Guidance for HA Clinicians on Advance Directives in Adults

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Background

1. The Hospital Authority (HA) first issued the *HA Guidelines on Life-sustaining Treatment in the Terminally Ill* in 2002. Among other stipulations and guidance, it is stated that a valid advance directive of the patient refusing life-sustaining treatment is respected.

2. In August 2006, the Law Reform Commission (LRC) released the report *Substitute Decision-making and Advance Directives in Relation to Medical Treatment*. Among other reform proposals, the report recommends Advance Directives (AD) to be promoted under the existing common law framework.

3. In the common law context in Hong Kong, an adult[1] may make an advance refusal of life-sustaining treatment. A proxy directive does not have legal status in Hong Kong.

4. The LRC has put forward a model form of AD, which could be used by those wishing to make decisions as to their future health care. The model form aims at reducing difficulties and uncertainty by specifying how the directions should be set out in the AD. The LRC model form is not the only format of AD that can be used.

5. The LRC model form of AD stipulates that it would be applicable only when the individual no longer has the capacity to make health care decision and is terminally ill, in a persistent vegetative state or in an irreversible coma.

6. In December 2009, HKSAR Government published *Consultation Paper on the Introduction of the Concept of Advance Directives in Hong Kong*. In the Paper, the Government considers it useful to provide more information to the public about the concept of AD and develop guideline on AD. In addition, the LRC model form is modified to insert a choice box for the patient to request to continue artificial nutrition and hydration if clinically indicated, hereafter called "modified LRC model form".

7. In the light of the LRC recommendations and the Government's *Consultation Paper*, the Working Group on Advance Directive (WGAD) has produced the following set of guidance for reference by clinicians working in the HA hospital setting in 2010. The WGAD was a working group under the Hospital Authority Clinical Ethics Committee (HACEC).

8. It is important to recognize that, for patients with end-of-life care needs, AD is mainly used as a tool for advance care planning[2]. For these patients, it is essential to have early and good communication with patients and families about the medical care plan.

Guidance for clinicians

When patient wants to make an AD

9. The patient could be the one who raises the issue of making an AD. Health care workers should be sensitive to the psychosocial aspects and personal values of the patient, and the views of the family members when the patient raises the issue of AD. By making an AD, the patient is in effect making advance refusal of medical treatments and directions on the kind of life-sustaining treatments that should be withheld/withdrawn when he/she is no longer mentally capable of making health care decisions.

10. In some clinical situations, the health care team may also raise the issue of AD as part of advance care planning[2].

11. In HA setting, before 2014, an AD might be made in the format of the modified LRC model form, with minor modifications made and footnotes added by HA in 2010, which covered the clinical conditions of "terminally ill" (Case 1)[3] and "irreversible coma or persistent vegetative state" (Case 2)[4]. In 2014, with the promulgation of the DNACPR (Do Not Attempt CPR) Guidelines, an additional category of clinical condition namely "other end-stage irreversible life-limiting condition" (Case 3)[5] is added to that form, hereafter called "full HA AD form" **(Appendix 1)**. In addition, a short HA AD form is designed for terminally ill patients refusing CPR only, hereafter called "short HA AD form" **(Appendix 2)**.

12. Note that both HA AD forms require two witnesses, one of whom must be a medical practitioner. Neither witness should have an interest in the estate of the person making the AD. This witness requirement is not mandatory under the common law framework, but tighter requirement can reduce uncertainty and risk of arguments when the AD eventually becomes applicable.

13. Before a doctor signs as witness on an HA AD form, he/she should be satisfied that the patient is mentally capable of understanding the nature and effect of making an AD and is properly informed[6]. AD does not require formal assessment of the patient's mental capacity by psychiatrists unless circumstances suggest it.

14. The patient should be encouraged to discuss with the family members before making the AD.

15. Using the full HA AD form, a patient can choose (using the first set of boxes) to refuse cardiopulmonary resuscitation (CPR) and/or other life-sustaining treatment(s). Some patients may choose to refuse all life-sustaining treatments other than basic and palliative care (using the fourth box onwards). In addition, the patient may use the fifth box to make instruction to continue to receive artificial hydration and nutrition if clinically indicated until death is imminent and inevitable. (please refer to Q&A Q1 and Q2)

16. If a patient chooses to indicate refusal all life-sustaining treatments other than basic and palliative care using the fourth box, care should be taken to ensure that the patient has really decided not to receive all life-sustaining treatments.

Keeping record of the AD Form

17. Not all AD are made within HA. The original copy of an AD, whether made within HA or in private setting, is the property of the patient. The patient has the primary responsibility of storing it, and making it known to someone (usually family members) that he/she trusts.

18. For AD made within HA and witnessed by an HA doctor, a hard copy of the AD form should be kept in the medical record, and the occasion and process of making the AD (usually in clinic or in ward) should be documented.

19. Whether HA should set up a central registry of AD made by HA patients will need further consideration. In the meantime, flagging alert in the HA Clinical Management System (CMS) has been set up to facilitate communications. The flagging points to the date and occasion when the HA doctor witnessed the making of the AD, and to the medical record where a copy of the AD was filed. (please refer to Q&A Q9 and Q10)

20. It should be emphasised that flagging in the CMS is not an AD registry as such. Even with flagging alert, there is a chance that a patient has subsequently revoked or modified an AD made (and flagged) earlier on. Hence, the information contained in flagging alert can only be used as reference for ascertaining the patient's wish. (please refer to Q&A Q11)

Assessing validity of an AD

21. An AD presented to the health care team should be recognised as valid if it is sufficiently clear and is not being challenged. The AD so presented, if made in HA, may be cross-checked with the information available in CMS flagging and hard copy in medical record, as mentioned in Paragraphs 18 and 19.

22. Doubts about the validity of an AD may arise if:
    i. The AD was ambiguously drafted;
    ii. It was not properly signed;
    iii. There are claims or suggestions that the patient had been under undue influence at the time of making the AD;
    iv. There is reason to suspect that the patient was not mentally capable or was not properly informed[6] when the directive was made;
    v. The patient has done something that clearly goes against the advance decision which suggests that he/she has changed his/her mind.

    (please refer to Q&A Q3)

23. There may be occasions when AD not being the HA AD forms are presented to the HA health care team. These AD may still be valid, if the statements are clearly written and not ambiguous. The same applies to AD made on conditions other than the specified ones in the HA AD forms, and to AD made overseas. Although AD made on an HA AD form requires two witnesses one of whom must be a medical practitioner, such witness requirement is not mandatory under the common law framework, and AD without such witnesses could still be valid. However, without such witnesses, the validity of the AD may be prone to challenge.

24. Where there are significant grounds for doubt about the validity of an AD, the health care team should continue to provide clinically indicated emergency life-sustaining treatments, while waiting for clarifications. Such initiated treatment may be withdrawn at a later stage after the validity of the AD is confirmed. To confirm the validity of the AD, it would be useful to discuss with the witnesses of the AD, the family members of the patient, and the health care team looking after the patient recently.

25. Likewise, if an AD is said to exist but cannot be presented in time to guide medical treatment decisions, the health care team should continue to provide clinically indicated emergency life-sustaining treatment, while waiting for clarifications. (please refer to Q&A Q4)

26. A health care professional who knowingly provides treatment in the face of a valid and applicable advance refusal may be liable to legal action for battery or assault. However, treatment should not be delayed in order to look for an advance directive if there is nothing to suggest that one exists. Note that it is the responsibility of the person making the AD and the family to draw attention to the health care team that an AD exists.

Assessing applicability of an AD

27. A valid AD becomes applicable when the patient suffers from the pre-specified conditions, and is no longer mentally capable of making health care decisions.

28. To facilitate the assessment of applicability, if the patient is already in one of the pre-specified conditions, s/he or the family should be advised to attach to his/her AD a medical certification of his/her conditions. The certification has to be signed by the attending doctor and at least one other doctor. In 2014, with the promulgation of the updated DNACPR (Do Not Attempt CPR) Guidelines, a DNACPR form is available to facilitate communication of an advance decision on DNACPR for non-hospitalized patients. For an individual patient with both an AD and a signed DNACPR form (non-hospitalized patients), the latter also serves the purpose of this medical certification.

29. In the case of a terminally ill patient, the AD is in effect only when the patient has deteriorated to become mentally incapable of making health care decisions. As long as the patient is still conscious and mentally capable, his/her contemporaneous wish must be respected.

30. Rare scenarios may arise where the medical conditions causing the deterioration may be totally unforeseen by a patient (e.g. major injury caused by a traffic accident in a patient who has made an AD for his terminal cancer condition). The AD is not applicable if there are reasonable grounds for believing that the current circumstances were not anticipated by the patient, and if they had been anticipated by him/her, they would have affected his/her advance decision. The health care team should treat such deterioration by considering the risks and benefits, medical futility and the patient's values expressed in the AD, in accordance with the *HA Guidelines on Life-sustaining Treatment in the Terminally Ill*. (please refer to Q&A Q13)

Legal status and general implications of an AD

31. AD is recognized under common law in Hong Kong. Question has been raised as to whether the doctor can under the Mental Health Ordinance carry out a life-sustaining treatment without consent of a mentally incapacitated person ("MIP"), in the presence of a valid and applicable AD made while mentally capable which refuses that life-sustaining treatment. HA's position has always been that a valid and applicable AD must be respected and hence the doctor should not carry out the treatment in the circumstances.[7] This position holds true even if the MIP has a guardian who wishes to consent to the treatment.

32. An AD refusing specific life-sustaining treatments does not mean that other non-specified life-sustaining treatment should always be provided, nor should always be withheld or withdrawn. Decisions on other life-sustaining treatments not specified in the AD should be individualized and should be made in accordance with the *HA Guidelines on Life-sustaining Treatment in the Terminally Ill* in the best interests of the patient. The patient's values expressed in the AD should be considered in the assessment of the best interests of the patient.

33. The presence of an AD refusing life-sustaining treatment does not preclude the patient from receiving appropriate basic care and palliative care.

Revoking an AD

34. A patient may at any time revoke his/her AD, as long as he/she is mentally capable and is not under undue influence. The revocation of AD can also be made orally, and the AD may be considered not valid if there is evidence that the patient has revoked the AD orally before the deterioration. However, written, signed and witnessed revocation is the better method as it minimises uncertainty and risk of dispute.

35. It is recommended that written revocation should be directly signed on the AD form, or on a piece of paper attached to the AD.

Challenges to an AD

36. Situations may arise in which family members of the patient challenge the validity and/or applicability of an AD made by the patient. As noted above, while waiting clarifications, clinically indicated life-sustaining treatments should be provided / continued.

37. If the validity/applicability of the AD is not in question, but the family members simply do not agree with, or cannot accept the patient's choice, the health care team should communicate and explain to them on the purpose and legal status (ref. Paragraph 31) of an AD, and on the importance of respecting the patient's choice. Communication should be made with sensitivity. In difficult and complex cases, the health care team may consider to consult the cluster/hospital clinical ethics committee for advice.

Special caution for withdrawing artificial nutrition and hydration from non-terminally ill patients in persistent vegetative state or irreversible coma

38. In terminally ill patients with an AD, artificial nutrition and hydration can usually be withheld/ withdrawn from the patient in accordance with the AD direction, when the patient becomes mentally incapable of making health care decisions.

39. It can be contentious to withhold/withdraw artificial nutrition and hydration in a non-terminally ill patient who is mentally incapable of making health care decisions, even in the presence of an AD. If there is any concern about the decision, the cluster/hospital clinical ethics committee should be alerted to review such case as it arises. For patients in a persistent vegetative state or a state of irreversible coma, advice should be sought from the HCE/CCE and HAHO to consider whether an application to the Court is required. Such consideration is necessary until case law is established by a court ruling in Hong Kong SAR.

40. When a patient completes Section 4(B) of the full HA AD form, the HA doctor signing as witness should alert the patient of the special caution as outlined in Paragraph 39, if the patient wishes to make a directive to withdraw artificial nutrition and hydration or to withdraw all life-sustaining treatments, in a persistent vegetative state or irreversible coma.

Audit and compliance

41. The hospital should have in place an audit system on the compliance with the Guidance.

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Endnotes:

1. Common law only accepts AD made by adults aged 18 and above.

2. Advance care planning is "a process of communication among patients, their health care providers, their families, and important others regarding the kind of care that will be considered appropriate when the patient cannot make decisions.". (Ref: Teno JM, Nelson HL, Lynn J. Advance care planning: priorities for ethical and empirical research. Hastings Center Report 1994; 24(suppl): S32) For details, please refer to the HA Guidelines on Advance Care Planning 2019.

3. 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. (Ref: HA Guidelines on Life-sustaining Treatment in the Terminally Ill 2002/2015)

4. The persistent vegetative state means a condition caused by catastrophic brain damage whereby the patients have a permanent and irreversible lack of awareness of their surroundings and no ability to interact at any level with those around them. (Ref: Mental Capacity Act Code of Practice of England and Wales 2007, p.289)

5. "Other end-stage irreversible life limiting condition" means suffering from an advanced, progressive, and irreversible condition not belonging to Case 1 or Case 2, but has reached the end-stage of the condition, limiting survival of the patient. Examples include:

    i. patents with end-stage renal failure, end-stage motor neuron disease, or end-stage chronic obstructive pulmonary disease who may not fall into the definition of terminal illness in Case 1, because their survival may be prolonged by dialysis or assisted ventilation, and

    ii. patients with irreversible loss of major cerebral function and extremely poor functional status who do not fall into Case 2 (This means a condition caused by catastrophic or long term brain damage whereby the patients are bedridden and have little awareness of their surroundings and little ability to interact at any level with those around them, and the condition is irreversible).

6. Properly informed means that "the patient had been offered sufficient, accurate information to make an informed decision.". (Ref: British Medical Association. Withholding and Withdrawing Life-prolonging Medical Treatment: Guidance for Decision Making, 3rd ed. 2007, p.65)

7. Even when the best interests of the MIP is considered under the Mental Health Ordinance, the doctor and the guardian must take into account not only clinical benefit but also the MIP's value and belief and what the MIP might have wanted if competent. A valid and applicable AD must be treated as an explicit expression of a patient's wish to refuse medical treatments in specified conditions.

Attachments:

Appendix 1: Full HA AD form

Appendix 2: Short HA AD form

Q&A

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Membership of the Working Group on Advance Directives (July 2010)

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Vice-Chairman:	Dr Derrick AU
Secretary:	Dr S P LIM
Members:	Ms Betty AU
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	Dr K S CHAN
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