

**Submission from the Joint Ethico-Medical Committee
of
The Catholic Union of Great Britain
and the
Guild of Catholic Doctors
to
The Scrutinising Committee on
The Draft Mental Incapacity Bill 2003**

The Joint Ethico-Medical Committee is composed of members drawn from the two parent bodies. The Catholic Union is an organisation of the Catholic laity which is not affiliated to the hierarchy but which represents the Catholic viewpoint, where relevant, in Parliamentary and legislative matters. The Guild of Catholic Doctors represents Catholic Medical Practitioners in the United Kingdom.

Summary

In the Bill:-

- There is no legal definition of 'best interests', only a list of matters to be considered, with reliance on presumed wishes and feelings of the incapacitated patient.
- There is no provision of an independent second medical opinion or appeals process before taking matters to the court
- The lasting power of attorney has considerable power with no accountability. This opens the possibility of withdrawing nutrition and hydration or other measures with the intention of ending life. There needs to be a prescribed duty of care and accountability for decisions taken.
- There is no registration, validation of the authenticity or process to establish that an advance directive was made by a person whilst they had mental capacity.
- It appears that several of the recommendations are contrary to the articles of the European Convention of Human Rights

We consider that:-

- Advance directives should be advisory and not mandatory. Current case law is sufficiently robust to enforce advance decisions in circumstances that would be acceptable to all.

General points

1. In this submission we will restrict ourselves to those matters covered in the draft bill which affect the medical care of those with incapacity.
2. We welcome the principle of the Bill's proposed protection of the welfare needs of persons lacking capacity and the introduction of the principle of a 'general authority' where actions of medical personnel, which have previously been performed using the principle of 'necessity', will now have a legal basis.
3. We welcome the Government's statement made recently that there is no intention to change the law on Euthanasia, which will remain illegal. However we note that the Government definition of euthanasia is "A deliberate intervention undertaken with the express intention of ending a life..." (Annex C), whereas the Catholic understanding of euthanasia is "Euthanasia in the strict sense is understood to be an action or **omission** (our emphasis) which of itself and by intention causes death..." (*Evangelium vitae* 65). This may lead to serious issues of conscience for many healthcare staff in some situations of the withdrawal of nutrition and hydration, which we will refer to later in this submission.
4. The implementation of the Scottish Mental Incapacity Act has shown that the complexity of the legislation has led to difficulties in delivering good medical care; e.g. it has proved difficult to administer flu vaccine to demented patients without going through a complex administrative process. We therefore suggest that legislation affecting medical care in this area should be permissive, to be used only when necessary, rather than mandatory and applying to all medical care of mentally incapacitated patients. Eg – if there is a lasting power of attorney it could seriously hamper good medical care if consent had to be sought from the attorney for every medical decision taken.

Clause 2 – Inability to make decisions

5. We acknowledge that determining mental incapacity can be difficult and point out that in the context of a busy A&E department, the most that can be expected from busy junior doctors is an assessment of a patient's orientation in time, place and person using indices such as the 'Mini Mental Test' - a list of 10 simple questions. This gives a working indication of their mental state but has limitations and would not seem to constitute a formal assessment of mental incapacity according to this bill.
6. **Subsection 1 (b)** We suggest that not only does a patient need to retain the information, they also need to believe it. Eg a person suffering from paranoia. We also suggest that it is important to be confident that the patient does not feel either external or internal pressure which may hinder them in making a decision as in *Re: T (Adult: refusal of treatment)* [1992] 4 All ER 649 where it was deemed that the advance refusal of blood transfusion, by a pregnant Jehovah's Witness, had been invalid as it was made under duress.

Clause 4 - Best interests

7. We are seriously concerned that there is no legal definition of a person's 'best interests', but only a list of matters to be considered. It is important to clarify that in the healthcare setting the medical best interests, as determined by the patient's doctor, must be

taken into account. Once the patient's condition and circumstances has been assessed, a decision needs to be made taking any other relevant factors into account. However, we do not believe that the 'best interests' of the patient can be properly considered without regard to their clinical need.

8. The best interests of an individual can be regarded from different aspects. Healthcare professionals are primarily concerned with their patients' medical/clinical best interests, which are directed to preserving life and promoting good health. The purpose of medical treatment is to cure or alleviate a pathological process and is directed towards the restoration of physical and psychological wellbeing of the person and the alleviation of pain and suffering. Where life is approaching its natural end, treatment should be palliative.

9. We accept that a person with capacity can exercise their right of autonomy and act contrary to their best interest. However a difficulty arises when considering substituted capacity (either as a general authority or lasting power of attorney). There is no provision in this bill for the resolution of a conflict when the presumed wishes of an incapacitated patient are at variance with a common view, or a medical view, on what is in a person's best interest. The legislation needs to recognise that an individual's wishes may be very different from their 'best interests' particularly from a medical point of view. In the medical context there is a need for a quick and simple method to resolve conflicts between an attorney's and clinician's view on what is a patient's best medical interest, otherwise medical harm may be done.

10. **Clause 4 Subsection 2(a).** We suggest that this section is badly drafted. The explanatory notes indicate that the intention of this section is that if a period of incapacity is likely to be temporary, then delay in making a decision should be considered so that the person themselves can make the decision on recovery of the capacity. However, as the bill is written this clause could imply that what is in a person's best interests is dependent on whether they are likely to have capacity in the future, and as such can be construed to mean that those with permanent incapacity should be treated medically differently to those who are likely to regain mental capacity.

11. Limiting consideration to "his past and present wishes and feelings" is totally inadequate in the medical context. For instance, a depressed or suicidal patient may wish that his life should no longer continue and acceptance of this patient's wishes and desires would therefore lead to medical decisions against giving life sustaining or curative treatment.

12. **Clause 4, Subsection 4.** Doctors accept that patients have a right to refuse treatment, even though their reasons for doing so may be irrational. Healthcare professionals have a duty to provide best possible medical care and are accountable for a failure to do so. However, under this bill attorneys or deputies can make decisions to refuse treatment which are binding on healthcare staff, without any corresponding accountability for such decisions. We believe that the phrase 'if the person reasonably believes that what he does or decides is in the best interests of the person concerned' will be a unassailable defence against even the most gross violation of 'best interests'.

13. We suggest that the attorney must present firm evidence that he or she truly understands what they are proposing and that 'informed consent' is contemporaneously applicable; that is to the current situation.

Clause 6 - The general authority

14. We support the concept of general authority, and the provision of a legal authority to do what doctors have previously done under the “rule of necessity”.

15. The experience of some of our colleagues in Scotland has highlighted that the working of the lasting power of attorney has led to burdensome bureaucratic procedures which have impeded the administration of routine medical care. We would expect that most routine care will continue to be provided under common law.

Clause 7 - Restrictions on the general authority

16. **Subsection 1(a).** We commend the final paragraph of this clause. It is often necessary to restrain incapacitated patients when administering medication. For instance a diabetic suffering from hypoglycaemia may become extremely aggressive and the urgent administration of intravenous glucose, usually whilst restraining the patient, is vitally important and instantly curative.

17. **Subsection 2.** We are concerned that a decision by the donee of a lasting power of attorney will override the medical decision of the healthcare team. There is no provision in the Bill for a second independent medical opinion procedure in the case of disputes between the attorney and doctor. In Scotland, disputes are first referred to a second opinion doctor. If they cannot be resolved then interested parties can apply to the Court of Session to determine if the treatment may proceed. There is no such provision in the current Bill and disputes would need to be referred directly to the Court.

18. The courts have a primary role in addressing matters of law and not the merits of a particular medical treatment. We are concerned that when cases are referred to the court, it will, quite properly, concentrate on the legality of the decisions made by the donee of a lasting power of attorney and not properly address the merits of the medical treatment being disputed by the attorney, to the potential detriment of the patient. Hence our suggestion for an independent medical opinion or appeals process prior to any court process.

19. **Subsection 3.** The Catholic (and other religions) understanding of euthanasia is an act or omission to bring about the death of a patient. We believe that provision of food and fluids normally constitutes part of basic care necessary to sustain life. We believe that there are many circumstances where the removal of nutrition and hydration (including some cases authorised by the Courts) constitute euthanasia by omission and so are contrary to the conscientiously held views of many. The religious principles of a substantial body of those working in healthcare need to be preserved and upheld. In the same way that patient's religious views are accepted, so too the religious views of healthcare personnel must equally be respected.

Clause 8 – Lasting powers of attorney

20. We believe that medical management of the mentally incapacitated should remain with health care professionals who, as a matter of good clinical practice, should consult the patient's nearest relatives, carers and attorney. Involvement of the attorney should be regarded as evidence of acting reasonably under the circumstances. If the attorney is to be empowered to make clinical decisions, they also should be under a duty of care in civil law to

the patient for wrongful decisions. In Scotland, according to the Regulation of the Adults with Incapacity Scotland Act (2000), welfare attorneys have a duty of care under common law:-

“6.1 An attorney, guardian or other person acting under the Act is held at common law to owe a duty of care to the adult with incapacity. They must act with due skill and care in exercising the power they have been given in relation to the adult. A professional person acting as a proxy must demonstrate the skill and care that would be expected of a reasonably competent member of that profession.

6.2 An attorney has what is known as a “fiduciary duty” to the granter. This means that you are in a position of trust with repeat to the matters covered by your powers. The adult has placed trust in you to exercise the powers properly.”

Conflicts of Interest

21. The attorney will have the power to refuse medically advised treatment. The attorney may also have power over the patient’s financial affairs. The explanatory notes (Annex A, para 4) highlight that there may be financial abuse in 10-15% of enduring powers of attorney. There will certainly be circumstances where the family will benefit financially from the patient’s death, and under this bill the donee will now have the power to refuse treatment and so hasten that patient’s death. This potential conflict of interest is not addressed in this bill.

Clause 10, subsection 4

22. We suggest that there is an additional paragraph which specified that basic treatment and care cannot be refused. Basic care consists of those measures necessary to the survival of the person. (see also our comment on Clause 17 (d) below)

Clause 12, subsection 2

23. There is a contradiction between this section, which simply states “P may, at any time when he has capacity to do so, revoke the power”, whilst Paragraph 14, sub-paragraph 1(a) of Schedule 3, Part 4 states that “no revocation of the power by the donor is valid unless and until the court confirms the revocation under paragraph 15(3)”. This would certainly appear to prevent an immediate revocation of the kind which might be necessary in a medical emergency.

Clause 17, subsection (d) - Section 16 powers: personal welfare

24. We note that the Law Commission document 'Mental Incapacity' (Law Comm 231, 1995) stated that no court, attorney or deputy should be permitted to refuse 'basic care'. This is no longer present in the current bill. We support the original Law Commission recommendation and add that basic care not only includes food and fluids, but the continuation of ordinary care already being given - eg. we do not believe that it is acceptable to withdraw insulin from a long standing diabetic as part of the decision to withdraw medical treatment on the grounds that it is futile or burdensome.

25. We accept that the placing of a feeding tube should be regarded as a medical procedure, but we would argue that the administration of food and fluids through an established feeding tube is normally part of basic care and should not be regarded as ‘medical treatment’ which can be refused or withdrawn. (There are rare circumstances where the food

and fluids cannot be absorbed and so can be withdrawn as continuation of administration will not achieve its purpose)

Clause 23 - Advance decisions to refuse treatment: general

26. It is a key principle of informed consent and good medical practice that a patient must have an explanation of the risks and benefits of a specified treatment, as well as an explanation of the potential consequences of refusal of that treatment (if a patient indicates they wish to refuse treatment). We therefore accept in principle that a patient can give an advance refusal of treatment, but we would wish there to be a system of validation of such an advance refusal.

27. We believe that case law has already established the principles of advanced refusals, particularly the judgment of Mr Justice Hughes in the case *Re: AK* (High Court of Justice, Family Division: Hughes J. (2000) 58 B.M.L.R. 151; [2001] 1 FLR 129) and suggest that this judgement should be a basis for accepting advance refusals and specified in the Act. Mr Justice Hughes said:

"It is clearly the law that the doctors are not entitled so to act if it is known that the patient, provided he was of sound mind and full capacity, has let it be known that he does not consent and that such treatment is against his wishes. To this extent an advanced indication of the wishes of a patient of full capacity and sound mind are effective. Care will of course have to be taken to ensure that such anticipatory declarations of wishes still represent the wishes of the patient. Care must be taken to investigate how long ago the expression of wishes was made. Care must be taken to investigate with what knowledge the expression of wishes was made. All the circumstances in which the expression of wishes was given will of course have to be investigated. In 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."

28. In the majority of advance refusals of treatment, which are currently being proposed by various organisations, there is no way to establish what understanding the patient had of the risks and benefits of treatment, and more significantly whether they were fully aware of the consequences of refusal. Advance directives, rarely if ever, meet the standards of informed consent that is required from patients with capacity. The wording of the bill "...expressed in broad terms or non-scientific language." is an antithesis of case law and the principles expressed in other areas of the bill, i.e. that the circumstances and treatment must be specified.

29. There are regulations which must be adhered to in order to accept the validity of a last will and testament. This bill gives no indication of how the medical team are to assess the validity of an advanced refusal of treatment. The bill does not even specify that an advance decision needs to be in writing. Situations could be envisaged where the relatives would prefer that an aged incapacitated patient died. They may fraudulently prepare and present an advance directive worded so that it appears to be specific and applicable to the current situation. Without prior registration of such a document with medical authorities, where it can be validated that it truly was made by the patient and whilst they had capacity, how are the medical team expected to even make the simplest judgment about its validity?

30. When considering refusal of treatments in patients with capacity, the clinicians will verify with the patient that they understand implications of refusal, and established practice is that the patient is normally asked to sign that they are refusing such treatment. There is no way of assessing in an advance directive that the patient does understand the potential

consequences of refusal of treatment, even though they may have specified refusal of life sustaining treatment. It may well be that refusal does not lead to death but leads to worsening disability and increased suffering.

31. There is no logic in the bill limiting advance directives to refusal of treatment. It is now common medical practice to prepare a treatment plan for patients suffering with progressive degenerative diseases whilst they still have the capacity to make decisions. Such a treatment plan will include both therapy they would wish to receive as well as those they would wish to refuse. However such plans are regarded as advisory and circumstances may occur which would override the original treatment plans.

32. Another example where legally binding advance refusals of treatment can be dangerous is in women presenting their obstetricians with 'Birth plans' on how they would like their delivery to proceed – e.g. these may state refusal of forceps delivery etc. When the delivery is proceeding well such plans can be fully respected. However if complications then arise, it may be the case that the woman has already been sedated sufficiently to make her mentally incapacitated within the meaning of the bill, and adherence to the directives of the 'birth plan' could result in brain damage to or death of the baby. Clinicians in our own committee have direct experience of such circumstances.

33. For these reasons we strongly argue that advance directives should be respected as advisory documents, and we believe that current case law is sufficiently strong to allow patient's wishes to be respected, but equally allowing appropriate medical treatment to be given when the situation demands.

Clause 24 – Validity and applicability of advance decisions

34. Our preceding and following comments clearly explain our concern at the proposed legally binding nature of advanced directives as laid out in this bill. We clearly state our view that legislation will make it very difficult for practitioners faced with the need to make rapid decisions in acute medical emergencies to easily and clearly decide when an advance directive is valid and applicable. Fear of litigation may well result in doctors withholding appropriate care with resultant harm to the patient.

35. **Subsection 1(a).** There is no definition of what constitutes a valid advance decision, or how it is to be established.

36. **Subsection 1(b).** This should read at least 'clearly applicable to the treatment'

37. **Subsection 4(c).** This should read at least 'circumstances and treatment opportunities which were not clearly understood or clearly anticipated by P at the time.....'

Clause 25 - Effects of advance decisions

38. There has been extensive debate about the morality of the Bland judgment which declared that food and fluids can be regarded as medical treatment and therefore withdrawn. There is a considerable body of medical opinion that believe that elective withdrawal of nutrition and hydration given through an established feeding tube is euthanasia and therefore ethically unacceptable. This act gives no protection to those members of the healthcare team who hold such views as part of their religious/ethical convictions. We ask that the Act allows for those with conscientious objection to refuse the implementation of some forms of advance directive without the individuals concerned suffering any professional harm.

39. We accept specific advance refusals of treatment such as in Re: C, (Adult: refusal of treatment) [1994] 1 All ER 819) - the Broadmoor patient who refused an amputation, where the circumstances were present whilst the patient had capacity and the consequences of refusal were clearly explained. We also accept the principle that Jehovah's witnesses may wish to refuse all blood transfusions. We are strongly opposed to blanket refusals of a wide spectrum of treatments in a broad set of circumstances, that cannot be known about at the time the advance refusal is drawn up. We note that subsection 1 provides that "The advance decision will need to specify the treatment that is refused and may specify the circumstances in which the refusal will apply" (Explanatory notes). However, below is a typical format of an advance refusal currently being presented to doctors:-

5. If I have any condition described in paragraph 4, above, I direct that all procedures which might prolong my life be withheld or withdrawn, and that I be permitted to die with only the performance of any medical procedure necessary to provide me with comfort or to alleviate unnecessary pain. Specifically, but without limiting myself, I do not want surgery, medication (except pain relief), cardiopulmonary resuscitation, antibiotics, kidney dialysis, blood transfusions, radiation or chemotherapy, or a mechanical respirator.

6. I do NOT want my life prolonged by tube or other artificial feeding or fluids if my condition is as stated above in paragraph 4.

40. We believe that this is a broadly based blanket refusal of all treatment, which should not be regarded as valid, despite it specifying the circumstances and specifying refusal of almost all or any treatment. If such an all embracing list of refusals were to be acceptable under the present bill, proper treatment in accordance with medical criteria would effectively be excluded. We argue that the above example of refusal of treatment is made on a hypothetical basis without the fullest possible knowledge of the impending reality.

41. We can also envisage the scenario where a suicidal patient may prepare an advance directive which clearly specifies that they have taken a particular drug and then specify that they refuse to have their stomach washed out or receive the specific antidote to that drug. According to this bill, the circumstances and life saving treatment being refused will be very specifically addressed making that advance directive legally binding. The doctors will then be legally barred from attempting to resuscitate that patient. It could even occur that the overdose is not fatal, but that the patient is left with significant permanent and disabling organ damage. It is because of likely scenarios such as this that we oppose making advance refusals of treatment legally binding, other than in the circumstances already present under case law. (Re: AK quoted above)

42. **Clause 25 subsection 2.** We would suggest the addition of paragraph (c). 'he has reasonable grounds to doubt the validity of an advance directive.'

43. **Clause 25 subsection 3.** We propose that there must be some accountability for decisions made on behalf of the incapacitated. Granting immunity to one who withholds or withdraws treatment merely on the basis 'in the belief that that a valid advance decision is applicable.' and that 'his belief is reasonable' is an inadequate safeguard where life or death are in question. Furthermore it is not clear whether such 'belief' relates to the interpretation of an known advance directive or to the alleged existence of an unseen one.

Clauses 26 – 29. Excluded decisions

44. We would suggest the addition of clauses which state that no-one can make decisions relating to abortion, sterilisation or non-therapeutic research on behalf of a mentally incapacitated person.

Clause 30- Codes of practice

45. We submit that the codes of practice should be prepared at an early stage and presented as part of the legislation. In this way it can be seen how the Act is to work in practice, with particular emphasis of its impact in the day-to-day delivery of healthcare to those with mental incapacity. We fear that implementation of the bill may hamper delivery of good medical care, as is being experienced in Scotland with the working of their equivalent Act.

Clause 32 - Concealing or destroying advance decision to refuse treatment

46. The bill provides no criteria for the establishment of the validity or the date of an advance directive, so how can it be that a person can be found guilty of concealing or destroying another person's written advance directive?

Human Rights

47. We have been given an opinion by Mr Richard Gordon QC, a human rights lawyer, that the bill is contrary to the European Convention on Human Rights. Specifically he states that:-

- (a) The Mental Incapacity Bill is incompatible with Article 2 taken in conjunction with Article 6 of the European Convention on Human Rights because it fails to comply with the State's obligations under Article 2 to provide practical and effective protection of the right to life.
- (b) In particular, the concept of 'best interests' in the Mental Incapacity Bill is defined by reference to criteria that are, at least primarily, relevant to autonomy as opposed to best interests. The decision-making powers of the donee of the lasting powers of attorney are made by reference to such criteria but leaving an area of judgment to the donee that is neither statutorily defined nor protected by access to the Court within the meaning of Article 6. Similar concerns arise in respect of exercise of the general authority.
- (c) The machinery of recognition and implementation of advance decisions to refuse treatment are similarly contrary to Article 2 because they provide wholly inadequate protection for safeguarding the best interests of persons entitled to protection under Article 2 at the time that life saving medical treatment falls to be considered.
- (d) Article 14, protecting as it does against discrimination in the enjoyment of Convention rights, appears to discriminate between those incapacitated persons who can communicate objection to certain proposed conduct (see clauses 7 and 10) and those who cannot. Such discrimination is neither logical nor (therefore) objectively justified under Article 14.

Signed

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