HA Guidelines on Advance Care Planning

Version	Effective Date
1	10 June 2019

Document Number	CEC-GE-9
Author	Working Group on ACP Guidelines with Standardised ACP Template
Custodian	Patient Safety & Risk Management Department
Approved By	HA Clinical Ethics Committee
Approval Date	16 January 2019

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Member List of HA Clinical Ethics Committee (HACEC) (January 2019)

Member List of Working Group on ACP Guidelines with Standardised ACP Template (January 2019)

Appendix 1: ACP form for Mentally Competent Adult

Appendix 2: ACP form for Mentally Incompetent Adult

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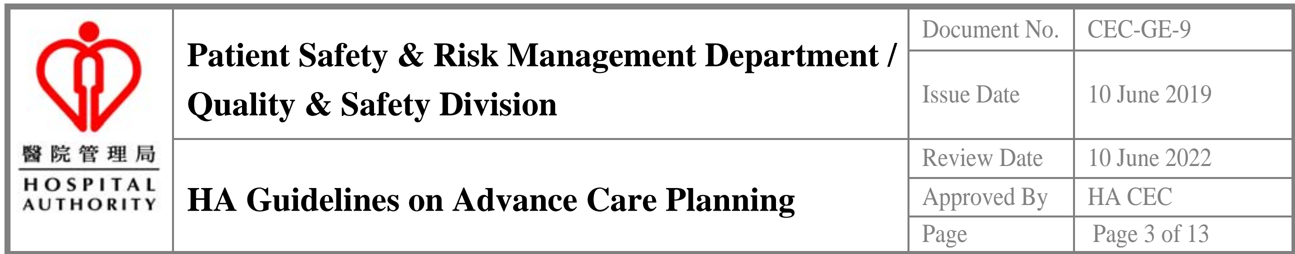
Q&A for ACP Guidelines



1. Background

1.1 Medical treatment decisions in end-of-life care must be carefully made according to the best interests of the patient, taking into account his/her expressed wish, preferences and values, and weighing benefits, risks and burdens of treatment options. Advance care planning (ACP) is an overarching process of proactive communication regarding end-of-life care. Through this process of communication, a patient with advanced progressive disease, his/her health care providers, and his/her family members and caregivers can consider ahead of time what kind of care is appropriate when the patient can no longer make a decision. [1] Such a communication process usually takes place in the context of anticipated deterioration in the patient's condition in the future. "Family members" in this context denote not only the family members in the traditional sense, but also the guardian and persons close to or significant to the patient.

1.2 ACP is recognized as an integral part of care for patients with advanced progressive disease. This HA Guidelines on Advance Care Planning is developed to provide practical guidance, and serves to standardize HA forms to facilitate ACP in clinical operation.

1.3 This set of guidelines should be used together with the other related guidelines which together stipulate the ethical framework for different aspects of making end-of-life decisions. The guidelines already in place include: HA Guidelines on Life-Sustaining Treatment in the Terminally Ill, Guidance for HA Clinicians on Advance Directives in Adults, and HA Guidelines on Do-Not-Attempt Cardiopulmonary Resuscitation (DNACPR).

2. Scope

2.1 In the Hospital Authority, the term ACP extends beyond communication with mentally competent adult patients to include that with family members of the mentally incompetent and minor patients. [2] This is in line with the scope of ACP adopted by some international organisations. [3, 4]

2.2 Conceptually and in practice, an advance care plan should be differentiated from:

(a) an advance directive (AD): a legally binding document which the patient can specify the treatment(s) that he/she is going to refuse in case he/she becomes mentally incapacitated to make decisions with disease progression.

- The term ACP emphasizes the process of communication. An AD is one of the tools that can be used during the ACP process if the patient wishes to do so.

- After the ACP process, a mentally competent adult patient may choose to make an AD to document his /her advance decision to refuse specific life-sustaining treatment(s). An ACP form is used to document the communication process, the patient's wishes and values, and preferences for medical and personal care.
- An AD is legally binding under common law. The contents of an ACP form serve as important reference for the healthcare team to make decisions in the best interests of the patient, and are not legally binding.

(b) a care plan: a plan formulated contemporaneously for immediate use during the current admission. A treatment plan formulated contemporaneously for a patient in the last days of life is a care plan and not an advance care plan.

3. Purpose of ACP

3.1 ACP is an overarching and preceding process for expressing preferences for medical and personal care, which in turn will shape the care for the patients thereafter and at the end-of-life.

3.2 Through the ACP process: [5]

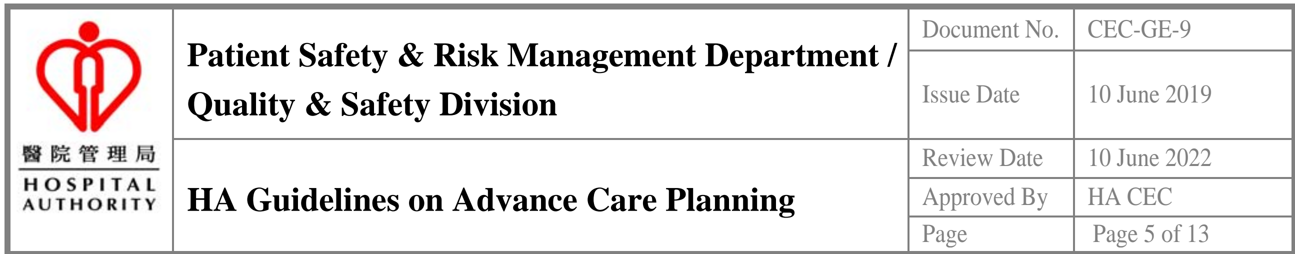
a) A mentally competent and properly informed patient may
- express his/her values, beliefs and wishes,
- express preferences for future medical or personal care,
- make an advance directive refusing life-sustaining treatment, including DNACPR,
- assign a family member to be the key person for future consultation.

b) The family members of a mentally incompetent adult or a minor together with the healthcare team may make plans on future medical or personal care, by consensus building according to the best interests of the patient, taking into account any expressed wish, preferences and values, and weighing benefits, risks and burdens of available options.

c) The patient and the family can be better prepared emotionally for future deterioration of the patient's condition.

4. Initiation of ACP

4.1 While ACP discussion is often initiated by healthcare workers, it may also be initiated by patients or their family members.



4.2 The appropriate time for triggering the ACP discussion for patients with progressive disease depends on the state of the disease and the readiness of the patients. ACP is voluntary and should not be initiated simply as a routine procedure.

4.3 Discussions may be appropriately initiated in a range of situations including: [6]

- Following the diagnosis of a life limiting condition with a more rapid downhill course e.g. advanced cancer, motor neuron disease. It should be noted that some patients may not be ready to discuss ACP immediately after such a diagnosis. Thus, the approach should be individualized.
- Early cognitive decline in dementia
- Significant disease progression in terms of functional decline, biochemical parameters, symptom burden, deteriorating quality of life
- Discontinuation of disease targeted treatments
- Transition to palliative care
- Recovery from an acute severe episode of a chronic disease
- Following multiple hospital admissions
- Patient becomes institutionalized

5. The ACP process [7]

5.1 ACP is an operator dependent process. The healthcare professionals act as facilitators of the ACP process, and should have appropriate communication skill and knowledge of the subject, in order to achieve satisfactory outcome.

5.2 The doctor is usually the core member among the facilitators. The process may be assisted or followed up by nurses or medical social workers as appropriate.

5.3 Before ACP, the facilitator should be aware of:

5.3.1 The ethical framework in making decisions for end-of-life, which is stipulated in the existing sets of HA guidelines including this HA Guidelines on ACP, the HA Guidelines on Life-Sustaining Treatment in the Terminally Ill, Guidance for HA Clinicians on AD in Adults, and HA Guidelines on DNACPR.

5.3.2 The clinical conditions that the patient is suffering from and the prognosis; the treatment options and the associated benefits, harms and risks so as to facilitate informed choices. Providing sufficient and appropriate information is particularly

important before the patient decides to make an AD for refusal of specific treatments.

5.3.3 The social background of the patient and who to invite to join the process, as a family based decision making model is common locally. The presence of family members is encouraged to facilitate discussion.

5.3.4 The limits of their own knowledge and skills so that appropriate advice can be sought when needed.

5.4 The ACP facilitator should approach the discussion sensitively with good communication skills, including:

5.4.1 Active empathetic listening, attention to details/cues, asking open questions, providing appropriate and sufficient information in understandable terms, and handling emotions that emerge from the discussions.

5.4.2 Sensitivity to assess the readiness of the patient in continuing the discussion. A rigid or routinized approach should be avoided so that patients are not forced on ACP discussions. Discussions take time and effort and cannot be completed as a simple check list exercise.

5.4.3 Respecting patient's autonomy. The agenda should be patient centred. The facilitator should be sensitive to 'cues' which indicate a desire to make specific wishes known.

5.4.4 Sensitivity to local culture that family based decisions may be preferred by some patients and families.

5.4.5 Consensus building in decision making and minimizing conflicts among the patient and other family members.

5.4.6 Confidentiality must be respected.

5.5 Involvement of paediatric patients and adult patients with impaired capacity as appropriate:

5.5.1 Some paediatric patients may be able to participate in the ACP discussion commensurate with their development. The ACP discussion should be conducted using language appropriate to their developmental stage.

5.5.2 Some adults with impaired capacity, though not having capacity to sign an AD, may still be able to participate in the ACP discussion when given appropriate support.

5.6 The initial ACP discussion may take one or more sessions to arrive at a consensus. ACP is also an ongoing process, and review may be required as the patient's condition or preference changes.

6. Scope of ACP discussion

6.1 The scope of ACP discussion may include but is not limited to:

Disease	anticipated progression and prognosis
Treatments	options available, benefits and risks
Patient's preferences and values	• expectation from treatments • preferences for treatment limits • preferences for personal care • personal goals to accomplish
Family members	• family values and concerns • views and preferences of parents for minors • patient's prior wish or preference for incompetent patients

6.2 Deliberation as above should identify the patient's preferences in two aspects of care, medical and personal. The preference for medical treatment may be in broad terms of treatment limits, with or without decisions for refusal of specific treatments. The preference for personal care may include preferred place of care, worries, goals to accomplish before death etc.

7. Outcome of ACP discussion

7.1 To facilitate continuity of care and respect patient's preferences, details of the ACP discussion should be documented. Standardized ACP forms are designed for the purpose, with separate forms for a mentally competent adult, a mentally incompetent adult, and a minor. Contents of the ACP forms include (where applicable):

- values, beliefs and wishes,

- designated family member for future consultation,
- preference for personal care,
- overall preferences regarding limits on life-sustaining treatments; with preferences regarding specific life-sustaining treatments if any.

Please see appendices for the forms, and please see section 8 for how to use the forms.

7.2 If a mentally competent adult makes an advance decision to refuse any specific treatment, he/she should sign an advance directive (HA-short AD form or HA-full AD form).

7.3 Unlike a valid AD, statements on preferences for medical or personal care as contained in the ACP form are not legally binding, though these can help the healthcare workers to formulate individualized care plan in the future. The clinical staff should guide the patient/family to avoid incompatibility between specific treatment preferences and an AD signed before or during the ACP discussion.

7.4 If a DNACPR decision is made, the standardized DNACPR form must be used.

8. The standardized ACP forms

8.1 The standardized forms are designed to provide a framework to guide discussion and to facilitate documentation. The forms are not to be treated as a tool for a check list exercise. The scope of the discussion should be individualized. The patient or family member may choose NOT to complete any particular items regarding values, wishes, and preferences. The examples listed under values, wishes and personal preferences should not be regarded as check lists.

8.2 Regarding medical treatment, the focus of the form design is on "preferences regarding limits on life-sustaining treatments". Comfort care, symptom control and quality of life are not listed as choice items, because these should be treatment goals for all patients, regardless of the limits on medical treatment to be chosen. This message should be appropriately conveyed to the patient and family during the ACP process.

8.3 According to the definition provided in the ACP form, life-sustaining treatment means any of the treatments which have the potential to postpone the patient's death, and may include resuscitative measures as well as specialised treatments for particular conditions such as chemotherapy or dialysis etc. The definition should be appropriately conveyed to the patient and family during the ACP process, especially if an overall preference "not to receive/give life-sustaining treatments if possible" is chosen.

8.4 In the Section on "preferences regarding limits on life-sustaining treatments" in the

Forms for adults, there is a free text space for "other end-stage clinical conditions", in addition to "terminally ill". This allows the patient/family to express, if necessary, preferences in other end-stage clinical conditions that are envisaged in the disease trajectory.

8.5 The form is designed to be filled in by a healthcare team member according to the result of the ACP discussion, instead of asking the patients or family members to fill in the form by themselves. The discussion process may take one or more sessions to complete. At the end of the ACP discussion, the patient or family member would then sign on the form, when they are satisfied with the contents of the filled form.

8.6 The ACP form for minors should be signed by a parent/legal guardian of the minor. In special circumstances when the parent/legal guardian is not available, ACP discussion with other family members can still be made, but the results of the discussion would be documented in the medical notes and the ACP form would not be filled.

8.7 For a group of patients with similar clinical profile, if an individual unit/specialty wants to have a specific list of medical treatment to guide frontline staff in the discussion, a list made and labeled specifically for the purpose can be added as an appendix to the standardized form.

8.8 An individual unit/specialty may find it desirable to tailor-make or customize the general design of an ACP form for a particular group of patients with similar clinical profile, with or without adding check boxes for a specific list of medical treatment in the subsection "specific preferences for life-sustaining treatments". When such customization is initiated, the following conditions must be followed:

a) The customized form should follow closely the terminology, format and concept of the standardized forms;

b) The customized form designed for one specific group of patients should labeled clearly as such, and should not be used for other patients with different clinical profiles;

c) The customized form has to be vetted and approved by HACEC before it can be used.

9. Follow up actions

9.1 **Keeping the forms:** Upon completion of ACP, the original copy of the ACP form, together with the original copy of the full or short AD form, and DNACPR form for non-hospitalized patients, if any, should be kept by the patient or by a family member if

the patient is incompetent or minor. A photocopy of the forms should be kept in the medical record, and flagging at Clinical Management System (CMS) of AD and DNACPR should be done as appropriate. The patient and family members should be advised to take proper steps in storage and presentation of the forms to healthcare workers as needed, and to inform other family members about where the forms are kept. On discharge from the hospital, original copies of the above forms should be returned to the patient and family members.

9.2 **Communication with stakeholders in the community:**

9.2.1 If the patient has no family members, or if the patient is cared in residential care homes, the patient would be encouraged to share their preferences and decisions with their caregivers. If needed, the healthcare team should communicate with the community caregivers directly to align understanding of the preferred care process. When the patient becomes unconscious, the caregivers should be aware of their role in presenting the forms to the healthcare team.

9.2.2 For patients residing in residential care homes for the elderly (RCHE), a more systematic approach is preferred to standardize the practice as far as possible. The Community Geriatric Assessment Service (CGAS) team shall conduct review of the residents who are recruited into end-of-life (EOL) care program as necessary.

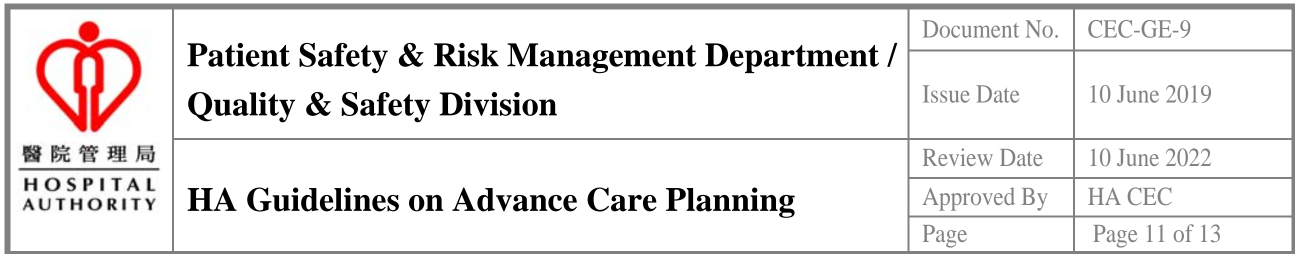
9.3 **Follow up of special issues:** If there are any specific issues identified during the ACP process that need special follow up, e.g. social issues, the relevant team members of the healthcare team should be informed.

9.4 **Review of ACP:** When the advance care plan is reviewed and there are changes in the values, wishes, preferences or advance decisions, a new ACP form should be filled in. The old form should be crossed out, and the crossing out should be signed by the patient or family member.

9.5 **Signing a DNACPR form for non-hospitalized patients:** If a non-hospitalized patient falls into the condition specified in the ACP form with preference against CPR or in an AD refusing CPR, the healthcare team may wish to convey a DNACPR decision to the receiving team in an emergency situation. A DNACPR form for non-hospitalized patients can then be signed, if not yet signed during the ACP process.

9.6 **Putting plans into action:** When the patient's condition deteriorates and the patient is unable to make decisions:

a) A valid and applicable AD should be respected according to the HA Guidance on AD.



b) A DNACPR Form for non-hospitalized patients should be followed according to the HA Guidelines on DNACPR.

c) Values, wishes and preferences documented during the ACP should serve as important reference when the healthcare team discuss with family members to formulate care plans and make in-the-moment treatment decisions according to the best interests of the patient. It should be noted that prognostication in end-stage illnesses can sometimes be difficult, and prudence in assessing applicability of the ACP is needed. In an emergency situation, if there is doubt whether a life-sustaining treatment is still in the best interests of the patient, the treatment should be provided.

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7. Royal College of Physicians. *Advance Care Planning: National Guidelines*. London: Royal College of Physicians, 2009.

Attachments:

Appendix 1: ACP form for Mentally Competent Adult
Appendix 2: ACP form for Mentally Incompetent Adult
Appendix 3: ACP form for Minor
Q&A for ACP Guidelines

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Member List of HA Clinical Ethic Committee (HACEC)

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