An advance directive for health care is a statement, usually in writing, in which a person indicates when mentally competent the form of health care he/she would like to have in a future time when he/she is no longer competent. The development of advance directives is largely derived from the principle of informed consent and the belief in a person’s autonomy in health care decisions. Advance directives include the so-called “living wills” and “durable or enduring powers of attorney for health care.”

The term “living will” was coined by Luis Kutner in 1969. The document is a will because it contains the person’s instructions and directions for the future. The word “living” indicates that in contrast to the usual will, this takes effect before death. In the enduring powers of attorney for health care, a person appoints someone to make decisions on his/her behalf when he/she becomes mentally incapacitated. The “enduring powers of attorney” takes effect when the person is mentally incapacitated whereas the usual “powers of attorney” ceases to take effect when the person is incapacitated. There are slight differences in the scope of authority in the enduring powers of attorney in various places. For health care decisions, the term “enduring powers of attorney for health care” is more appropriate. A point to note is that a living will is effective only when the declarant is incompetent as well as terminally ill while the enduring powers of attorney for health care take effect once the declarant is incompetent.

The impetus behind the development of advance directives is a growing fear of the public of being provided with high technology treatment to prolong life without consideration of the quality or dignity of life. The historical development of the use of advance directives in the United States is described in articles by Annas and Hong et al and the interested reader could refer to these papers. In brief, a young woman, Karen Ann Quinlan, was in a persistent vegetative state and her parents asked to remove her ventilator in 1976. The Court finally granted their request, but this case aroused a lot of public interest in self-determination of health care issues and subsequently led to the enactment of California’s Natural Death Act which contained a prescribed form of living will.

In 1990, there was another important case in the United States, that of Nancy Cruzan. Her parents asked for the removal of her tube feeding after she was left in a persistent vegetative state due to a car accident. Initially, the Court required convincing evidence that this was what the patient would have opted for. Eventually, additional evidence by Nancy’s friends was accepted and the court allowed the cessation of administering food and fluids. This case led to another wave of widespread public concern about the recognition of living wills and health care proxies.

In 1991, U.S. Congress passed the Patient Self-Determination Act which specifies that all hospitals reimbursed by Medicare should have a policy on living wills and that all hospitals, nursing homes and home health agencies should advise patients of their rights on medical care and to execute an advance directive.

Legislation for advance directives has been in place in the United States since the enactment of the California Natural Death Act in 1976. Currently most of the states in the United States have laws related to advance directives. In the United Kingdom, the development of advance directives has been slower and less legalistic than in the United States. A recent case was that of Tony Bland, a young man in a persistent vegetative state after an accident. Tony’s family and medical staff sought to stop his treatment, in the absence of an advance directive. The court’s decision was that if Tony had made any advance directive, the doctors would have acted unlawfully if they had not carried out his wishes. Thus the Court’s decision showed that an advance directive was valid and legally binding. In the last few years, the Law Commission and UK Government has prepared a number of consultation papers on the subject and...
there has been a lot of discussion and debate on the issue. Recently it has been decided that the concept of advance directive in living wills should not be legislated for as the current law is already adequate and they do have legal status when properly enacted\(^9\). As for proxy directives, the Enduring Powers of Attorney Act enacted in 1985 allowed a person to delegate another person to make decision on financial matters for him/her when he/she becomes mentally incapacitated. Currently the Law Commission recommends the development of Continuing Powers of Attorney which allows a person to delegate decision-making powers on finance, health care and personal welfare to another person\(^5\).

In practice, a living will is considered valid only when the following criteria are satisfied: it must be made by a mentally competent person, the consequences of refusal of treatment should be known, the person is free from undue influence of others and the refusal of treatment applies only to the situations specified in the will\(^6\). It is noteworthy that there is a common misperception that the implementation of advance directives is a kind of assisted death or euthanasia. In actual fact, advance directives allow for refusal of “heroic” or “extraordinary” measures in case of terminal illness\(^7\), but cannot authorize a doctor to do anything illegal, or to hasten the death of a patient. Advance directives are but a means for a person to exercise his/her right to choose - to accept or refuse treatment. So it is different from euthanasia or assisted death, which brings forward a patient’s death.

The major benefit of an advance directive is that it enables patients to have control over their medical care and to exercise their autonomy. It also removes the very difficult task facing medical staff and family members when they have to make decisions about withdrawing life-sustaining treatment in the uncertainty of what the patient would have preferred\(^8\). Without an advance directive from the patient, some family members might feel very guilty about their decisions afterwards and might even develop pathological grief or a depressive illness. In addition, an advance directive might avoid recourse to the courts to settle disputes in end-of-life decisions for incapacitated patients\(^3\).

Despite their appeal, advance directives are still infrequently used. For instance, it was found that only around 10% of Americans had written advance directives for medical care\(^8\). The low rate of use of advance directives may be due to patient avoidance and lack of awareness as well as physician’s reluctance to discuss end-of-life decisions\(^9\).

Further, there are also difficulties in the practical implementation of advance directives. It may be difficult for people to be fully aware of all the treatment options in future should they become incompetent and to imagine the whole range of situations that might happen to them. Thus it has been argued that competent people may not be well placed to make decisions concerning their future incompetent selves\(^10\). Another criticism is that healthy people may make decisions that would change when they become sick or mentally incompetent\(^6\). There is also concern that advance directives may preclude patients from the benefits of treatment and hence add to their suffering\(^6\).

As for the use of enduring powers of attorney for health care, the person appointed as attorney may not know about the patient’s wishes and preferences. Further, appropriate surrogates may not be available universally\(^7\). In addition, there may be financial conflicts and ethical concerns if institutions use advance directives as a means to contain cost\(^11\). Thus it has been emphasized that advance directives should be part of a clinical process and not merely an administrative one\(^11\). Nevertheless, despite its limitations, advance directives are useful and important instruments when properly enacted.

In Hong Kong, the ageing of the population has led to increasing attention on issues of health care provision for our elderly. In particular, there is a growing interest and concern about the treatment of terminally ill elderly. From time to time, clinicians and front line staff, together with patients’ relatives, have to face difficult end-of-life decisions of whether to withdraw life-sustaining treatment in these elderly, often without knowledge of what the elderly would prefer. The issue of advance directives is emerging as an important agenda especially in the area of dementia care, since dementia is the commonest condition for which an advance directive is used\(^6\). So far, progress on this front is extremely slow. The Enduring Powers of Attorney Ordinance is enacted in 1997. However, it only gives authority to the attorney to act in relation to the property and financial matters of the donor. The problems of this ordinance are two fold: very few people know about it and the application procedure is excessively cumbersome. The donor must sign the instrument before a solicitor and a registered medical practitioner who are satisfied that the donor is mentally capable and is signing the instrument voluntarily. At present,
living wills and Enduring Powers of Attorney for health care are still not available in Hong Kong. There is an urgent need to discuss and debate this issue locally, including the implementation of advance directives and how to define mental incapacity. There is a need to discuss the issue further among professionals, policy makers and the public. In the end, the concept of advance directives is an important step forward to allow our patients more autonomy and to have a freedom of choice in their future care plan.

References