# The Guild of St Luke, St Cosmas and St Damian Hong Kong

Response to Consultation by the Food and Health Bureau on the Consultation Paper "Introduction of the Concept of Advance Directives in Hong Kong"

The Guild of St Luke, St Cosmas and St Damian Hong Kong 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. Before proceeding with this response, attention should be paid to what the Guild has submitted in response to the consultation document of the Law Reform Commission of Hong Kong on this matter in September 2004[1], to which reference will be made within this response.

Remarks about the information pack for the general public

Before proceeding to respond to the section for the medical profession, we feel that it is important to look at the draft information pack for the general public and see if the information contained therein is helpful in promulgating the concept of advance directives here in Hong Kong. We have examined both the Chinese and English documents in the way that members of research ethics committees would examine the information sheets (normally used in conjunction with consent forms) to see if adequate explanation had been given the relevant risks have been disclosed, so as to enable prospective participants to decide on whether to enroll.

In this respect, both the information packs were found wanting as they are not user-friendly. There is an unfortunate impression that those drafting the information pack are more concerned about avoidance of legal liability than the wide dissemination of information to the general public. AS an example, the answer to Q6 of the FAQ is overly legalistic in terms of language used in both versions; virtually to the point of hampering understanding. Some information packs for medical experiments reviewed by research ethics committees are more user-friendly than this, and those documents have a more direct legal impact on the adequacy and validity of informed consent obtained from the participants.

The Chinese version is particularly awkward to read, with some sentences looking as if it was a word for word translation from the English. On the other hand, there are also a few

[1] 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" http://www.doctor.catholic.org.hk/publications/GuildSubmissiontoHKLRC.pdf

instances in which the Chinese version is less misleading than the English. In the section "Should I make an advance directive? (p30 in the English version), the advance directive is portrayed as an expression of preference, but in the model form (Enclosure 1 to Annex B), both refusal of consent as well as request for treatment are presented in the choices to be "ticked" by the person making an advance directive. This is less confusing in the Chinese draft. In the last paragraph before FAQs (p31), persons considering making an advance directive are asked to make sure that doctors and family are kept informed. There is a natural temptation for someone reading this to ask a family member to witness the directive although they are not reminded there and then that family members are often excluded because they usually have interests in the estate of the person wishing to execute such an instrument. Again the Chinese version is less misleading in this aspect.

For the medical profession

(a) The general guidance on advance directives as set out in Annex B on the making, altering and revoking advance directives are somewhat useful and should be promulgated for general use by the medical profession. The Hospital Authority has, we understand, been working on some guidelines and this should prove helpful for the public sector.

We have some reservations about witness requirements. The person making a written directive or revocation has to declare that he or she has done this in front of a witness that he or she knows not to be a beneficiary under any instruments he or she had executed (at the time of making or revoking the said directive). On the other hand, the recorder of an oral revocation only needs to declare that he or she is not related and is not a beneficiary to the best of his or her knowledge. The latter is reasonable but not necessarily the former. Whilst it may be reasonable for someone to declare that his witness is not a beneficiary when he makes an advance directive, it may not be so for a revocation, especially if some acute event has been the cause of the revocation. In the stress of such an event, stringent requirements which hamper a person to change his mind do not serve to protect or enhance his autonomy. Of course we do recognise that a delicate balance must be made between ease of changing minds and possible conflict of interests of witnesses, so that undue influence may not be brought to bear upon the person wanting to make or revoke a directive.

In Q4 of the FAQs, a proxy was mentioned in both versions, but there does not seem to be any other mention of this in the information package. The mention here of proxies seem to be most inappropriate in relation to advance directives, seeing that the LRC had ruled out the appointment of proxies either for decision making as part of a living will or to help interpret the fine nuances of refusal in the sort of advance directives they

recommended. We stand by our position in our response to the LRC consultation document that the possibility of appointing a decision making proxy or one for interpreting the fine details of a directive could be considered as an additional option.[2]

(b) Guidelines on procedural matters in handling advance directives etc would be useful to frontline healthcare workers and again the Hospital Authority can be asked to include these in the guidelines they are preparing. In the case where guidelines already exist, they may be suitably amended to take account of the new situations which may arise from the introduction of advance directives.

One area in which Catholic medical ethics differ from secular medicine is the need to administer artificial nutrition and hydration (ANH) to patients in the persistent vegetative state. Whilst there is no question that the use of general anaesthesia, surgery or endoscopy to place a feeding tube would be properly regarded as a medical procedure or treatment, the use of a functional feeding tube to provide liquid food and water to a patient is regarded by the Catholic Church as basic care, which the healthcare worker is obliged to provide and the patient equally morally obliged to receive. This has already been pointed out in our earlier response to the LRC consultation[3]. The Congregation for the Doctrine of the Faith has since issued a specific statement, declaring that such tube feeding is obligatory for patients in the vegetative state as well as for those in irreversible coma.[4] We welcome the amendment of the model form to include a request for continuing artificial nutrition and hydration. We hope that the Government will ensure that such requests in validly executed advance directives would be followed.

We would like to express our concern for the plight of healthcare workers who may have objections to some aspects of treatment (or non-treatment) contained within a validly executed advance directive. We note that the right to freedom of conscience necessarily includes the right to refuse to participate in an act to which one has a conscientious objection. The right to freedom of conscience, enshrined in both the Universal Declaration of Human Rights as well as the International Convention on Civil and Political Rights (to which Hong Kong is a signatory), is codified in the Hong Kong Bill of Rights (Cap 383, Section 8, Article 15) and provisions for conscientious refusal are also found in Subsection 6 of Section 47A of Cap 212 as well as Section 20 of Cap 561. Referring to our previous response[5], we would again urge the Government to put in place administrative procedures to provide protection to a conscientious objector.

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[2] Ibid, para 56-58

[3] Ibid, para 67-75

4 Responses to Certain Questions of ohe United States Conference of Catholic Bishops Concerning Artificial Nutrition and Hydration

http://www.vatican.va/roman_curia/congregations/cfaith/documents/rc_con_cfaith_doc_20070801_risposte-usa_en.html

[5] Ibid, para 85-88

(c) The concept of advance directive and ACP is relevant to the work of all looking after patients whose conditions may render them mentally incapacitated and whose illnesses may lead to a terminal condition, irreversible coma or the persistent vegetative state. That includes a very wide spectrum of patients. That also argues for a case for the medical schools to include it in the medical curriculum.

Some general remarks

Dementia is an illness which often causes a diminution of mental capacity before it is lost completely, and then often at time significantly before the patient is about to die from whatever cause. It was a disappointment that first the LRC consultation and then its report both started outlining the problem of dementia and ended with dropping it altogether in the proposals. Notwithstanding this, concerned groups have looked at both advance directives as well as advance care planning and a symposium was held by the Sau Po Center on Ageing, The University of Hong Kong and School of Nursing, The Hong Kong Polytechnic University in association with Hong Kong Alzheimer's Disease Association, Hong Kong Geriatrics Society, IDEAL and Society for the Promotion of Hospice Care in June 2009 to further explore these issues.[6] This is an area which the Government should not ignore.

The Guild of St Luke, St Cosmas and St Damian, Hong Kong
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[6] See http://sn.polyu.edu.hk/adsymposium/index.html