Response from the Joint Ethico-Medical Committee of The Catholic Union of Great Britain and the Guild of Catholic Doctors to the Lord Chancellor's Department on Making Decisions: Helping People who have Difficulty Deciding for Themselves

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.

In drafting our response to the Consultation Paper we decided that it would be most helpful if we addressed the booklet in page order, for the most part dealing with each subject at the point where it first arises. A few topics, however, are held over to where they are most relevant.

Covering Statement for all leaflets

Page 4, Para 1. It seems as if two parts of the original sentence have become separated. "and also for those involved in caring for them." should follow on after "who need support to make decisions." The reasons for the disability should form a separate sentence.

Page 5, Third bullet point. ".... to achieving what they themselves would have wanted." Using the tense 'would have wanted' implies time in the past. The task is to determine what the patient now wishes and would decide if he/she were able to do so.

Leaflet 1

Page 10, Fluctuating Capacity. One of the most important and common medical causes of fluctuating capacity seems not to be mentioned, namely acute illness. Patients, frequently the elderly, who have an acute infection, such as pneumonia or urinary tract infection, may become confused and incapable for the time being. This is usually simply remedied by treatment and must never be seen as a reason for treatment to be withheld or delayed.

A drug "overdose" is also a common reason for temporary impairment of capacity and should be regarded as calling for treatment. A suicide note detailing that it is the patient's desire to end their life should not be regarded as an advanced directive refusing treatment. Most doctors' experience is that patients are usually very glad to be alive after having been treated.

As indicated on page 28, para 2, the degree of functional capacity required may vary with the actual decision to be taken.

Page 12 & 13, Best Interests. We are surprised that medical best interests are only mentioned here indirectly (bottom of page 15), but we will return to this later. (see at pages 32,33,34)

Page 13, line 6. We understand the use of the conditional clause here but what the relative or proxy is trying to establish is what the person themselves (now) wishes (and would decide if they were able). [See our comment above referring to page 5]

Page 16, second para. We will address advance statements later (see also our comment on leaflet 6, at page 106).

Page 16, third para. We understand that the word "They" at the beginning of this paragraph refers back to "health professionals'' in the first paragraph and not to "advance statements" in the second paragraph. We suggest this paragraph should start with ''Professionals must also .... ".

Page 17, line 10. We understand that for an advance directive to be legally recognised, the addition of the words "specific and applicable in the circumstances" is necessary after "clear". In view of the necessity of these conditions it is entirely inappropriate to give as an example of an advance refusal of treatment (as given in para 1) ".... some people may not want to be kept alive by artificial means.' What is meant by the term 'artificial means' is certainly not clear and can range from nasogastric tube feeding to full intensive care with mechanical ventilation. See also our more detailed comments on "Refusal of Treatment" below referring to page 33..

Leaflet 2

Page 31.Fluctuating capacity. See our comments on fluctuating capacity above (at Page 10).

Pages 32, 33, 34. Best Interests. We fully support the view that "The only decision which health professionals can make on behalf of people unable to make their own decisions relate to health care and treatment" (page 32) The advice offered by health professionals should therefore be based on clinical criteria, taking into account psychological and emotional factors - which are an accepted part of good medical practice. A competent patient may then use other values and preferences (as given in your examples on page 34) to decide whether to accept or refuse the treatment offered. In the case of patients lacking capacity to decide, the health professionals advice should

remain based on clinical criteria. Health care professionals are not competent to assess and weigh the various values and preferences the patient may have had prior to incapacity. If there is a conflict between the medical and other 'best interests', as advised by relatives or proxies, then a court has the competence to take all the possible ramifications of best interests into account.

In summary a doctor has to advise on what is medically best for the patient. A competent patient may reject that advice and make a medically 'bad' choice. The doctor is unlikely to have any difficulty in reaching agreement with the patient and him/herself in such cases, but could have problems with relatives or proxies, whose interests may be different from the patient's.

Page 33, Refusing treatment in advance
It is logical, supported by legal precedent, that a clear cut and specific refusal of a particular treatment should continue after the patient has lost capacity. We criticise the use, in all the leaflets, of the example: "For example, some people may not want to be kept alive by artificial means,....." It is both dangerous and misleading to use such an example, as this is not a refusal of a specific treatment, but a "blanket refusal" of all measures which might be necessary for proper management in an emergency. The meaning of the term 'artificial means' is not defined and could be interpreted differently by different individuals. Whilst the refusal of one particular form of management might be based on a specific objection (eg. blood transfusion for Jehovah's Witnesses) it is extremely unwise to seek to prevent all medical treatment. This is not merely because of the risk of death but because of the risk of becoming a survivor in a "damaged" state which could otherwise have been avoided.

In the case of T ((adult: refusal of medical treatment) All England Law Reports [1992] 4 All E R at 650e), Lord Donaldson MR and Lady Justice Butler-Sloss refer to "an anticipatory choice whether to accept or refuse specific treatment, eg a blood transfusion" so that they, at least, were talking about specific and not blanket refusals. Also, Re T was applied in Re C (adult: refusal of medical treatment) (1994) 1 All ER 819 (Thorpe J), and considered in Re S (hospital patients: Court's jurisdiction) (1995) 3 All ER 290 (Court of Appeal). Therefore as a minimum the sentence on **Page 33, line 19** should have "specific" inserted after "clear.

Page 33, line 20 &21. ('..health care professionals are bound by that earlier decision...')
We accept the general principle of advance refusal of treatment, but believe it is important to consider in more detail how health professionals are to verify that an advance refusal of treatment is valid. Here 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) offers very practical and explicit advice to doctors. We recommend that the relevant part of his guidance is quoted in full in the leaflet for health professionals. 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. [Our emphasis] **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."

Page 37. Recovering Capacity. See comments above re page 10.

Page 37 para 6. The significance of the statement that doctors should be aware that in some cases of dementia recovery may be only temporary is not clear.

Leaflet 3

Page 48, third full paragraph. We are pleased to see that medical best interests are specifically mentioned, (line 11). The last sentence, however, (as in the case of page 13, line 6) should read "what they want" rather than "what they would have wanted".

Page 48, Best Interests. Please see above re pages 32, 33, 34.

Page 54, Refusing treatment in advance. See our comments above referring to page 33.

Page 68, line 2. for "of" read "as to".

Leaflet 4

Page 70, Refusing treatment in advance. See our comments above referring to page 33.

Leaflet 5

We recommend a careful reconsideration of the language used. Though intended for those with learning difficulties this leaflet is not all that easy for the fully capable.

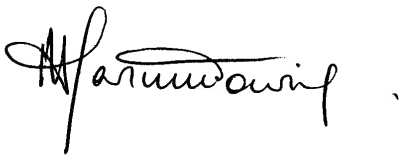
Leaflet 6

Page 97, second bullet. We believe the word "Enduring" is missing before "Power of Attorney"

Page 105. A refusal of treatment. See our comments above referring to page 33.

Page 106. Sources of help on consent to treatment.
We find it quite unacceptable that the only reference as a source of advance directives is the Voluntary Euthanasia Society. There are many sources of such documents, including the Guild of Catholic Doctors, and it is inappropriate in a government document to display bias by referring readers directly to only one. This is particularly true as the organisation in question puts forward advance directives as a step on the way to euthanasia and these are, in any case, of the "blanket" type seeking to encompass all sorts of treatments and almost any situation and are thus incompatible with any genuine informed choice.

Signed:



Dr Anthony Cole JP., KHS., FRCPCH

Chairman. Catholic Union of Great Britain

Dr Michael Jarmulowicz. FRCPath., MB BS., BSc

Master, Guild of Catholic Doctors

8th July 2002