



### Advance Directives Consultation Paper

The Food and Health Bureau published the Concept of Advance Directives Consultation Paper. To enhance the awareness of this consultation, the Federation has invited a doctor, a medical ethicist, and a lawyer to each contribute a short article on this subject. We would like to thank all three authors for writing and sharing their personal views and perspectives in this issue.

## Advance Directives: Their Role in Clinical Practice and Their Difficulties

**Dr. Chun-yan TSE**

*Honorary Advisor of the Hong Kong Society of Palliative Medicine*

### Background

In the Hong Kong context, the term "advance directive" (AD) usually refers to a set of instructions about what kind of life sustaining treatment (LST) that a patient wishes to refuse when he becomes mentally incapacitated under some specified circumstances. In Hong Kong, a proxy directive appointing another person to decide on the patient's behalf does not have legal status. Under the common law framework in countries like UK, Australia, Canada and USA, a valid and applicable AD refusing LST is legally binding. The courts in Hong Kong would very likely take this view. In 2006, the Law Reform Commission published a report on AD recommending promotion of the concept of AD via non-legislative means in Hong Kong. However, there are different views on this in the community, and the Food and Health Bureau has issued a consultation paper in December 2009 asking for comments, among other questions, whether the concept of AD should be more widely promoted in Hong Kong or not.

There is little dispute about the importance of understanding a patient's values and treatment preferences in end of life care. Such an understanding could be achieved through discussions among the patient, the healthcare providers, and the family members in the "advance care planning" (ACP) process. The concept of ACP should be promoted in Hong Kong among patients with advanced incurable diseases. ACP does not necessarily end up in a legally binding AD. A non-legally binding expression of the patient's values and preferences in end of life care may be adequate in many cases, and can guide the doctor and family to make decisions in the patient's best interests when the patient is incompetent.

### Role of AD in Clinical Practice

Sometimes, AD as a legally binding tool in ACP has its role in clinical practice:

- When there is a need to express the decision of the patient effectively to clinicians not familiar to the patient: For example, a terminally ill patient who plans to stay at home as much as possible may die at home. A statement that he declines CPR would be helpful. Another example is a severe COPD patient with repeated intubation for respiratory failure. If the patient does not want further intubation on his next admission for respiratory failure, a statement indicating his decision would be helpful.

- When it is difficult to judge what is in the best interests of the patient: In some cases, a decision based on the best interests principle for an incompetent patient can be difficult, even if the patient's values and wishes are known. A statement indicating his decision would be helpful.
- When the wish of the patient appears not in the best interests of the patient: Occasionally, a patient may have idiosyncratic view on a particular LST, for example, a Jehovah Witness patient would not want transfusion. A statement indicating his decision would be helpful.

### Difficulties

However, there are practical difficulties in executing an AD. Unlike contemporaneous refusals, a patient may have difficulty to make a rational advance decision before the actual scenario happens. On the other hand, the clinical team may have difficulty to judge whether the AD is valid or applicable. Also, unlike a contemporaneous refusal, the clinical team may find it difficult to accept an advance refusal which appears not in the best interests of the patient, without the chance of further discussing with the already incompetent patient. Such difficulties should be greater in patients without a terminal illness.

Another problematic area is an AD demanding withdrawal of artificial nutrition and hydration when PVS status is confirmed. This is highly controversial. Common law framework seems to support that such AD should be followed. However, many people think this is euthanasia.

Furthermore, without specific legislation in Hong Kong, there are legal uncertainties. Recently, doubts have been raised whether a valid and applicable AD can really override the best interests principle. For example, can a doctor transfuse a Jehovah Witness patient (with a valid AD refusing transfusion) dying of bleeding when he becomes unconscious, based on the best interests principle according to the Mental Health Ordinance Cap 136 Section 59ZF?

### The Way Forward

There are no easy answers to the above difficulties. In the 2006 report, taking reference mainly from the Singapore model, which has a rigid legislation with statutory forms and procedures, the Law Reform



Commission considers that legislation would not help the promotion of AD in Hong Kong. However, there are some recent developments. In 2007, the Mental Capacity Act became operative in England and Wales. The legislation on AD there is just on the basic principles only, allowing flexibility in its execution, but it confirms the legal status of AD and its relationship to the best interests principle. I think Hong Kong should work towards legislation for AD along the UK approach, to confirm the legal status of AD, but to allow flexibility in its execution.

At this moment, I think AD should be promoted in selected patients as part of ACP in advanced incurable illnesses. However, it may be prudent to wait till enactment of specific legislation on AD before promoting AD to the general public in Hong Kong. Meanwhile, it would be useful to develop guidelines for clinicians on how to handle an AD.

Regardless of whether AD is promoted in Hong Kong or not, it should be noted that AD is not a panacea for the difficulties faced by dying patients. Firstly, an AD cannot (and should not) cover all possible future scenarios. Scenarios not covered by the AD should be managed along the best interests principle, taking into account the values and wishes of the patient. Secondly, AD is a legal tool only. In patients faced with an advanced incurable disease, AD should be part of ACP, and ACP should be part of the full spectrum of palliative care for a terminally ill patient.