COMMENTS OF THE HONG KONG BAR ASSOCIATION

ON THE CONSULATION PAPER CONCERNING THE INTRODUCTION OF THE CONCEPT OF ADVANCE DIRECTIVES IN HONG KONG

General Observations

1. It should be made clear that an advance directive is outside the scope of an enduring power of attorney made under s.8(1)(a) Cap 501. It only deals with medical treatment and not property or affairs of the patient. This should be made clear in Annex C.

2. A valid advance directive should allow the maker to express their right to determine some end-of-life decisions by allowing an individual to participate indirectly in future medical care decisions, even if they become decisionally incapacitated. This statement is restricted to 'some' end-of-life decisions because it is not possible to predict and cater for every end-of-life scenario as there is too much variability in clinical decision making to make all-encompassing advance directives possible.

3. Advance directives are intended to absolve family, friends and medical personnel of the responsibility for end-of-life decision making, in favour of the dying person's lawful wishes. However the maker should be warned that these documents are insufficient to ensure that all decisions regarding care at the end-of-life will be made in accordance with their written wishes.

4. If advance directives are not in place, the family and doctor must be prepared to make decisions consistent with what they believe the person would have wanted while acting in that person's best interest, with the latter being determinant, should there be a conflict.

5. The utility of advance directives has been questioned in other jurisdictions because the written document may not be available at the time and place needed. However when advance directives can be applied, they decrease the anxiety and conflict that may accompany death and dying.

Degree of Formality required

6. A valid advance directive can be made informally but will not have the same degree of certainty that attends a formal document. The legal profession have been asked to comment on whether the explanatory guidance sufficiently explains the making, altering and revoking of advance directives. Perhaps more apposite is the question: How much formality is required if an informal advance directive can be valid?

Form Issues

7. The 2nd and 3rd sentences debating the theoretical merits of allowing oral advance directives are not appropriate to a 'Guidance' document (Annex B, at p.13). The key points to be made are that oral advance directives may not be acted upon because of uncertainty as to intention, the possibility of undue influence and lack of documentation for medical personnel to refer to. These points are clearly made in the last two sentences of the 1st paragraph.

8. Wording of the documents:

   (a) "making an advance directive is a matter of ***grave*** importance" (page 15 para (g)) is an unfortunate choice of words in the context of a matter dealing with death.

   (b) Enclosure I refers to "***difficult*** decisions" at the top of page 20. These are end-of-life decisions, the difficulty of which is irrelevant to the subject matter and the nature of the advance directive.

   (c) Enclosure I refers to .."I am unable to ***take part*** in decisions".. at para 4, page 20. This might be more accurately be expressed as *"unable to meaningfully participate in decisions"*.

9. The following are useful practical considerations for a person considering making an advance directive[1]:

Matters to consider when planning an advance directive					
Opinion about the following situations	*Would prefer to die*	*Would probably prefer to die*	*Uncertain either way*	*Would probably prefer to live*	*Eager to stay alive*
Permanently paralysed but able to relate to others					
Totally dependent on others. Needs to be fed.					
Aware but unable to communicate					
Confused and very poor memory					
Constant uncontrolled pain					
Brain damage. In coma. If regained consciousness markedly impaired					
Terminal illness, not necessarily cancer					

10. This could be followed by tick boxes in simple language which specify particular treatment which is wanted or unwanted in particular circumstances:

[1] http://www.patient.co.uk/doctor/Advance-Directives-%28Living-Wills%29.htm, Patient UK, last accessed 21/1/2010.

(a) In the circumstances of ..... I do not want .....

(b) If I am nearing my death, I want the following care given to me:

(i) keep me warm, dry and pain free;

(ii) only give measures which enhance comfort and/or minimise pain;

(iii) do not transfer me to hospital;

(iv) do not perform tests on me like x-rays, blood tests or give me antibiotics.

11. The current language of Annex C has a degree of formality which might make the practical application of the advance directive difficult for the lay person to understand.

Practical Issues

12. There are some practical issues which have not been touched upon in the Consultation Paper.

13. The section on 'Making an advance directive' explains the need for the maker to be competent, that is, possess decision-making capacity which requires **all** three of the following components: understanding, reasoning and meaningful communication (Annex B, para (a)(i) page 13-14).

14. Section II of Enclosure I to Annex B attests only to understanding. It does not record that the person making the advance directive has read and understood the importance of the document, nor does it record that the maker has had the document explained and that all questions asked have been answered to the maker's satisfaction. Although the document records that the doctor believes that he has explained to the maker, the nature and implications of making the directive, this gives no express indication of the maker's acceptance of that explanation.

15. Further, there is no confirmation in the document that the maker has discussed or understands the importance of discussing the directive and/or his wishes, with his family and/or friends and doctor, so that they are aware of them. In the Hong Kong jurisdiction, the attending doctor at the time of implementation of an advance directive is unlikely to have witnessed the document or assessed capacity at the time the directive was made.

16. An advanced directive should include an option for those people who want all reasonable life-prolonging treatments to be commenced and continued while they are deemed medically appropriate by the treating team and remain in their best interest. For example, this would include cardiopulmonary resuscitation (CPR) and mechanical ventilation but might not include a new, experimental, expensive treatment that would unreasonably drain limited private or public resources. An advance directive expressly selecting 'all reasonable life prolonging treatment' could usefully be included in Annex B.

17. The usual wish of a person issuing an advanced directive is that they be allowed to die naturally and be cared for with dignity. Death with dignity can be achieved by way of palliative care which includes medications, treatments and care that will alleviate

suffering and provide comfort. An explanation of what constitutes palliative care in the circumstances of terminal illness could usefully be included in Annex B.

18. In Paragraph 13 of the Consultation Paper, it is explained that since the Advance Directives are not statue-based, they should give way to other existing legislations in case of conflict. One important example is the procedure for obtaining consent in respect of a mentally incapacitated recipient under the Human Organ Transplant Ordinance (Cap. 465). It should be made clear in Annex C that Advance Directives are not meant to cover organ transplants.

19. Acutely ill people without an ability to communicate often collapse out of office hours and resuscitation is commenced without implementation of an advance directive which expresses their wish not to prolong their life by extraordinary or overly burdensome treatments, such as CPR and mechanical ventilation. It would be appropriate for Annex B to include a directive for expressly discontinuing these treatments, if they have been commenced in such circumstances.

20. Advance directives take effect only in situations where a patient is unable to participate directly in medical decision making. Assessment of capacity is a matter of evidence and not just a matter of expertise. The sample directives are written to apply only in clinical situations of terminal illness and persistent vegetative state or a state of irreversible coma. Although defined in Enclosure I, these terms will have to be interpreted by caregivers.

21. It may be more practical if the advance directive is activated once the maker has become acutely ill, unable to communicate and it is reasonably certain that they will not recover, without defining technical clinical states and life-expectancy, which necessitate 2 doctors to certify (para 4, page 20). This would be more in keeping with the validity of informal directives and might be more appropriate in practice.

22. The Questions and Answers extracted from the Legal Services New Jersey, USA[2] (see Attachment) might be useful additions to those in the Guideline, for the layperson comprehending the practicalities of Advance Directives.

Altering and Revoking

23. An advance directive should be updated regularly to reflect a person's current wishes, for example on an annual basis or if there is progression of a chronic illness.

24. Can and should the witness be a carer? A witness has to sign and say that they saw the maker sign the revocation and that the maker is, in their opinion, well enough to understand and intend the effects of his revocation. Anybody can do this. If the witness helps the maker draft the amendment, it is preferable that a different carer witness the amendment.

Annex C

25. The 2nd paragraph of the information package (Annex C) omits to state that under common law principles, a valid advance directive may be made in Hong Kong.

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[2] http://www.nj.gov/health/healthfacilities/documents/ltc/advance_directives.pdf, last visited 1/3/2010.

26. What is an advance directive? The utility of the document extends much further than the maker's doctor. It informs the maker's health care team and family of their future wishes as regards their care.

27. In answer to the question "When will my advance directive become operative?" in Annex C :

(a) *"According to the recommendation of LRC, your advance directive will become operative only when ..."* is a consequence of the model advance directive proposed by the LRC which was adopted with only minor modification.

(b) The answer omits to state that mental incapacity is a precondition of an advance directive relating to terminal illness becoming operative.

(c) There are practical difficulties in activating - *"It is your responsibility to ensure that the directive is available to the doctor at the time when the doctor makes a treatment decision"* when the *"you"* will be in a state of mental incapacity at the time a treatment decision is made in accordance with *"your"* advance directive. If the maker is unconscious and terminally ill, having made an advance directive say, 5 years previously, and is now rushed to a general hospital to a treating doctor who has never seen the maker previously, how can it be the maker's responsibility to ensure that the directive is available to that treating doctor.

(d) Perhaps this may be amended to read : *"You should provide a copy of your advance directive to your treating doctor so that he can act in accordance with your wishes in the event the conditions for your advance directive to become operative eventuate."*

Final note:

28. It could be considered whether an Advance Directive might also be a convenient document to record the makers wishes as regards organ donation, any parting message to family and friends.

Hong Kong Bar Association
25th March 2010

Attachment

Questions and Answers extracted from the paper of the Legal Services New Jersey, USA

(a) **Why should I consider writing an advance directive?**

Serious injury, illness or mental incapacity may make it impossible for you to make health care decisions for yourself. In these situations, those responsible for your care will have to make decisions for you. Advance directives are legal documents, which provide information about your treatment preferences to those caring for you, helping to insure that your wishes are respected even when you can't make decisions yourself.

(b) **When does my advance directive take effect?**

Your directive takes effect when you no longer have the ability to make decisions about your health care. This judgment is normally made by your attending doctor. If there is any doubt about your ability to make such decisions, your treating doctor will consult with another doctor with training and experience in this area. Together they will decide if you are unable to make your own health care decisions.

This has been highlighted as it has practical repercussions which are different from the recommended procedure.

(c) **What happens if I regain the ability to make my own decisions?**

If you regain your ability to make decisions, then you resume making your own decisions directly. Your directive is in effect only as long as you are unable to make your own decisions.

(d) **Should I discuss my wishes with my family and doctor?**

Absolutely! Your family members are the most probable people who will speak for you when you can't speak for yourself. It is very important that they have a clear understanding of your feelings, attitudes and health care preferences. You should also discuss your wishes with your doctor and any others who will be involved in caring for you.

(e) **If I want to give specific instructions about my medical care, what should I say?**

If you have any special concerns about particular treatments you should clearly express them in your directive. If you feel there are medical conditions, which would lead you to decide to forego all medical treatment, including life-sustaining measures, and accept an earlier death, this should be clearly indicated in your directive.

(f) **Are there particular treatments I should specifically mention in my directive?**

It is a good idea to indicate your specific preferences concerning two specific kinds of life-sustaining measures: artificially provided fluids and nutrition and cardiopulmonary resuscitation. Stating your preferences clearly concerning these two treatments will be of considerable help in avoiding uncertainty, disagreements or confusion about your wishes.

(g) **Can I request all measures to be taken to sustain my life?**

Yes. You should make this choice clear in your advance directive. A directive can be used to request medical treatments as well as to refuse unwanted ones.

(h) **Does my doctor have to carry out my wishes as stated in my advance directive?**

If your treatment preferences are clear, then your doctor is legally obligated to implement your wishes, unless doing this would be unlawful.

(i) **Can I make changes to my directive?**

Yes. An advance directive can be updated or modified, in whole or part, at any time. You should update your directive whenever you feel it no longer accurately reflects your wishes.

(j) **Can I revoke my directive at any time?**

Yes. You can revoke your directive at any time, regardless of your physical or mental condition. This can be done in writing, orally, or by any action, which indicates that you no longer want the directive to be in effect.

(k) **Who should have copies of my advance directive?**

A copy should be given to your family, your doctor, and others who are important to you. If you enter a hospital, nursing home, or hospice, a copy of

your advance directive should be provided so that it can be made part of your medical records.

(l) **Can I be required to sign an advance directive?**

No. An advance directive is not required for admission to a hospital, nursing home, or other health care facility. You cannot be refused admission to a hospital, nursing home, or other health care facility because you do not have an advance directive.

(m) **Can I use my advance directives to make an organ donation upon my death?**

Yes. The sample combined directive and instruction directive provide a place for you to state your wishes regarding organ donation. Also, there is a wallet size organ donor card. If you decide to make a gift of your organs upon your death please complete the card and carry it with you at all times. (These forms are available at the bottom of this page.) For further information regarding organ donation, you should contact either an organ procurement agency or your local hospital.

(n) **Do I need a lawyer or a doctor to write one?**

You should consult with anyone you think can be helpful, but it is not a prerequisite for a valid advance directive. Information contained in the Guideline and the sample forms are designed to enable you to complete your advance directive without the need for legal or medical advice. If any medical terminology is unclear to you, most health care professionals will be able to help you understand it.