The Guild of St. Luke, St. Cosmas & St. Damian, Hong Kong
香港天主教醫生協會

Submission of to the Law Reform Commission of Hong Kong

on their Consultation Paper

"Substitute Decision-Making and Advance Directives

in Relation to Medical Treatment"

September 2004

The Guild of St Luke, St Cosmas and St Damian is an association of Catholic doctors formed in 1953, aimed at facilitating the intercourse between Catholic members of the medical profession of Hong Kong with a view to the study and discussion of bioethical issues, and of upholding the principles of Catholic morality.

The consultation paper to which this document is a response, sets out the various problems relating to decision-making incapacity in healthcare and other areas, reviews the recommendations for reform in this area of a number of jurisdictions with similar legal systems, considers a number of options for reform and makes its final recommendation.

Having reviewed the information contained in the paper, the Guild draws upon the teachings of the Catholic Church to comment on the proposals for reform as well as the principles upon which those proposals are founded. We have also referred to the latest legal ruling from England, *R (Burke) v The General Medical Council* [2004] EWHC 1879 (Admin) (hereafter referred to as "*Burke*"), handed down on 30th July 2004, which was after the publication of the consultation paper.

Considerations of Underlying Principles

Respect for Individual Autonomy

1. One of the main underlying principles behind the consultation exercise is that of respect for individual autonomy, which is also an important principle in medical ethics. We acknowledge the importance of this principle, but would emphasize that this principle is not absolute. There are limits to individual autonomy recognized in law and by the society at large.
2. In dealing with the problem of mental incapacity, it is recognized that individual autonomy does not diminish even if the individual is mentally incapacitated or cannot sense the violation of autonomy (cf 4.10 of the consultation paper). A constant theme running throughout the paper is the attempt to find ways of enhancing autonomy in individuals with varying degrees of mental incapacity, so that respect for the wishes of an individual can be maximized at all times. It is noted that in the absence of anticipatory decision-making, a person with mental incapacity is not provided with any option when competent to influence the surrogate who would be given authority for substitute decision-making. This is an area which could merit further exploration.

The Limits of Individual Autonomy

3. Certain limits are set on individual autonomy. Although individual autonomy and the right to self determination is recognized by Law to include "how one chooses to pass the closing days and moments of one's life and how one manages one's death" (*Burke*, para 62), this does not extend to euthanasia in most jurisdictions.
4. In the extreme case of individuals of unsound mind, the Law may opt to take away the autonomy of "people who are quite capable of taking the decision, in the sense that they understand what it is and what it will mean, but are nevertheless suffering from such a degree of mental disorder that it is thought appropriate to take the decision out of their hands, either in their own interests or for the protection of others." (Para 1.2 of consultation paper, quoting The English Law Commission Consultation Paper No.119, *Mentally Incapacitated Adults and Decision-Making: An Overview* (1991), at paras 2.10-2.11)

5. Neither can individual autonomy in healthcare "require a doctor to treat a patient in a way that was contrary to the doctor's professional judgment and duty to the patient." (*In re J (A Minor) (Child in Care: Medical Treatment)* [1993] Fam 15, para 31)
6. The Catholic Church holds that "the first premise of personal autonomy is *being alive*" (*Respect for the Dignity of the Dying*, Pontifical Academy for Life, 9 Dec 2000; no.5). There can be no appeal to personal autonomy as a justification for euthanasia, assisted suicide and the like, because "to suppress life means to destroy the roots of the human person's freedom and autonomy." (*ibid*, no.5)
7. At a recent conference on the Vegetative State, the participants "acknowledge that the dignity of every person can also be expressed in the practice of autonomous choices; however, personal autonomy can never justify decisions or actions against one's own life or that of others: in fact, the exercise of freedom is impossible outside of life." (*FIAMC and Pontifical Academy for Life Joint Statement on Vegetative State*, Rome, 24 March 2004, no.9)

<u>The Sanctity of Life</u>

8. The principle of sanctity of life is well recognised. Paragraphs 4.17 and 4.18 of the consultation paper elucidated the arguments of the judges in the *Bland* case. (*Airedale N.H.S. Trust v Bland* [1993] 1 All ER 821) The principle of sanctity of life "forbids the taking of active measures to cut short the life of a terminally ill patient", but "does not compel a medical practitioner…. to treat a patient, who will die if he does not, contrary to the express wishes of the patient. " Nor does it hold "that the patient's life must be prolonged … , regardless of the circumstances."
9. Paragraphs 4.22 to 4.27 examined the legal considerations of the right to life as embodied by Article 2 of the European Convention for the Protection of Human Rights and Fundamental Freedoms 1950. Although that article "contain a positive obligation to take adequate and appropriate steps to safeguard life, … that positive obligation upon a state to protect life was not absolute."
10. The fifth Commandment "Thou shall not kill" (Deuteronomy 5:17) forbids the taking of innocent human life. However, the Church allows pain relief to terminal patients even if a secondary effect of such analgesia might be to shorten their lives. (Address of Pope Pius XII to the IXth

Congress of the Italian Anaesthesiological Society, 24th February 1957 (AAS 49 (1957), pp146-7)).

11. The Church also agrees with the view that the sanctity of life principle does not compel the prolongation of life by all means. The Reanimation Address by Pope Pius XII to the World Congress of Anaesthesiologists 24th November 1957 (AAS 49(1957), pp1027-1033) elucidated the much used distinction between ordinary and extra-ordinary means of therapy, and specifically stated that there is no moral obligation to put a patient on a ventilator even when there is no prospect of survival.
12. The Declaration on Euthanasia in May 1980 (AAS 72(1980), pp 542-552) elucidates the distinction between euthanasia and the withholding of burdensome therapy by emphasizing due proportion in the use of remedies.
13. In *Evangelium Vitae* (AAS 87(1995), pp401-522), Pope John Paul II reiterated that a person can in conscience "refuse forms of treatment that would only secure a precarious and burdensome prolongation of life," and that "[t]o forego extraordinary or disproportionate means is not the equivalent of suicide or euthanasia; it rather expresses acceptance of the human condition in the face of death." (*ibid*, no.65)
14. Indeed, it is recognized that the "approach to the gravely ill and the dying must therefore be inspired by the respect for the life and the dignity of the person. It should pursue the aim of making proportionate treatment available but without engaging in any form of "overzealous treatment" (cf. *CCC*, n. 2278)." (*Respect for the Dignity of the Dying*, Pontifical Academy for Life, 9 Dec 2000; no.6)
15. In the recent conference on the Vegetative State, the joint statement observes that "we refuse any form of therapeutic obstinacy in the context of resuscitation, which can be a substantial cause of post-anoxic VS." (*FIAMC and Pontifical Academy for Life Joint Statement on Vegetative State*, Rome, 24 March 2004, no.10)

General Comments

The Problem of Mental Incapacity

16. In the discussion on decision making disability, a direction for assistance to be given to persons so affected was given in para 1.16, quoting the Queensland Law Reform Commission, "Where a person with a decision-making disability is unable to make a decision alone, he or she may be able to make that decision with an appropriate level of assistance." (The Queensland Law Reform Commission Report No 49, *Assisted and Substituted Decisions: Decision-making by and for people with a decision-making disability*, Vol 1(1996), Ch 1, para 3.)
17. There is a concept in some jurisdictions that mental capacity should "assessed according to each decision that needs to be taken", and that individuals are not "incapable" in a general sense, but "they would only be regarded as lacking capacity for certain decisions at the time that that decision needed to be taken." (para 7.141, quoting Overview of the Mental Incapacity Bill issued by the Department for Constitutional Affairs on June 2003, p.2, (6 Aug 2003))
18. Disturbance in mental function leading to decision-making disability was implied throughout the consultation document more or less as an on off phenomenon rather than as a continuum. There is also the implication that once disabled there is no going back. There seemed to be no allowance for a person of fluctuating decision-making capacity (cf. fluctuating levels of consciousness).

The Causes of Mental Incapacity

19. The document makes special mention of dementia (paras 1.6 to 1.13), coma (para 1.14) and the vegetative state (VS) (para 1.15).
20. We agree that dementia will become an increasingly important source of mental incapacity, but wish to point out that in the context of advance directives (AD), as proposed by the Commission in this document, dementia is not particularly catered for, if the disease is not so advanced, so as to cause coma, or for the person afflicted to be considered "terminally ill", in the manner set forth in Recommendation 4(a) of this document.
21. We note that para 1.15 quoted the Brain Injury Association of America on

coma, "The length of a coma cannot be accurately predicted or known" and find it difficult to reconcile with ***Case 2 – Persistent vegetative state or a state of irreversible coma*** of the sample advance directive. When is coma irreversible? It could be argued that the only thing that can be said at any point in time is that the person has not yet recovered from coma, no matter how long the preceding period of coma has lasted.

The Special Considerations of the Vegetative State

22. We express our disquiet about the problem of VS persons. Inherent in the limitation of AD to terminal disease, VS and irreversible coma is a value judgment that the three conditions are similarly hopeless.
23. The diagnosis of VS "is still clinical in nature and requires careful and prolonged observation, carried out by specialized and experienced personnel, using specific assessment standardized for VS patients in an optimum controlled environment. … shows diagnostic errors in a substantially high proportion of cases." (*FIAMC and Pontifical Academy for Life Joint Statement on Vegetative State*, Rome, 24 March 2004, no.5) "No single investigation method available today allows us to predict, in individual cases, who will recover and who will not among VS patients" (*ibid*, no.7) and "statistical prognostic indexes regarding VS have been obtained from studies quite limited as to number of cases considered and duration of observation." (*ibid*, no.8)
24. However hopeless VS may seem to some, we "reaffirm strongly that the intrinsic value and personal dignity of every human being do not change, no matter what the concrete circumstances of his or her life." Persons "who find themselves in the clinical condition of a "vegetative state" retain their human dignity in all its fullness." (*Speech Of John Paul II To The Participants At The International Congress on Life Sustaining Treatments And Vegetative State Saturday 20 March 2004*, no.3)
25. We also reiterate "the general principle according to which the value of a man's life cannot be made subordinate to any judgement of its quality expressed by other men;" (*Speech Of John Paul II To The Participants At The International Congress on Life Sustaining Treatments And Vegetative State Saturday 20 March 2004*, no.6)
26. We agree with the conference that "VS patients cannot be considered as "burdens" for society; rather, they should be viewed as a "challenge" to implement new and more effective models of health care and of social

solidarity." (*FIAMC and Pontifical Academy for Life Joint Statement on Vegetative State*, Rome, 24 March 2004, no.14)

Advance Directives and Euthanasia

27. Euthanasia is "an action or an omission which of itself or by intention causes death, in order that all suffering may in this way be eliminated." (*Declaration on Euthanasia* (AAS 72(1980), pp 542-552)).
28. Euthanasia "is illegal and unethical". (Professional Code and Conduct, Hong Kong Medical Council, November 2000 Version, no.26.2)
29. We assert that AD must not be allowed to effect euthanasia, either via a direct request for treatment which can death, or via a refusal of appropriate non-futile life-sustaining therapy.

Proposals for Pre-Incapacity Decision-Making

Advance Directives

30. We agree in principle that validly made advance directives (AD) help preserve individual autonomy in the area of healthcare decisions during the time when the person concerned has become mentally incapacitated.

Status of Advance Directives

31. Noting that the current final recommendation for reform does not involve the drafting of legislation, we would urge the Commission to clarify the status of the proposed AD, or whether this is an advance expression of views and preferences or an advance decision. (cf para 2.2)
32. The current situation offers no assistance. A written statement of refusal of blood transfusion from say, a Jehovah's Witness, is treated as a decision and the doctor is obliged to treat that decision in the same manner as a contemporaneous refusal. (cf para 5.13-5.14)
33. Noting that organ donation is specifically excluded in the consultation paper, it is salutary to observe that the organ donation form or card is basically an AD, limited to the question of organ donation. Currently, "both the card and the organ donation form are legally valid. We need to stress that even with a legally valid document, doctors in Hong Kong will not remove any organ if the close relatives object. In any event, the authorization from the close relatives will be obtained before the organs are removed." (Commonly Asked Questions on Organ Donation, from The Hong Kong Medical Association Website <http://www.hkma.com.hk/english/care/bfaqdonaset.htm >) The question then pertains: is the organ donation card an advance decision, or merely an advance expression of views and preferences?

Validity of Advance Directives

34. We agree that the witness requirements for the proposed AD, especially the involvement of a medical practitioner, would help in ensuring that the AD was made when the person is not mentally incapacitated. (Recommendation 5)
35. The stipulation that "Neither witness should have an interest in the estate

of the person making the advance directive." (Recommendation 5) also goes some way in ensuring that undue influence, which can have a vitiating effect on validity, is minimized.

36. We note the more comprehensive approach to witness requirements in the Singapore AD. (Annex 4). This has certain advantages:
    a. There are no implications on validity if, at the time the AD was made, the witness does not know of benefit or interest in the estate, … etc of the person making the AD.
    b. The list of potential conflicts is more comprehensive.
37. We also note that the approach in Singapore protects against undue influence (which can vitiate validity) by making it "an offence for any person to require or prohibit the making of an AMD as a condition for receiving medical services or for being health insured." (para 7.172, section 6(2)) This is an area which merits further investigation.

Applicability of Advance Directives

38. The applicability of AD stems in part from the ability of the maker of the AD to foresee a particular situation which warrants a decision and then makes a decision which takes into account all material aspects of the situation.
39. The problem is made all the more difficult by the reality that in a serious illness leading to incapacity before death, the circumstances change and "what is in the best interests of someone who, although suffering from some incurable condition, is not yet terminally ill will not necessarily be in the best interests of someone who is terminally ill; and what is in the best interests of someone who is terminally ill, but not yet dying, will not necessarily be in the best interests of someone who is dying. Similarly, a patient may want one form of treatment when death is still a long way off, another form of treatment once he becomes terminally ill, and another form of treatment – or perhaps no treatment at all – when he is dying." (*Burke*, para 47)
40. Although para 8.48 quoted the observations of the Law Commission of England and Wales on the problems of living wills, the same can be said of AD. "Very detailed living wills risk failing to foresee a particular turn of events, whereas those written in general terms may be ambiguous in their application to particular circumstances and require considerable interpretation by medical practitioners."

Scope of Advance Directives

41. The current proposed form (Annex 1) includes both directions for treatment, advance refusal and specific instructions.
42. The direction for treatment **"I want to be kept alive for as long as is reasonably possible by all available treatment"** is very vague, and assuming that the advance directive is legally binding, could result in the person's wish being overridden.
43. Summarising the reasons for dismissing the Appeal in *In re J (A Minor) (Child in Care: Medical Treatment)* [1993] Fam 15, Mr Munby noted that one of the reasons that the Court of Appeal felt that the order should not have been made was that "the lack of certainty as to what precisely the order required" (*Burke*, para 187) The above direction for treatment risks being overridden in this manner.
44. Another concern is that directions for treatment and even specific instructions contained in AD might compel the doctor to provide unreasonable treatment. The legal position has already been alluded to in para 5 above. *Burke* adds that "it is wrong to make an order requiring a doctor to treat a patient in a particular way contrary to his will or requiring him to adopt a course of treatment which in his bona fide clinical judgment is not in the best interests of the patient: for this, it was said, is to require the doctor to act contrary to the fundamental duty he owes his patient, which is to act in accordance with his best clinical judgment. A doctor should not be put in a position where he may be required to choose between his conscience and imprisonment for contempt." (*Burke*, para 187)
45. Another facet relating to the scope of advance directives is its limitation to terminal illness, irreversible coma and vegetative state. There are other causes of mental incapacity, temporary or permanent, which may require decisions to be made for a mentally incapacitated person. In some of these situations, the time course of illness can be short, but the rate of deterioration fast, so that urgent decisions have to be made about medical treatment.
46. In some of these case, the mentally incapacitated person may be on the brink of becoming "terminally ill", in other times persons who are otherwise "terminally ill" by other definitions may not be covered by AD. The definition in Recommendation 4 would not necessarily cover a

patient with advanced cancer with a median expected survival say two months, a condition which many would consider as a terminal cancer.

47. Could the AD be treated as an advance expression of views and preferences in cases other than terminal illness, irreversible coma and vegetative state, for which the AD is seen as an advance decision?
48. The problem of applicability arises. "[W]hat is in the best interests of someone who, although suffering from some incurable condition, is not yet terminally ill will not necessarily be in the best interests of someone who is terminally ill; and what is in the best interests of someone who is terminally ill, but not yet dying, will not necessarily be in the best interests of someone who is dying. Similarly, a patient may want one form of treatment when death is still a long way off, another form of treatment once he becomes terminally ill, and another form of treatment – or perhaps no treatment at all – when he is dying." (*Burke*, para 47) How can we be sure that the differences in circumstances will not make for a different decision?

Other Problems of Advance Directives

49. We consider that revocation of AD should be made as simple as possible. Just as complex procedures can deter people from making AD, complex procedures can also be a barrier for their revocation.
50. We consider the need for written revocation an unnecessary hurdle for a person who has made a written AD (Recommendation 6b), should he feel the need to revoke his previously made AD during the course of a serious illness, and suggests that no such requirement be needed for revocation of AD in any circumstances.
51. The local Chinese society is wary of issues surrounding death, and it is well known that many people are reluctant to consider writing wills. The revelation in the consultation paper that "in the six years since the enactment of the Enduring Powers of Attorney Ordinance (Cap 501) in 1997 only three enduring powers of attorney have been registered." (para 8.71) could be taken as further evidence supportive of a general reluctance of the society to for end-of-life planning.
52. We welcome the recommendations of the Commission for the Government to "launch publicity programmes to promote public awareness and understanding of the concept of advance directives" (Recommendation 2) and of end-of-life healthcare planning to involve

"the Medical Council, the Medical Association, the Bar Association, the Law Society, the Hospital Authority, all hospitals and medical clinics, and religious and community groups" in that effort. (Recommendation 3)

53. The setting up of a central registry (Recommendation 7) also gave cause for concern. The implication that end-of-life treatment decisions should be made after a "search" of the central registry for relevant AD deposited by the person concerned could lead to delays in decision-making. This might lead to undesirable consequences when there is urgency for decision-making.
54. There might also be the impression that only written ADs lodged with the registry are valid. The results of other therapeutic planning not resulting in a written AD are then denied their rightful role in the management of a person who has made the aforementioned advance decision.
55. We also commend the steps taken by the Singapore authorities to ensure that "the existence of an AMD must never be allowed to influence medical treatment and management decisions before the patient is certified to be terminally ill." (para 7.172, section 6(2)) We urge the Commission to consider this approach before making their final recommendations.

<u>Other Options for Pre-Incapacity Decision-Making</u>

56. The Commission considers the options whereby a person appoints, or excludes person or persons to act as their substitute or surrogate decision-maker when incapacity arises as unsuitable. We would like to point out that such proposals may also extend the autonomy of a mentally incapacitated person.
57. The appointment of a surrogate decision maker is open to abuse, but probably no more than any other options for substitute decision-making. The drafting of rules and procedures to regulate substitute/surrogate decision-making may limit problems in this area.
58. The appointment of a guardian or other substitute decision maker under current law and any proposed reform fails to take any account of the wishes of the mentally incapacitated person. We feel that as a minimum, his autonomy can be enhanced by providing options to exclude specific persons from acting as a surrogate decision-maker for him.

Proposals for Post-Incapacity Surrogate Decision-Making

59. We welcome the proposals to "bring comatose and vegetative persons within the protection of the existing legal framework" by amendment of the Mental Health Ordinance (Cap 136) (Recommendation 9)
60. We welcome the proposal to "encourage the Medical Council or other relevant professional body to review the existing practice in the light of our proposals on advance directives and to issue guidelines in this area to enhance consistency of medical practice." (Recommendation 10)
61. We note that some jurisdictions "set(s) out a number of principles to be followed, rather than a general test of what is in the best interests of the adult." (para 7.157 commenting on the Adults with Incapacity (Scotland) Act 2000)
62. We also note that "Best interests are not limited to best medical interests." (Butler-Sloss LJ in *Re MB (Medical Treatment)* [1997] 2 FLR 426 at p 439), and "best interests encompasses medical, emotional and all other welfare issues." (*Re A (Male Sterilisation)* [2000] 1 FLR 549 at p 555).
63. This point was further illustrated by Mr Munby in *Burke*, with particular reference to the limitations of doctors in evaluating best interests: "Two patients both suffering from the same terminal complaint are offered chemotherapy as a means of obtaining some prolongation of their lives. The treatment has unpleasant side-effects. Is it in their best interests to have the treatment or not? There is no simple answer. It all depends. One is anxious to prolong his life as long as possible, irrespective of the quality of his life, because he is desperate to live long enough to see his daughter married or his first grandchild born. He takes the view that it is in his best interests as he sees them to have the treatment. The other is determined to complete some project – a book, perhaps, or a work of art – for which he needs a clear mind free of the unpleasant side effects. He takes the view that it is in his best interests as he sees them *not* to have the treatment. These are both intensely personal decisions. The doctor can advise on the likely expectation of life with or without the treatment; he can advise on the likely side-effects; but he cannot take the ultimate decision. He is not qualified to do so. It would be wrong for him to do so. The ultimate decision can only be for the patient, assuming, that is, that he is in law competent." (*Burke*, para 97)
64. We would urge the Commission to recommend that guidelines and or procedures for assessment of best interests be drawn up to assist in

substitute decision-making.

65. The options to provide a competent person to influence the choice of a surrogate decision-maker when he has become subsequently mentally incapacitated has already been discussed in paras 55-57 above.
66. We urge the Commission to consider whether to include some of the options we have discussed when making the final recommendation for reform.

Areas of Special Concern

Artificial Nutrition and Hydration

67. The withdrawal of artificial nutrition and hydration (ANH) in the mentally incompetent patient is not without controversy. The Queensland Powers of Attorney Act 1998 treats the withdrawal of ANH as a special case, and stipulates that "for a direction to withhold or withdraw artificial nutrition or artificial hydration--the commencement or continuation of the measure would be inconsistent with good medical practice;" (Powers of Attorney Act 1998, section 36, Subsection 2(b)).
68. The *Burke* case sets out the circumstances when the prior authorisation of the court is required as a matter of law before ANH could be withdrawn (para 214 (g)).
69. We therefore welcome the decision of the Commission to consider the provision of hydration and nutrition as part of palliative and basic care (para 8.65) which should always be given.
70. However, sufficient leeway exists for a wide interpretation of what is meant by hydration and nutrition. Dr Au-Yeung pointed out that "spoon feeding a disabled patient is very far removed from total parenteral nutrition (TPN) in a renal failure patient prone to fluid overload; yet both constitute no more than the provision of the basic needs of nutrition and hydration. They are just different parts of the same spectrum." (Letter to Editor, Catholic Medical Quarterly, Feb 1999, p29)
71. Drs Treloar and Howard argued cogently "that the placement of feeding tubes constitutes medical treatment from an ethical standpoint. However following tube placement, a different moral situation pertains: the provision of feeding through such means constitutes ordinary care." (Treloar A and Howard P. Tube Feeding: Medical Treatment or Basic Care? Catholic Medical Quarterly, Aug 1998, pp5-7)
72. The Pontifical Academy for Life asserts "One must always provide ordinary care (including artificial nutrition and hydration), palliative treatment, especially the proper therapy for pain, in a dialogue with the patient which keeps him informed." (*Respect for the Dignity of the Dying*, Pontifical Academy for Life, 9 Dec 2000; no 6)
73. In an address to an International of the World Federation of Catholic Medical Associations (FIAMC) with the Pontifical Academy for Life in March 2004, the Pope reminds the participants that "the administration

of water and food, even when provided by artificial means, always represents a natural means of preserving life, not a medical act. Its use, furthermore, should be considered, in principle, ordinary and proportionate, and as such morally obligatory," (*Speech Of John Paul II To The Participants At The International Congress on Life Sustaining Treatments And Vegetative State Saturday 20 March 2004*, no.4)

74. The Joint Statement issued at the conclusion of the Congress reiterates "The possible decision of withdrawing nutrition and hydration, necessarily administered to VS patients in an assisted way, is followed inevitably by the patients' death as a direct consequence. Therefore, it has to be considered a genuine act of euthanasia by omission, which is morally unacceptable." (*FIAMC and Pontifical Academy for Life Joint Statement on Vegetative State*, Rome, 24 March 2004, no.10)
75. We therefore reaffirm our absolute opposition to any proposal which allows the withdrawal of ANH to be authorized by AD or by substitute decision making in mental incapacity.

Medical Research

76. Conducting medical research in mentally incapacitated persons is a controversial area. Potential for abuse and exploitation exists.
77. Yet denying these people a chance to try out new forms of therapy which may be more be effective than current standard treatment could be viewed as a form of discrimination of the disabled.
78. Whilst there is no obligation for anyone to undertake anything other than proportionate therapy, a person may wish to submit to treatment "still at the experimental stage and are not without a certain risk. By accepting them, the patient can even show generosity in the service of humanity."(*Declaration on Euthanasia* (AAS 72(1980), pp 542-552))
79. There does not seem to be any reason why persons, who may wish to participate in medical research when competent, should be denied the right to similar altruistic philanthropy when he has become mentally incapacitated, provided always that safeguards against abuse and exploitation be instituted.
80. Non-therapeutic research into mechanisms of the disease, diagnosis and even of assessing prognosis could benefit future persons suffering the same affliction but is deemed not to be beneficial to the person concerned.

81. If safeguards against abuse and exploitation can be guaranteed, is there any fundamental reason why mentally incapacitated person cannot in principle participate in non-therapeutic research of the kind mentioned above?
82. The approach of the Law Commission of England and Wales (paras 7.113-7.114) and of the Scottish Law Commission (para 7.152) in relation to medical research in mentally incapacitated persons can offer some directions for further consideration.

Protection for Healthcare Workers

Action in good faith

83. Noting that the current final recommendation for reform does not involve the drafting of legislation, we urge the Commission to advise the Government to take administrative steps to provide protection for healthcare workers who act in good faith, instituting or omitting therapy according to the provisions of an advance direction without knowing that it is invalid; or instituting or omitting therapy according to the best interests of a person without knowing that of the existence of a valid advance directive. (cf para 7.28 Queensland, Powers of Attorney Act 1998, Ch. 5; para 7.62 Alberta, Personal Directives Act 1996, section 28(3); para 7.72 Manitoba Health Care Directives Act 1992 and para 7.136 on a similar provision proposed in law reform in England and Wales)
84. We also urge the Commission to advise the Government to take administrative steps to provide protection for healthcare workers who act in good faith, to preserve the life of a mentally incapacitated person, or to prevent a serious deterioration in the health of such a person, when the validity or applicability of an AD is doubted or disputed, and the urgency for treatment does not afford the time necessary to establish its validity and/or its applicability. (cf para 7.136, penultimate sub-paragraph)

Conscientious Objectors

85. We believe there should be provision to protect the healthcare worker who has a conscientious objection to the provision or withdrawal of therapy resulting from anticipatory decisions by or substituted decisions

for a mentally incapacitated person.

86. The right to some form of protection is recognized both in Law and in professional guidelines here in Hong Kong:
    a. Subsection 6 of Section 47A of the Offences Against the Person Ordinance (Cap 212) states, in relation to medical termination of pregnancy, that "Subject to subsection (7), no person shall be under any duty, whether by contract or by any statutory or other legal requirement, to participate in any treatment authorized by this section to which he has a conscientious objection, but in any legal proceedings the burden of proof of conscientious objection rests on the person claiming to rely on it. [cf. 1967 c. 87 s. 4 U.K.]"
    b. The November 2000 version of the Professional Code and Conduct of the Hong Kong Medical Council states "If a medical practitioner …. should have any objection to a procedure which is beneficial to the patient, he should give a full explanation to the patient and ask the patient to seek advice from another qualified medical practitioner." (no.25.2)
87. Case law does not seem to afford such protection:
    a. Lord Keith of Kinkel said in *Bland* at p 858, "Where one individual has assumed responsibility for the care of another who cannot look after himself or herself, whether as a medical practitioner or otherwise, that responsibility cannot lawfully be shed unless arrangements are made for the responsibility to be taken over by someone else."
    b. Mr Munby in *Burke* concluded that "Once the duty to care has arisen, the doctor and the hospital are under a continuing obligation that cannot lawfully be shed unless arrangements are made for the responsibility to be taken over by someone else." (para 213 (b))

88. Noting that the current final recommendation for reform does not involve the drafting of legislation, we urge the Commission to advise the Government to take administrative steps to provide protection to a conscientious objector.

Summary

89. We summarize the response of the Guild of St Luke, St Cosmas and St Damien as follows:
    a. We note that individual autonomy, which is not diminished in mental incapacity, as the basis of this consultation exercise, but that it is limited in a number of ways.
    b. We assert that the first premise of personal autonomy is being alive, because the exercise of freedom is impossible outside of life.
    c. We reaffirm the sanctity of life, which allows that a person can in conscience refuse forms of treatment that would only secure a precarious and burdensome prolongation of life. Indeed, the approach to a person's death should be to use proportionate treatment available without engaging in any form of overzealous treatment.
    d. We note that incapacity is relative to the decision to be made, but the document tended to treat incapacity as on-off and makes little allowance for fluctuations in decision-making capacity.
    e. We note the problems of dementia in relation to the terms of AD as proposed by this consultation paper.
    f. We note the diagnostic and prognostic uncertainties of VS and assert that the value and dignity of VS persons are in no way affected by their state. VS persons should not be considered burdens of society.
    g. We assert that AD must not be allowed to effect euthanasia, which is illegal and unethical.
    h. We voiced our concerns over the status of AD, illustrating them with problems involving the organ donation card.
    i. We welcome the witness requirements which ensure validity of AD, but suggest the Singapore witness requirements may be better. We note their approach to protect against undue influence, which merits further exploration.
    j. We note the problem of the applicability of AD, including being able to foresee future situations in which the AD should operate. We note that an AD which is too specific can fail to take certain situations into account whilst a general AD can be too vague
    k. The problem of the scope of AD being only advance refusal or (as is the present case) both refusal and directions for treatment was

discussed. The problems of limiting AD to terminal illness, irreversible coma and VS were highlighted.

l. We outlined other problems with AD including those concerning revocation and the setting up of a central registry. We note the reluctance of the local population regarding end-of-life issues and commend the Commission for recommending strategies to promote understanding.

m. We suggested that additional options for pre-incapacity decision-making be considered.

n. We welcome the proposal to amend the Mental Health Ordinance (Cap 136) so that comatose and VS patients are brought into the legal protection within the framework of that statute.

o. We urge the Commission to recommend setting up a framework for assessing the best interests of mentally incapacitated persons.

p. We suggest that the Commission consider options (see para 89m above) to provide a competent person to influence the choice of a surrogate decision-maker when he has become subsequently mentally incapacitated.

q. We commend the Commission's decision to include nutrition and hydration as basic care which should always be given. We also argue that withdrawal of ANH in VS persons and dying patients represent the withdrawal of basic care and such withdrawal is condemned by us as euthanasia by omission, to which we express our absolute opposition.

r. We note the thorny issue of medical research in mentally incapacitated persons. The approaches of the Law Commissions of England and Wales and Scotland provide pointers to avenues warranting further exploration.

s. There should be administrative steps to provide protection for healthcare workers acting in good faith for following an advance directive which they do not know is invalid; or for instituting or withholding treatment against an advance directive, of which they have no knowledge.

t. There should be administrative steps to provide protection for healthcare workers acting in good faith, to preserve the life of a mentally incapacitated person, or to prevent a serious deterioration in the health of such a person, in an urgent situation, when the validity or applicability of his AD is doubted or disputed.

u. There should be administrative steps taken to provide protection for conscientious objectors.