

Response to the Draft Mental Incapacity Bill ¹

A Joint Submission
by the
Catholic Bishops' Conference of England and Wales
and the
Linacre Centre for Healthcare Ethics

Introduction

1. We¹ welcome the opportunity to comment on the Draft Mental Incapacity Bill which the Government has proposed. In so doing, we focus on health-related issues: we do not comment on the Draft Bill's provisions on financial matters, which may indeed be useful in protecting the interests of those with mental incapacity. In contrast, we believe that the provisions of the Bill relating to health, while these may be similarly well-intentioned, will in fact exacerbate threats to the lives and health of mentally incapacitated people.

2. There are four points we wish to make briefly:

- A. lack of effective safeguards against suicide and homicide by omission;
- B. weakness in the definition of 'best interests';
- C. dangers in the proposed scheme for proxy decision making; and

D. dangers inherent in enforcing advance directives in the manner proposed.

A. Lack of effective safeguards against suicide and homicide by omission

3. Existing case-law already permits patients in a persistent vegetative state to have 'treatment' (including tube-feeding) withheld with the aim of causing death.² In permitting omissions, though not actions, with a homicidal purpose, the law has been left, in the words of one Law Lord, in a 'morally and intellectually misshapen state'.³ The Draft Bill does nothing to reverse this unfortunate situation; nor does it stipulate that life-sustaining measures may not be withheld from non-PVS patients with the aim of causing death. The Bill does not distinguish between choices on the part of doctors, patients or proxies with the aim of causing death and choices with the aim of avoiding the burden of certain interventions. Rather, in emphasising the need to respect the patient's past 'wishes and feelings' - whatever (it appears) they may be - the Bill would apparently require doctors to respect advance refusals which are suicidally motivated; i.e., where the patient's aim was to end a life predicted to be not worth living. Indeed, the Bill would apparently permit doctors intentionally to assist

¹ This Response has been prepared by Dr Helen Watt, the Director of the Centre, in consultation with Professor Luke Gormally, Senior Research Fellow at the Centre, and Professor John Keown of the Kennedy Institute of Ethics. For a more detailed account of our approach to healthcare decisions for the mentally incapacitated, see John Keown and Luke Gormally, 'Human Dignity, Autonomy and Mentally Incapacitated Persons: A Critique of *Who Decides?*' [1999] 4 *Web Journal of Current Legal Issues*, at www.webjcli.ncl.ac.uk/1999/issue4; and the Linacre Centre Responses to *Who Decides* and *Making Decisions*, at www.linacre.org.

² See *Airedale NHS Trust v Bland* [1993] AC 789.

³ *Bland* [1993] AC 789 at 887, per Lord Mustill.

such a suicidal refusal. Similarly, proxies who wish to end the patient's life - whether for the patient's sake or for their own - will evidently have full power to do this, on claiming this is what the patient wanted.⁴ It is the doctor who seeks to override a suicidal or homicidal refusal (and so protect the patient from death or disability) who would seem to be made liable to criminal proceedings.

4. We would urge that treatment should in no case be withheld with the aim of causing death: this should be a criminal offence whatever the patient's state of health.⁵ It is important to recognize that proscribing choices made with the aim of ending life would not commit anyone to pursuing or agreeing to medical treatment which is futile or burdensome. What needs to be stressed here is the key distinction between aiming to end life (albeit by omission), and not aiming to prolong life by inappropriate means.

B. Weakness in the definition of 'best interests'

5. We are alarmed by the reduction of the patients' interests to subjective 'wishes and feelings' of the patient in clause 1.4. It is remarkable that the Draft Bill makes no mention, in what it says about the patient's best interests,

⁴ The Bill does contain a clause [1. 31] on the mistreatment or neglect of incapacitated people. However, by defining 'best interests' of the incapacitated person solely in relation to that person's actual or hypothetical desires [1.4], the Bill, in conjunction with existing case-law, would appear to allow proxies to refuse treatment with a homicidal motive, providing the refusal is defended in terms of such desires. We would urge that clause 1.31 proscribe any refusal of treatment or care which is based on the aim of hastening death - whether this aim be that of the carer, proxy and / or the patient at an earlier time.

⁵ See note [iv].

of the interest in life and health.⁶ While not the only aspect of a person's welfare, life and health is certainly one aspect, which traditionally the medical profession has been committed to promoting. To ask doctors to ignore the health interests of patients wherever the patient had, in the past, some conflicting 'wish or feeling' is to ask doctors to abandon their traditional role in caring for incapacitated people.

C. Dangers in the proposed scheme for proxy decision making

6. The Draft Bill gives significant powers to proxy decision makers, and grants them legal status in the context of health care. There are, however, risks in giving such powers to those not medically qualified, who are not like doctors held accountable for medical negligence, and who may even have a conflict of interest such as a financial expectation on the patient's death. As presently drafted, the Bill gives proxy decision makers power without accountability. At the very least there needs to be a prescribed duty of care and accountability in law for decisions taken by the donee of a lasting power of attorney or a deputy appointed by the court. The donee or deputy should be required to give due weight to the patient's health interests, and not simply to his or her desires at some earlier time. Furthermore, in the case of a dispute between the donee or deputy and a doctor there should be reference to a second independent medical opinion, and if the matter still cannot be resolved, a reference to the court.

⁶ This interest was strongly emphasised by Lord Brandon in *Re F*, who held that treatment of non-competent patients was in the best interests of such patients only if 'carried out in order either to save their lives or to ensure improvement or prevent deterioration in their physical or mental health' (*Re F v West Berkshire Health Authority and Another* [1989] 2 All ER 545, at 546.

D. Dangers inherent in enforcing advance directives in the manner proposed

7. Competent patients do, of course, have first responsibility for their own health: a responsibility which extends a certain way into periods of incapacity. With regard to advance refusals, there is no objection to doctors following a refusal which is recent, well-informed and is not suicidally motivated. However, the same cannot be said of a refusal which is made on the basis of inadequate information and / or has the aim of ending life. Those who are, or have been, suicidal need to be treated in their objective interests, not to have their lives ended out of 'respect' for their wish that this be done. If patients, living as they do in a society which devalues the lives of disabled people, act on the basis that such a life would be worthless and should be curtailed, this is not an intention which it is in their interests, or society's interests, to respect.

8. Advance refusals will often be ill-informed: unlike the situation with contemporaneous refusals, the person making the advance refusal may not have been offered any information (for example, by a doctor) on what he or she is refusing. (In particular, those refusing 'treatment' may not realise that tube-feeding is classed as treatment in the law.) The Bill is vague on what is to count as an advance refusal, merely saying that such a refusal may be expressed 'in broad terms and non-scientific language' [1.23(2)].⁷ Previous

⁷ Any legislation on advance refusals of treatment should require that these be well-documented, witnessed to by two witnesses without a vested interest in the estate of the patient, based on accurate medical information and motivated otherwise than by a desire to end one's own life. In the current Bill, a

information from the Lord Chancellor's Department suggests that even passing oral comments by the patient could have legal force.⁸ (Certainly, a proxy may refuse treatment on the basis of just such an informal statement.) While wills disposing of a person's financial assets rightly have a strict form, it is anomalous that advance refusals - which may result in death or increased disability for the patient - could be so vaguely specified and still be binding on doctors. In the Bill, it seems that advance refusals are 'valid unless proven otherwise': in practice, the onus of proof will be on anyone who wants to treat the patient to show that a purported refusal is not, in fact, binding. For many patients, there will be no-one to challenge the claim that a binding refusal has been made.⁹

9. In some cases, even a well-informed, non-suicidal advance refusal should, in our view, be overridden, though this would certainly be the exception. In particular, an advance refusal of pain relief, hygienic care or feeding - whether orally or by tube - should not bind absolutely. Patients should be given a minimum level of care, both for their own sake and for the sake of protecting an ethic of care

paragraph to this effect might be inserted to replace 1.23 (2), which is far too vague in counting as valid refusals those 'expressed in broad terms'.

⁸ *Making decisions: A guide for social care professionals*, p.18.

⁹ We are also concerned that it will be difficult and time-consuming for patients who have regained capacity to cancel an advance directive or power of attorney (see Schedule 3, Part 4, 14: 1-2). Given the life-and-death issues at stake, it should, at the very least, be more difficult to make, than to cancel, such arrangements. Moreover, the Bill makes no provision for patients without capacity to show by their behaviour (signs of hunger, distress at a treatable condition) that their wishes have changed.

on the part of doctors and nurses. It needs to be stressed that incapacitated people have objective health interests, which doctors and nurses should be permitted to promote to a certain basic standard. No advance directive, and no attorney or deputy, should have the power to refuse such basic interventions in the patient's interest. This should be stated on the face of the Bill.

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