

# Advance Care Planning (ACP)? Advance Directives (AD)? Do-Not-Attempt Cardiopulmonary Resuscitation (DNACPR)? Patients and families should know more!



## Foreword



As medical technology advances, many diseases become curable or can be controlled. However, there is an end to everyone's life. Some diseases will progress to a point when all treatments become futile. Yet, with modern medical technology, life-sustaining treatment (LST) (e.g. artificial ventilation, cardiopulmonary resuscitation, etc.) can still be applied to a dying patient with end stage disease. As the disease is irreversible, such treatment can only prolong the dying process which may be of little meaning to the patient, or even aggravate his/her suffering. In such a case, the patient, family and healthcare workers can discuss whether futile LST should be provided or not, so that the patient can secure a peaceful death.

The Hospital Authority agrees that it is acceptable to withhold or withdraw LST when:

- A mentally competent and properly informed patient refuses the LST; and
- The treatment is futile.

If the patient is unconscious, a decision on futility of treatment is made by discussion between clinicians and the family according to the best interests of the patient. If the patient has not previously expressed his/her values and treatment preferences, which are important in the consideration of his/her best interests, then the medical team may have difficulty reaching a consensus with the family. Therefore, it is useful if the patient has expressed prior wishes on the preferred care, or even signed an AD when he/she is mentally competent.

Indeed, it is not easy for healthcare workers to discuss death with the patient and family. When the timing is appropriate, healthcare workers can discuss with the patient and family via an ACP process, to enable them to understand the issues and options, before a decision is made. The aim of this website is to provide relevant information for better understanding of the subject by the patient, family and the public.





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# 1

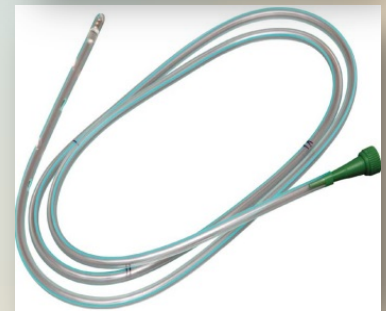
## First, we have to understand what is “life-sustaining treatment” (LST) and what kinds of treatment are included?

LST means any treatments which may prolong the patient’s survival. But as some treatments are invasive, they may cause suffering and physical harm to the patient. Once the patient is disconnected from these life-sustaining devices, survival is often impossible.



### LST often includes:

- Cardiopulmonary resuscitation
- Artificial ventilation (ventilator)
- Blood products (transfusion, blood platelet, blood plasma)
- Pacemakers and vasopressors
- Chemotherapy
- Dialysis (renal replacement)
- Antibiotics
- Artificial nutrition and hydration (nasogastric tube)



### What is cardiopulmonary resuscitation (CPR)?

CPR is an emergency procedure for a person suffering cardiac arrest. The steps involved are (1) perform chest compression to restore blood flow temporarily; (2) ensure an unobstructed airway; (3) use artificial ventilation in place of autonomous breathing. Healthcare workers will also use drugs and automated external defibrillators as appropriate to restore the patient’s normal heart rhythm.





## Why would LST become futile?

LST such as CPR is an invasive emergency intervention, the outcome of which depends on various factors. In a terminally ill patient, as the underlying factor such as cancer and organ failure causing cardiac arrest has not changed, the success rate of CPR resulting in effective rescue is very low. On the other hand, CPR may cause complications, e.g. rib fracture. Performing futile CPR on a dying patient can only prolong the dying process while causing unnecessary pain and suffering.



For other kinds of LST, it may simply be impossible to sustain life in certain end-stage situations. In other situations, though LST can temporarily sustain life, the disease condition is irreversible. These interventions can only prolong the dying process which may be of little meaning to the patient, or even aggravate his/her suffering and thus not in the best interests of the patient. Overall speaking, these treatments are futile. In such cases, adopting the palliative care approach is more appropriate.



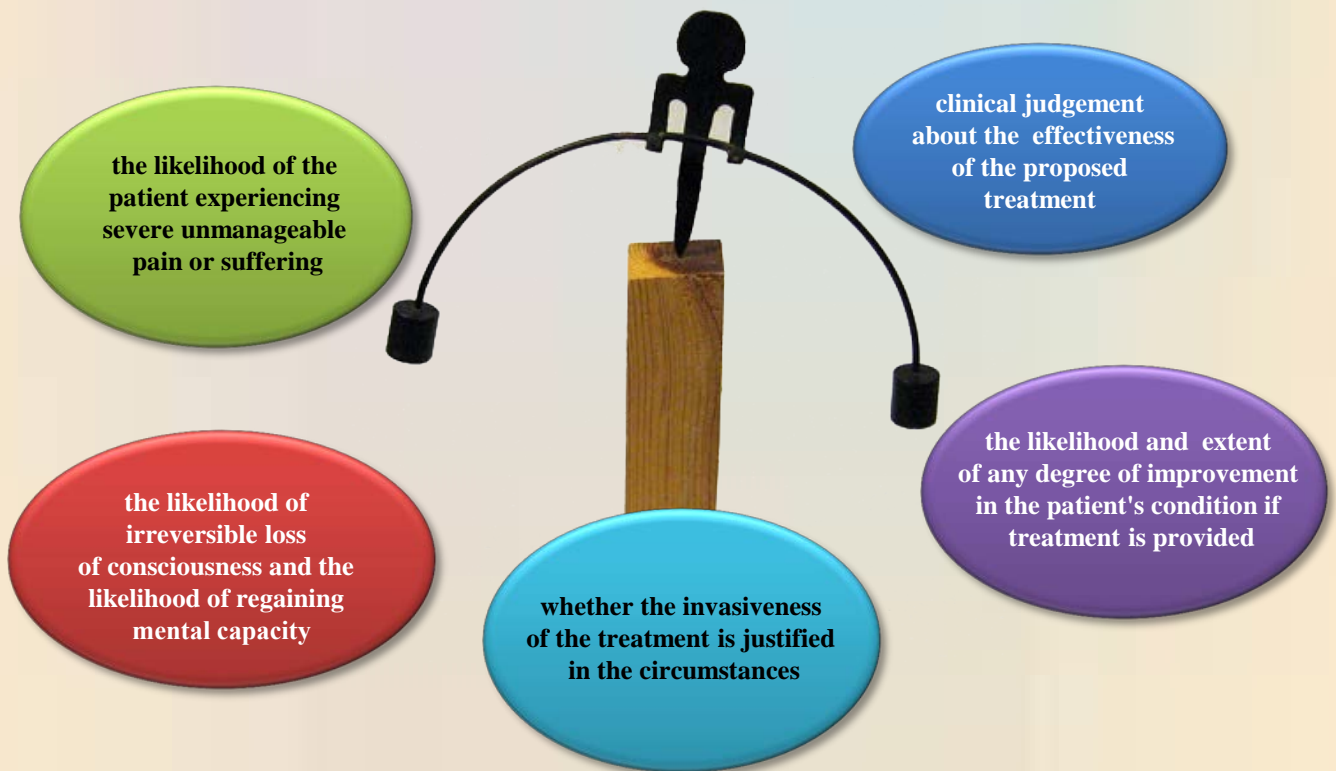


## 2

## What is “in the patient's best interests” ?

Something that is “in the patient’s best interests” refers to the balance of potential benefits over potential harm, distress and suffering resulting from the pursuit of a given treatment.

When deciding whether a treatment is in the patient’s best interests, the following should be contemplated in balancing burdens over benefits.



When considering what is in the patient's best interests, it is more than a healthcare issue. In balancing benefits and burdens, the patient’s wish carries more weight. Also important are the patient’s beliefs and values. If the patient is unable to express himself/herself, views of family members concerning the patient's values, preferences, cultural and religious beliefs should be solicited to determine what is in the best interests of the patient.



# 3

## Is withholding or withdrawing futile life-sustaining treatment (LST) the same as euthanasia?

Euthanasia is defined as “direct intentional killing of a person as part of the medical care being offered” , which is in essence killing a patient to end his/her suffering. The act can be considered as criminal and is ethically controversial. Same as most places in the world, Hong Kong does not legally permit euthanasia and it violates the professional ethics of healthcare workers.

**Withholding/withdrawing futile LST**

**= Euthanasia?**



The patient has the right to refuse unwanted treatment, including LST. A healthcare professional who provides treatment against the patient’s will may be liable to legal action for battery or assault. Withholding such treatment in this case is an act of respecting the patient’s wish and ensuring him/her a peaceful death. This is not tantamount to performing euthanasia.



Withholding or withdrawing futile treatment for a patient is not performing euthanasia as the treatment is not in the best interests of the patient. Administering futile LST on a dying patient would only inflict more suffering. What the patient needs in the final days is not futile treatment, but end-of-life care and a peaceful death.



# 4

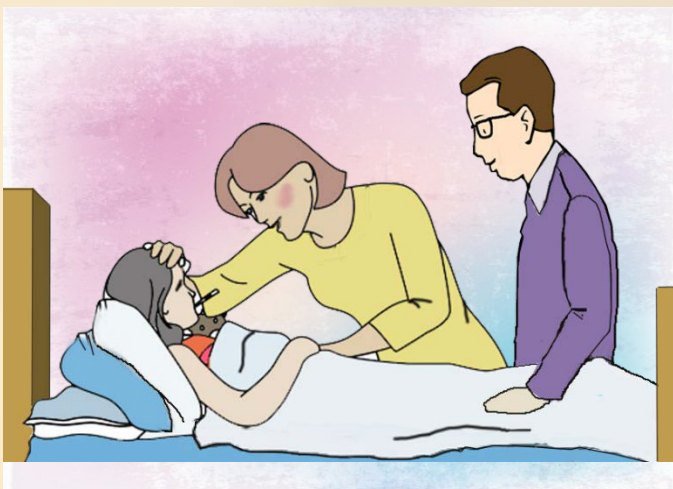
## What is advance care planning (ACP)?



For a patient who has a serious illness, planning on future medical and personal care at the end of life can be made via an ACP process among the patient, family and healthcare workers taking into consideration factors such as disease prognosis, benefits and burdens of treatment, values and preferences of the patient, etc.

Usually ACP is a process of communication intended for mentally competent patients. Participation of family members is encouraged. The patient can express preferences for future medical or personal care, or make an advance directive (AD) refusing life-sustaining treatment (LST).

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. Decision-making regarding the patient's future medical or personal care should be by consensus building among members of the healthcare team and with the patient's family, based on the best interests of the patient.





# Parties involved in the ACP process and their roles

## Clinicians



- In the communication process, clinicians often assume a facilitating and guiding role, and:
  - Provide information on disease prognosis, treatment options available, benefits and risks, as well as related medical evidence, including end-of-life scenarios;
  - Facilitate the patient to express his/her values and preferences for treatment with good communication skills using a patient-centered approach and empower patient autonomy;
  - Encourage the family to listen to the patient's concerns and elicit views from family members; and
  - Resolve disagreement and deal with emotional responses as necessary and work towards a consensus for an agreed care plan.

## Patient



- The patient takes a central role in the discussion. He/she can express his/her views, values and needs to the medical team and the family. Healthcare workers will assist if difficulties arise.
- Scope of views expressed can include expectation for medical and personal care, expected roles of healthcare workers and the family. The patient can also refuse specified LST in the end stage, including cardiopulmonary resuscitation.
- As for paediatric patients, they are encouraged to participate in the discussion. However, the extent of participation depends on their mental capacity. There is currently no international standard on the age requirement, but a minor cannot sign an AD.

## Family



- In traditional Chinese culture, family factors and views of family members are important considerations.
- Depending on circumstances, family members may assume the following roles:
  - Understand the wish of the patient, who is mentally competent and take up the expected role in the future care plan;
  - If the patient is mentally incompetent, give input on the patient's prior wish or preference to the medical team, who would work out a care plan with the family by consensus building based on the best interests of the patient; and
  - Parents of a minor can communicate with the medical team and arrive at a consensus, taking into consideration all the aspects stated above.
- Family support is important to the patient. We understand that the family may be under stress. Should they need assistance, healthcare workers are ready to help.





## Scope of ACP discussion:

|   |  |
|---|--|
| <b>Disease</b>                          | <b>Disease anticipated progression and prognosis</b>   |
| <b>Treatment</b>                        | <b>Treatment options available, benefits and risks</b>   |
| <b>Patient's preferences and values</b> | <b>Patient's expectation from treatments<br/>Preference for treatment limits<br/>Preference for personal care<br/>Personal goals to accomplish</b> |
| <b>Family members</b>                   | <b>Family values and concerns<br/>Views and preferences of parents for minors<br/>Prior wish or preference of incompetent patients</b>             |
| <b>Other</b>                            | <b>May include arrangements after death, e.g. funeral process, organ donation, etc.</b>  |

## What is the appropriate timing for ACP discussion ?

Regarding the appropriate timing for ACP discussion, first we need to understand the progression of the severe chronic diseases. The state and functional status of these patients would worsen with time, with some experiencing acute deterioration at some point. The length of progression depends on the disease and patient's condition, ranging from a few months to several years. In the later stages the disease may follow a more rapid and obvious downhill course.

Therefore, if ACP is conducted too late, the mental state of the patient may not allow him/her to participate in the discussion.

On the contrary, if ACP is initiated too early, the patient and family may not have sufficient understanding of the disease and thus psychologically not ready for the discussion.

The followings are some suggestions for the initiation of ACP :

- Significant decline in functional status and level of physical activity, or need to be institutionalized;
- Considerable discomfort in terms of physical and psychological symptoms, and social anxiety;
- Obvious commencement of the final stage, e.g. following multiple hospital admissions, recurrent acute episodes, having experienced an acute severe episode when death is imminent; and
- Futility of disease targeted treatments established and transition from curative treatment to palliative care.



The above may occur in the later stages of the disease. But in some diseases, ACP may be necessary shortly after diagnosis for:

- Dementia patients when they are still competent in the early stage;
- Cancer patients when the cancers have widely spread to other parts; and
- Some severe diseases such as motor neuron disease that may have a more rapid downhill course after diagnosis.

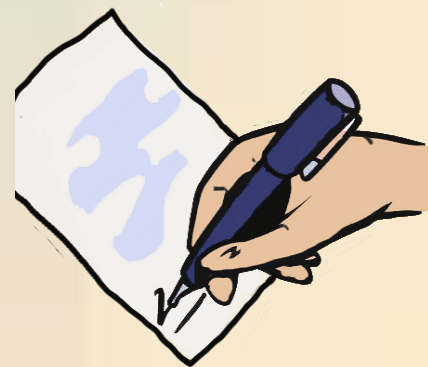
## What follow-up is needed after the ACP?

### **The discussion is not one-off**

The ACP is an ongoing process. Consensus may not be reached via one single discussion and review may be required as the patient's condition or preference changes.

### **Details of the ACP discussion should be documented to facilitate continuity of care**

Healthcare workers will document the details of the ACP discussion, including the patient's preference and choice. The results of discussion will be documented in the ACP form. When the patient is critically ill and has lost capacity, clinicians can make reference to these records and provide appropriate care respecting the patient's wish.



**A mentally competent adult patient may choose to complete an AD as necessary**



# 5

## What is an advance directive (AD)?

A mentally competent and properly informed adult patient aged 18 and above can make an AD, explicitly expressing his/her wish to refuse specified life-sustaining treatment (LST) in pre-specified conditions when he/she is in an end-stage condition and mentally incapable of making health care decisions. A valid and applicable AD is legally binding under common law.



### Use of AD in Hospital Authority (HA) patients

The law of Hong Kong does not require an AD to be made in a specified format. But in HA, an AD form is designed for use by HA patients covering the following situations:

1

**Case 1** “Terminally ill” which means suffering from an 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 LST would only serve to postpone the moment of death.

2

**Case 2** “In a persistent vegetative state or a state of irreversible coma”

3

**Case 3** “Other end-stage irreversible life limiting condition” which 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) patients 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.



## Points to note for making an AD

- If a patient wants to make an AD applicable to other conditions, revise the form or use other forms/formats to express his/her wish, but he/she should discuss with the clinicians first.
- The HA AD form<sup>#</sup> must be signed by the patient and two witnesses, one of whom must be a medical practitioner in Hong Kong. Neither witness should have an interest in the estate of the person making the AD.
- A completed AD is the property of the patient. The patient and family have the primary responsibility of keeping it, and presenting the original copy to the clinicians on the patient's admission. The patient's directive will be in effect if the applicability of the AD is established.
- If the patient changes his/her mind after making an AD, the medical team should be informed as soon as possible with the AD document amended or revoked. In case there are different versions and discrepancies, the original copy held by the patient shall be deemed authentic.
- An AD is in effect only when the patient is no longer mentally capable of making decisions and confirmed by clinicians as suffering from the pre-specified conditions stated in the AD. If the clinicians think the applicability of the AD (e.g. the coma is caused by other factors) or the validity of the document (e.g. being damaged) is in question, they can provide emergency treatment to the patient first.
- If an AD is applicable and valid, clinicians have the responsibility to follow the directive. No one including family members may revoke the AD made by the patient.

<sup>#</sup>Advance Directive Form: [https://www.ha.org.hk/haho/ho/psrm/ADform\\_Eng.pdf](https://www.ha.org.hk/haho/ho/psrm/ADform_Eng.pdf)



# 6

## Overcome Barriers to Advance Care Planning (ACP)

It is understandable people are often reluctant to discuss topics about illness, loss of mental capacity and death. Discussing death is considered a social taboo and people think this would bring bad luck. However, birth, aging, sickness and death are in fact the inescapable realities of life. Now with a rapidly aging population, there is even a greater need to know more about ACP.

**It is not good to discuss this .....or talk about it later.**

The patient and family may be coy about the subject or lack the necessary skills, or worried about possible emotional outbursts resulting from discussion of the serious topic. Healthcare workers can assume a coordinating role in the communication process and deal with emotions. Traditional Chinese people are more subtle and they hope the others can understand their meaning behind. However, healthcare decision-making is a complicated process. It is advisable to make use of the appropriate time when the patient can make autonomous decisions before his/her illness progresses to an advanced stage.

**The healthcare workers are too busy!**

In a busy clinical environment, it is not easy to initiate ACP discussions. Special arrangement may be needed for such a purpose and the discussion is not one-off. The patient, family and healthcare workers may need to find time and conduct ACP through concerted efforts.

**Will the patient become down-hearted and depressed?**

The patient's family may worry such discussions would inflict negative emotions on the patient. But a lot of literature reveals patients generally hope their "right to know" being respected. Telling lies and withholding facts will make the patient feel uneasy, and cannot help him/her face up to the illness and make the necessary arrangement for his/her life thereafter. Healthcare workers would conduct the discussion sensitively with skills, avoiding a rigid or forcing approach.

**Will the doctor give up on me because I refuse life-sustaining treatment (LST)?**

Healthcare workers will never give up on patients. Such anxiety is unnecessary. Even if LST is withheld, effective relief from pain and other distressing symptoms would be continued. For incurable end-stage diseases when dying is unavoidable, the care approach would change from curative to palliative, ensuring the patient a peaceful and respectful death.

# What are the advantages of ACP?



|  |   |
|--|---|
| <b>Patients' right to know</b>             | <p>The patient needs the healthcare workers to provide sufficient information, such as disease prognosis, benefits and burdens of LST as well as clarifications on the meaning of “withholding LST” before he/she can make an informed choice. This is a good chance for the patient and family to gain an in-depth understanding of the illness.</p>   |
| <b>Respect patient autonomy</b>            | <p>Modern healthcare emphasises patient engagement. Mentally competent adult patients have the legal right to autonomous decisions, including refusing or accepting specified treatment and care.</p> <p>ACP provides an opportunity for a terminal ill patient to exercise autonomous decision-making, by expressing in advance wishes about his/her values and preferences and refusal of futile LST. In the future when the patient is no longer capable of making decisions, his/her directive would be respected by the medical team and family members.</p> |
| <b>Of best interests to the patient</b>    | <p>When considering what is of best interests to the patient, it is not solely a medical decision. The wish of the patient carries more weight. If the patient is unable to express himself/herself, his/her family members and carers can give input on the patient's values, preferences, cultural and religious beliefs, etc. for determining what is in the best interests of the patient.</p>  |
| <b>Avoid future disputes</b>               | <p>Healthcare workers, the patient, family and carers may have different views on life as well as LST. If they can deal with any disagreement and conflicts through open communication as early as possible and acknowledge the patient's wish, this can avoid disagreement and conflicts between the healthcare workers and the family over decision making in the patient's terminal phase. In this way, the patient's right to a peaceful death is ensured.</p>  |
| <b>Promote family relationships</b>        | <p>In the course of discussion, healthcare workers will encourage and guide the patient to express his intrinsic values and preferences which may rarely be or not facilitated to be discussed at home. If the family knows more about the patient and his/her wish, this would in turn shape the care for the patient.</p>   |
| <b>Reduce suffering at the end of life</b> | <p>If the patient has decided to refuse futile LST and opts for a natural and respectful death, this can reduce unnecessary suffering of the patient and relieve the grief of the family.</p>   |



# 7

## Besides patients with advanced illnesses, should healthy people also initiate advance care planning (ACP) or make an advance directive (AD)?

- In the Hospital Authority setting, ACP and AD are mainly for patients with advanced irreversible illnesses. For people without advanced irreversible illnesses, it is not easy for them to make decisions and sign an AD applicable to conditions other than being in a persistent vegetative state or in an irreversible coma.
- A sudden stroke or brain injury may cause a person to fall into a persistent vegetative state or an irreversible coma. It is thus reasonable that a healthy person would make prior treatment decisions for such conditions. But for a person without illness, it is debatable whether he/she should make treatment plans for a terminal illness:
  - As many diseases can progress to a terminal stage and the symptoms and treatment outcomes of various diseases are different, a person needs a vast amount of complex medical information before he/she can make a meaningful directive;
  - For most terminal diseases, the patient is still conscious at the time of diagnosis. As the patient knows by then what kind of disease he/she is facing with, it is easier to make decisions; and
  - The patient's acceptance of disease symptoms and disability may change with his/her bodily condition. Therefore it may not be appropriate to make decisions too early.
- As such, it is not always appropriate for elderly people who are not ill to make an AD. However, getting to know early what are life sustaining treatment, ACP and AD can facilitate a person's discussion with clinicians once unfortunately falling ill. Discussing with the family the practical arrangements and expressing one's values regarding the dying process at an appropriate time is also helpful.



# 8

## Special Circumstances

### If the patient is under the age of 18, what can the parents do?

- Same as adult patients mentioned above, people under the age of 18 may also suffer from terminal diseases. Parents of these minors should discuss in advance with healthcare workers the most appropriate care plan for the patient. This is to avoid making hasty decisions by the parents when the patient falls into a critical condition, thus generating anxiety, confusion, guilt and conflicts. As the patient has not reached the legal age to sign an advance directive (AD), healthcare workers would discuss with the patient and family via an advance care planning (ACP) process. Details of the ACP discussion will be documented in the patient's medical record. The clinical team would provide the most appropriate care in accordance with the consensus reached. When the patient's condition deteriorates, the information can serve as important reference.
- Children are encouraged to take part in the discussion. However, the extent of participation depends on the patient's mental capacity. There is currently no international standard on the age requirement.







## Background

- Dementia is a broad category of brain diseases that cause a severe decline in mental ability. This is not a normal process of aging. The death of brain cells leads to mental deterioration and gradual cognitive decline that can affect daily life. Dementia is common in people aged over 65, but also seen in middle-aged people. The most common type of dementia is Alzheimer's diseases, which makes up 50% to 75% of cases. Other types include vascular dementia, Lewy body dementia and frontotemporal dementia. Patients confirmed with dementia would gradually experience in the following several years short-term memory loss, weakened self-care ability, difficulty in expressing and understanding language, decreased ability in thinking and judgement, and disorientation to person, time and space. At present, except for drugs that can slow the pace of mental decline, there is no cure for dementia.
- As the disease progresses, the patient would gradually lose the ability to make decisions. Appropriate care planning enables the patient to enjoy better quality of life, ensuring his/her wish being respected and followed.



## Diagnosis of early stage dementia

- At the moment dementia is diagnosed, the patient and the family begin to face a big challenge. The patient usually experiences complex emotions such as disbelief, shock, anger and grief which are all natural reactions. Thereafter, the patient should take advantage of the early phase when his/her mind is still sound to discuss ACP with the family and medical team, or even make an AD if considered appropriate, ensuring he/she can have the preferred choice of care. If ACP is conducted too late, the patient may not be able to participate in the discussion due to cognitive impairment and thus his/her preferred option of care cannot take effect.

## Advanced dementia

- As elderly patients with dementia enter the advanced stage, many of them would lose the ability to make decisions. If they have not conducted ACP or made an AD, the medical team can only discuss ACP and “Do Not Attempt Cardiopulmonary Resuscitation” (DNACPR) with the family with regard to the patient's end-of-life care. Family members may have to make decisions for the patient who has not expressed prior wishes about his/her care preferences. Having to do so, family members may feel anxious, guilty and stressed. Therefore conducting ACP in the early stage of dementia can reduce unnecessary stress on the family, with the choice of the elderly patient being understood and respected.



# 9

## Patient Stories

### A cancer patient

Oi-ming was a optimistic and cheerful woman aged 70. She was married and lived happily with her husband and two daughters. She had always been healthy until two years ago she was diagnosed with colon cancer. She underwent surgical resection but half a year later the cancer spread to the lungs. She refused chemotherapy and electrotherapy and chose traditional Chinese medicine for treatment. A palliative care team helped her to manage her discomfort. She had not been admitted to hospital for over a year. She attended outpatient palliative care and day rehabilitation program regularly and established good relationships with the palliative care team. Three months ago, Oi-ming's functional course went downhill, presented with shortness of breath, decreased appetite, fatigue and pleural effusion.

She had made it clear to the medical team her refusal of any invasive treatment and did not want futile treatment just to prolong her survival. She was not afraid of death. She told the doctor her family would miss her and they hoped she could live longer. But she had a different view and worried her family might put her on unnecessary life-sustaining treatment. To facilitate Oi-ming in making a properly informed healthcare choice and enable her family to understand her decision, the doctor met Oi-ming and three of her family members to discuss advance care planning (ACP). This was to ensure they knew Oi-ming's values, preferences and rationale for her choice which would be respected by healthcare workers. During the ACP process, Oi-ming made an advance directive specifying what treatment she did not want.



Oi-ming also made preparations for the arrangement after death. She let her family know that she had not given up on her life, and had lived a contented life. She hoped her family could accede to her wish for a respectful death. Oi-ming did not change her mind thereafter, and opted to receive palliative care only. Her family understood and respected her choice. Eventually she died peacefully in the presence of her family members.



## A dementia patient

Ms Lee, aged 70, had been diagnosed with early signs of Lewy body dementia. According to the doctor, her disease might progress with a faster course of deterioration than that of Alzheimer's disease (a more common form of dementia), likely to present with serious Parkinson's disease symptoms and hallucination, loss of the ability of decision-making and feeding problems in the advanced stage. Many similar late-stage patients need to rely on nasogastric tube feeding and become bed-ridden, with the quality of life seriously affected. Discussions on ACP were then conducted between the doctor and Ms Lee with her family. Since Ms Lee did not want to receive invasive treatment in the final stage, she had decided not to accept nasogastric tube feeding and cardiopulmonary resuscitation (CPR).



Ms Lee's decisions were understood and supported by her family. The medical team was informed. A few years later, Ms Lee experienced mental decline as well as worsening physical capabilities, and had serious feeding problems. The medical team provided all palliative measures according to her wish, including comfort feeding instead of nasogastric tube feeding. Finally Ms Lee passed away peacefully in hospital in the presence of her family members. No CPR was administered. Her family found psychological comfort, witnessing the patient's passing with dignity and her wish being respected.