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Panel on Health Services

Background brief prepared by the Legislative Council Secretariat for the meeting on 12 May 2023

End-of-life care: Legislative proposals on advance directives and dying in place

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 end-of-life care legislative proposals regarding advance directives ("ADs") and dying in place.

Background

What is advance directive?

2. An AD may be described as "a statement, usually in writing, in which a person indicates when mentally competent what medical treatment he/she would refuse at a future time when he/she is no longer mentally competent".

3. AD was first introduced for public discussion through the 2004 public consultation paper and 2006 report on "Substitute decision-making and advance directives in relation to medical treatment" by the Law Reform Commission of Hong Kong ("LRC"). In response to LRC's report, the Food and Health Bureau[1] issued a consultation paper in 2009 titled "Introduction of the Concept of Advance Directives in Hong Kong" to consult stakeholders on the relevant issues. The majority of views received at the time were in support of the adoption of a non-legislative approach to promote

[1] Currently known as the Health Bureau.

ADs in Hong Kong first, and then consideration of whether legislation was appropriate when there was greater awareness in society. The Government recommended at the time that guidance should be developed for the medical and other relevant professions on the making and handling of ADs.[2]

4. Currently, Hong Kong had neither statute nor direct case law on the legal status of ADs, and what Hong Kong was relying on was the general requirement for the patient's consent to receiving medical treatment under the common law to make validly-made ADs refusing life-sustaining treatment legally binding.

Dying in place of patients

5. Dying in place usually means spending the final days at the place of choice of the patient, be it at home, in a residential care home for the elderly ("RCHE") or nursing home, and not necessarily a hospital.

6. Under the Coroners Ordinance (Cap. 504), when a person dies at home due to natural cause, there is no requirement to report to the Coroner, if he/she was diagnosed as having terminal illness before his/her death or if he/she was attended to by a registered medical practitioner during his/her last illness within 14 days prior to his/her death. However, for cases of deaths due to natural causes in RCHEs, all such deaths must be reported to the Coroner via the Police, irrespective of whether the person had been diagnosed with terminal illness or whether the person had been attended to by a registered medical practitioner during his/her last illness within 14 days prior to his/her death. If necessary, an investigation by the Police and forensic pathologist and a post-mortem examination will follow. According to the Administration, while these requirements are important safeguards for RCHE residents, they also pose a serious disincentive for RCHEs to allow elderly residents to die in their premises.

Public consultation in 2019

7. To gauge public views on end-of-life care legislative proposals regarding ADs and dying in place, a public consultation was conducted in 2019 and 30 consultation questions were set out on the Government's proposal in the consultation paper to:

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[2] The Hospital Authority ("HA") had respectively put in place since 2002, 2010 and 2014 HA Guidelines on Life-Sustaining Treatment in the Terminally Ill, Guidance for HA Clinicians on Advance Directives in Adults, and HA Guidelines on Do-Not-Attempt Cardiopulmonary Resuscitation for reference by clinicians in the public hospital setting.

(a) codify the current common law position in respect of an AD and to increase safeguards attached to it;

(b) remove legislative impediments to implementation of ADs by emergency rescue personnel; and

(c) amend the relevant provisions of the Coroners Ordinance to facilitate dying in place in RCHEs.

8. At the Panel meeting on 8 November 2019, the Administration briefed the members on the above public consultation issues and subsequently provided an information paper on the outcome of the consultation and the way forward to the Panel in July 2020.[3] According to the information paper, there was a clear support from most respondents for the initial proposals on execution details in respect of ADs and amendments to the Coroners Ordinance. Alternative views, such as witness requirements for AD making and revocation, validity proof for AD, statutory prescribed form for Do-Not-Attempt Cardiopulmonary Resuscitation ("DNACPR"), and safeguards for RCHE deaths were raised.

9. It was also mentioned in the information paper that taking account of the views of the respondents, four major refinements are made to the original proposals as follows:

(a) the role expected of the medical practitioner witness, who should be satisfied that the person making the AD has been informed of the nature and effect of the AD and the consequences of refusing the relevant treatments, would be expressly spelt out;

(b) a second witness would be required for a verbal revocation of an AD reported by a family member or carer;

(c) a statutory prescribed DNACPR form would be used, instead of a non-statutory model form; and

(d) the proposed exemption to the reporting requirement under the Coroners Ordinance in respect of natural deaths in RCHEs in which the deceased was attended to by a medical practitioner within 14 days of death will only be applicable for persons who have been previously diagnosed as having a terminal illness.

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3 LC Paper No. CB(2)1388/19-20(01)

10. The Administration advised that it would proceed with drafting the relevant legislations, to be supplemented by stepped up efforts on public education on end-of-life care and life and death issues, and training and development of the healthcare, elderly care and emergency rescue workforce.

Major deliberations and concerns of members

11. The Panel and the Joint Subcommittee had discussed issues and received views from deputations relating to ADs and dying in place of patients at five meetings in 2004, 2008, 2017 and 2019 respectively. Members generally supported the legislative proposal. The major concerns raised by members are summarized in the following paragraphs.

Difference between advance directives and euthanasia

12. Members sought clarification from the Administration about the difference between ADs 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 AD.

13. The Administration explained that ADs 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 AD. Healthcare professionals should not act as instructed even if such a wish was expressly requested.

Promotion of advance directives

14. Members were of the view that the Government should promote public awareness and understanding of the concept of ADs; enhance life-and-death education in the school setting; and endeavour to enlist the support of relevant bodies such as the Medical Council of Hong Kong and Hospital Authority ("HA") in the campaign. They queried why the Administration did not intend to actively advocate or encourage the public to make ADs. Some members went further to ask if the Administration would consider requiring all patients planning to undergo operation to make ADs.

15. The Administration advised that it would work with HA to consult and disseminate information about ADs 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 ADs. The Administration however had no plan to actively advocate or encourage the making of ADs as it remained voluntary.

The Administration's proposal in respect of advance directives

16. Members in general were supportive to the proposal of introducing clear provisions for ADs such that if an AD was both valid and applicable,[4] 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 AD should be presented under normal circumstances, as the patients concerned or their family members might not always have the AD document readily available at the scene of resuscitation, in particular 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 AD document, such as keeping it in smart identify card, to facilitate emergency rescue personnel to be aware of an AD made.

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

18. According to the Administration, the use of a model DNACPR form with a valid AD attached was proposed to facilitate an AD being followed outside the hospital setting. Detailed guideline on how ADs and DNACPR 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 AD records.

19. The Administration further advised that treatment providers would be encouraged to initiate discussion of advance care planning and ADs with mentally competent patients and their family members. They would explain to the patients' family members the ADs made by the patients when the patients concerned became no longer competent of making healthcare decisions.

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[4] Under the Administration's proposal, an AD 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.

20. Some members enquired whether the future legislative proposal in respect of ADs would include a definition of "family member". The Administration explained that the only proposed requirements concerning the two witnesses of an AD were that one witness had to be a medical practitioner, and both persons had no interest in the estate of the maker of AD. The witness did not need to be a family member.

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

The Administration's proposal in respect of dying in place

22. As regards the proposal in paragraph 9(d) above, some Members enquired about the justifications for setting the 14 days requirement. Some members expressed concern as to whether the Administration would put in place any legal safeguards when the death of a RCHE resident was caused by negligence on the part of the RCHE. 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. Some other members suggested to make it a mandatory requirement that all RCHEs had to set up hospice care facilities to facilitate the implementation of dying at RCHEs.

23. The Administration advised that the 14 days requirement was in line with the existing arrangement under the Coroners Ordinance. According to the Ordinance, 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 she was attended to by a registered medical practitioner during his or her last illness within 14 days prior to his or her death.

24. The Administration further 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.

25. Some members expressed concern 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, would result in a depreciation of the value of the flat concerned and even flats in the immediate vicinity. They asked the

Administration how it would address the issue. Some other members raised concern about the handling of dead bodies in case of dying at home.

26. 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

27. Members expressed concern about the inadequate provision of palliative care beds in public hospitals. They enquired about the details and timetable of the Administration's enhanced palliative inpatient service and palliative home care service.

28. According to the Administration, HA had over 350 palliative care beds as at end of December 2017. 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.

29. 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.

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

Relevant papers

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

Recent developments

32. At the Panel meeting on 17 January 2023, Hon CHAN Hoi-yan proposed discussion of healthcare support for and directives in relation to

medical treatment of terminally-ill patients and patients with irreversible disease.

33. The Administration will brief the Panel on 19 April 2023 on the legislative proposals regarding ADs and dying in place.

Council Business Division 4
Legislative Council Secretariat
9 May 2023

Appendix

Relevant papers on
End-of-life care: legislative proposals on advance directives and dying in place

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 Minutes
	13.12.2019 (Item V)	Agenda Minutes
	24.7.2020 *	Paper provided by the Administration on the outcome and way forward of the public consultation on end-of-life care legislative proposals regarding advance directives and dying in place
Joint Subcommittee on Long-term Care Policy	12.12.2017 (Item II)	Agenda Minutes Supplementary information paper provided by the Administration
Research Office of the Information Services Division of the Legislative Council Secretariat	6.6.2019 *	Essentials entitled "Advance healthcare directives of patients"

* *Issue date*

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