to sections 30 and 31 of the 2005 Act which authorise non-therapeutic research that has no potential to benefit P even without P's consent provided that the research is "intended to provide knowledge of the *causes or treatment of, or of the care of persons affected by the same or a similar condition,*" it is clear that the minimal requirements set out in the Code are far from adequate safeguards. The requirement that there "be no significant interference with the freedom of action or privacy of the person who lacks capacity, and nothing . . . done to or in

relation to the person who lacks capacity which is unduly invasive or restrictive" (Code 2007, para. 11.12, p. 207) does nothing to safeguard the incapacitated patient. Given that *Bland* makes it clear that a patient may be regarded as having "no best interests" and "no meaningful life" it is logically impossible to see what intrinsic reason could possibly be given for *not* performing invasive research. Such patients would suffer "no significant interference with their freedom of action or privacy" and since they had "no best interests" risks would indeed be, by definition "negligible."

There are good reasons to think that the numerous and diverse pieces of legislation in this area both overlap and contradict one another. That analysis is beyond the remit of this paper. If true, it would be natural to infer further independently based injustice to the vulnerable non-consenting. As in other areas, contradiction, inconsistency and lack of clarity in the articulation of law are the blithe companions of injustice.

Articles 2, 3, 8 and 14, suggest that States have a duty to protect against human rights violations notwithstanding any potentially advantageous end. Legislation that promotes non-consensual non-therapeutic research, experimentation, organ removal, mutilation and homicide itself, on the inherently discriminatory ground that a non-consenting mentally incapacitated person is a "non-person" living a worthless life, suggests human rights incompatibilities. On any analysis, treatment that is experimental may be inhuman if it is found to be detrimental.[21] To permit research procedures to be carried out on a patient who lacks capacity to object, where there is no requirement to act in the best interests of such a person and where research may not even be of any personal benefit to the patient, is certainly capable of constituting degrading or inhuman treatment within the meaning of Article 3 of the ECHR. Moreover, it is arguably also an affront to dignity and a breach of Article 14 of the ECHR, which prevents discrimination in the enjoyment of Convention rights. The discrimination also arises here between incapacitated patients who have capacity to object to research procedures taking place on them and those who have no such capacity. The distinction between those who have the capacity to object and articulate an objection to research being conducted on them and those who have no such capacity is an arbitrary one with respect to the enjoyment of Convention rights and therefore bears the hallmarks of discrimination envisaged by Article 14. Whether or not research on the mentally incapacitated in fact furthers the ends of social utility, scientific research or those who desperately need organs, cannot obscure the legitimate interests of the vulnerable incapacitated. There is every reason to regard these novel alterations to the positive law of England and Wales as an affront to the dignity of the individual and a breach of the ECHR.

Plainly for the same reasons, and *a fortiori*, laws permitting intentional dehydration are arguably also incompatible with Articles 3 and 14. Intentionally dehydrating a patient to death, even with analgesic pain relief, is a form of the very worst kind of inhuman and degrading treatment. It is a distressing death both to undergo and to observe: the tongue goes black, the eye sockets dry out, the skin also dries and flakes. It is often at such a point that deeply disturbed relatives begin to press for

euthanasia and a swift death by lethal injection. Accordingly, the process becomes self-fulfilling. Because "the decision (to dehydrate) has been taken," there is resultant distress to the patient and onlookers. The distress is then used as a rationale for arguing "in favour of a more expeditious mode of death, for example, administration of a lethal drug."

This was Kuhse's strategy in the mid-eighties when at the Fifth Biennial Conference of the World Federation of Right to Die Societies held in Nice, she suggested that once people accepted the removal of all treatment and care—especially the removal of food and fluids—they would upon observing what a painful way it was to die, accept the notion of the lethal injection (Marker, 1993, pp. 94, 267). Kuhse's strategy is probably well-founded. Rather than asking the question about the wisdom and justice of dehydrating "non-persons" to death, a willing populace already seduced by the language of consumerism is likely to call for state sanctioned medical killing.

Further, the decision to dehydrate a patient in turn raises Hoffenberg et al.'s question about "the possible use of organs from those patients in whom a decision has already been taken." Usefully too, the organs are fresh because the body is still alive and has not been subject to dehydration (Hoffenberg et al., 1997, p. 1321). Thus the cycle of death becomes self-perpetuating and, indeed, fuelled by interests in medical research, clinical trials, eugenics (implicit in sterilising and aborting the young of the "non-productive, unfit") and state efficiency.

To argue for the intentional dehydration of PVS patients or the administration of a lethal injection, I suggest, is to argue for the routine abandonment of the most fundamental of rights under the European Convention on Human Rights which itself came into existence precisely because these very same rights had been so flagrantly and systematically violated in 20th century Europe.

4.7 Other International Law

Shortly after the war, various international instruments supported a total ban on non-therapeutic research on the mentally incompetent. These included the Nuremberg Code (1947) at 1 "The voluntary consent of the human subject is absolutely essential." The World Medical Association Declaration of Helsinki: Recommendations Guiding Physicians in Biomedical Research Involving Human Subjects, adopted by the 18th World Medical Assembly, Helsinki Finland, June 1964 required that "[i]n research on man, the interests of science and society *should never* take precedence over the interests of the subject."[22] Other Covenants seeking to prohibit utilitarian invasions on the non-consenting included the International Covenant on Civil and Political Rights (G. A. Resolution 2200 (XXI), 999 U.N.T.S. 171 [1966]), article 7 which stated that "No-one shall be subjected without his free consent to medical or scientific experimentation." The World Health Organizations, Guidelines for good clinical practice for trials on pharmaceutical products (1995) WHO Technical Report series No. 850, Annex 3 at 3.3 (f) and (g) also articulate outright prohibitions on non-therapeutic research without express consent. Likewise there is hope for the vul-

nerable incapacitated in the Convention on the Rights of Persons with Disabilities which contains numerous re-statements and clarifications of some of the protections already mentioned: the right to life (Article 10), freedom from medical and scientific experimentation without consent (Article 15), freedom from exploitation and abuse (Article 16(5)), respect for physical and mental integrity on an equal basis with others (Article 17), retention of fertility on an equal basis with others (Article 23(1)(c)), freedom from discriminatory denial of health care or food and fluids on the basis of disability (Article 25 (f)). This Convention manifestly opens up new avenues for challenging the kinds of abuse, mutilation and homicide apparently licensed by the 2005 Act and related legislation.

It should not be assumed, however, that all international law favours the interests of the disabled. The 2000 Helsinki Declaration by contrast outlines the following:

> 2. It is the duty of the physician to promote and safeguard the *health of the people*. The physician's knowledge and conscience are dedicated to the fulfilment of this duty.
>
> 3. The Declaration of Geneva of the World Medical Association binds the physician with the words, "The health of my patient will be my first consideration," and the International Code of Medical Ethics declares that, "A physician shall act only in the patient's interest when providing medical care which might have the effect of weakening the physical and mental condition of the patient." (This latter no longer appears in the updated version of the I.C.M.E.)
>
> 4. Medical progress is based on research which ultimately must rest in part on experimentation involving human subjects.
>
> 5. In medical research on human subjects, considerations related to the well-being of the human subject *should take precedence* over the interests of science and society . . ..
>
> 26. Research on individuals from whom it is not possible to obtain consent, including proxy or advance consent, should be done only if the physical/mental condition that prevents obtaining informed consent is a necessary characteristic of the research population. The specific reasons for involving research subjects with a condition that renders them unable to give informed consent should be stated in the experimental protocol for consideration and approval of the review committee. The protocol should state that consent to remain in the research should be obtained as soon as possible from the individual or a legally authorized surrogate.

The absolute prohibitions have been removed. The duties of the doctor relate in part to "the health of the people" not that of his "patient". The International Code of Medical Ethics articulates an incoherent duty of physicians. The demands of medical progress alone are outlined in unmistakable terms.

There is now growing international support for the view that non-therapeutic research can be legitimately conducted without prior consent. This view is reflected in paragraph 4.8.14 of the 1996 guidelines of the self-styled *International Conference on Harmonisation of Technical Requirements for Registration of Pharmaceuticals for Human Use*, Article 26 of the 2000 version of the *Helsinki Declaration and the European Convention on Human Rights and Biomedicine* (the Biomedicine Convention), interpreted by reference to its Additional Protocol concerning Biomedical Research (see Council of Europe 1997, 2005). The most recent of these is the Additional Protocol to the Biomedicine Convention, which opened for signature on 25 January 2005. While the UK has neither signed the Biomedicine Convention, nor its Additional Protocols, the explanatory notes to the *Mental Capacity Act* suggest

that the Act's research provisions are based on those laid down in the Biomedicine Convention (para. 96). The Convention could also have an interpretative impact on the ECHR, as given domestic effect by the *Human Rights Act 1998*. In short, Article 17(2) of the Biomedicine Convention permits research that will not benefit the participant, as long as it is intended to benefit those with the participant's condition or of the same age and satisfies certain risk requirements. The Convention thereby adopts provisions for research on all those who lack capacity that are similar to those adopted by the Clinical Trials Directive for children but not incapacitated adults. Emergency research is also addressed by the Additional Protocol concerning Biomedical Research, the provisions of which will constitute additional articles to the Convention once the Protocol is in force (Article 33 of the Protocol "Relation between this Protocol and the Convention"). Article 19 of the Protocol states that where the urgency of the situation renders it impossible to obtain consent in a sufficiently timely manner from the participant or a legal proxy, research may still take place on certain conditions. These require that research of comparable effectiveness cannot be carried out in non-emergency situations, the result is approved by the competent body, that the participant's previously expressed objections are respected, and research that is not intended to produce a benefit to the participant must seek to *benefit persons in the same population* and entail minimal risk and burden (Article 19(2)).

International law is as good as those who make and apply it. I will venture to say that it is quite possible that some of the research and intervention contemplated is indeed minor and justifiable. However, the scientistic concerns of recent conventions are unmistakable and given the utilitarian thrust of positive international law and domestic law like *Bland* (which highlights the kind of reasoning being applied in respect of patients thought "grotesquely alive" with "no best interests of any kind"), it cannot safely be supposed that the interests of science and society would not take precedence over the interests of those regarded as having none. If a patient has no best interests of any kind, then logically speaking, virtually anything may be done to him, so long, perhaps, as it does not upset onlookers. It is this logical progression of the "no best interests" argument that constitutes the mechanism by which assault, experimentation, mutilation and homicide ensue.

It is precisely because of the dubious reasoning evinced by thinkers as eminent as certain judges in *Bland*, the International Transplant Ethics Committee (i.e. Hoffenberg et al., 1997) and renowned utilitarians writing on this subject, that we cannot suppose that attempts to foster research and other financial interests would be performed in a manner consonant with the inherent dignity of all human beings irrespective of disability. Accordingly, in relation to "non-persons" or those having "no best interests" and no "meaningful life" the trumping power of illicit financial, medical and scientific interests should not be underestimated.

4.8 Conclusion

The experience of the twentieth century bears witness to the abuse, mutilation and homicide of the vulnerable made possible by the power of the state, mass markets, and medical and financial interests. Suggestions for reform of the law regarding food and fluids typically take place in the context of utilitarian personistic "quality-of-life" presuppositions, and interests in shifting legal responsibility for life-and-death decisions, medical research, drug trials, organ harvesting as well as more mundane bureaucratic concerns like bed-clearing. With the Western world undergoing massive demographic change and a growing ageing and non-productive population, it cannot be assumed that these alterations to the positive law are problem-free. By allowing new agents power to require that food and fluids be withdrawn, non-therapeutic research and other procedures (like abortion and sterilisation) be performed on non-consenting patients, novel legislation such as that discussed cannot be regarded as autonomy enhancing so much as a threat to human rights. These laws although touted as progressive, more often than not invite routine abuse and destruction of the vulnerable, obscure accountability and create an inconsistent body of law, with conflicting obligations for health professionals.

Notes

[1] The *Adults with Incapacity (Scotland) Act 2004* governs the position in relation to Scotland. I concentrate on the sweeping changes introduced in England and Wales for the purposes of this paper. A broader study would consider the position throughout Britain and Europe.

[2] *Frenchay Healthcare NHS Trust v S* [1994] 1 WLR 601; *Re D (Adult: Medical Treatment)* [1998]1. FLR 411; *Re H (A patient)* [1998]2 FLR 36; *NHS Trust A v M; NHS Trust B v H* [2001] 1 All ER 801.

[3] See also: Zeman (1996, p. 144): "It is difficult to establish with certainty whether a patient is unaware, which is underlined by the high rates of misdiagnosis in PVS."

[4] Stokes, P. (1997) 'Hillsborough victim emerges from coma' *The Daily Telegraph* Thursday 27 March.

[5] In one case a young woman was able to communicate her desire to live days before a court was due to hear an application to remove her tube-feeding. Lightfoot, L. and Rogers, L (1996) 'Dead woman casts vote for right to stay alive' 7 January *The Sunday Times*; Cramb, A. (2002) 'GP who survived coma sues hospital' *The Daily Telegraph* 6 September; See also Laing, (2002, p. 1272).

[6] Sample, I (2006) 'For first time doctors communicate with patients in PVS' *The Guardian* 8 September; Owen et al. (2005 pp. 290–306) Owen et al. (2006, p. 1402) Cohen, J. (1996) 'Coma Patient Back From Dead' *The Daily Telegraph* 13 February; Anon, (1994) 'Coma Man: I was awake' *Evening Standard* 8 December; McFadyean, M. (1992) 'Lifelong Support' *The Independent* 29 November. Melanie McFadyean writes: "Mark's experiences complicate issues about the apparent quality of life sustained by people in PVS . . ." I could hear my friends talking, he says" I remember people saying things about me and they were wrong – I couldn't answer, of course. You feel a raging anxiety."; Toy, M. (1996) "Miracle Men" *The Sunday Telegraph* 24 March.

[7] See also *NHS Trust, A v M; NHS Trust, B v H* [2001] 2 FLR 3671, FD; *NHS Trust A v H* [2001] 2 FLR 501 (Dame Elizabeth Butler Sloss), *NHS Trust v I* [2003] EWHC 2243, Dame Elizabeth Butler-Sloss, *Re G (Adult Incompetent: Withdrawal of Treatment)* (2002) 65 B.M.L.R. 6 2001 WL

1819861 (Dame Elizabeth Butler-Sloss). In *Re G* the evidence of one expert witness was accepted both as to the severity of G's condition and as to her complete inability to recover from it. She had apparently "exhibited no meaningful response for over nine months."

[8] For a fuller discussion of personism, the idea that some human lives are worthless, a term, in any case, reminiscent of the "*lebensunwerten Lebens*" concept employed by the Nazis in mid-twentieth century Germany, (see Laing, 1996, pp. 196–225).

[9] R v *Gibbins and Proctor* (1918) 13 Cr. App. R. 134. See also Laing (1994, pp. 57–80).

[10] See the long established principle of double effect referred to in *Pretty* by Lord Bingham. He observed that the common law recognizes the principle of double effect: "Under the double effect principle medical treatment may be administered to a terminally ill person to alleviate pain although it may hasten death. . . . the case of *Bland* involved a further step . . . see also *NHS Trust v H* . . . These are at present the only inroads on the sanctity of life principle in English law." He also adds in the same paragraph "mercy killing in the form of euthanasia is murder and assisted suicide is a statutory offence punishable by fourteen years imprisonment." R (*Pretty*) v *DPP and the Home Secretary* (2002) 1 All ER 1, para. 55 per Lord Bingham.

[11] Archbishop Peter Smith and Finnis, (July, 2004). Indeed, on December 14, 2004 the intervention of Roman Catholic Archbishop Peter Smith (December, 2004) ensured that the Bill was passed in the House of Commons without amendment and without delay. Delay might have scuppered the Bill because parliament was soon to be dissolved for the coming election. *The Daily Mail* had this to say, the following morning: "It gets worse. When [Blair's] political thuggery seemed likely to backfire, he offered an apparent concession to critics. But MPs only learned of it minutes before the debate ended, when in farcical 'Parliamentary games' they were handed copies of a letter from Lord Chancellor Lord Falconer to a Catholic Archbishop setting out the terms of a possible deal. So it comes to this. Ministers refuse to compromise in Parliament, but stitch up a private understanding with a churchman, which they then use to get the Bill through unamended. It stinks. And those MPs who swallowed the party line should be ashamed of themselves. The only hope is that the Lords will give this wretched measure a mauling." In fact, the mauling in the Lords never transpired. The Bill was passed. Parliament was promptly dissolved for the election. Leader writer, (2004) 'Conscience and Abuse of Power,' *The Daily Mail*, 15 December, p. 12. See also: Ann Treneman (2004) 'No dignity in this sorry victory' *The Times*, 15 December, p. 6. Compare Laing, 2004a, p. 1165; 2004b, p. 12; 2005a, p. 11; 2005b, pp. 137–145.

[12] See also Cottingham (1996, pp. 128–143).

[13] (http://news.bbc.co.uk/1/hi/health/6353339.stm).

[14] (S.I. 2004/1031).

[15] *Medicines for Human Use (Clinical Trials) Regulations 2004* Schedule 1 Part 5 Regulation 12.

[16] Schedule 1 Part 5 Regulation 9.

[17] Nicholson, (2004 p. 1212).

[18] Harris (1992, pp. 104–107); Singer, (1994).

[19] See Singer, (1979, p. 12); cf. Laing, (1996 pp. 196–225).

[20] *Re Y* commentary (1996) *Medical Law Review* 205–207. It is useful to consider by analogy the position in relation to incompetent minors. In the US, the courts have authorised several forms of donation by minors aged seven and younger. In *Hart v Brown* 289 2 Ad 386 (1972) [29 Conn. Supp. 368, 289 A.2d 386 (Super Ct. 1972)] donation by a 7 year old to his twin was authorised. In *Cayouette v Mathieu* [1987] RJQ 2230 (Sup. Ct.) donation of bone marrow by a 5 year old to his brother was authorised.

[21] *X v Denmark* 1983 Application No 9974/82 32 DR 282.

[22] World Medical Association, *Declaration of Helsinki: Recommendations Guiding Physicians in Biomedical Research Involving Human Subjects*, adopted by the 18th World Medical Assembly, Helsinki Finland, June 1964. Recent alterations to the Declaration merely highlight the novelty of recent moves to permit what was, at one time, regarded as unthinkable.

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