END-OF-LIFE CARE : MOVING FORWARD

Legislative Proposals on Advance Directives and Dying in Place - **Consultation Report**

食物及衞生局
Food and Health Bureau

Moving Forward

End-of-life Care:

Legislative Proposals on Advance Directives and Dying in Place

Food and Health Bureau

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VOTE OF THANKS

To all the respondents who provided to us their views on the legislative proposals to improve end-of-life care in Hong Kong; organisers and participants of public forums during the consultation; commentators who voiced their views via the mass media; and many others who made known their views through other means and platforms, including those at the meetings of the Legislative Council Panel on Health Services, I would like to express my heartfelt gratitude to your support of, and participation in, this public consultation. I should thank in particular the Hospital Authority and the Jockey Club End-of-Life Community Care Project for rendering us invaluable support and assistance throughout the consultation.

The views expressed are extremely useful, including those in support of the initial government proposals, and those that offered alternative ideas. I am most happy to note that almost all stakeholders are in agreement, and I dare say in support, of the need for us to take the matter forward in the general direction that we have proposed to make legislative changes to improve end-of-life care in Hong Kong.

There are individual issues that we need to deliberate on further so as to resolve differences through refinement, amendment or clarification of the proposals. Nevertheless, this strong consensus points to a clear direction for us to move forward. Benefitting from the wisdom we have gathered from this public consultation, we are augmenting the relevant legislative work and will address the remaining issues in the process.

As we are addressing life and death issues, we do not under-estimate the complexity and sensitivity and would proceed boldly but carefully. We are fully aware that besides legislative changes, actual end-of-life care and related service planning and improvement need to be implemented concurrently. Nevertheless, I am confident that we can look forward to, and build on, the support of the stakeholders, and the community at large, to take another pivotal step to improve end-of-life care in Hong Kong in pursuit of our policy objective of providing quality and holistic end-of-life care to persons and families to meet their preferences and needs.

Professor Sophia CHAN, JP
Secretary for Food and Health

EXECUTIVE SUMMARY

The Consultation

The *End-of-life Care: Legislative Proposals on Advance Directives and Dying in Place* public consultation was conducted between 6 September 2019 and 16 December 2019. We received 607 written submissions.

The Response

We garnered the clear support of the initial proposals (recapitulated in Chapter 2) from most respondents on execution details in respect of advance directives and amendments to the Coroners Ordinance (Cap. 504).

Refined Proposals

Taking account of the views of respondents, we have refined the proposals. The four major refinements are –

First, we will expressly spell out the role expected of the medical practitioner witness, who should be satisfied that the person making the advance directive has been informed of the nature and effect of the advance directive and the consequences of refusing the relevant treatments;

Secondly, in respect of the report of a verbal revocation of an advance directive made by a family member or carer, a second witness is required;

Thirdly, we recommend the use of a statutory prescribed Do-Not-Attempt Cardiopulmonary Resuscitation ("DNACPR") form, instead of a non-statutory model form; and

Fourthly, the proposed exemption to the reporting requirement under the Coroners Ordinance in respect of natural deaths in residential care homes for the elderly ("RCHEs") in which the deceased was attended to

by a medical practitioner within 14 days of death will only be applicable for persons who was previously diagnosed as having a terminal illness.

With the above refinements, the final legislative proposals are outlined as follows -

Advance Directives

(a) Any mentally competent person who is aged 18 or above could make an advance directive to refuse life-sustaining treatment (including artificial nutrition and hydration) under pre-specified conditions. We recommend the use of a non-statutory model form covering the following pre-specified conditions: (i) terminally ill; (ii) in persistent vegetative state or a state of irreversible coma; (iii) in other end-stage irreversible life-limiting condition. As long as the person is mentally competent and not under undue influence, there are no restrictions as to when a person could make, modify or revoke an advance directive. Making and modifying an advance directive must be in writing. Revocation could be made verbally or in written form.

(b) When making or modifying an advance directive, two witnesses with no interests in the estate of the person making the advance directive are required, one of whom must be a medical practitioner. The medical practitioner should be satisfied that the person has capability to make an advance directive, and has been informed of the nature and effect of the advance directive and the consequences of refusing the treatments specified in the advance directive.

(c) In respect of revocation, no witness is required for a written revocation. Crossing out and signing onto an advance directive, and tearing or otherwise destroying by the person who made the advance directive, or by some person in his/her presence and by his/her direction, could be taken as revoking the advance directive. For verbal revocation, at least one witness who has no interests in the estate of the person making the advance directive is required. A second witness is required for the report of verbal revocation made by a single family member or carer.

(d) A person with an advance directive would have the primary responsibility of keeping the advance directive and of ensuring that the original copy shall be presented to treatment providers as proof of a valid advance directive. Even when an advance directive is validly

made, it will be applicable only when the person suffers from the pre-specified conditions in the advance directive form, and is no longer mentally capable of making healthcare decisions. To facilitate an advance directive being followed outside the hospital setting, statutory prescribed DNACPR form will be used. The original copy shall be presented to emergency personnel and/or treatment providers as the valid proof of a DNACPR form. The DNACPR form can also be used for minors and incompetent adults without an advance directive and suffering from advanced irreversible illnesses, if there is consensus that cardiopulmonary resuscitation ("CPR") is not in the best interests of the patient and thus should not be performed. The Electronic Health Record Sharing System ("eHRSS") will be leveraged to store records of advance directives and DNACPRs on a voluntary basis.

(e) Safeguards will be provided to treatment providers acting in good faith and with reasonable care. We would also ensure that other relevant legislation, including the Fire Services Ordinance ("FSO") (Cap. 95), Mental Health Ordinance ("MHO") (Cap.136) and the proposed Continuing Powers of Attorney ("CPA") Bill, would not hinder the administration of advance directives. A registered doctor or dentist or an appointed guardian cannot, based on his/her interpretation of the best interests of the patient, override a validly made advance directive.

Dying in Place

(f) Provisions in the Coroners Ordinance will be amended to exempt the reporting requirements to the Coroner if an RCHE resident who was diagnosed as having a terminal illness, was attended to by a registered medical practitioner within 14 days prior to death, and with a registered medical practitioner having made a final diagnosis and determined the death was due to natural causes.

Moving Forward

We would proceed with drafting the legislation with a view to introducing the draft bill(s) in the next Legislative Council term. The legislative initiatives will be supplemented by stepped up efforts on public education on end-of-life care and life and death issues, training and development of the healthcare, elderly care and emergency rescue workforce, etc.

Ongoing non-legislative initiatives to improve the quality of life of patients up to the last moments and the wellbeing of their families even beyond the patients' departure will be sustained.

CHAPTER 1: THE CONSULTATION

1.1 The *End-of-life Care: Legislative Proposals on Advance Directives and Dying in Place* public consultation was conducted between 6 September 2019 and 16 December 2019. We consulted the public on the proposals to –

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

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

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

Publicity

1.2 The Secretary for Food and Health ("SFH") launched the consultation on 6 September 2019 and published the Consultation Document. The Document was distributed to stakeholders and attendees of public forums and seminars. Copies were available at public hospitals, district offices, district elderly community centres and some private hospitals, together with a leaflet and a questionnaire. The consultation materials were also available via a dedicated webpage - https://www.fhb.gov.hk/en/press_and_publications/consultation/190900_eolcare/index.html. Besides online blogs and advertisements in the print media, we also publicised the consultation through Announcement in the Public Interest broadcast.

1.3 Supplementing media interviews of the SFH, representatives of the Food and Health Bureau ("FHB") and the Hospital Authority ("HA") held a press briefing and appeared on TV and radio programmes to explain the issues under consultation to the public.

Briefings/Seminars/Forums

1.4 In collaboration with the Jockey Club End-of-Life Community Care Project, FHB co-organised six[1] public seminars with the dual purpose of introducing and explaining the proposals to stakeholders and the community and listening to their views. The programmes of the seminars included introduction of the legislative proposals, case sharing by practitioners and families or carers and question-and-answer sessions.

1.5 Representatives of the FHB also attended meetings, briefings, seminars and forums with professional organisations, healthcare staff consultative bodies, patients groups and other non-governmental organisations ("NGOs") to exchange views on the proposals.

Legislative Council

1.6 We attended the meeting of the Panel on Health Services of the Legislative Council on 8 November 2019 to brief Members on the Consultation Document. We also listened to the views of a total of 18 deputations at another meeting of the Panel on 13 December 2019. Minutes of the two meetings are available at https://www.legco.gov.hk/yr19-20/english/panels/hs/general/hs1920.htm.

Written Submissions

1.7 The Government received 607 submissions on the proposals from individuals and organisations by hand, email, post and facsimile, etc. We have also monitored commentaries and views expressed through other channels, including the print and electronic media. Such views are taken into account when analysing the public responses.

[1] Seven seminars were originally planned with two cancelled due to traffic disruptions. An additional session was held in December 2019.

CHAPTER 2: INITIAL PROPOSALS

2.1 The initial proposals concerning advance directives and dying in place were set out in Chapters 4 and 5 of the Consultation Document respectively. The key consultation questions and initial government positions are summarised below –

Advance Directives

(i) Is Hong Kong ready to accept the concept of advance directive and legislate on it?

Yes. There are signs of growing acceptance and adoption of advance directives, and it is opportune to re-consider the legislative route.

(ii) What are the fundamental principles of advance directives?

We proposed four fundamental principles –

(a) respecting a person's right to self-determination;

(b) a valid and applicable advance directive, which has the same effect as a contemporaneous refusal of treatment by a person with mental capacity, overrides treatment decisions based on treatment provider's interpretation of a patient's best interests;

(c) a person should have the primary responsibility of keeping an advance directive and of ensuring that the original copy shall be presented to treatment providers as proof of a valid advance directive; and

(d) sufficient safeguards should be provided to preserve lives.

(iii) Who can make an advance directive?

Any mentally competent person who is aged 18 or above.

(iv) What can be refused in an advance directive?

Life-sustaining treatments (including artificial nutrition and hydration) under pre-specified conditions stated on the advance directive.

(v) What are the pre-specified conditions?

The "pre-specified conditions" in the non-statutory model form should cover –

(a) terminal illness;

(b) persistent vegetative state or a state of irreversible coma; and

(c) other end-stage irreversible life-limiting condition.

A person may choose to adopt other advance directive forms to set out other (additional) pre-specified conditions.

(vi) When can a person make, modify or revoke an advance directive?

Any time as long as the person is mentally capable and is not under undue influence.

(vii) How to make, modify and revoke an advance directive?

An advance directive must be made and modified in writing, witnessed by two individuals with no interests in the estate of the person making or modifying the advance directive, one of whom must be a medical practitioner. The advance directive could be made on a non-statutory model form. Advance directives not made in a model form should still be accepted if the statements are clearly written and not ambiguous.

Revocation could be made verbally or in writing. No witness is required for written revocation. When a single family member or carer reports that the patient has verbally revoked his/her advance directive before becoming mentally incapable, a second witness is also not required.

(viii) How to ensure that an advance directive is valid?

Safeguards provided include –

(a) the original copy of the advance directive should be presented under normal circumstances;

(b) the advance directive should be sufficiently clear and is not being challenged;

(c) the advance directive must not have been withdrawn; and

(d) the person has not done something that clearly goes against the advance directive which suggests that he/she has changed his/her mind.

(ix) When is an advance directive applicable?

Only when the person suffers from the pre-specified conditions in the advance directive form (see Question (v) above) and is no longer mentally capable of making healthcare decisions. It will not be applicable –

(a) if the patient has the capacity to make the decision when the treatment concerned is proposed;

(b) to treatments or conditions not specified in the advance directive; or

(c) if there are reasonable grounds for believing that the current circumstances were not anticipated by the patient and, if they had been anticipated by him/her, would have affected his/her decision.

(x) How to facilitate an advance directive being followed outside the hospital setting?

DNACPR forms would help emergency rescue personnel or treatment providers outside the hospital setting respect the advance decision of the patient not to perform CPR. Similar to the proposed arrangements for advance directives, a non-statutory model form was suggested.

For minors and incompetent adults without an advance directive and suffering from advanced irreversible illnesses, if there is consensus[2] that CPR is not in the best interests of the patient, doctors can sign a DNACPR form for non-hospitalised patients to certify that CPR is not in the best interest of the patient and thus should not be performed.

We proposed to amend the FSO accordingly to enable emergency rescue personnel to accept DNACPR forms (with or without an advance directive).

(xi) How to facilitate treatment providers to be aware of an advance directive?

Leveraging the existing eHRSS to store records of advance directives and DNACPRs on a voluntary basis should be considered.

(xii) How to provide legal protection for treatment providers in implementing advance directives?

A treatment provider will not incur any civil or criminal liability for carrying out or continuing a treatment if, at the time, he/she reasonably believes that a valid and applicable advance directive does not exist. Similarly, a treatment provider does not incur any civil or criminal liability for the consequences of withholding or withdrawing life-sustaining treatment from individuals if, at the time, he/she reasonably believes that a valid and applicable advance directive exists. The same safeguard is applicable to DNACPR forms. Medical professionals may also be exempted from disciplinary proceedings for professional misconduct for a decision made by him/her in good faith and with reasonable care.

(xiii) What is the inter-relationship between an advance directive and provisions in MHO and the proposed CPA Bill?

Under the current MHO, a doctor or a dentist may provide life-sustaining treatment to a mentally incompetent person without consent in urgent or non-urgent situation if the doctor or dentist considers that the treatment is necessary and in the best interests of the person, notwithstanding whether

[2] Currently, HA's healthcare team may discuss and build consensus with family members of an incompetent adult or parents of a minor, via advance care planning, as to whether it is in the best interests of the patient to perform CPR if the patient develops cardiac arrest.

there exists a valid and applicable advance directive. It was proposed that the MHO be amended to provide that a valid and applicable advance directive made by the relevant person shall prevail over the judgment of the doctor or dentist.

For the proposed CPA Bill, the donor confers on the attorney authority to act for the donor on any matters relating to personal care and property or financial affairs of the donor. It was proposed that new provisions be made to state that an advance directive shall take precedence over a CPA, and that the attorney should not be empowered to make an advance directive on behalf of the donor.

Dying in Place

(xiv) How to overcome legal barriers against dying in place in RCHEs?

Currently, deaths in RCHEs are subject to reporting requirements under the Coroners Ordinance[3], which is a serious disincentive for RCHEs to allow elderly residents to die on their premises.

To facilitate dying in place, we proposed to amend the Coroners Ordinance to provide that if an RCHE resident (regardless of whether he/she was diagnosed as having a terminal illness) has been attended to by a registered medical practitioner within 14 days prior to death and a medical practitioner makes a final diagnosis to determine the cause of death being of natural causes, the reporting requirements to the Coroner should be exempted.

[3] According to Schedule 1 to the Coroners Ordinance, 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 (other than in any premises which comprise a hospital, nursing home or maternity home registered under the Hospitals, Nursing Homes and Maternity Homes Registration Ordinance (Cap. 165)) is a reportable death.

CHAPTER 3: ISSUES FOR FURTHER DELIBERATION

3.1 While most respondents expressed support for the legislative proposals outlined in the preceding chapter (and set out in Chapters 4 and 5 of the Consultation Document), a number of submissions addressed certain issues from different angles and we think it is useful to take on board some of these views, which help refine the advance directive and dying in place arrangements. Against the relevant questions we posed in the Consultation Document, the issues are summarised as follows –

Public Education

3.2 Although persons signing advance directives in the HA are mostly limited to patients with advanced illness only, there is no limitation for healthy individuals to sign advance directives in the private sector or with the assistance of NGOs. Under common law, there is no limitation for healthy individuals to sign advance directives. On this we asked:

> *(7) Do you agree that the public is sufficiently aware of the pros and cons of making an advance directive when healthy?*

3.3 There were divergent views on the awareness of the public in this regard. A significant number of submissions pointed out the need for further education to raise awareness in respect of advance directives and end-of-life care in the community, given healthy individuals may also make advance directives. Some recognised the challenge, if not impracticality, for doctors to explain the full effects of irreversible illness to healthy individuals covering a wide range of scenarios. Enhanced promotion of advance care planning ("ACP") to patients with advanced illness was hence advocated.

3.4 On the other hand, given the critical role medical professionals play in the process of making an advance directive, some are concerned with the knowledge of healthcare personnel on this front. It was submitted that dedicated training and education should be rendered to the relevant practitioners, many of whom are currently perceived as inadequately trained and lacking in proper experience.

Witness Requirement for Making an Advance Directive

3.5 In our original proposals, we adopted the current practice of the HA to require two witnesses when a person makes an advance directive, one of whom must be a medical practitioner and both witnesses should not have an interest in the estate of the person concerned. On this we asked:

> *(12) Do you agree to the proposed arrangement to require two witnesses for making and modifying an advance directive, one of whom must be a medical practitioner, and both witnesses should not have an interest in the estate of the person making the advance directive?*

3.6 Almost all respondents supported the proposal. Nevertheless, there were calls to clarify the role of the medical practitioner witness, who is expected to "properly inform" the person making the advance directive the consequences of the decision. Suggestions were made to set out explicitly what that role should entail.

Witness Requirement for Verbal Revocation

3.7 We considered that unnecessary hurdles should not be imposed for persons changing their minds so as to receive life-sustaining treatments and thus proposed that a witness is not required for written revocations. On this we asked:

> *(13) Do you agree that written revocation of advance directive need not be witnessed to avoid imposing unnecessary hurdles?*
>
> *(14) Do you agree that, when a single family member or carer reports that the patient has verbally revoked his/her advance directive before becoming mentally incapable, a second witness is not required before the treatment provider considers the advance directive is no longer valid?*

3.8 Views were split on the proposal that written revocation of advance directive need not be witnessed. A minority of respondents against the

proposal questioned the validity or reliability of the revocation without any witness, the duty of whom is to testify that the person has the mental capacity and is not under undue influence when making the decision. Avoidance of disputes was an oft-cited justification for the above stance.

3.9 On the other hand, views supporting the proposed arrangement contended that any form of revocation demonstrates the patient's desire to live on, which is an inalienable right that everyone is entitled to. Imposition of witness requirements for written revocation was deemed unreasonable as suitable witness(es) may not be available at critical times.

3.10 Some submissions also showed hesitation to readily accept the plausibility of the report of verbal revocation of an advance directive by a single family member or carer before the patient becomes mentally incapable without a second witness. Views against the proposal argued that the essence of making an advance directive in the first place would be lost should the report of a single family member displace the documented wish of the patient. If verbal revocation need not be witnessed by a second person, extra burden of resolving family conflicts will be placed on frontline medical professionals. On this account, some suggested requiring a medical professional as the second witness for single family member or carer report on verbal revocations to be valid.

Safeguards for Validity

3.11 Taking reference from the HA's guidelines, implementation experience since 2010 and relevant overseas practices, four safeguards were proposed to ensure validity of an advance directive. They are –

(a) the original copy of the advance directive should be presented under normal circumstances. In the case that a valid advance directive is said to exist but the original copy is not immediately available, the treatment provider should continue to provide clinically indicated emergency life-sustaining treatment, while waiting for clarifications;

(b) the advance directive should be sufficiently clear and is not being challenged;

(c) the advance directive must not have been withdrawn or revoked; and

(d) the person has not done something that clearly goes against the advance directive which suggests that he/she has changed his/her mind.

On this we asked:

> *(16) Do you think that the proposed safeguards to ensure validity of an advance directive are sufficient?*

3.12 The views received generally regarded the proposed safeguards to ensure validity of an advance directive as sufficient. Some respondents submitted that in addition to the proposed safeguards, the patient should inform family members, carers or healthcare professionals when he/she makes, modifies or revokes an advance directive, as the patient shoulders the first responsibility to safeguard his/her own right to self-determination.

3.13 Respondents holding reservations for the safeguards were mostly concerned with the viability of presenting the original copy of the advance directive. Arguments comprised difficulty for frail patients to present the advance directive and misplacement of the document. Centrally registered electronic copy and advance directive in card format (similar to that for organ donation) were hence suggested with a view to enhancing the current safeguards. The record at the central registry was regarded as the remedy against potential challenges by family or medical practitioners.

Statutory Prescribed Form for DNACPR

3.14 To facilitate emergency rescue personnel to respect advance directives, the DNACPR form was introduced. We originally proposed to use a non-statutory model DNACPR form, similar to the arrangement for advance directives. On this we asked:

> *(20) Do you agree to the use of a model DNACPR form, rather than a statutory prescribed form?*

3.15 A majority of submissions supported the use of a model DNACPR form, rather than a statutory prescribed form. However, some stakeholders advocated that a statutory prescribed form with standardised clauses and a

clearly verifiable format would minimise disputes and critically facilitate the work of emergency rescue personnel which is a race against time.

Use of eHRSS

3.16 We proposed to consider the feasibility of leveraging eHRSS to voluntarily store advance directive records. On this we asked:

> *(24) Do you agree that the original advance directive document should still be required as proof of a valid advance directive, even when an advance directive record could be found in eHRSS?*

3.17 Requiring the original advance directive document as proof of a valid advance directive was supported by a majority of submissions. Those in favour of the proposal reiterated the limited time frame for emergency rescue personnel to access the electronic record, as against reading from the original paper copy. The presentation of the original copy was regarded as necessary given any potential difference between HA's Clinical Management System ("CMS") record, eHRSS record, and the original copy of the advance directive. To facilitate the process, some suggested stepping up efforts in education for patients and family members to carry the original copy of an advance directive at all critical times together with other documents essential for hospital admissions or medical treatment – an advice already common to all terminal patients outside the hospital setting.

3.18 Respondents against the proposal advocated the establishment of a central registry, storing electronic records of all advance directives and granting access to relevant healthcare and rescue personnel in real time. It would serve as the valid proof of advance directives and obviates the safekeeping of the paper documents.

Safeguards for RCHE Residents

3.19 To remove one of the barriers to dying in place, we proposed to amend the Coroners Ordinance to provide that if an RCHE resident (regardless of whether he/she was diagnosed as having a terminal illness) who died of natural causes and who was attended to by a registered medical practitioner

within 14 days prior to death and a medical practitioner had made a final diagnosis and determined the cause of death, the reporting requirements to the Coroner should be exempted. On this we asked:

> *(30) Do you think that the proposed safeguard for RCHE residents is sufficient if deaths in RCHEs may be exempted from reportable deaths?*

3.20 Views generally considered the proposed safeguard for RCHE residents sufficient. However, the variation of service quality in RCHEs was highlighted by respondents who have reservations about the level of protection provided by the proposed safeguard. They alternatively suggested that the death reporting requirements could be exempted only for an RCHE resident who was previously diagnosed as having a terminal illness and who was attended to by a registered medical practitioner within 14 days prior to a natural death.

3.21 Separately, some respondents thought that there was a similar case to exempt the reporting requirements in respect of deaths at institutions similar to RCHEs, e.g. residential care homes for persons with disabilities ("RCHDs") to facilitate dying in place in these institutions, subject to the same safeguards.

3.22 Some respondents suggested providing training to staff in RCHEs on end-of-life care, notably on timely recognition of health deterioration that would require attention from medical practitioners, to better support the arrangements for dying in place.

CHAPTER 4: REFINED PROPOSALS

4.1 We welcome the general support of the initial proposals by respondents in this public consultation. Having due consideration of the alternative views on certain detailed proposals as set out in the preceding chapter of this report, we have refined our proposals. For ease of reference, key refinements against the original proposals are set out in blue.

Advance Directives

Eligibility and Format

4.2 We should take steps to introduce draft legislation to enable any mentally competent person who is aged 18 or above to make an advance directive to refuse life-sustaining treatments (including artificial nutrition and hydration) under pre-specified conditions.

4.3 We recommend the use of a model form, to be drawn up in consultation with stakeholders and publicised through official channels. The pre-specified conditions to be covered in the non-statutory model form includes –

(a) terminally ill,

(b) in persistent vegetative state or a state of irreversible coma,

(c) in other end-stage irreversible life-limiting condition.

4.4 While we actively and strongly encourage the public to use the model form which could serve to enhance clarity and accuracy, ensure procedural probity, and as a result lessen the chance of disputes and challenges, we do not preclude the use of advance directives drawn in other formats. A patient may still choose to adopt other advance directive forms with other and/or additional pre-specified conditions. This should help retain advance directives made outside Hong Kong or before enactment of the legislation.

Modes of Making, Modification and Revocation

4.5 As long as the person is mentally competent and not under undue influence, there are no restrictions as to when a person could make, modify or revoke an advance directive. Making and modifying an advance directive must be in writing. Revocation could be made verbally or in written form.

4.6 We do not propose to preclude healthy persons from signing advance directives entirely. However, as alluded to in Chapter 4 of the Consultation Document, the validity of such advance directives could often be open to challenges due to circumstances which could not have been anticipated when signing the advance directive. We therefore caution that it is not easy for healthy persons to make decisions and sign a valid advance directive to conditions other than being in permanent severe neurological damage.

Witness Requirement

4.7 When making or modifying an advance directive, two witnesses with no interests in the estate of the person making the advance directive are required, one of whom must be a medical practitioner. The medical practitioner should be satisfied that the person has capability to make an advance directive and has been informed of the nature and effect of the directive and the consequences of refusing the treatments specified in the advance directive. Guidelines or protocols should be developed to assist medical professionals to understand their role.

4.8 In respect of revocation of an advance directive, no witness is required for a written revocation. For instance, a person crossing out an advance directive and signing onto it could be taken as revoking the advance directive. In respect of verbal revocation, at least one witness who has no interests in the estate of the person making the advance directive is required. A second witness is required for the report of verbal revocation made by a single family member or carer. Revocation could also be executed by tearing or otherwise destroying the advance directive by the person who made it, or by some person in his/her presence and by his/her direction.

4.9 The preceding revocation arrangements seek to uphold the fundamental principle that a person should be free to make an advance directive and revoke it at any time, without any unnecessary hurdles. We accept that verbal revocations (in particular) and the lessened requirements for witnesses as compared to making of an advance directive may at times increase the incidence of disputes and challenges.

4.10 The above said, the alternative may be to impose the same requirements for both making and revoking advance directives. In that case, we may be seen as imposing unnecessary hurdles to honour the patient's wish, as illustrated in the following scenario –

Case scenario (A)

A patient with end-stage chronic obstructive pulmonary disease has made an advance directive to refuse life-sustaining treatment after understanding the prognosis and discussing ACP with his doctor.

Over the course of receiving treatment, the patient changed his mind and determined that he would like to survive at least until the end of the year (for reasons that he was not prepared to divulge so as to avoid discussion with a family member) with the use of life-sustaining treatment as required. He did not share his decision with his family members or his doctor, and then crossed out the original advance directive on his own with his signature.

The patient's health deteriorated sharply after the revocation and the original advance directive known to the doctor and family members became applicable. The family members and doctor obtained the original copy of the advance directive concerned, just to find that the patient has crossed out the advance directive with his signature.

Should we persist with the witness requirement, the written revocation made by the patient would be considered invalid given the absence of witnesses during revocation. The advance directive would hence be administered, with life-sustaining treatment not given or removed, which was against the patient's wish.

4.11 By the same token, we would be obligated to accept the scenario that a frail terminal patient who could no longer write would not be allowed to revoke an advance directive. Or a written revocation would not be accepted when two suitable witnesses could not be found at a critical time when the person decides to change his/her mind before he/she loses capability. We do not find this alternative acceptable.

4.12 While due process, certainty, lower likelihood of disputes and challenges, ease of administration, etc., are all preferable considerations in the operation of advance directives, we believe that the refined proposals in paragraph 4.8 above serve to respect the sacrosanct principle of a patient-centred arrangement to uphold self-determination. Overly stringent revocation requirements could potentially undermine the effort to promote the use of advance directives to enhance patient self-determination in the first place. After all, even acknowledging the risks of disputes and challenges, it is utterly inconceivable having to tell a patient with a valid and applicable advance directive that he/she is now refused life-sustaining treatment, not until his/her sudden change of mind is recorded in writing and signed personally with the presence of two suitable witnesses.

Acceptable Proof

4.13 A person with an advance directive would have the primary responsibility of keeping the advance directive and of ensuring that the original copy shall be presented to treatment providers as proof of a valid advance directive. The advance directive should be sufficiently clear, is not being challenged, and has not been revoked or withdrawn. The person should also not have done something that clearly goes against the advance directive which suggests that he/she has changed his/her mind.

4.14 We reaffirm the proposed arrangement that the original copy of the advance directive should be the best proof of an advance directive. While electronic record such as eHRSS and CMS could serve to alert treatment providers to the possible existence of an advance directive, there is always the risk that the status of an advance directive has changed since the electronic record was last updated, as illustrated in the following case –

Case scenario (B)

A patient with terminal lung cancer, who has participated in eHRSS, signed an advance directive at the HA to refuse life-sustaining treatment when he is terminally ill. His doctor has logged the advance directive record onto CMS and eHRSS as instructed.

Later on, the patient changed his mind regarding his prior refusal to life-sustaining treatment, as he hoped to see his expected first grandson in a few weeks' time. He crossed out his advance directive with a signature. Soon after his revocation and before he could show the revocation and (ask

his doctor to) update the eHRSS record, he was admitted to the hospital for rapid deterioration in condition and became terminally ill.

The patient's advance directive, as stated in the eHRSS record, would then be applicable. However, the patient has revoked the advance directive in writing without notifying his doctor of the change. The record on eHRSS is unable to reflect the most updated status of an advance directive in situations like these, and could result in irreversible consequences.

4.15 In some cases (as the one illustrated above), there may be an unavoidable time gap between a change of mind regarding an advance directive on the part of the person who made it and the updating of an electronic record. In any updating of electronic record, checking and verification procedures are indispensable. While use of an electronic version of the advance directive is technically feasible in this digital age, we have to accept that currently there is no reasonably fool-proof solution to overcome this time gap problem. As such, any failure or delay to instantaneously effect changes to an electronic version of the advance directive could result in clearly unacceptable and irreversible consequences. This is particularly the case if we are to accept verbal revocation arrangements as alluded to in paragraph 4.8 above.

4.16 There is always the likelihood of misplacing the original copy of an advance directive or the failure to produce it in a timely manner, despite clear guidance and strong advice to patients and families to safe-keep the advance directive together with documents essential for hospital admissions. Benefitting from the HA's experience in the past decade, whilst upholding the principle of respecting the patient's right to self-determination, the flagging alert in CMS (that is in line with the advance directive record voluntarily stored on eHRSS, if any) coupled with unanimous family verbal agreement could be taken as acceptable proof for an advance directive, subject to prudential scrutiny and approval. We could also give consideration to accept certified true copies of advance directives so that a patient's trusted family member or carer could help ensure the timely production of the advance directive.

Applicability

4.17 Even when an advance directive is validly made, it will be applicable only when the person suffers from the pre-specified conditions in the advance

directive form, and is no longer mentally capable of making healthcare decisions. It will not be applicable if there are reasonable grounds for believing that the current circumstances were not anticipated by the patient and, if they had been anticipated by him/her, would have affected his/her decision.

DNACPR

4.18 DNACPR form is a written direction by the doctors not to perform CPR on a person, made in advance when cardiac arrest is anticipated. Given a person may make an advance decision to refuse CPR when he/she falls into the pre-specified conditions in an advance directive, the DNACPR form attached serves to facilitate an advance directive being followed outside the hospital setting. For minors and incompetent adults without an advance directive and suffering from advanced irreversible illnesses, if there is consensus that CPR is not in the best interests of the patient, doctors can sign a DNACPR form for non-hospitalised patients to certify that CPR is not in the best interests of the patient and thus should not be performed. The original copy should be presented to emergency rescue personnel and/or treatment providers as proof of a valid DNACPR form.

4.19 We propose to use a statutory prescribed DNACPR form, instead of a non-statutory model form. Unlike an advance directive which can specify conditions and treatments which could vary among different individuals, DNACPR forms are relatively more straightforward and standardised. We believe that a statutorily prescribed format would serve to lessen uncertainty and critically facilitate timely acceptance by emergency rescue personnel who are not afforded the luxury to scrutinise details of “tailor-made” documents without compromising urgent rescue effort.

Legal Protection for Treatment Providers

4.20 A treatment provider will not incur any civil or criminal liability for carrying out or continuing a treatment if, at the time, he/she reasonably believes that a valid and applicable advance directive does not exist. Similarly, a treatment provider does not incur any civil or criminal liability for the consequences of withholding or withdrawing life-sustaining treatment from individuals if, at the time, he/she reasonably believes that a valid and applicable advance directive exists. The same protection is applicable to the implementation of DNACPR forms.

4.21 Medical professionals will also be exempted from disciplinary proceedings for professional misconduct for a decision made by him/her in good faith and with reasonable care. The above protection should encourage them to initiate discussion of ACP and advance directives with patients, family members and carers.

Related Legal Provisions

4.22 Specific provisions in the MHO will be made to state that a valid and applicable advance directive made by the relevant person shall prevail. A registered doctor or dentist or an appointed guardian cannot, based on his/her interpretation of the best interests of the patient, override a validly made advance directive.

4.23 The FSO provisions in respect of the duty to resuscitate will be changed, enabling DNACPR forms to be accepted and enforced. We do not propose ambulance or fire personnel to accept advance directives per se, as it may not be within their expertise to determine the applicability of an advance directive (which requires confirmation that a pre-specified medical condition has arisen).

4.24 We will also ensure that other relevant legislation, including the proposed CPA Bill, if and when enacted, will have regard to the operation of advance directives and DNACPR forms and not undermine the principle of patient self-determination.

Dying in Place

4.25 Provisions in the Coroners Ordinance will be amended to state that if an RCHE resident who was diagnosed as having a terminal illness, was attended to by a registered medical practitioner within 14 days prior to death, with a registered medical practitioner having made a final diagnosis and determined the cause of death being of natural causes, the reporting requirements to the Coroner should be exempted.

4.26 Bearing in mind the substantial number of hospital death cases having lived in elderly homes[4], we reaffirm the weightiness of the exemption for encouraging dying in place in RCHEs. We expect fewer last-minute ambulance calls to take the patient to the accident and emergency department of hospitals, which cause considerable discomfort to the patient at the last moments of life. Currently, even if an RCHE is accommodating to the resident's wish to die in place, the death reporting requirement may put a damper on similar arrangements for future residents, as illustrated in the following case –

Case scenario (C)

An RCHE resident was diagnosed with lung cancer three years ago. He frequented the hospital for treatment over the years. Last year, he slipped in the bathroom and had a hip fracture. From then on, he was wheelchair bound and would require two RCHE staff to accompany him for every hospital visit. He showed fatigue from the visits and expressed his preference for RCHE over hospital as the place of care, treatment and death to his family and carers. Thereafter, he mainly relied on the Community Geriatric Assessment Team of the HA for medical care and support.

The patient later passed away naturally in his RCHE, just as he had wished. However, given any death in RCHE is reportable to the Coroner, staff at his RCHE had to report his death via the Police. The subsequent police investigation and administrative procedures took days to complete, which strained the family and the manpower at the RCHE, on top of pathologist, police and court resources.

It is only natural for the RCHE management to be more circumspect about further arrangements for residents to receive the full range of end-of-life care at their premises and to die in place.

4.27 Compared with home deaths, the preceding refined proposal introduces an additional safeguard that only natural deaths of patients previously diagnosed as having terminal illness would be exempted from the reporting requirement. While we believe that there may be a case in future

[4] According to the report produced by the JC School of Public Health and Primary Care in August 2017, more than 96% of elderly patients (aged 65 or above) died in hospitals and about 40% of hospital death cases lived in elderly homes (including RCHEs and nursing homes).

to align RCHE death and home death reporting requirements, we submit that it is prudent to have the additional safeguard in respect of RCHE at this stage.

4.28 Separately, some institutions similar to RCHEs, such as RCHDs, may be in a position to provide quality end-of-life care services to their residents. In the legislative exercise covering the Coroners Ordinance, we will examine the feasibility and justifications to include some of these institutions to facilitate dying in place thereat.

CHAPTER 5: MOVING FORWARD

Conclusion

5.1 The public consultation shows that Hong Kong is in need of legislative changes to improve end-of-life care in respect of advance directives and dying in place. We are under no illusion that legislative changes *per se* are the panacea to solving our ageing population problem but recognise that concurrent efforts are required to improve end-of-life care service planning, delivery and quality. Unlike the previous public consultations in 2004 and 2009[5], we now have a clear consensus to embark on the legislative route on advance directives and on dying in place, having benefitted from non-legislative experience gained in the past decade or so.

5.2 We are now prepared to proceed with the refined proposals as outlined in Chapter 4 to prepare possible new legislation and legislative amendments to implement advance directives and dying in place. Along the way, we would further refine the proposals to ease the compliance and administration burden, lessen the likelihood of disputes, challenges and complaints but not forgetting that the original (and ultimate) objective is to respect a person's wishes regarding his/her end-of-life care.

Next Steps

5.3 The Government will now proceed to make arrangements to implement the refined proposals as outlined in Chapter 4.

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[5] In 2004, the Law Reform Commission of Hong Kong ("LRC") issued a public consultation paper on *Substitute Decision-Making and Advance Directives in Relation to Medical Treatment*. In its 2006 report, LRC recommended that the Government should promote the concept of advance directives under the existing common law framework instead of by legislation, and should consider the appropriateness of legislation once the community has become more widely familiar with the concept.

In response to LRC's report, FHB 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 agreed to adopt a non-legislative approach to promote advance directives in Hong Kong first, and then consider whether legislation is appropriate when there is greater awareness in society.

Legislative Work

5.4 We are taking steps to iron out details of the legislation in collaboration with various government bureaux and departments and stakeholders. As drafting of legislation of comparable complexity takes about a year after finalisation of the drafting instructions, we will strive to finalise a draft bill for introduction in the next Legislative Council term.

Public Education

5.5 Gaining experience from this consultation, we reckon that the receptive level of the general public to end-of-life care publicity and public education varies. General messages may be of limited value for sectors of the public that are not ready for discussion of end-of-life issues. Rather, we consider that the objective of improving end-of-life care will be best accomplished if the promotion effort is directed at a target audience. Elderly and patients with chronic diseases and onset of terminal illness, their family members and carers are the targets of promotion in respect of advance directives and the concept of ACP.

5.6 We will consider means to reach out to this audience, with possible assistance from NGO partners. For instance, we will seek to dedicate additional resources to academic institutions or NGOs to facilitate promotion in the community.

Training and Development

5.7 Besides better hardware, a well-trained and resourced healthcare, elderly care and emergency rescue workforce is essential to improving end-of-life care. We will take steps to ensure that the relevant workforce is suitably educated and supplemented with operational and professional guidance and protocols. Initial approaches has been made to contemplate enhanced undergraduate and postgraduate training to familiarise the professionals and others with modern end-of-life care standards and practices. For instance, we advocate that the communication skills to initiate ACP discussions with patients and families should form part of the essential training for doctors and nurses of most specialties, not restricted to oncology or palliative medicine specialists. These efforts will be continued.

Other Efforts

5.8 Individual respondents have proposed that we should enact an all-encompassing legislation for mental incapacity, which could subsume issues such as advance directives, healthcare decision-making by attorneys, guardians, etc., and possibly other relevant issues. This is indeed a mammoth and worthy task. However, we do not propose to go down this route at this juncture as we have yet to engage and consult the public on the complex, sensitive and potentially controversial subject of mental incapacity, which strays into many areas beyond end-of-life care and has wider implications yet to be surveyed, whereas we have already in place a draft bill on CPA since 2018, and completed a consultation with concrete proposals on advance directives in 2019/20. It would drag down the legislative timetable for the more mature items if we were to attempt a comprehensive legislation (more or less) from scratch. We nevertheless take note that mental incapacity and other related issues would need to be tackled separately in another major legislative exercise in future.

5.9 As foreshadowed in Annex A of the Consultation Document, besides legislative changes, the Government has already embarked on a wide range of initiatives, from promotion of ACP, improvements in hospital and RCHE hardware and services, public education on ageing, end-of-life and death to after-death arrangements, etc. These will continue to enable Hong Kong to serve our growing ageing population with a view to improving the quality of life of patients up to the last moments and the wellbeing of their families even beyond the patients' departure.

Food and Health Bureau
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