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Panel on Health Services

Updated background brief prepared by the Legislative Council Secretariat for the meeting on 13 December 2019

Advance directives in relation to medical treatment and the provision of palliative care services

Purpose

This paper provides background information and summarizes the concerns of members of the Panel on Health Services ("the Panel") and the Joint Subcommittee on Long-term Care Policy ("the Joint Subcommittee") formed under the Panel and the Panel on Welfare Services in the Sixth Legislative Council ("LegCo") on advance directives in relation to medical treatment and the provision of palliative care services.

Background

2. In 2002, the Secretary for Justice and the Chief Justice directed the Law Reform Commission ("LRC") to review the law relating to (a) decision-making for persons who are comatose or in a vegetative state, with particular reference to the management of their property and their affairs and the giving or refusing of consent to medical treatment; and (b) the giving of advance directives by persons when mentally competent as to the management of their affairs or the form of health care or medical treatment which they would like to receive at a future time when they are no longer competent, and to consider and make recommendations for such reform as may be necessary.

3. The Sub-committee on Decision-making and Advance Directives was appointed under LRC in May 2002 to examine and to advise on the present state of the law and to make proposals for reform. In July 2004, LRC issued a Consultation Paper on Substitute Decision-making and Advance Directives in

relation to Medical Treatment,[1] which set out proposals to reform the law relating to the above two aspects of decision-making in relation to medical treatment for persons who were unable to make those decisions at the time of execution of the associated action, for public consultation until end of September 2004. LRC released its Report on Substitute Decision-making and Advance Directives in relation to Medical Treatment in August 2006.[2] It recommended, among others, that the concept of advance directives should be promoted initially by non-legislative means until the community had become more widely familiar with the concept and the use of its proposed model form of advance directive should be encouraged.

4. Having considered LRC's recommendations and recognizing the need to enhance the public's understanding of advance directives; to provide information for those who wished to make such directives; and to strengthen the doctor-patient relationship in the handling of such directives through close communication, the Administration consulted the parties concerned[3] between December 2009 and March 2010 on the introduction of the concept of advance directives as a personal decision.[4] Having regard to the outcome of the consultation, the Administration advised in 2010 that it was more advisable to implement advance directives by way of legislation when there was a greater degree of awareness and consensus over the use of advance directives and that the community was ready for it. Separately, the Hospital Authority ("HA") has put in place since 2010 and 2014 respectively a Guidance for HA Clinicians on Advance Directives in Adults[5] and a set of Guidelines on Do-Not-Attempt Cardiopulmonary Resuscitation[6], and updated in 2015 its Guidelines on Life-Sustaining Treatment in the Terminally Ill[7] for reference by clinicians in public hospital setting.

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1 The Consultation Paper can be assessed at LRC's website at https://www.hkreform.gov.hk/en/publications/decision.htm.

2 The Report can be assessed at LRC's website at https://www.hkreform.gov.hk/en/publications/decision.htm.

3 According to the Administration, these parties included public and private hospitals, the medical profession (including the Medical Council of Hong Kong), the legal profession, the healthcare sector, patient groups and non-governmental organizations providing healthcare-related services to patients.

4 The consultation paper can be assessed at https://www.gov.hk/en/residents/government/publication/consultation/docs/2010/AdvanceDirectives.pdf.

5 The Guidance can be assessed at HA's website at http://www.ha.org.hk/haho/ho/psrm/EngcopyAD.pdf. Under the Guidance, an advance directive covers the clinical conditions of being (a) terminally ill; (b) in a persistent vegetative state or a state of irreversible coma; and (c) in other specified end-stage irreversible life limiting condition.

6 The Guidelines (in English version only) can be assessed at HA's website at http://www.ha.org.hk/haho/ho/psrm/CEC-GE-6_en.pdf.

7 The Guidelines can be assessed at HA's website at http://www.ha.org.hk/haho/ho/psrm/HA_Guidelines_on_Life_sustaining_treatement_en_2015.pdf.

5. As stated in its Report on Substitute Decision-making and Advance Directives in relation to Medical Treatment, LRC takes the view that palliative and basic care which is necessary to maintain patient's comfort, dignity, or for the relief of pain should always be provided after the effect of advance directives to not to receive life-sustaining treatment. In 2015, the Food and Health Bureau commissioned The Chinese University of Hong Kong to conduct a three-year research study on the quality of healthcare for the ageing ("the Study") so as to identify barriers and recommend service models for end-of-life care, and to recommend changes (including legislation) if required. At present, palliative care is mainly provided by HA to patients facing terminal illness to improve the quality of care and facilitate a more peaceful dying process. A Strategic Service Framework for Palliative Care[8] was formulated by HA in 2017 to guide the development of its palliative care service in the next five to 10 years. As regards contract homes providing subsidized residential care services for the elderly, they are required by the Social Welfare Department ("SWD") to provide end-of-life care services to render holistic care to elderly residents suffering from life threatening illness and approaching the end of life, and provide support for their carers.

6. A public consultation exercise was launched by the Administration on 6 September 2019 to solicit public views on end-of-life care legislative proposals regarding advance directives and dying in place until 16 December 2019.

Deliberations of the Panel and the Joint Subcommittee

7. The Panel and the Joint Subcommittee discussed issues relating to advance directives in relation to medical treatment and the provision of palliative care services at four meetings in 2004 and 2008, and in 2017 and 2019 respectively. Views from deputations were received at a meeting of the Joint Subcommittee. The deliberations and concerns of members are summarized in the following paragraphs.

Difference between advance directives and euthanasia

8. Members sought clarification from the Administration about the difference between advance directives in relation to medical treatment and euthanasia, given that a prior instruction to not to receive life-sustaining treatment would have the effect of shortening the life of the maker of advance

[8] The Strategic Service Framework can be assessed at HA's website at https://www.ha.org.hk/haho/ho/ap/PCSSF_1.pdf.

directive. The Administration explained that advance directives were completely unrelated to euthanasia which was an illegal act of direct intentional killing of a person as part of the medical care. No one in Hong Kong could indicate a wish for receiving euthanasia in the advance directive. Healthcare professionals should not act as instructed even if such a wish was expressly requested. Members agreed with the LRC's view of not legislating advance directives in relation to medical treatment at this stage, as the concept of advance directives was still little understood in Hong Kong.

Promotion of advance directives

9. Members shared the LRC's view that the Government should play a role in promoting public awareness and understanding of the concept of advance directives in relation to medical treatment, and should endeavour to enlist the support of relevant bodies, such as the Medical Council of Hong Kong and HA, in the campaign. They queried why the Administration did not intend to actively advocate or encourage the public to make advance directives. Some members went further to ask if the Administration would consider requiring all patients planning to undergo operation to make advance directives.

10. The Administration advised that it would work with HA to consult and disseminate information about advance directives to the healthcare sector, legal profession, patient groups and non-governmental organizations providing healthcare-related services for patients, with a view to enhancing public understanding of the concept and enabling an informed choice by those who wished to make advance directives. The Administration however had no plan to actively advocate or encourage the making of advance directives as it remained voluntary.

The current implementation of advance directives

11. Some members pointed out that without the backing of legislation, the use of a non-statutory model form of advance directives might result in disputes between the healthcare professionals and a patient's family members as to the patient's wishes. LRC advised that in such cases, recourse might have to be made to the court. It however believed that the use of a model form which, if completed fully, would offer a clear and unambiguous statement of the patient's wishes and could reduce disputes to a minimum. LRC recommended that the Government should encourage those who wished to make an advance directive to seek legal advice and to discuss the matter first with their family members. Family members should also be encouraged to accompany the individual when he made the advance directive. Some members called on the Administration to take more proactive steps in taking forward the concept of advance directives through legislation at a later stage to ensure that the prior wishes of the makers

of advance directive were followed if they were at odds with the wishes of their family members.

12. Concern was raised over the role of doctors in implementing a patient's advance directives. The Administration advised that a doctor's decision should always be guided by the best interest of the patient. According to relevant professional codes of conduct, the healthcare team had to maintain close communication with the family on the medical conditions of the patient and wherever possible, forge consensus with the family in the execution of the advance directives. In case of insoluble disagreement, the advice of and facilitation by the clinical ethics committee of the hospital concerned should be sought.

13. Members shared the concern of some deputations about the reluctance of public hospital doctors in certifying patients' advance directives or accepting advance directives validly made outside HA. The Administration advised that guidelines were in place to guide HA's clinical teams to handle issues relating to advance directives. Under HA's practice, patients who had their advance directives made outside HA would be invited to also make the advance directive using HA's form in order to reduce the scope of uncertainty and dispute.

The Administration's latest proposal in respect of advance directives

14. Members in general were supportive to the proposal of introducing clear provisions for advance directives such that if an advance directive was both valid and applicable,[9] it had the same effect as a contemporaneous refusal of treatment by a mentally competent person (i.e. the treatment could not be lawfully given). However, they expressed concern about the proposed safeguard that the original copy of the advance directive should be presented under normal circumstances, as the patients concerned or their family members might not always have the advance directive document readily available at the scene of resuscitation, in particular that outside the hospital setting. In such case, treatment providers (including emergency rescue personnel) had to continue to provide clinically indicated emergency life-sustaining treatment, while waiting for clarifications. They suggested that the Administration should consider providing an option of digitalizing the advance directive document, such as keeping it in smart identify card, to facilitate emergency rescue personnel to be aware of an advance directive made. There was also a concern

[9] Under the Administration's proposal, an advance directive was considered valid if it was sufficiently clear and was not being challenged on ground of undue influence or mental incapacity, etc. It became applicable when the patient suffered from the proposed pre-specified conditions (i.e. terminal illness; persistent vegetative state or a state of irreversible coma; and other end-stage irreversible life-limiting condition), and was no longer mentally capable of making healthcare decisions.

that since it was proposed that both witnesses for making an advance directive should not have an interest in the estate of the person making the advance directive, those immediately family members of a patient who had interest in the estate of the patient might hence not be aware of the advance directive of the patient. This might cause disputes among family members regarding the patient's wishes.

15. According to the Administration, the use of a model do-not-attempt cardiopulmonary resuscitation form with a valid advance directive attached was proposed to facilitate an advance directive being followed outside the hospital setting. Detailed guideline on how advance directives and do-not-attempt cardiopulmonary resuscitation forms should be implemented would be developed for use by emergency rescue personnel. This apart, the Electronic Health Record Sharing System could be leveraged to store and allow access by designated healthcare professionals to the advance directive records. The Administration further advised that treatment providers would be encouraged to initiate discussion of advance care planning and advance directives with mentally competent patients and their family members. They would explain to the patients' family members the advance directives made by the patients when the patients concerned became no longer competent of making healthcare decisions.

16. Members sought information on whether the future legislative proposal in respect of advance directives would include a definition of "family member" and, if so, whether a same-sex partner would be regarded as a family member. The Administration explained that the only proposed requirements concerning the two witnesses of an advance directive were that one witness had to be a medical practitioner, and both persons had no interest in the estate of the maker of advance directive. The witness did not need to be a family member.

17. Concern was raised over the arrangement of advance directives for mentally incompetent persons. According to the Administration, its proposal was that only those advance directives made by a person who was at the age of 18 or above and was mentally competent would be legally valid. An advance directive did not require formal assessment of the person's mental capacity by psychiatrists unless circumstances suggested it.

<u>The Administration's proposal in respect of dying in place</u>

18. Some members were concerned about the proposed amendments to the Coroners Ordinance (Cap. 504) to exempt the reporting requirements to the Coroner regardless of whether a resident of residential care homes for the elderly ("RCHEs") was diagnosed as having a terminal illness if he or she had been attended to by a registered medical practitioner within 14 days prior to

death and a medical practitioner made a final diagnosis and determined the cause of death. They asked about the legal safeguard if the death was caused by negligence on the part of RCHEs. Some other members asked whether patients who had indicated their wish to spend their last days in RCHEs would be given a priority in allocation of RCHE places. The Administration advised that by exempting the reporting requirement to the Coroner, it was expected that a barrier to facilitate dying in place in RCHEs would be removed. Efforts would continuously be made to promote dying in place, either at home or any residence choice including a RCHE.

19. On the reason why a 14 day-requirement was proposed, the Administration advised that the 14 days requirement was in line with the existing arrangement under the Coroners Ordinance that when there was no requirement to report to the Coroner if the person who died at home due to natural cause had been diagnosed as having terminal illness before his or her death or he or her was attended to by a registered medical practitioner during his or her last illness within 14 days prior to his or her death.

20. Some members were concerned about the impact of dying in place on property value. They pointed out that a flat where a person died became inauspicious in Chinese society, which resulted in a depreciation of the value of the flat concerned and even flats in the immediate vicinity. They enquired the Administration how it would address the issue. The Administration stressed that the intent of its proposal was to provide more options in the place of care for persons who would want to spend their last days in a familiar environment. It acknowledged that there were other concerns in society that needed to be addressed to facilitate the implementation of dying in place.

Palliative and end-of-life care

21. Members were concerned about the inadequate provision of palliative care beds in public hospitals. They noted with concern that according to a 2015 Quality of Death Index which evaluated the quality and availability of palliative care to adults of 80 countries across the categories of palliative and healthcare environment; human resources; affordability of care; quality of care; and level of community engagement, Hong Kong, which was at position 22, was ranked lower than Taiwan, Singapore, Japan and South Korea which were at positions six, 12, 14 and 18 respectively. They sought information on the details and timetable of the Administration's plan to enhance palliative inpatient service and palliative home care service. According to the Administration, HA had over 350 palliative care beds as at end of December 2017. The overall inpatient bed occupancy rate of the palliative care in HA was around 90% in 2017-2018. HA would further enhance its palliative care services in 2018-2019 by strengthening palliative care consultative service in hospitals; enhancing palliative care home

care service through nurse visits; strengthening the competency of nursing staff supporting terminally ill patients beyond palliative care setting through training; strengthening end-of-life care for elderly patients in RCHEs; and establishing a centralized multi-disciplinary team at the Hong Kong Children's Hospital.

22. Some members called on the Administration to consider increasing the provision of end-of-life care rooms in RCHEs to meet the needs of severely sick or terminally ill residents and their families or carers. The Administration undertook to relay the suggestion to the relevant bureau for consideration.

23. On the timetable for the introduction of end-of-life care services by subvented and private RCHEs, the Administration advised that SWD would discuss with the operators on how to enhance training for the staff in this regard.

Relevant papers

24. A list of the relevant papers on the Legislative Council website is in the **Appendix**.

Council Business Division 2
Legislative Council Secretariat
12 December 2019

Appendix

Relevant papers on advance directives in relation to medical treatment and the provision of palliative care services

Committee	Date of meeting	Paper
Panel on Health Services	19.7.2004 (Item VI)	Agenda Minutes
	8.12.2008 (Item IV)	Agenda Minutes
	8.11.2019 (Item III)	Agenda
Joint Subcommittee on Long-term Care Policy	12.12.2017 (Item II)	Agenda Minutes CB(2)1449/17-18(01)
Research Office of the Information Services Division of the Legislative Council Secretariat	6.6.2019 *	Essentials entitled "Advance healthcare directives of patients"

* *Issued date*

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