Scottish Council on Human Bioethics
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Response to Draft Mental Incapacity Bill for England and Wales

The Scottish Council on Human Bioethics is an independent, non-partisan group of doctors, lawyers, psychologists, ethicists and other professionals from disciplines associated with medical ethics. The principles to which we subscribe are set out in the United Nations Universal Declaration of Human Rights which was adopted and proclaimed by the UN General Assembly by resolution 217A (III) on 10 December 1948.

Our aims include the assessment and analysis of policy proposals from an ethical perspective.

We were involved in commenting on the Adults with Incapacity (Scotland) Act 2000 during its passage through the Scottish Parliament. We gave evidence to the Parliament's Justice and Health Committees and met with Ministers and Civil Servants to discuss aspects of the Bill.

One point we would make at the outset is that insufficient time has been allowed for consultation on this Bill. The consultation has coincided with the holiday period and even the customary minimum time for responses (in our experience three months) has not been allowed.

Given the shortage of time, we have restricted ourselves to commenting only on the legal and medical aspects of the Bill as they relate to decisions about medical treatment made on behalf of those with incapacity. Had we had more time, we would also have liked to comment on the effect of the Scottish Act on medical practice north of the border.

1. Overview

1.1 One matter which is immediately striking about this Bill is the extent to which it changes the balance of power in the healthcare setting. Although we understand from the accompanying Ministerial Foreward, that the stated aim is to empower those with incapacity, in practical terms, this Bill would have the opposite effect.

1.2 Under the Bill the legal protection currently given to vulnerable incapable people will be substantially reduced.[1] In particular, the Bill would allow passive involuntary euthanasia to be practised on incapable people whose lives are deemed by doctors or proxy decision-makers not to benefit them. It is imperative to preserve and, indeed enhance existing legal protection for incapable people because they are so vulnerable.

1.3 We consider that the Bill 'dumbs down' the protection currently accorded to this vulnerable group in the following ways. It removes basic protection by redefining "best interests" to make it a subjective test in Clause 4 and by creating proxy decision makers who will have power to refuse medical treatment on non-medical grounds. The principles of the Bill upon which patient protection depends (Clause 4) are not capable of being objectively established by reliable evidence in all cases.

2. Best interests

2.1 In the commentary issued with the Bill, it is implied that the common law 'best interests' principle is enshrined in the Bill. This appears somewhat disingenuous. At common law, a doctor can lawfully provide treatment to an adult incapable of giving consent provided the treatment is in the patient's best interests. In this context, at common law, "best interests" means treatment given to save the patient's life, or to improve or prevent deterioration of the patient's physical or mental health.[2]

2.2 This Bill does not enshrine that principle, it enshrines something quite different. The 'new best interests test' in Section 4 is a guiding principle which doctors and proxies must use in deciding whether to give or authorise medical treatment (including tube feeding and fluids) under the Bill. Doctors must use it in deciding whether to give or withhold treatment under clause 6. Proxies must use it in deciding whether to refuse treatment under clauses 8(1)(a) or 17(1)(d) (they have no power to compel treatment, only to refuse it). The Court of Protection must use it in resolving any disputes about whether 'treatment' should be provided.

2.3 At common law, it is relatively simple to establish whether a given treatment is appropriate in terms of saving life, preventing deterioration etc. This can be proved reasonably objectively on the basis of evidence of physical examination of the patient and expert testimony as to the treatment proposed.

However, the new "best interests" test proposed introduces factors which are much more subjective such as alleged oral expressions of past wishes and feelings; views of carers and others as to what factors the person would consider if he were capable etc. As explained below, research in America appears to show that the possibility of a proxy actually choosing as the patient would have done is little better than chance. The effect of introducing a vague and subjective test is to remove such protection as currently exists. This leaves the law open to abuse by the unscrupulous.

3. Proxy decision makers – power without responsibility

3.1 This Bill fails to safeguard people with incapacity from passive euthanasia and perverse decisions and abuses of power by proxy decision makers.

3.2 The proxy decision makers created by the Bill can take decisions in relation to healthcare and also financial and property matters on behalf of adults with incapacity. It is likely that some proxy decision makers who have powers in both areas will face conflicts of interest. For example, the proxy may be a prospective beneficiary in the adult’s estate and may be called upon to decide whether or not the adult should receive life sustaining medical treatment. It is possible that such a treatment decision may be taken in circumstances where, if life sustaining treatment is refused or withdrawn, there will be more money available for beneficiaries because nursing or care home fees will be saved.

3.3 In its memorandum to the Justice and Home Affairs Committee of the Scottish Parliament during the passage of the Adults with Incapacity (Scotland) Act 2000 dated 11 November 1999 the Scottish Neurological Consultants’ Forum said “ a … difficulty arises when close relatives appear not to be acting in the best interests of the patient; this is not common but neither is it rare”. [Note that they are referring here to clinical best interests and not to the new test proposed.]

3.4 It is very important to recognise that while the majority of proxy decision makers can be presumed to be acting in good faith in what they believe to be the best interests of the incapable person, there are those who would not do so. (Almost all of our medical members questioned about this can relate such instances from their own experience).

No duty of Care

3.5 Incapable people are currently protected at least to some extent because doctors have a duty of care in relation to medical decisions taken on their behalf and can be prosecuted, sued or disciplined for breaching their duties to patients (depending on the gravity of the breach). However, proxies are not subject to the same duties or standards of care and they cannot therefore be prosecuted or sued for breaching or falling below them.

3.6 This means that if proxies refuse say tube-feeding or insulin on behalf of the patient and thus cause the patient’s death, they cannot be held liable. All they need claim is that the patient once expressed a wish not to have the treatment in these circumstances (section 4(2)(c)(I)) or that they thought the treatment was ‘not in their best interests’ under section 4(1). Alternatively, where the patient had an advance directive or was even believed to have one, this would be binding. Even if the patient was alleged to have made a past remark, this would be taken as evidence of past wishes and feelings about treatment under clause 4 and treatment would be denied. The evidential problems are obvious. Since the Bill entitles proxies to refuse treatment subject only to the guiding principles, then provided they can bring themselves within these as suggested above, neither the criminal law nor the civil law can touch them. The doctor could not be prosecuted either because he or she would have no authority to treat in the face of a refusal by a proxy. Although he or she has the option of appealing against this refusal to the Court of Protection, the physician has no obligation to do so.

3.7 A closer examination of the Bill’s guiding principles and the common law makes it clear that if the Bill were enacted in its present form it would be almost impossible to successfully prosecute a proxy or doctor who caused the death of a person with incapacity by withholding or refusing treatment.

3.8 As Professor McLean said “I am not sure on what basis you could challenge them because a proxy decision maker could always say they that they had acted in good faith”.[3] At the Scottish Parliament’s Justice Committee Meeting on 17 November Ben Wallace MSP asked Professor McLean[4] “Are you saying there is no way of putting a safeguard on the actions of a proxy?” She replied “ I cannot think of any way that would do more than allow us to make the presumption that the person is acting in good faith.” She went on to describe research in the USA which suggested that the possibility of a proxy making the same decision as the patient himself would have made is little better than chance.

3.9 If this research is correct, it suggests that this Bill removes vital protection from vulnerable people without conferring any benefit on them in terms of increased autonomy. In practical terms it is difficult to see any justification or ethical benefit from the medical aspects of this Bill. Some of the financial aspects of the Scottish Act were actually necessary but the medical sections have caused confusion and an increased burden of bureaucracy on doctors without improving the healthcare of adults with incapacity to any marked extent.

4. Advance refusals of treatment

4.1 In the green paper which preceded the Scottish Act, the Scottish Executive made the following statement:-

"We have examined carefully a number of other proposals made by the Scottish Law commission, by the Alliance for the Promotion of the Incapable Adults Bill, and by others. Such proposals have included legislation to give clear legal force to Advance statements ("Living Wills") and to provide for the withholding or withdrawal of treatment from patients who may be in ……PVS. Although such proposals have the sincere support of particular interest groups, we do not consider that they command general support . Attempts to legislate in this area will not adequately cover all situations which might arise, and could produce unintended and undesirable results in individual cases."[5]

We share the Executive's concern in relation to Advance Directives or refusals of treatment for the following reasons:-

- They are open to abuse, particularly where, as here, it is proposed that they may be oral. Patients may have been coerced into making them or may have simply made them because they feared being a burden on relatives. They may have been depressed or have been experiencing feelings of low self worth.
- It may be difficult to establish retrospectively whether the person had capacity at the time of making the advance refusal. It is unclear what level of capacity is required in order to revoke a refusal, once made.
- If a person makes such a decision in advance it is unlikely that they will have access to medical advice and to all the relevant clinical considerations needed to make a good decision. Such decisions may be made in ignorance of important factors. They may increasingly be made on the basis of unreliable medical information downloaded from dubious web sites. This may also become a problem in relation to proxies who may be tempted to act as 'amateur clinicians'.
- It may be very difficult to prove what circumstances were or were not anticipated by the patient at the time of the advance decision for the purposes of challenging validity under clause 24(4)(c).
- Advance refusals of treatment will mean that some patients will receive sub – optimal care. This will inevitably mean that patients who might otherwise have been rehabilitated will not receive treatment they need and may then require hospital care on a long term basis with consequent implications for allocation of resources.

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[1] As Professor McLean pointed out in her evidence to the Justice and Home Affairs Committee during the passage of the Scottish Act, it will amount to no more than an assumption that a proxy decision maker will act in good faith. Official Report - Scottish Parliament JHAC 17 November 1999.

[2] Re F 1990 2 AC 1

[3] Col 395 17 November.

[4] Justice Cttee transcript 17.11.99 at para 400.

[5] Making the Right Moves published by the Scottish Executive 1999 http//:www.scotland.gov.uk/rightmoves/docs