# δ Articles

# THE MENTAL CAPACITY BILL 2004: HUMAN RIGHTS CONCERNS

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The Mental Capacity Bill 2004 (the Bill) represents the culmination of efforts to enact wide-ranging legislation in respect of the mentally incapacitated to encompass the management and control not merely of their financial affairs, but also, more controversially, of their healthcare and medical treatment. Defenders of the Bill argue that it empowers mentally incapacitated patients by allowing them to make decisions for themselves, first, by way of court appointed deputies and attorneys authorised to make treatment and other decisions on their behalf, and, secondly, by way of legally binding advance statements. It is argued that the Bill goes no further than the common law already does and in no way licences abuse, exploitation or homicide of the vulnerable incapacitated.

Since the Bill's first reading on 17 June 2004, however, human rights concerns have been articulated about certain premises upon which the Bill is founded. Despite being many years in the making, the Bill's rationale and methodology has been called into question in two cases: *R (Burke) v General Medical Council* [2004] EWHC 1879 (Admin), [2004] 2 FLR 1121 and *HL v United Kingdom* (Application No 45508/99) (unreported) 5 October 2004. The 23rd Report of the Joint Committee on Human Rights (29 November 2004) suggests the need for radical revision before the Bill can be regarded as compatible with the European Convention for the Protection of Human Rights and Fundamental Freedoms 1950 (the European Convention).

## BACKGROUND

The Law Commission first introduced its Report and *Draft Bill on Mental Incapacity* in 1995 (Law Commission Report No 231) under a previous Conservative government. The proposals attracted much opposition and were soon dropped. The new government reintroduced the proposals with *Who Decides?* (Cm 3803), the consultation paper of December 1997, and *Making Decisions* (Cm 4465*)* the 1999 statement of government policy. The Mental Capacity Bill 2004 was introduced in the House of Commons on 17 June 2004 and has continued to excite debate. Representatives from all shades of the political spectrum have voiced concerns over potential human rights incompatibilities implicit in the Bill. At third reading, concerns articulated by Claire Curtis-Thomas were reinforced by such diverse political figures as Iain Duncan Smith, Frank Field, Sir Gerald Kaufman, Sir John Butterfill, Dr Brian Iddon and others. Among the more controversial clauses of the Bill are those that permit:

- removal of 'treatment' which, after the controversial decision in *Airedale NHS Trust v Bland* [1993] AC 789, includes tube and, in certain cases, also spoon-feeding;
- third parties (such as attorneys (cls 9–14), court appointed deputies (cls 15–21) and those claiming to know the advance decisions (cls 24–26) of the patient) to demand that health professionals, on pain of an assault charge, remove and withhold 'treatment' (including food and fluids);
- controversial procedures like non-voluntary sterilisation and non-voluntary abortion (now permitted only on court order *Re F (Mental Patient:*

*Sterilisation)* [1990] 2 AC 1; *Re MB (Medical Treatment)* [1997] 2 FLR 426 respectively) to be performed on people suffering from mental disabilities, at the behest of novel third parties;

- non-therapeutic research to be performed on certain mentally incapacitated patients without their consent (cl 30);
- the abolition of 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 affords none of the transparency, requirement of representation, ordinary appeal and procedural form demanded by a genuine court;
- arbitrary deprivations of liberty occasioned by insufficient procedural safeguards outlined in *Winterwerp v Netherlands* (1979) 2 EHRR 387 and the recent case of *HL v United Kingdom* (Application No 45508/99) (unreported) 5 October 2004; and
- easily alterable Codes of Practice to be used to specify matters that affect the law of homicide and assault thus suggesting an absence of procedural safeguards against abuse of fundamental human rights.

The recent 23rd Report of the Joint Committee on Human Rights confirms a number of these concerns. Although welcomed by numerous parties such as the Making Decisions Alliance, the Law Society, as well as the Voluntary Euthanasia Society, the Bill is opposed 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 and anti-eugenics organisations also oppose the Bill.

## HUMAN RIGHTS IMPLICATIONS OF THE BILL

Among the key human rights concerns outlined in the Committee's Report are the right to life under Art 2 of the European Convention, the right to dignity and personal autonomy protected by Arts 3 and 8 of the Convention, the right to liberty protected by Art 5 and the right not to be discriminated against in the enjoyment of any of these rights particularly, in this context, on grounds of mental disability (Art 14).

## WITHHOLDING OR WITHDRAWING LIFE-SUSTAINING TREATMENT

Clauses 24–26 of the Bill make provision for the removal of life-sustaining treatment upon the demand of certain specified persons. The Joint Committee points out that, as a result, it raises issues of compatibility with the right to life under Art 2, the right not to be subjected to inhuman of degrading treatment under Art 3 and the right to physical and moral integrity under Art 8 of the European Convention. Among the questions highlighted in this regard is the important matter that the 'classification of "artificial nutrition and hydration" as "treatment" may not be well known to lay people' (at para 2.46). In fact, this point demands further elaboration. For the landmark decision that makes this point about terms is also the case that suggests that tube- and in certain circumstances spoon-feeding is also to be regarded as 'treatment' and thus properly withheld or withdrawn.

It was the *Bland* decision (above) that first established the principle that it could be lawful for artificial feeding and fluids to be withheld from a man who was not dying with the aim of bringing about his death because he was diagnosed as in a persistent vegetative state and judged to be 'grotesquely alive' (Lord Hoffman, at 863) and having 'no best interests of any kind' (Lord Mustill, at 897). The case was subject to scathing criticism at the time (see John Finnis, 'Bland: Crossing the Rubicon' (1993) 109 LQR 481; John Keown, 'Restoring the Intellectual and Moral Shape to the Law after *Bland*' (1997) 113 LQR 481). Subsequent findings that 40% of cases of permanent vegetative state (PVS) were misdiagnosed (1996) 313 BMJ 13 and the subsequent emergence from a state diagnosed as 'PVS' of Andrew Devine another Hillsborough victim some years after *Bland* was decided, supplied fuel to the fire of criticism of the case ('Hillsborough victim emerges from coma' reported in the *Daily Telegraph*, 27 March 1997). Nonetheless, it should be pointed out that the *Bland* decision has been applied and extended to those not in a PVS but 'tracking' (able to watch objects) and evincing a menace response, in cases such as *Re D (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] Fam 348. First, it should be mentioned that the very use of the language of 'vegetative state' is thought by disability rights advocates to involve unfair discrimination against people with certain kinds of severe disability. It is argued that no human being, however impaired, is a vegetable, that every human being has intrinsic dignity and use of the language is itself evidence of the process of dehumanisation characteristic of eugenics and discrimination against the disabled. This point aside, one of the principal objections to the *Bland* judgment was precisely that the decision of the majority for the first time involved the UK courts in discriminatory judgments about what constituted a 'worthwhile life' with a view to permitting intentional killings by omission of those deemed to be worthless, to have no best interests or a best interest in being killed.

The notion of equal dignity is one that informs much international and pre-*Bland* domestic law, as well as ancient professional norms, such as the Hippocratic oath. Prior to *Bland* it was commonly thought that it was not for judges to make judgments about the value of a victim's life before deciding whether it could be intentionally shortened. The notion of the 'life worthy of life' was in any case reminiscent of the Nazi notion of the 'lives unworthy of life' or '*lebensunwerten Lebens*' an arbitrary concept manufactured to relieve the State of the non-productive and put them to use in medical research and asset redistribution schemes. Critics pointed out that the majority judges in *Bland* had undertaken this subjective task and come up with their own definitions of the notion thus involving the courts in discrimination against the severely disabled and infringing the principle of equal dignity (see Finnis, above). It was suggested that whereas it would be appropriate to consider the worth of *treatment* as possibly futile, over-burdensome to the patient, or over-expensive, it was inappropriate and discriminatory to undertake an enquiry into the futility, burden or expense of a person's *life*. The former investigation involved no unacceptable eugenics or discrimination and was instead a perfectly licit determination about treatment.

The decision in *Bland*, however, has been applied and extended. Importantly, it has introduced the idea of bringing about a patient's death intentionally albeit by omitting to feed the patient. Since many patients in a PVS are able to be fed by spoon, it has been pointed out that the withholding and withdrawal of tube-feeding (or artificial nutrition and hydration) is not all that is implied by the *Bland* judgment, but also, in certain circumstances, spoon-feeding (Finnis, above).

Because the Bill introduces the concept of third parties newly empowered to remove 'treatment', which after *Bland* includes food and fluids and introduces the notion of third parties empowered to authorise 'treatment' in a patient's 'best interests', it must inevitably widen the scope of *Bland* in ways that spell danger to vulnerable incapacitated patients. A refusal of 'treatment' by an attorney, court appointed deputy or third party claiming to know the advance decisions of the patient would, in the absence of time-consuming Court of Protection proceedings, legally bind health professionals, on pain of an assault charge, not to feed the patient and not to administer simple cures, such as antibiotics and insulin. As the law stands at present, if health professionals were to withhold food and fluids or ordinary treatment such as insulin, negligently, recklessly or with the intention of bringing about the death of the patient, staff might be subject to criminal charges, proceedings in tort or disciplinary proceedings. After the Bill, they would be subject to such proceedings for any act of intervening to save the life of the patient.

It is true that the law has until very recently recognised up-to-date advance refusals of treatment by the patient. In

*Re AK (Medical Treatment: Consent)* [2001] 1 FLR 129, for example, it was thought to be significant that:

> '[i]n the present case, the expression of AK's decision are recent and made not on any hypothetical basis but in the fullest possible knowledge of impending reality.'

The Bill, however, radically alters the scope of advance decisions. As at the time of writing this article, the Bill contains no requirements that advance refusals be up-to-date nor that they even be so much as written and signed in the presence of witnesses who can testify to the freedom and understanding of the patient in making the decision to refuse treatment. This may be remedied when the Bill appears in the House of Lords.

Not surprisingly, therefore, the Joint Committee Report points out that it should be understood that advance decisions to refuse treatment do not include refusals of food and fluids delivered by tube and that 'this should mean in practice that a specific advance refusal of [artificial nutrition and hydration] would be required in order to be effective' (at para 2.46). It also suggests that this general presumption against advance refusals of 'treatment' including food and fluids should also be incorporated into the codes of practice (at para 2.46).

On 30 July 2004, after the Bill received its first reading, the High Court handed down an important judgment declaring unlawful certain General Medical Council guidelines on withholding and withdrawing tube-feeding (and in certain cases also spoon-feeding) from patients. In *R (Burke) v General Medical Council* [2004] EWHC 1879 (Admin), [2004] 2 FLR 1121, the High Court held that the General Medical Council guidelines, *Withholding and Withdrawing Life-Prolonging Treatment: Good Practice in Decision-Making*, were unlawful. The guidance was defective because it allowed that artificial food and fluids could be withdrawn from patients who are not dying, if they are in 'a very serious condition' and because it failed to protect against breaches of Arts 2, 3 and 8 of the European Convention. Reporting on the human rights implications of the Bill, the Joint Committee is likewise concerned that in relation to the removal of 'artificial nutrition and hydration', the:

> 'presumption in favour of life-sustaining treatment is not sufficiently strong in the Bill to satisfy the requirements in Arts 2, 3 and 8 as explained by the High Court in *Burke*.' (at para 2.51)

They also indicate that an attorney might not appreciate that 'artificial nutrition and hydration' counts as 'treatment' and that 'health care professionals will be obliged to comply with such consent by the attorney, even if they believe it to be contrary to the best interests of the patient' (ibid).

## NON-THERAPEUTIC RESEARCH

Among other concerns expressed by the Joint Committee are those in respect of research on non-consenting mentally incapacitated patients permitted in cls 30–33. It tests these clauses against the Council of Europe's Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine 1997, a document criticised for its failure to take seriously the prohibitions on non-therapeutic research and procedures on the non-consenting mentally incapacitated as outlined in the Nuremberg Code and the original Declaration of Helsinki, both of which placed a complete ban on non-therapeutic research on the non-consenting mentally incapacitated. The most recent expression of the Convention is regarded by critics as placing commercial and scientific demands over those of human dignity.

Even tested against the relatively undemanding requirements of the 1997 Convention, the Joint Committee suggests the inadequacy of safeguards provided in the Bill. It regards the introduction of the reference to there being 'reasonable grounds' for believing that the research would be less effective if carried out only on persons with capacity as diluting conditions contained in the 1997 Convention. It also maintains that the absence in cl 31(4) of the potential benefit being 'real and direct', that the breadth of the test suggested and the absence of language that suggests that this research should only be conducted in 'exceptional circumstances' is unacceptable. The Committee also criticises the failure of the Bill to specify the 'appropriate authority' empowered to licence such non-therapeutic research and how it will go about deciding whether to approve a research project on a non-consenting individual. Accordingly, it suggests that there is a failure of the procedural protections required by the 1997 Convention.

## ARBITRARY DEPRIVATIONS OF LIBERTY

The Joint Committee also indicates that permission to use or threaten force or other restrictions of liberty of movement constitutes an Art 5(1) breach. Clauses 5 and 6 could be used to force informal admissions to hospital for treatment of persons lacking capacity to make decisions about their treatment and resisting admission to hospital. In this case the individual would be deprived of the procedural safeguards which come into force when a patient is compulsorily admitted under the Mental Health Act 1983. This would constitute a deprivation of liberty incompatible with Art 5(1) because it would not comply with conditions outlined in *Winterwerp v Netherlands* (1979) 2 EHRR 387, at para 39, that deprivations of liberty be based on objective medical expertise and the least restrictive alternative available. Accordingly, it is suggested, the Bill does not contain procedural safeguards against arbitrary deprivations of liberty and, the Committee adds, nothing in cl 28 which deals with the relationship between the Mental Health Act 1983 and the Bill rectifies this inadequacy.

Another issue of compatibility arises out of the decisions of the courts in *R v Bournewood Community and Mental Health NHS Trust ex Parte L* [1999] 1 AC 458. The question in that case related to whether a person who lacks capacity to consent to medical treatment had been unlawfully detained when he was admitted to hospital informally and did not object to admission. The House of Lords had held that such persons could be informally admitted under s 131(1) of the Mental Health Act 1983 without the formalities for admission necessary for detention under the Act. The recent judgment of the European Court of Human Rights demonstrates that this is not so. The Joint Committee agrees that:

> 'the Government cannot maintain that the current position is Convention compatible and proceed with the adoption of new legislation premised on that assumption.' (at para 2.42).

In short, the decision in *HL v United Kingdom* makes it clear that the failure to provide procedural safeguards to people recognised to be excluded from safeguards will give rise to future findings of Art 5 incompatibility. The Joint Committee states baldly that they are:

> 'concerned at the apparent remedial measure following the judgement in *HL v UK* … It is obviously undesirable for the present Bill to proceed to enactment on its original assumption that there was no *Bournewood* gap to be filled.' (ibid)

## NON-VOLUNTARY ABORTION AND STERILISATION

Just as the controversial *Bland* judgment, read in conjunction with the Bill, appears to suggest wide scope for abuse of the vulnerable, *Re F (Mental Patient: Sterilisation)* [1990] 2 AC 1 and *Re SG (Medical Treatment)* [1991] 2 FLR 329 suggests further cause for disquiet. *Re F* authorises non-voluntary sterilisation of mentally incompetent non-consenting patients while *Re SG* authorises non-voluntary abortion of their offspring. As with *Bland*, these procedures are currently being undertaken upon court order and not upon the requirement of novel third parties (although in the case of non-voluntary sterilisation, though not non-voluntary abortion, the Codes of Practice suggest that the Court of Protection should also be involved). Critics of these decisions suggest that these invasive procedures should never be performed on the non-consenting – as suggested by the original Declaration of Helsinki and the Nuremberg Code. It is argued that if an individual is not sufficiently rational or autonomous as to be able to consent to marriage, like a child, they should not be left open to sexual or physical abuse by predators. Disability rights groups opposing the Bill outlined above object to the widening of the scope for abuse of the mentally impaired in this area with the introduction of deputies, attorneys and others empowered to require these procedures. The practice itself, whether undertaken on an order of the High Court or with the consent of the less transparent Court of Protection or indeed other third parties, suggests Arts 3 and 8 incompatibilities.

## OTHER PROCEDURAL DEFECTS

Among other human rights concerns identified are those surrounding the Court of Protection. This organisation is not any ordinary court with requirements of representation by opposing parties, transparency, procedural form and ordinary right of appeal to a genuine court. Again, it raises the possibility of Art 5 incompatibilities of the kind outlined above. Likewise, Codes of Practice, because they are not legislative in character at all and are easily alterable, are also thought to be procedurally inadequate to safeguard against Arts 2, 3 and 8 violations (above). Hence they are argued to be a defective safeguard against human rights abuses.

## CONCLUSION

The human rights concerns identified in the recent cases of *Burke*, *HL v United Kingdom* and in the Joint Committee's Report are profound enough to suggest that the Bill has been drafted on false assumptions. They are not assuaged by minor amendments. Indeed, they are so fundamental and so comprehensive as to suggest a thorough reconsideration of the function and purpose of the Bill would be more appropriate. To press ahead with the legislation as an expression of political might would be to underestimate the potential for human rights violations so graphically outlined by the High Court, the European Court of Human Rights and the Joint Committee, and to treat with contempt the rights and interests of vulnerable incapacitated patients.