Introduction of the Concept of Advance Directives in Hong Kong Consultation Paper



Food and Health Bureau

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Introduction

The Code of Professional Conduct for the Guidance of Registered Medical Practitioners ("the Code of Professional Conduct") (revised edition as at January 2009) published by the Medical Council of Hong Kong requires that a physician shall "respect a competent patient's right to accept or refuse treatment" and "act in the patient's best interests when providing medical care"¹. In case of a conflict between the wishes of the patient and his² family members, the patients' right of self-determination should prevail over the wishes of his relatives³. However, when a patient is terminally ill, in a state of irreversible coma or in a persistent vegetative state and does not have the mental capacity to make decisions, healthcare professionals and family members caring for the patient often encounter the problem of how to ascertain the wish of the patient.

2. Under the common law as established in the case of *Airedale NHS v* $Bland^4$, administering medical treatment to an adult, who is conscious and of sound mind, without his consent constitute both a tort and the crime of battery. Such a person is completely at liberty to decline to undergo treatment, even if the result of his doing so will be that he will die. In the same case, it was said that respect must be given to the wishes of the patient so that, if an adult patient of sound mind refuses, however unreasonably, to consent to treatment or care by which his life would or might be prolonged, the doctors responsible for his care must give effect to his wishes, even though they do not consider it to be in his best interests to do so. It was also held in *Re F (Mental Patient: Sterilisation)* that if a patient's wishes cannot be ascertained, treatment should be given in accordance with the principle of the best interests of the patient.⁵

3. To minimize the uncertainty faced by a doctor or family members about the medical treatment that a patient wishes to receive when he is no longer mentally competent to make such decisions, the concept of advance directives has been introduced in countries such as Australia, Canada, United Kingdom, Singapore, the United States, etc. A person, while he is mentally competent, can give instructions through an advance directive to indicate the form of health care or medical treatment that he would like to receive at a future time when he

¹ See Part I of the Code of Professional Conduct.

 $^{^{2}}$ The masculine pronoun in this document is meant to be a neutral reference to any person.

³ Clause 34.4, the Code of Professional Conduct

⁴ [1993] 1 All ER 821.

⁵ [1990] 2 AC 1, at 55.

is no longer mentally competent. The development of the concept of advance directives is largely derived from the principle of informed consent and the principle of self-determination in healthcare decisions.

4. The Law Reform Commission (LRC) published in August 2006 a report entitled Substitute Decision-making and Advanced Directives in Relation to Medical Treatment (the Report). The Report aims to review, inter alia, the law relating to the giving of advance directives by persons when mentally competent as to the form of health care or medical treatment which they would like to receive at a future time when they are no longer competent. The full available LRC's website report is at at http://www.hkreform.gov.hk/en/publications/rdecision.htm. A summary of LRC's recommendations is at *Annex A*.

5 This consultation paper is issued in response to LRC's recommendations to consult stakeholders on matters relating to the introduction of the concept of advance directives in Hong Kong. Specifically, we would like to work with the healthcare profession, legal profession, patient groups, organisations involved in providing elderly care services, and other stakeholders to provide relevant information to the public on the subject matter of advance directives and to develop any necessary guidelines for the medical profession and any other professions on handling advance directives.

What is Advance Directive?

6. An advance directive for health care is described as "a statement, usually writing, in which a person indicates when mentally competent the form of health care he would like to have at a future time when he is no longer competent", a definition that is cited in *the Report*. Such a definition is broad enough to cover a wide range of scenarios in practice, where the making of advance directives serves to provide both doctors and family members a clear indication on the preferences of the patients when they become unable to make decisions on their own, e.g. when they are in a coma.

7. The making of advance directives provides an avenue for individuals to exercise their right of self-determination and make known their choices for their own health care in the eventuality that they may no longer be able to make such decisions. The advance directives thus made provide the individuals' family members a clear indication of the former's wishes. It also helps doctors to fulfil their professional responsibility to patients, especially when facing the difficult choice of whether life-sustaining treatments should be withheld or withdrawn in the best interests of the patients.

8. While a patient's right of self-determination should always be respected, he cannot make an advance directive for an act that contradicts the law or professional ethics. One example is euthanasia, which is defined in *the Code of Professional Conduct* as "direct intentional killing of a person as part of the medical care being offered". It involves a third party's unlawful acts of intentional killing, manslaughter, or aiding, abetting, counselling or procuring the suicide of another, or an attempt by another to commit suicide, which are outlawed in Hong Kong. Euthanasia is thus both medically unethical and illegal in Hong Kong. Hence, even if a person expressly requests for euthanasia to be administered, such requests cannot and should not be carried out.

How Does an Advance Directive Operate?

9. Any adult who has the necessary mental capacity to make his own healthcare decisions is free to make an advance directive. The question is how to determine the mental competence of the individual. This question arises at the time the person makes an advance directive, and when the advance directive is invoked after the person has become incompetent to make decisions. In practice, the determination is usually made by the attending doctor on the basis of a number of criteria, with the assistance of other professionals (e.g. the individual's psychiatrist or lawyer) as necessary. Existing guidance or practices on determination of mental competence are described at *Annex B*.

10. LRC recommends that the person making an advance directive may specify in the advance directive that, when he is in any of the three conditions below -

- (a) terminally ill;
- (b) in a state of irreversible coma; or
- (c) in a persistent vegetative state,

he does not agree to receive any life-sustaining treatment or any other treatment he has specified save for basic and palliative care. The advance directive will become operative only when he is in one of the three conditions above. Existing definitions and criteria for determining these conditions are described at *Annex B*. In addition, an advance directive is only valid if the person who made it was free from undue influence and had sufficient information to make that particular directive. It is also the responsibility of the person who made the advance directive to ensure that it is available to the doctor at the time when the doctor makes a treatment decision.

11. While a life-sustaining treatment to be withheld or withdrawn under an advance directive does not need to be medically futile, futility of treatment sometimes can be one of the considerations for a patient when he makes an advance directive, and doctors very often will be asked to give advice by the patients and their family members in this regard. It should be noted that futility is a complex concept with both medical prognostication and value-laden aspects. The doctor should provide appropriate clinical information to the patient to facilitate decision-making. Existing guidance in the public sector as well as guidance provided under the common law on determination of futility of treatment are given at *Annex B*.

Legal Status of Advance Directives

12. Hong Kong has neither statute nor case law on the legal status of advance directives. However, validly-made advance directives refusing life sustaining treatment have been held to be legally binding at common law in the United Kingdom⁶ and other jurisdictions such as Australia, Canada, Singapore and the United States of America⁷. Some countries such as Canada and Singapore also have legislation providing for the procedures and the necessary safeguards relating to advance directives. Notwithstanding that there is currently no legislation governing advance directives in Hong Kong, any person is free to make an advance directive in Hong Kong if he so wishes. Such directive will be recognised as valid unless challenged on the grounds of, for instance, incapacity or undue influence⁸.

13. Having regard to the existing *Code of Professional Conduct* and the principle of self- determination, even in the absence of express statute or ruling on the legal status of advance directives in Hong Kong, doctors are required to respect the wish of a patient expressed through the advance directives, even if they are contrary to their personal beliefs, unless the directives involve unlawful acts (e.g. euthanasia). As a general principle, since advance directives are not yet covered by legislation in Hong Kong, in cases of conflict with other statutory provisions, advance directives are always superseded by existing legislation. Where a dispute arises over the patient's prior instructions or

⁶ See, for example, Re T (Adult: Refusal of Treatment) [1992] 3 W.L.R 782; Airedale NHS Trust v Bland [1993] A.C. 789; Re C (Adult: Refusal of Treatment) [1994] 1 W.L.R. 290.

⁷ See Chapter 7 of *the Report*.

⁸ Paragraph 8.33 of *the Report*.

wishes as to his medical treatment, application may be made to the court for a decision.⁹

Government's Position on Advance Directives

14. The Government recognizes the potential usefulness that advance directives may serve to doctors, patients, and family members of the patients. However, the Government also recognizes that the concept of advance directives is fairly new to the community, and Hong Kong people are not yet familiar with the concept of advance directives. We also recognize that advance directives touch upon a wide range of issues beyond its legal and practical aspects, which warrant very careful consideration and deliberation. The Government thus agrees with LRC's view that it would be premature to attempt to formulate a statutory framework and to embark on any legislative process for advance directives, without greater public awareness of the issues involved¹⁰.

15. The Government also recognizes that the making of an advance directive is entirely a personal decision and that a person is already free at present to make an advance directive if he so wishes. Respecting individuals' freedom of making such a decision, the Government has no intention at this stage to actively advocate or encourage the public to make advance directives. It should remain an individual's choice and decision of making an advance directive if he so wishes. However, there is the question of how to enhance the public's understanding of advance directives and how to make the necessary information available for those who wish to make such directives.

16. Regarding concerns about the absence of specific statute governing advance directives, the Government recognizes that doctors are already required to act in the best interests of their patients and respect their patients' wish, including any advance directives that their patients are already free to make at present. As also pointed out in *the Report*, the existing common law should be able to provide sufficient clarity and guidance for deciding the validity and applicability of advance directives, and should offer adequate protection to doctors as long as they have acted in the best interests of the patients, or the provision or otherwise of medical treatment is in accordance with the patients' instructions previously made¹¹. In this regard, we recognize that there may be a need for guidance to be provided to the medical profession, and/or the legal

⁹ Paragraph 8.33 of *the Report*

¹⁰ Paragraph 8.36 of *the Report*

¹¹ Paragraph 8.38 of *the Report*

profession or any other relevant professions or parties, on the making and handling of advance directives.

Advance Care Planning

17. We would also like to take this opportunity of issuing this consultation paper to invite views on the concept of "advance care planning" (ACP) for patients.

18. ACP is "a process of communication among patients, their healthcare providers, their families, and important others regarding the kind of care that will be considered appropriate when the patient cannot make decision"¹². It will usually take place in the context of an anticipated deterioration in the patient's condition in the future, with loss of capacity to make decisions and/or ability to communicate wishes to others. With the patient's agreement, this communication will be documented and regularly reviewed. It can also form an integral part of the care and communication process of the regular review of his care plan. Some countries such as the United Kingdom and Australia have already made the making of the advance directives as part of ACP for patients.

19. An ACP discussion might include the patient's concerns, his important values or personal goals for care, his understanding about his illness and prognosis, and his preferences for types of care or treatment that may be beneficial in the future and the availability of these. Hence, ACP is much wider in scope than a written advance directive. Through communication, documentation and regular review, ACP provides the doctor taking care of the patient as well as the patient's family members with even greater certainty about the wish of the patient. As ACP involves giving assistance to the patient by the healthcare professionals and family members in formulating his own advance directive, it will be easier for them to get guidance from the advance directive and interpret it in the same way as the patient making it.

20. While there have been many local and overseas cases about how ACP can help a patient prepare for his loss of mental competency, and death in some cases, ACP is not widely or commonly practised in Hong Kong, possibly because discussion about a person's death while he is still alive remains very much a taboo for most people. The Government welcome views on whether ACP would be a concept acceptable to the public and should be promoted as a routine part of end-of-life care when the public has become more familiar with

¹² Teno JM, Nelson HL, Lynn J. Advance Care Planning: Priorities for Ethical and Empirical Research. Hastings Center Report 1994;24(suppl):S32.

the concept of advance directive.

Government's Proposed Actions

21. In view of the foregoing, the Government is now proposing to take the following actions –

- To formulate an information package on advance directives for the (a) The purpose is to make the concept of advance general public. directive accessible to the general public, and make relevant information available to those who intend to make advance directives to facilitate an informed decision. We have prepared a draft information package on advance directives at Annex C, and our intention is to make the information package available at hospitals, healthcare institutions, etc. for access by the public. We would seek the views of the healthcare and legal professions, public and private hospitals, organizations providing elderly care, other professions and organizations that may be involved in handling advance directives, patients groups and other stakeholders on the information package.
- To consult on the need for developing procedures and guidelines on (b) making and handling advance directives for the medical profession, hospitals, organizations providing elderly care, or other professions and organizations that may be involved in handling advance We have extracted at Annex B some guidance in directives. relation to making, altering, revoking and activating advance directives based on LRC's recommendations, existing guidelines and practice in HA as well as common law principles. These may form the basis for further developing any necessary guidelines on advance directives. In this connection, as public hospitals and doctors are likely at the forefront of treating patients who may be in a situation to make or invoke advance directives, HA is developing their guidelines for doctors working in public hospital on handling advance directives.

22. Based on the views received on the above, the Government intends to make the information package on advance directives available to the general public, and to formulate any necessary guidelines and procedures for handling advance directives in consultation with the relevant professional bodies. We may also consider whether, and if so how, to promote the concept of advance care planning in Hong Kong.

Consultation

23. The Government would like to invite your views on the following questions:

For general public

- (a) Do you agree that the concept of advance directives should be introduced in Hong Kong and whether the concept and its use should be more widely promoted as part of end-of-life care? Do you agree that the concept of ACP should also be introduced in Hong Kong?
- (b) Do you consider that the information provided in *Annex C* sufficient for the purpose of informing you about advance directives, and allowing you to make an informed decision should you wish to make one? If not, what aspects of information you find missing?
- (c) Do you have other suggestions on how the concept of advance directives and advance care planning may be further promoted in Hong Kong? What specific aspects relating to advance directives and ACP do you consider deserving promotion?

For the medical profession

- (a) Do you find the general guidance on advance directives as set out in *Annex B* on the making, altering and revoking advance directives useful? Do you think they should be promulgated for general use by the medical profession, and if so, how?
- (b) Do you consider that guidelines are needed on procedural matters in handling advance directives, e.g. the witnessing the making of advance directives, assessing the validity of advance directives, assessing the mental competency of a person, treatment of persons in a vegetative or comatose state, criteria of basic care, etc.?
- (c) Do you consider the concept of advance directive and ACP relevant to your field of work, and if so, what specific aspects relating to advance directives and ACP do you consider requiring attention for promotion on a wider basis?

For the legal profession

- (a) Do you find the general guidance on advance directives as set out in *Annex B* on the making, altering and revoking advance directives useful? Do you think they should be promulgated for general use by the legal profession, and if so, how?
- (b) Do you consider that any guidance or other tools are needed for the legal profession on advance directives, e.g. tendering advice to patients who wish to make, alter or revoke advance directives?
- (c) What other aspects of advance directive do you consider as requiring legal inputs to ensure the legal validity of advance directives and their proper handling by the medical profession?

24. Please send us your views on this consultation paper on or before 22 March 2010 through the contact below:

- Address: Food and Health Bureau 19/F, Murray Building Garden Road Central, Hong Kong
- Fax: 2868 3049
- Email: advancedirective@fhb.gov.hk

Food and Health Bureau 23 December 2009

Annex A

Recommendations Concerning Advance Directives in the Law Reform Commission's Report "Substitute Decision-making and Advance Directives"

Recommendation 1

The concept of advance directives should be promoted initially by non-legislative means. The Government should review the position in due course once the community has become more widely familiar with the concept and should consider the appropriateness of legislation at that stage. That review should take into consideration three factors, namely, how widely the use of advance directives had been taken up; how many disputes had arisen; and the extent to which people had accepted the model form of advance directive.

Recommendation 2

The publication and wide dissemination of the model form of advance directive that the LRC proposes, and the use of the model form should be encouraged.

Recommendation 3

Appropriate publicity should be given to encourage individuals to consider and complete advance directives in advance of any life-threatening illness.

Recommendation 4

The Government should launch publicity programmes to promote public awareness and understanding of the concept of advance directives. The Department of Health and all District Offices should have available for public reference material which provides general guidance to the public on the making and consequences of an advance directive and should provide copies of the model form of advance directive for public use.

Recommendation 5

The Government should endeavour to enlist the support of the Medical Council,

medical associations, the Bar Association, the Law Society, the Hospital Authority, all hospitals and medical clinics, non-governmental organisations involved in care for the elderly, and religious and community groups in this information campaign about the use and effect of advance directives.

Recommendation 6

For the purpose of making an advance directive, the terms "terminally ill" and "life-sustaining treatment" should be defined as follows:

(a) the "terminally ill" are patients who suffer from advanced, progressive, and irreversible disease, and who fail to respond to curative therapy, having a short life expectancy in terms of days, weeks or a few months.

(b) "life sustaining treatment" means any of the treatments which have the potential to postpone the patient's death and includes, for example, cardiopulmonary resuscitation, artificial ventilation, blood products, pacemakers, vasopressors, specialized treatments for particular conditions such as chemotherapy or dialysis, antibiotics when given for a potentially life-threatening infection, and artificial nutrition and hydration. Artificial nutrition and hydration means the feeding of food and water to a person through a tube.

Recommendation 7

(a) The model form of advance directive requires that it be witnessed by two witnesses, one of whom must be a medical practitioner, neither witness having an interest in the estate of the person making the advance directive.

(b) The Government should encourage bodies such as the Hospital Authority, the Medical Council, the Hong Kong Medical Association and other relevant professional bodies to consider issuing guidelines for doctors witnessing the making of advance directives to ensure consistency of medical practice in this area. The guidelines should also provide guidance for the medical profession (a) as to the effect of advance directives and (b) in assessing the validity of an advance directive.

(c) If in circumstances an individual may not be able to make a written advance directive, the oral advance directive should be made before a doctor, lawyer or other independent person who should not have an interest in the estate of the person making the advance directive.

Recommendation 8

(a) For the sake of certainty and the avoidance of doubt, those wishing to revoke an advance directive should be encouraged to do so in writing;

(b) If an advance directive is revoked in writing, it should be witnessed by an independent witness who should not have an interest in the estate of the person making the revocation;

(c) If an advance directive is revoked orally, the revocation should be made before a doctor, lawyer or other independent person who should not have an interest in the estate of the person making the revocation, and where practicable that witness should make a written record of the oral revocation; and

(d) If medical staff learn that an individual has revoked his advance directive, that information should be properly documented in the individual's medical records.

Recommendation 9

The Government should, as part of its public awareness campaign about advance directives, encourage those who wish to make an advance directive to seek legal advice and to discuss the matter first with their family members. Family members should also be encouraged to accompany the individual when he makes the advance directive.

[Recommendations 10 and 11 omitted as they are not related to advance directives]

Recommendation 12

The Government should encourage the Medical Council or other relevant professional body to issue guidelines or a code of conduct to enhance consistency of medical practice in relation to:

- (a) the assessment of a person's ability to communicate;
- (b) the treatment of persons in a vegetative or comatose state;
- (c) the criteria for basic care;
- (d) the assessment of the validity of an advance directive; and
- (e) the implementation of advance directives

Annex B

Guidance on Making, Altering, Revoking and Activating Advance Directives

Making, altering and revoking advance directives

The common law does not impose any formality in the making, altering and revoking of advance directives. In theory, a valid advance directive can be made orally. This approach is of course the most flexible in the sense that it will protect the autonomy of those who do not pay much attention to the formality requirements. From the perspective of the patient's right to self-determination, it is also arguable, if not unreasonable, if a patient's genuine decision about the medical treatment that he wishes to receive is rendered invalid simply because it was made in manners that fell short of certain extent of formalities. On the other hand, appropriate procedural requirements can increase certainty and provide opportunity to counter undue influence and misinformation, thus making the advance directives reflect more accurately the autonomous choice of patients. Moreover, appropriate procedural requirements can assist healthcare professionals in documenting the advance directives and to ascertain their existence and content.

2. While every hospital and institution can draw up procedures for making, altering and revoking of advance directives that best suit its own mission, value, operational need, etc., to encourage consistency in practice and to ensure that the advance directives thus made are legally enforceable, we set out below some guidance based on LRC's recommendations, existing guidelines and practice in HA and common law principles as quoted in *the Report* for further developing guidelines on advance directives.

Making an advance directive

- (a) First and foremost, the attending doctor has to ensure that the patient who wishes to make an advance directive has the necessary mental capacity at the time when the directive is made. Some existing guidelines in this regard are provided below for reference:
 - (i) In the public healthcare sector, determination of mental competence is made by the attending doctor in consultation with other caregivers. In *HA Guidelines on In-Hospital Resuscitation Decisions*, a competent adult is defined as one with decision-making capacity, which consists of the elements of (i) the

ability to understand the medical information presented; (ii) the ability to reason and consider this information in relation to his own personal values and goals; and (iii) the ability to communicate meaningfully.

- (ii) HA Guidelines on In-Hospital Resuscitation Decisions, adopting the British Medical Association's Guidelines on Withholding and Withdrawing Life-prolonging Medical Treatment, stipulates that for a patient to demonstrate capacity to refuse treatment, individuals should be able to:
 - understand in simple language what the medical treatment is, its purpose and nature and why it is being proposed;
 - understand its principal benefits, risks and alternatives;
 - understand in broad terms what will be the consequences of not receiving the proposed treatment;
 - retain the information for long enough to make an effective decision;
 - use the information and weigh it in the balance as part of the decision-making process; and
 - make a free choice (i.e. free from pressure).
- (iii) *HA Guidelines on Life-sustaining Treatment in the Terminally Ill* specifies that the healthcare professionals must ensure that the patient's capacity has not been influenced by depressive illness, medication, false assumptions or misinformation, undue influence of others or a delusional state. The capacity assessment process should be documented. When the patient's mental capacity is in doubt, assessment by a psychiatrist may be carried out.
- (b) A patient should be properly informed when he makes an advance directive, i.e. he should be offered sufficient, accurate information to make an informed decision. He should be clearly informed about the effect of an advance directive, and how he can alter or revoke it.
- (c) An advance directive should be in writing wherever possible. While patients are free to use their own form of directive, it would be beneficial for them to make reference to the model form suggested by LRC at

Enclosure 1 to Annex B, which provides a convenient way for an individual to make his wishes as to terminal health care known in advance so as to reduce uncertainty and dispute.

- (d) The advance directive should be executed in the presence of two witnesses, one of whom should be a medical practitioner, and neither witness should have an interest in the estate of the person making the advance directive.
- (e) Where a patient is unable to make a written advance directive, an oral advance directive may be made before a doctor, lawyer or other independent person who should not have an interest in the estate of the person making the advance directive. The directive should be properly documented.
- (f) Unless there is evidence to the contrary, advance directives which are made in the above manner will be considered as satisfying the formality requirements and will be presumed to be validly made.
- (g) Since making an advance directive is a matter of grave importance, we encourage those who wish to make advance directives to seek legal advice and to discuss the matter with their family members first. Family members are also encouraged to accompany the individual when he makes the advance directive. According to *the Code of Professional Conduct*, the decision of withholding or withdrawing life support should have sufficient participation of the patient himself, if possible, and his immediate family, who should be provided with full information relating to the circumstances and the doctors' recommendation. In case of conflict, a patient's right of self-determination should prevail over the wishes of his relatives. A doctor's decision should always be guided by the best interests of the patient.

Altering and revoking an advance directive

(a) For the sake of certainty and the avoidance of doubt, those wishing to revoke an advance directive should be encouraged to do so in writing. The model form adapted from the one proposed by LRC at Enclosure 2 to Annex B can be used for this purpose.¹³

¹³ Under Recommendation 6 of *the Report*, "life sustaining treatment" includes artificial nutrition and hydration. However, withdrawing or withholding artificial nutrition and hydration has always been a sensitive issue. Many people perceive that there is an important distinction between these techniques and other life sustaining treatments (section 8.3, *HA Guidelines on Life-sustaining Treatment in the Terminally Ill*). We therefore propose slightly modifying the model form

- (b) If an advance directive is revoked in writing, it should be witnessed by an independent witness of at least 18 years of age and does not have an interest in the estate of the person making the revocation.
- (c) If an advance directive is revoked orally, the revocation should be made before a doctor, lawyer or other independent person of at least 18 years of age who should not have an interest in the estate of the person making the revocation, and where practicable that witness should make a written record of the oral revocation using the proposed form at **Enclosure 3 to Annex B.**
- (d) If medical staff learn that an individual has revoked his advance directive, that information should be property documented in the individual's medical records.
- (e) An advance directive should be allowed to be revoked if there is a clear inconsistency with the behaviour of the patient, i.e. the patient's behaviour raises real doubts as to whether the advance directive is still valid and applicable. (It was held by the court in the United Kingdom that, under such circumstance, the doubts "must be resolved in favour of the preservation of life."¹⁴)

Activating an advance directive

3. An advance directive will be activated when the person who made it is terminally ill, in a state of irreversible coma or in a persistent vegetative state. As the activation of an advance directive is an important decision in the course of care for a patient, we propose the following guidance for drawing up the relevant procedures: -

- (a) The three medical conditions for activating an advance directive should be confirmed and certified by at least two doctors before any advance directive applicable in those conditions can take effect.
- (b) For the purpose of making and activating an advance directive, the following definitions of "terminally ill" and "life sustaining treatment" used in *HA Guidelines on Life-Sustaining Treatment in the Terminally Ill*

recommended by LRC to allow the person making the advance directive to state his intention to continue to receive artificial nutrition and hydration until death is imminent and inevitable notwithstanding the definition of "life sustaining treatment".

¹⁴ HE v A Hospital Trust [2003] E.W.H.C. 1017

can be adopted (which are also recommended by LRC):

- (i) "terminally ill" are patients who suffer from advanced, progressive, and irreversible disease, and who fail to respond to curative therapy, having a short life expectancy in terms of days, weeks or a few months.
- (ii) "life sustaining treatment" means any of the treatments which have the potential to postpone the patient's death and includes, for example, cardiopulmonary resuscitation, artificial ventilation, blood products, pacemakers, vasopressors, specialized treatments for particular conditions such as chemotherapy or dialysis, antibiotics when given for a potentially life-threatening infection, and artificial nutrition and hydration. Artificial nutrition and hydration means the feeding of food and water to a person through a tube.
- (c) Diagnosis of the conditions of persistent vegetative state and irreversible coma should follow accepted medical practice and guidelines.
- (d) In case of doubt, actions should be taken in favour of the preservation of life. In the case of *R* (on the application of Burke) v General Medical Council, it was said that "...the mere prolongation of life is not necessarily in a patient's best interest; ...the purpose of treatment or care is to bring about recovery, to prevent or retard deterioration in the patient's condition and to alleviate pain and suffering in body and mind; and...treatment that does not achieve any of these may be regarded as futile. But the starting point...must be the very strong presumption in favour of taking all steps which will prolong life. Save in exceptional circumstances, or where the patient is dying, the best interests of the patient will normally require such steps to be taken...Account has to be taken of the pain and suffering and quality of life which the [person] will experience if life is prolonged. Account has also to be taken of the pain and suffering involved in the proposed treatment itself...ⁿ¹⁵
- (e) When a doctor is asked by a patient or family members about the futility of a particular life-sustaining treatment, reference can be made to *HA Guidelines on Life-sustaining Treatment in the Terminally Ill* to determine whether a particular treatment is futile. According to the *Guidelines*, futility of treatment can be considered in two ways:
 - (i) It can be viewed in the strict sense of physiologic futility when

¹⁵ [2004] BMLR 126 as quoted in section 4.8 of *the Report*.

clinical reasoning or experience suggests that a life-sustaining treatment is highly unlikely to achieve its purpose. The decision is normally made by the healthcare team.

- (ii) In most other clinical situations where futility is considered, the decision involves balancing the burdens and benefits of the treatment towards the patient, and asking the question of whether the treatment, though potentially life-sustaining, is really in best interests of the patient. In this broader sense, futility is subject to the views of the healthcare team as well as those of patient and family, since an assessment of burdens and benefits may necessitate quality-of-life considerations and can be value-laden. It is not an appropriate goal of medicine to sustain life at all costs with no regard to its quality or the burdens of the treatment on the patient¹⁶. The decision-making process for balancing the burdens and benefits towards the patient should be a consensus-building process between the healthcare team and the patient and family.
- (f) Reference can also be made to the above *Guidelines* on factors that healthcare professionals should take into account when considering the futility of a particular medical treatment. These factors can include, but not limited to, the following in order to balance the burdens and benefits to the patient:
 - (i) clinical judgment about the effectiveness of the proposed treatment;
 - (ii) the likelihood of irreversible loss of consciousness;
 - (iii) the likelihood and extent of any degree of improvement in the patient's condition if treatment is provided;
 - (iv) whether the invasiveness of the treatment is justified in the circumstances;
 - (v) the patient's known values, preferences, culture and religion which may influence the treatment decision; and
 - (vi) information received from those who are significant in patient's life and who could help in determining his best interests.

¹⁶It has been established in *Airedale NHS Trust v Bland* that a doctor is not under an absolute obligation to prolong a patient's life by any means available to him, regardless of the quality of the patient's life (see section 4.29 of *the Report*).

Enclosure 1 to Annex B

Proposed Model Form of Advance Directive

ADVANCE DIRECTIVE

Section I : Personal details of the maker of this advance directive

Name :

(Note: Please use capital letters)

Identity document No.:

Sex : Male / Female

Date of birth : <u>(Day)</u> / <u>(Month)</u> / <u>(Year)</u>

Home Address :

Home Telephone No. :

Office Telephone No. :

Mobile Telephone No. :

Section II : Background

1. I understand that the object of this directive is to minimise distress or indignity which I may suffer or create when I am terminally ill or in a persistent vegetative state or a state of irreversible coma, and to spare my

medical advisers or relatives, or both, the burden of making difficult decisions on my behalf.

- 2. I understand that euthanasia will not be performed, nor will any unlawful instructions as to my medical treatment be followed in any circumstances, even if expressly requested.
- 3. I, ______ (please print name) being over the age of 18 years, revoke all previous advance directives made by me relating to my medical care and treatment (if any), and make the following advance directive of my own free will.
- 4. If I become terminally ill or if I am in a state of irreversible coma or in a persistent vegetative state as diagnosed by my attending doctor and at least one other doctor, so that I am unable to take part in decisions about my medical care and treatment, my wishes in relation to my medical care and treatment are as follows :

(Note: Complete the following by ticking the appropriate box(es) and writing your initials against that/those box(es), and drawing a line across any part you do not want to apply to you.)

(A) <u>Case 1 – Terminally ill</u>

(Note: In this instruction -

"terminally ill" means suffering from advanced, progressive, and irreversible disease, and failing to respond to curative therapy, having a short life expectancy in terms of days, weeks or a few months; and the application of life-sustaining treatment would only serve to postpone the moment of death, and

"life-sustaining treatment" means any of the treatments which have the potential to postpone the patient's death and includes, for example, cardiopulmonary resuscitation, artificial ventilation, blood products, pacemakers, vasopressors, specialised treatments for particular conditions such as chemotherapy or dialysis, antibiotics when given for a potentially life-threatening infection, and artificial nutrition and hydration. (Artificial nutrition and hydration means the feeding of food and water to a person through a tube.))

- □ Save for basic and palliative care, I do not consent to receive any life-sustaining treatment. Non-artificial nutrition and hydration shall, for the purposes of this form, form part of basic care.
- □ However, I want to continue to receive artificial nutrition and hydration, if clinically indicated, until death is imminent and inevitable.

I do not want to be given the following treatment:

(B) <u>Case 2 – Persistent vegetative state or a state of irreversible coma</u>

(Note: In this instruction -

"life-sustaining treatment" means any of the treatments which have the potential to postpone the patient's death and includes, for example, cardiopulmonary resuscitation, artificial ventilation, blood products, pacemakers, vasopressors, specialised treatments for particular conditions such as chemotherapy or dialysis, antibiotics when given for a potentially life-threatening infection, and artificial nutrition and hydration. (Artificial nutrition and hydration means the feeding of food and water to a person through a tube.))

- □ Save for basic and palliative care, I do not consent to receive any life-sustaining treatment. Non-artificial nutrition and hydration shall, for the purposes of this form, form part of basic care.
- □ However, I want to continue to receive artificial nutrition and hydration, if clinically indicated, until death is imminent and inevitable.

I do not want to be given the following treatment:

- 5. I make this directive in the presence of the two witnesses named in Section III of this advance directive, who are not beneficiaries under :
 - (i) my will; or
 - (ii) any policy of insurance held by me; or
 - (iii) any other instrument made by me or on my behalf.

Signature of the maker of this advance directive

Date

Section III : Witnesses

Notes for witness :

A witness must be a person who is not a beneficiary under –

- *(i) the will of the maker of this advance directive; or*
- *(ii) any policy of insurance held by the maker of this advance directive; or*
- *(iii) any other instrument made by or on behalf of the maker of this advance directive.*

Statement of Witnesses

First Witness

(Note: This witness must be a registered medical practitioner, who, at the option of the maker of this directive, could be a doctor other than one who is treating or has treated the maker of this directive.)

- (1) I, ______ (please print name) sign below as witness.
 - (a) as far as I know, the maker of this directive has made the directive voluntarily; and
 - (b) I have explained to the maker of this directive the nature and implications of making this directive.
- (2) I declare that this directive is made and signed in my presence together with the second witness named below.

(Signature of 1st witness)

(Date)

Name :

Identity document No. / Medical Council Registration No.

Office address :

Office Tel. No. :

Second witness

(Note: This witness must be at least 18 years of age)

- (1) I, ______ (please print name) sign below as a witness.
- (2) I declare that this directive is made and signed in my presence together with the first witness named above, and that the first witness has, in my presence, explained to the maker of this directive the nature and implications of making this directive.

(Signature of 2nd witness)

(Date)

Name :

Identity document No. :

Home address / Contact address :

Home Tel. No. / Contact No. :

Enclosure 2 to Annex B

Proposed Form of Revocation of Advance Directive

REVOCATION OF ADVANCE DIRECTIVE

Section I: Personal details of maker of this revocation

Name :

(Note: Please use capital letters)

Identity document No.:

Sex : Male / Female

Date of birth : (Day) / (Month) / (Year)

Home Address :

Home Telephone No. :

Office Telephone No. :

Mobile Telephone No. :

Section II : Revocation

- (1) I, ______ (please print name) being over the age of 18 years, revoke any advance directive relating to my medical care and treatment made by me before the date of this revocation.
- (2) I make this revocation in the presence of the witness named in Section III of this revocation, who is not beneficiary under:
 - (i) my will; or
 - (ii) any policy of insurance held by me; or
 - (iii) any other instrument made by me or on my behalf.

Signature of the maker of this revocation

Date

Section III : Witness

Statement of Witness

(Note: This witness must be at least 18 years of age)

- (1) I, _____ (please print name) sign below as witness.
- (2) I declare that this document is made and signed in my presence.

(Signature of witness)

(Date)

Name : Identity document No. : Home address / Contact address :

Home Tel. No. / Contact No. :

Enclosure 3 to Annex B

Proposed Form to Record an Oral Revocation of an Advance Directive

RECORD OF ORAL REVOCATION OF ADVANCE DIRECTIVE

Section I : Personal details of the maker of oral revocation

Name :

(Note: Please use capital letters)

Identity document No.:

Sex : Male / Female

Date of birth : <u>(Day)</u> / <u>(Month)</u> / <u>(Year)</u>

Home Address :

Home Telephone No. :

Office Telephone No. :

Mobile Telephone No. :

Section II : Witness

Statement of Witness

(Note: This witness must be at least 18 years of age)

(1) I, ______ (please print name) sign below as a witness.

- (2) I confirm that ______ (please print name) has, on ______ (date of revocation) at ______ am/pm, in my presence, orally revoked all previous advance directives relating to his/her medical care and treatment.
- (3) I am not related to ______ (please print name) by blood, marriage or adoption, nor to the best of my knowledge, am I a beneficiary under his/her will or any policy of insurance held by him/her or any other instrument made by him/her or on his/her behalf.

(Signature of witness)

(Date)

Name :

Occupation :

Identity document No. / Medical Council Registration No. :

Home address / Contact address :

Home Tel. No. / Contact No. :

Information Package for the Public on Advance Directives (Draft)

In many medically advanced countries, where a patient has lost the capacity to make a decision, a valid advance directive of the patient refusing life-sustaining treatment is respected. This operates either under common law principles or under specific legislation in countries like UK, USA, Australia, Canada and Singapore.

Hong Kong has not yet had specific legislation on advance directive. In response to the recommendation of the Law Reform Commission of Hong Kong published in 2006 the report entitled "Substitute decision-making and advance directives in relation to medical treatment", the Government has undertaken to enhance the public's understanding of advance directives, to provide information for those who wish to make advance directives, and to provide necessary guidance for the relevant professions on the handling of advance directives.

This package contains basic information about advance directives, some commonly asked questions, as well as a model form adapted from the one recommended by LRC for use by anyone who wishes to make advance directive. However, please note that the use of the model form is not a condition for making a valid an advance directive. While a correctly completed model form could reasonably assure an individual that his wishes would be executed, it would remain a matter for the individual to decide whether or not he wished to execute an advance directive in the form proposed, or to choose some other form.

What is an advance directive?

An advance directive tells your doctor what healthcare treatment you would like to receive at a future time when you are no longer mentally competent (e.g. when you are terminally ill, in a coma, etc), including the refusal of life-sustaining treatment. It is usually made in writing.

When can I make an advance directive?

If you are over the age of 18 and have the necessary mental capacity to make you own healthcare decisions, you are free to make an advance

directive. When you make the advance directive, you must be free from undue influence and be properly informed of the implications of making the directive. Otherwise the directive is invalid.

Should I make an advance directive?

In an advance directive, you express your preference about health care before you face serious injury or illness. This will spare your loved ones from the stress of making decisions about your care when you are no longer able to make your own healthcare decisions. People who are seriously ill are more likely to make advance directives, for example, a person with terminal cancer may wish to specify that he does not want to receive cardiopulmonary resuscitation when his heart stops. However, you might still wish to consider making an advance directive when you are in good health as serious injury or illness can happen suddenly.

When will my advance directive become operative?

According to the recommendation of LRC, your advance directive will become operative only when you are in one of the following three conditions:

- (a) terminally ill;
- (b) in a state of irreversible coma; or
- (c) in a persistent vegetative state.

It is your responsibility to ensure that the directive is available to the doctor at the time when the doctor makes a treatment decision.

Does the making of advance directives same as euthanasia?

Advance directives are totally unrelated to euthanasia. According to the existing *Code of Professional Conduct for the Guidance of Registered Medical Practitioners* of the Medical Council of Hong Kong, euthanasia is defined as "direct intentional killing of a person as part of the medical care being offered". Euthanasia is neither medically ethical nor legal in Hong Kong, and therefore no one in Hong Kong can indicate a wish for performing euthanasia in his advance directive. Even if a person expressly requests for such an illegal behaviour to be conducted, healthcare professionals should in no way act as instructed.

What do I need to think about before making an advance directive?

You may want to think about your values, whether you would want life-sustaining treatment in any circumstances, even if it is merely a burdensome prolonging life, or only if a recovery is possible. You may also wish to think about whether you want palliative care to ease pain and discomfort if you were terminally ill, any particular life-sustaining treatment that you wish to continue to receive until death is imminent, e.g. artificial nutrition and hydration, etc. It may help if you talk to your doctor about the possible forms of life-sustaining treatment.

How to talk about making advance directive with my family?

It is important that you let your family know that you are making an advance directive. Injury, illness and death are not easy subjects to talk about, but by planning ahead you can ensure that you receive the type of health care you want, and take the burden off your family of trying to make difficult healthcare decisions for you when you are no longer able to do so. Start by having a conversation with your loved ones. Explain your feelings about healthcare treatments and what you would want to be done in specific instances. We also encourage your attending doctor to communicate with your family members and let them understand and respect your wish.

Can I change or revoke an advance directive that I have made?

You can change or revoke an advance directive any time when you have the mental capacity. Once you have made a new valid advance directive, it will supersede the previous one. Make sure that the doctors and family members who knew about your advance directive are also aware that you have changed or revoked it.

Other Frequently Asked Questions

- Q1 Do I need a witness when I make an advance directive?
- A1 LRC suggests that the making of advance directive be witnessed by two witnesses, one of whom should be a medical practitioner, and neither witness should have an interest in your estate. The witnessing doctor would be in a position to explain to you as well as the other witness the nature and implications of an advance directive.

- Q2 Should I seek legal advice before making an advance directive?
- A2 While it is not mandatory, we encourage you to seek professional advice before making an advance directive. More importantly, you should also discuss the matter with your family members.
- Q3 What are the procedures for making an advance directive?
- A3 To encourage consistency in practice and to ensure that the advance directives made are legally enforceable, having considered LRC's recommendations, we suggest the following steps for making an advance directive:
 - (i) First and foremost, the attending doctor has to ensure that the person who wishes to make an advance directive has the necessary mental capacity at the time when the directive is made.
 - (ii) A person should be properly informed when he makes an advance directive, i.e. he should be offered sufficient, accurate information to make an informed decision. He should be clearly informed about the effect of an advance directive, and how he can alter or revoke it.
 - (iii) The person should be encouraged to make the advance directive in writing wherever possible. While the person is free to use his / her own form of directive, it would be beneficial for him / her to use the model form at Annex B so as to reduce uncertainty and dispute.
 - (iv) It is suggested that the advance directive should be executed in the presence of two witnesses, one of whom must be a medical practitioner, and neither witness should have an interest in the estate of the person making the advance directive.
 - (v) Where a person is unable to make a written advance directive, an oral advance directive may be made before a doctor, lawyer or other independent person who should not have an interest in the estate of the person making the advance

directive. The directive should be properly documented.

- (vi) Since making an advice directive is a matter of grave importance, we encourage those who wish to make advance directives to seek advice from medical and legal professionals and to discuss the matter with their family members first. Family members are also encouraged to accompany the individual when he makes the advance directive.
- Q4 Now that I have an advance directive, what do I do with it?
- A4 It is important that you share your advance directive your family members, healthcare providers, and proxy (if you have named one). Talk to them about what you have written and why you have chosen to be cared for in this way. You may wish to give each of them as well as your lawyer a copy of your advance directive. It is your responsibility to ensure that the directive is available to the doctor at the time when he makes a treatment decision.
- Q5 How can I alter or revoke an advance directive?
- A5 While you can alter or revoke the advance directive orally at any time when you have the mental capacity, for the sake of certainty and the avoidance of doubt, you are encouraged to revoke an advance directive in writing using the model form. LRC recommends that it should be witnessed by an independent witness of at least 18 years of age and does not have an interest your estate.

If you revoke an advance directive orally, the revocation should be made before a doctor, lawyer or other independent person of at least 18 of age who should not have an interest in your estate, and where practicable that witness should make a written record of the oral revocation using the model form.

- Q6 Must I use the model form for making or revoking an advance directive?
- A6 No. The use of the model form is not a condition for making a valid an advance directive. While a correctly completed model form could reasonably assure you that your wishes would be executed, it would remain a matter for you to decide whether or not

you wish to execute an advance directive in the form proposed, or to choose some other form.

- Q7 What happens if my family members disagree with the advance directive that I made?
- A7 We encourage you to discuss with your family members before making an advance directive, and they should accompany you when you make the directive. We also encourage your attending doctor to communicate with your family members and let them understand and respect your wish. In case of conflict, your right of self-determination will prevail over the wishes of your family members, and your doctor is required to act in your best interests and respect your wish.
- Q8 As a healthcare provider, do I have to follow a patient's advance directive?
- A validly-made advance directive on refusal of A8 Yes. life-sustaining treatment is held to be legal binding under common You are also required by the Code of Professional Conduct law. for the Guidance of Registered Medical Practitioners to act in the best interests of patients and respect their wish, unless the wish involves unlawful act (such as euthanasia). In case of conflict with the patient's family, you or your team should communicate with them and let them understand and respect the patient's wish. Where the conflict remains unresolved, as provided under section 34.5 of the Code of Professional Conduct, the matter should be referred to the ethics committee of the hospital concerned or relevant authority for advice. In case of further doubt, direction from the court may be sought, as necessary.
- Q9 As a healthcare provider, how do I know that the patient has not changed his or her mind about treatment?
- A9 You have to work with all the information available to you. Talk to the family to find out if the patient has said or documented anything that may contradict the advance directive.
- Q10 As a healthcare provider, what do I do if the patient's instructions in his or her advance directive are vague or ambiguous?

- A10 You should seek clarifications from the patient or his / her family members. In case of doubt, actions should be taken in favour of the preservation of life.
- Q11 What is the Government's position on advance directives?
- A11 The Government recognizes the potential benefit that advance directives can bring to doctors, patients, and family members of the patients, such as providing greater certainty to doctors and family members on the form of healthcare or medical treatment that the patients wish to receive when they are no longer mentally competent, minimise conflicts between the doctors and family members over the appropriate medical treatment that should be provided to the patients, give patients a sense of control and peace of mind that their autonomy and preferences will continue to be respected even when they become mentally incapacitated and so forth.

However, as Hong Kong people are not yet familiar with the concept of advance directive, and the making of an advance directive is entirely a personal decision, to respect individuals' freedom of making decisions, the Government has no policy at this stage to actively advocate or encourage the public to make advance directives. Neither does the Government have any plan to promote the concept of advance directives through legislative means.