

# HKGS response to the Consultation Paper on Substitute Decision-making and Advance Directives in Relation to Medical Treatment

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The Hong Kong Geriatrics Society (HKGS) is a specialist society with over 100 members who are doctors responsible for the management of acute illness, severe disability, and terminal conditions in elderly people. Together with multidisciplinary teams, these doctors are experienced in the management of the diseases of the aged and in meeting the related ethical challenges.

The HKGS is pleased to have the opportunity to respond to the Consultation Paper on Substitute Decision-making and Advance Directives in Relation to Medical Treatment<sup>1</sup> and makes the following points:

1. In principle, the Society welcomes the use of Advance Directives (AD), a mechanism whereby competent people can make decisions about their future health care should they become incompetent, to help patients to state their preferences thus enhancing their autonomy and improving communication between patients and their health care team. However, the Society is aware of the limitations of AD when applied to the medical care of elderly people (see paragraph 15 below), and that the concept of AD is not easily understood by the general public, especially elderly patients. Thus, the Society recommends that AD be implemented through non-legislative means (Option E [p.153] and recommendation 1 [p.155]<sup>1</sup>).
2. The context of AD should be confined to a living will. Expanding the current coverage of the Enduring Power of Attorney to health issues is inappropriate as abuse is difficult to avoid. Moreover, studies have shown that proxies may

not actually understand the patient's wishes even when that proxy is someone the patient thinks will understand him or her.<sup>2</sup> The Society is of the opinion that it is inappropriate for relatives to act as the second witness in the signing of AD. This does not imply, however, that relatives are to be excluded from the process of making the health care plan for a patient facing terminal illness (see paragraph 7 below).

3. The objective of AD should be explicitly stated in the AD form. A version from the *British Medical Journal* reproduced on p.179 of the consultation paper<sup>1</sup> is a good example: "The object of this directive is to minimise distress or indignity which I may suffer or create during an incurable illness, and to spare my medical advisers or relatives, or both, the burden of making difficult decisions on my behalf."<sup>3</sup>
4. Advance Directives should only be used to indicate the refusal of medical means to prolong life in terminal illnesses, except to relieve obvious suffering, including cardiopulmonary resuscitation, artificial ventilation, artificial hydration and nutrition (p.178<sup>1</sup>).<sup>3</sup> It is suggested that 'long-term physical restraint as medical management' be added to the list of refusal as this is a common problem faced by elderly patients in Hong Kong.
5. While AD can be used to indicate other requests from the patient, he/she should understand that only treatments available in the health facility and considered to be in the 'best interests' of the patient by the attending doctor will be given. Euthanasia should never be accepted as a request.
6. Advance Directives should mainly be used in a

terminal illness context. Whether dementia or other degenerative brain disorders should be included is controversial. The present Guardianship board mechanism appears to be effective and safe. Writing a living will beforehand can act as supportive evidence of one's authentic view for the board's consideration. As many such patients are of advanced age, geriatric specialist input into the board's decisions should be enhanced.

7. The writing of AD should be initiated during the process of making the health care plan for a patient facing terminal illness. As a basic requirement for good health care planning, the patient's psychosocial status should be carefully considered. Multidisciplinary and multiparty inputs, including those from formal and informal caregivers, should be taken when appropriate.
8. Advance Directives should be regarded as a formal tool to facilitate communication between patients and doctors. It should never become a 'duty' for every patient to consider nor should such a culture be allowed to develop. Everyone's right 'not to decide' should always be respected. This is to avoid the development of implicit coercion to force everyone, especially the old and the chronically ill, to write AD for the sake of relieving the burden on the family and/or the health care system.
9. The threshold for revoking AD should be very low. A patient should be allowed to revoke the AD at any time by any means (verbally to the attending doctor should be good enough). This is especially so if writing AD is extended to dementia patients. This forms a safety net for everyone. A 'wrong' revoking would only allow the doctor to offer 'extra' medical treatment to the patient based on the principle of 'best interests' for the patient in general. Overly demanding criteria for revocation may result in a tragedy whereby the patient actually changes his/her mind and wants the treatment but is deprived of it and dies as a consequence. The study by Danis et al<sup>4</sup> revealed that some patients' wishes were unstable and suggested that an instruction for future care cannot be assumed to be a permanent wish in the future.
10. Whenever there is reasonable doubt as to the validity of the AD by the medical staff, the principle of 'medical management for the best interests of the patient' should prevail. It is better to err on over-doing than under-doing. This is to safeguard the patient's benefit (benefit of doubt), and to protect the medical staff from unnecessary legal liability.
11. When writing an AD, the element of depression should be considered. A very good explanation to the patient (preferably to relatives also, within the context of health care planning) should be offered, especially to older patients. Thus, it is mandatory to have a medical doctor to sign as witness, preferably not the doctor providing the immediate care. The doctor should make a clinical judgement that the patient is of a sound mind and not obviously depressed.
12. The Society is against setting up a central registry for AD. The formality of central registration may deter patients from writing an AD as it appears to be something very official, and would put undesirable pressure on the frontline medical staff to search for its presence. Elderly patients may unnecessarily fear having difficulty revoking the AD if it is kept away from him/her in a central registry. The Society opines that it is sufficient for the AD form to be kept by the patient or the relatives and then shown to medical staff when the situation arises.
13. The government and the health authorities should make a major effort to educate the public about the proper use of AD. The older patient should not be deprived of the benefit of using an AD but should also be protected from any exploitation and abuse.
14. It is difficult for one to imagine the future scenario when one has a terminal illness. To make a properly informed AD, the patient will be required to make decisions about potential quality of life and a range of complex possible medical interventions. Patients need to be well informed in order to make a decision they will not regret about refusal of medical management. The Society advocates that the government and the health authorities should make every effort to produce guidelines for professional staff to offer adequate explanations, illustrative videos for explanations of conditions, etc. This is particularly important for elderly patients who may not be familiar with the medical terms, equipment, and procedures.
15. The Society would like to alert the public and the medical profession to the following

limitations of AD to ensure the quality care of elderly patients will not be compromised:

- 15.1 Goal-setting is of the utmost importance in geriatric care, rehabilitation, and palliative care. The listing of potential procedures in AD may divert attention from the overall treatment goals and may give rise to inappropriate care.<sup>5</sup>
- 15.2 Confusion (and thus mental incapacity) may arise from treatable conditions like constipation and urinary tract infection. Thus activation of AD should not be simply based on mental incompetence, which could be transient and reversible.
- 15.3 The elderly patient frequently presents with multiple illness, acute on chronic symptoms, and a combination of illness and underlying frailty. And the extent of impairment, the potential for treatment and rehabilitation, vary significantly in each individual. The complexity of illness in old age means that the potential patient often cannot be informed

adequately to allow tailoring of the AD to meet the circumstances that will prevail at the time the directive has to be implemented. The difficulty in relating an AD to the conditions prevailing at the time a decision has to be made has led to reported cases of misapplication in other countries.<sup>6</sup>

## References

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