For discussion
on 12 May 2023

Legislative Council Panel on Health Services

End-of-life Care: Legislative Proposals on Advance Medical Directives and Dying in Place

PURPOSE

This paper briefs Members on the legislative framework for end-of-life care legislative proposals with regard to advance medical directives (AMDs) and dying in place.

BACKGROUND

2. The recommendation to legislate on AMDs in Hong Kong was put forward as early as 2004. Policy initiatives to enable AMDs and dying in place are important measures to respect the choice of patients and improve the quality of life of the terminally ill. An AMD generally refers to a written statement in which a person indicates, while mentally capable, what life-sustaining treatment he/she would refuse when he/she is no longer capable of doing so. On the other hand, dying in place usually means spending the final days at the place of choice of a patient, be it at home or in a residential care home for the elderly (RCHE) or nursing home, and not necessarily in a hospital.

3. The adoption of AMDs was first proposed by the Law Reform Commission (LRC) in 2004 in its public consultation paper on "Substitute Decision-Making and Advance Directives in Relation to Medical Treatment". In its report released in 2006, the LRC recommended that the Government should promote the concept of AMDs under the existing common law framework instead of by legislation, and should consider whether legislation was appropriate when there was greater public awareness of the concept.

4. Currently, Hong Kong has neither legislation nor case law that stipulates the legal status of AMDs. According to the general requirement established under the common law to require patients' consent

to any medical treatment, validly-made AMDs under the common law remain legally binding. The Hospital Authority (HA) has been in fact allowing its patients to make AMDs when necessary in accordance with the common law. That said, considering that the practice has yet to be legally codified, this has caused uncertainties to both AMD makers and the industry. In addition, since 2012, the number of AMDs made by HA patients has been on the rise, in which the number of AMDs specifying refusal to cardiopulmonary resuscitation (CPR) rose from 325 in 2013 to 1 742 in 2021.

5. As regards dying in place, it is currently not considered a reportable death under the Coroners Ordinance (Cap. 504) if a patient who has been diagnosed with terminal illness dies at home due to natural causes, or that he/she had been attended to by a registered medical practitioner (RMP) within 14 days prior to his/her death. However, according to Section 16 of Part 1 of Schedule 1 to Cap. 504, all cases of death (including cases of natural deaths) in residential care homes for persons with disabilities (RCHDs) or RCHEs which are not nursing homes (specified RCHs)[1] are reportable deaths, irrespective of whether the person has been diagnosed with terminal illness or attended to by an RMP within 14 days prior to his/her death[2]. Although the relevant requirement of reportable deaths at specified RCHs provides important safeguards for residents of residential care homes (RCHs), it also results in RCHs being more reluctant to allow their terminally ill residents to pass away in their premises.

Public Consultation

6. In response to the LRC's report, the former Food and Health Bureau (FHB) conducted two public consultations in 2009 and 2019 respectively. In the public consultation conducted in 2019, the Government's legislative proposals received broad support from the respondents, with submissions generally in favour of most of the proposals.

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[1] Generally speaking, according to Section 16 of Part 1 of Schedule 1 to Cap. 504, any death of a person where the death occurred in any premises in which the care of persons is carried on for reward or other financial consideration is a reportable death. However, the Section also stipulates exceptions, i.e. deaths occurring at a hospital for which a licence is issued under the Private Healthcare Facilities Ordinance (Cap. 633), a scheduled nursing home for which an exemption is granted under Cap. 633, or a nursing home for which a licence is issued under the Residential Care Homes (Elderly Persons) Ordinance (Cap. 459) are not reportable deaths. The legislative proposals will not cause changes to the above arrangements applicable to nursing homes.

[2] Relevant reportable deaths will be followed up by the Police and forensic pathologists, with investigations and post-mortem examinations to be conducted when necessary.

7. Following the completion of the public consultation, the Government released the consultation report on "End-of-life Care: Legislative Proposals on Advance Directives and Dying in Place" in July 2020. The Government concurrently announced the commencement of the legislative work on AMDs and dying in place. Riding on the consensus built during the public consultation, the Government is now proceeding with the legislative procedures to implement the various recommendations in the consultation report.

LEGISLATIVE FRAMEWORK

8. The legislative intent of the legislative proposals on AMDs and dying in place includes:

(a) to codify the current common law position in respect of AMDs and increase the safeguards attached;
(b) to remove legislative impediments to the implementation of AMDs by emergency rescue personnel; and
(c) to amend the relevant provisions of Cap. 504 to facilitate the choice of dying in place for terminally ill patients in RCHs.

9. The Government is currently drafting the Advance Decision on Life-Sustaining Treatment Bill (the Bill) and relevant legislative amendments in order to implement the recommendations relating to AMDs and dying in place. The proposals are mainly based on the recommendations in the end-of-life care consultation report released by the then FHB in 2020, with difference in proposals from the consultation report emphasized in paragraphs below.

10. The Bill consists of two main parts: (i) the AMD legislative framework, to be implemented with the inclusion of a statutory model form [3] to facilitate adoption, and (ii) the Do-Not-Attempt Cardiopulmonary Resuscitation (DNACPR) order legislative framework, to be implemented with the inclusion of a statutory prescribed form[4].

[3] The AMD model form will be included as a schedule to the Bill. Although we encourage makers to use the model form, AMDs not adopting the model form will be valid as long as they comply with the requirements under the Bill.

[4] The DNACPR order prescribed form will also be included as a schedule to the Bill. DNACPR orders which are not issued in accordance with the prescribed form will not be valid.

11. On the other hand, the proposals on dying in place will be implemented through amending Cap. 504 such that natural deaths of residents in specified RCHs would be exempted from the reporting requirement under Cap. 504, subject to certain safeguarding conditions being met.

Advance Medical Directives: Latest Proposals

12. Regarding the AMD framework, the Bill will specify that any mentally capable person, who is aged 18 or above, may make an AMD to indicate that certain specified life-sustaining treatments shall not be provided to the maker in the event that he/she becomes no longer mentally capable and the rest of the specified preconditions (e.g. suffering from specified illness in the document) are met.

13. The Bill will specify that the making of an AMD requires two witnesses, one of whom must be an RMP, who should be satisfied that the maker is mentally capable to make an AMD and has been informed of the nature and effect of the AMD as well as the consequences of refusing the specified treatment. In addition, the aforementioned two witnesses would need to satisfy certain conditions, including not being estate beneficiaries of the maker to the best of his/her knowledge.

14. The Bill will specify that an AMD maker could revoke or make a new AMD at any time as long as he/she is mentally capable. An AMD must be made in writing. Under the principle of "cautious making, easy revoking[5]", an AMD could also be revoked by burning, tearing[6], etc., apart from revocation by verbal or written means as proposed in the consultation report. Considering the industry's views and to streamline actual operation and enhance certainty, the Government will introduce in the Bill the modes of revoking AMDs and making new ones, instead of the arrangements of modifying AMDs as proposed in the consultation report.

15. In addition, an AMD maker shall have the primary responsibility of keeping the AMD. As proposed in the consultation report, makers should ensure that the original copy of the AMD could be presented to treatment providers by themselves or by their family as proof of validity. To facilitate such presentation by the family members of the maker, the

[5] "Cautious making, easy revoking" refers to stringent safeguards for making AMDs while facilitating revocation.

[6] Signing on the AMD form for confirmation is certainly the more secure mode of revocation when circumstances permit.

Bill will also allow presentation of certified true copies of an AMD as proof of validity.

Do-Not-Attempt Cardiopulmonary Resuscitation Order: Latest Proposals

16. To facilitate the implementation of AMDs outside the hospital setting, RMPs may issue DNACPR orders to AMD makers who had specified the refusal of CPR when the specified preconditions (e.g. suffering from specified illness in the document[7]) are met. The DNACPR order serves to provide instructions that CPR shall not be performed on the patient. A DNACPR order shall be issued by two RMPs, one of whom must be a specialist. A statutory prescribed form will be used for the DNACPR order for easy identification. Similar to the AMD arrangements, a maker could revoke a DNACPR order issued pursuant to an AMD by verbal or written means, or by burning, tearing, etc. Meanwhile, apart from the original copy of a DNACPR order as proposed in the consultation report, the Bill will also allow presentation of its certified true copies to emergency rescue personnel and/or treatment providers as proof of validity.

17. For minors and mentally incapable adults without the aforementioned AMD, if there is a consensus among related parties (including the RMP in charge of the patient and the patient's family) that CPR is not in the best interests of the patient, the RMP could also issue a DNACPR order to the patient.

18. The Bill will stipulate appropriate safeguards for treatment providers and rescuers (including ambulance personnel). For example, treatment providers and rescuers will not incur any civil, criminal and other legal liability for carrying out a specified treatment or CPR for a patient who has made an AMD or has been issued a DNACPR order if, at that time, they do not know that the patient has made an AMD or has been issued a DNACPR order, or honestly believe that the instruction or order is not valid and applicable. Similarly, treatment providers or rescuers will not incur any legal liability for withholding or withdrawing a specified treatment or CPR if they honestly believe that an instruction of an AMD or a DNACPR order is valid and applicable.

[7] A DNACPR order will only be issued when the patient is (i) terminally ill; (ii) in irreversible coma or in a persistent vegetative state; or (iii) suffering from other end-stage irreversible life limiting condition.

Consequential Amendments

19. Currently, ambulance personnel of the Fire Services Department are bound by the Fire Services Ordinance (Cap. 95) to assist any person who appears to need prompt or immediate medical attention by resuscitating or sustaining his/her life, regardless of whether the person holds a valid and applicable DNACPR order. On the other hand, under the Mental Health Ordinance (Cap. 136), an RMP may provide life-sustaining treatment to a mentally incapacitated person without consent in an urgent situation if the RMP considers that the treatment is necessary and in the best interests of the person, regardless of whether an instruction in the person's AMD (if any) is valid and applicable, and irrespective of whether the person holds a valid and applicable DNACPR order.

20. To avoid the above provisions from hindering ambulance personnel and treatment providers from complying with AMDs and DNACPR orders, the Government will concurrently amend Cap. 95 and Cap. 136 to stipulate the conditions and scope of application for AMDs and DNACPR orders under these provisions.

Dying in Place: Latest Proposals

21. According to the recommendations on dying in place in the consultation report, the Government will amend the provisions of Cap. 504 in this legislative exercise, stipulating that if a resident of a specified RCH passes away in the RCH, and the resident has been diagnosed with terminal illness and has been attended to by an RMP within 14 days prior to his/her death, the death is not a reportable death provided that an attending RMP is able to make a final diagnosis to confirm that the deceased resident had died from a natural cause. To further facilitate the dying in place arrangement of patients, apart from RCHEs as recommended in the consultation report, the Government also proposes to include RCHDs into specified RCHs to allow relevant arrangements to be implemented in RCHDs.

Legislative Timetable

22. The Government is currently drafting the legislation with a view to introducing the Bill and relevant amendments regarding dying in place to the Legislative Council within 2023. The Government will continue to take forward various relevant work, including strengthening public education on end-of-life care and life and death issues, enhancing training and development of healthcare professionals, elderly care workers and

emergency rescue personnel, etc.

23. The Government respects the choice of patients and will sustain its efforts on other non-legislative initiatives to improve the quality of life of the terminally ill to their last moments, and to enhance the well-being of family members of patients during their final stage of life and beyond their departure.

ADVICE SOUGHT

24. Members are invited to note the content of this paper and give views on the legislative **framework** on AMDs and dying in place.

Health Bureau
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