Ethical issues of Advance Directive in patients with Alzheimer's disease

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Older people with advanced dementia has high mortality

- Recent study showed 1-year mortality 34% among those living in RCHEs with advanced dementia (AMT=0)

  (Luk JKH et al. *HK Med J* 2013;19:518-24)

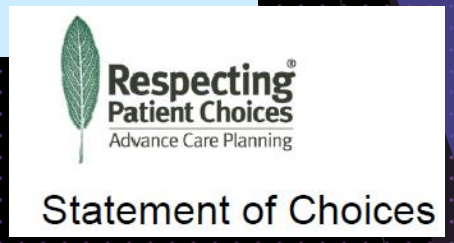
Protecting end of life patient's right of autonomy

- Autonomy-based standard using Advance Care Planning (ACP) and/or "advance directives"

Aims and benefits of Advance Directive in the context of patients with Alzheimer's disease

- Allows the competent patient (before dementia) to control his/her own post-competence medical interventions to fulfill his/her own life values and goals.
- Relieves relatives of the burden of making critical decisions of life and death.
- Resolves disputes among family members.

Advance Directives



- Many countries (USA, UK, Australia, Taiwan, Singapore) have developed legislations for Advance Directive.
- In HK, Advance Directive operates under Common Law principles.
  - It is believed that a non-legally binding Advance Directive can guide doctors and families to make decisions in the patient best interest in most cases.

Advance Directive in Hospital Authority

- 2010 version
- Terminally ill
- Persistent vegetative state or irreversible coma

- 2014 version
- Terminally ill
- Persistent vegetative state or irreversible coma

+

- Other irreversible end stage life limiting condition

- *A short form also available – refuse CPR if terminally ill*

(A) **Case 1 – Terminally ill**

Applicable to advance dementia with terminal illnesses

(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.))

☐ **I shall not be given the following life-sustaining treatment(s):**

- ☐ **Cardiopulmonary resuscitation (CPR)**
- ☐ **Others: _____**

  _____

☐ **Save for basic and palliative care, I shall not be given any life-sustaining treatment[2]. 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.**

Life Sustaining Treatments

- CPR,
- Artificial ventilation,
- Blood products,
- Pacemakers,
- Vasopressors,
- Treatments such as chemotherapy or dialysis,
- Antibiotics for a potentially life-threatening infection,
- Artificial nutrition and hydration (tube feeding).

HA Guidelines on Life-sustaining Treatment in the Terminally Ill 2002

(B) Case 2 – Persistent vegetative state or a state of irreversible coma

(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[3]. (Artificial nutrition and hydration means the feeding of food and water to a person through a tube.))

☐ **I shall not be given the following life-sustaining treatment(s):**

☐ **Cardiopulmonary resuscitation (CPR)**

☐ **Others: _____**

_____

☐ **Save for basic and palliative care, I shall not be given any life-sustaining treatment[4]. 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.**

(C) Case 3 – Other end-stage irreversible life limiting condition, namely: _____

Applicable to advance dementia with organ diseases

(Note: In this instruction -

"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:

(1) 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

(2) patients with irreversible loss of major cerebral function and extremely poor functional status who do not fall into Case 2.

"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.))

☐ **I shall not be given the following life-sustaining treatment(s):**

☐ **Cardiopulmonary resuscitation (CPR)**

☐ **Others: _____**

_____

☐ **Save for basic and palliative care, I shall not be given any life-sustaining treatment[5]. 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.**

Hospital Authority's position

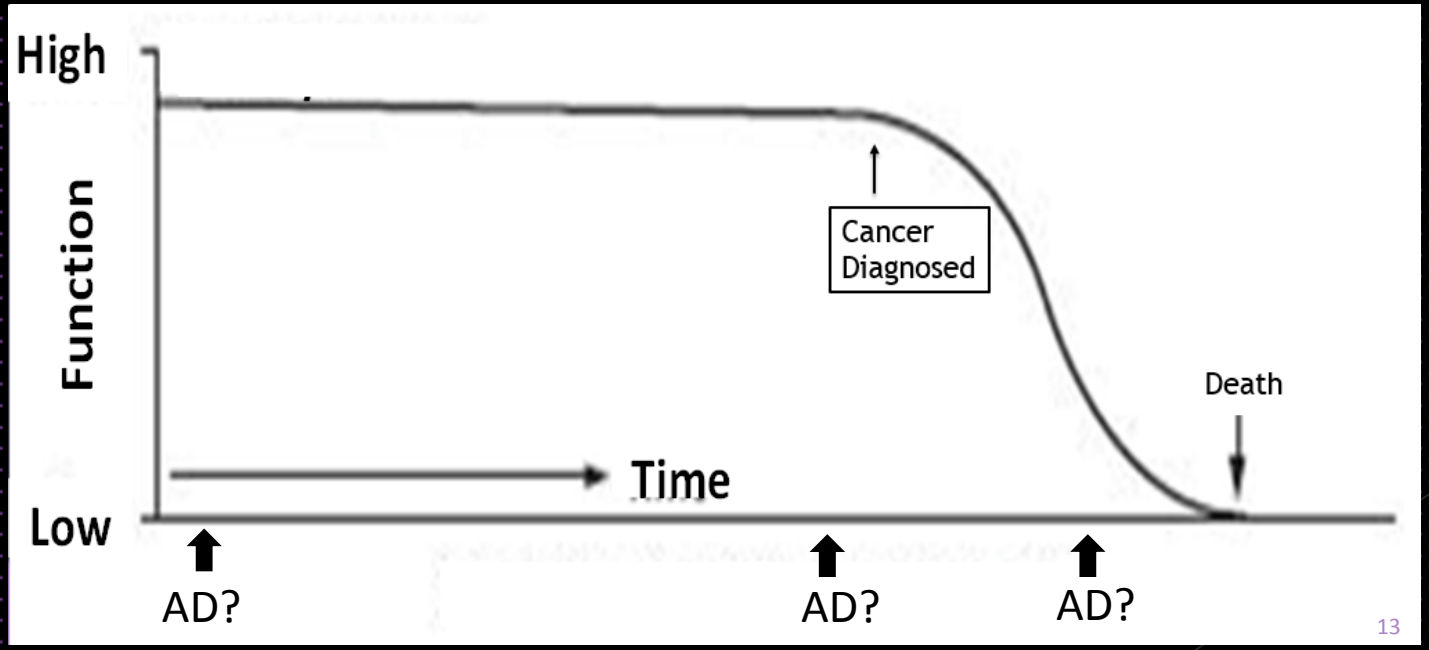
- A **valid and applicable** Advance Directive must be respected.

- 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**.

10 Ethical issues in implementing Advance Directive in Hong Kong

Ethical issue 1

- Patient may have difficulty to make a rational advance decision before the actual scenario happens.
- Best time to make Advance Directive?



Ethical issue 2

- Advance Directive assumes that the medical condition, prognosis, treatment options/outcome, and the patient's goals/values of life that are anticipated by the competent patient at the time he/she makes the Advance Directive is the same when it is implemented.
- This may not be true due to span of time elapsed between making and implementation of Advance Directive.

Ethical issue 3

- Advance directives are time consuming for health care professionals.
- Inadequate knowledge and training of doctors, nurses.
- Inadequate knowledge of patient, family and public.

Medical students' Knowledge of Advance Directives

- Felt their knowledge inadequate 90%
- Felt unprepared to discuss with patients 88%
- Supported the use of Advance Directive 79%
- Felt that there was inadequate education 51%

MW Siu, et al. The Preparedness of Hong Kong Medical Students towards Advance Directives and End of-life Issues. East Asian Arch Psychiatry 2010;20:155-62

Ethical issue 4

- Clinical team may be difficult to judge the validity of the Advance Directive.
- E.g. only copy of Advance Directive available, Advance Directive made in other countries etc

Hospital Authority guideline
When doubts about validity

- Should continue life sustaining treatment, while waiting for clarifications.
- Such treatment may be withdrawn later if validity is confirmed --- *easier said than done*.
- To confirm the validity, it may useful to discuss with
  - the witnesses of the Advance Directive,
  - the family members of the patient,
  - the health care team looking after the patient recently.

(*seek assistance from the hospital management, ethical team and legal advisor*)

Ethical issue 5

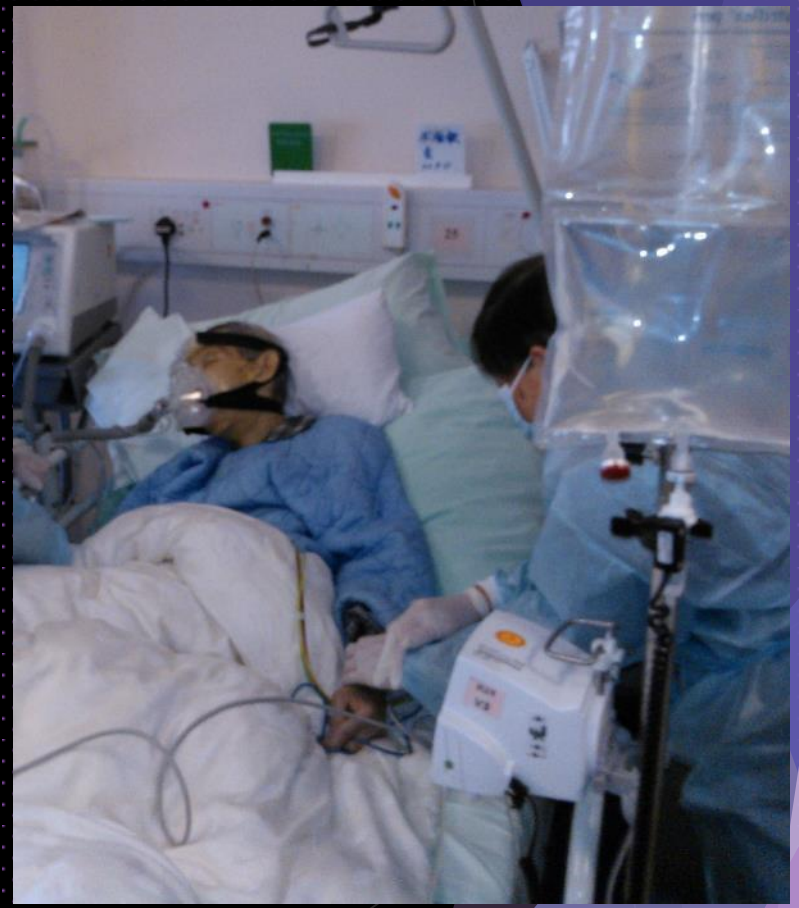
- The clinical team may be difficult to accept the Advance Directive which appears not in the best interests of the patient, without the chance of further discussion with the already incompetent patient.
  - E.g. an Advance Directive requests no ventilation BUT physician feels that the ventilator is only a temporary treatment that could extend life and diminish suffering.

Ethical issue 6

- Advance Directive demanding withdrawal of artificial nutrition or hydration is controversial – some people view this as euthanasia.

Ethical issue 7

- Advance directives may improperly influence health care providers to limit care, leading to under-treatment.



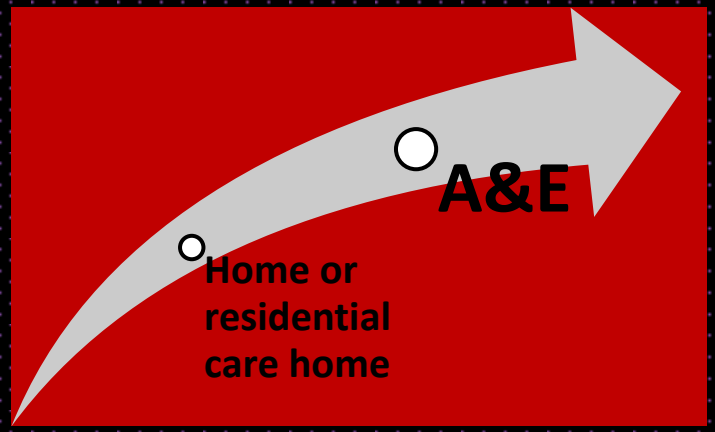
Ethical issue 8

- Without specific legislation in HK, there will be legal uncertainties.
  - When family members challenge the validity and/or applicability of an Advance Directive made by a patient.
  - When patient with dementia does not agree with his/her own Advance Directive (patient is a mental incapacitated person now)

→ provide life sustaining treatment, while waiting for clarifications.

Ethical issue 9

- Ambulance in Hong Kong – not involved in carrying out Advance Directive order. CPR may be performed untill reaching A&E.
- In A&E, the staff may not have time to read the Advance Directive, or to make sure that the patient is in a terminal condition.



Ethical issue 10

- Cultural difference
  - Advance directive – Western concept
  - Chinese family reliance more on collective decision by family
  - Having Enduring Power of Attorney better than Advance Directive?

Still a long way for successful Advance Directive in HK……..

Thank you