GOLDEN AGE FOUNDATION
黃金時代基金會

Golden Age Foundation
Response to Public Consultation on End-of-Life Care: Legislative Proposals on Advance Directives and Dying in Place

December 10, 2019

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Professor Sophia Chan,
Secretary for Food and Health,
Food and Health Bureau,
Hong Kong SAR Government.

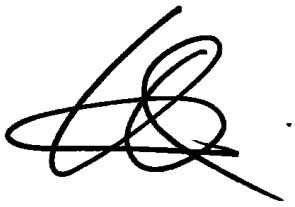
December 10, 2019
By email : eolcare@fhb.gov.hk &
sophia_chan@fhb.gov.hk

Dear Professor Chan,

On behalf of the Golden Age Foundation (GAF), we are pleased to submit the attached "Response to Public Consultation on End-of-Life Care Legislative Proposals" for your consideration.

Should you require any information regarding our response, please do not hesitate to contact the Secretariat at +852 8102-1068 or by email to: info@goldenage.foundation

Yours sincerely



Rebecca Choy Yung
Founder & Chair
Golden Age Foundation

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I. Background

Golden Age Foundation (GAF) is a registered non-profit organization (charity no 91/14446) formed in 2015 that aims at fostering the development of Smart Ageing Cities and empowering the Golden Agers (people who are 45+) to be a new force of social change. In an effort to drive universal participation on this issue, the first-ever Golden Age Expo and Summit was held in 2016 which successfully connected different sectors, generations and people from all walks of life to collaborate and innovate for Smart Ageing Cities. Since then, a number of new initiatives, including capacity-building and cross-generational programmes, community outreach, media programmes, have also been launched by GAF. As of mid-2019, we have over 700 individual members and more than 300 corporate members across different sectors.

We strive to improve and develop Hong Kong into a Smart Ageing City which covers 5 prioritized areas for strategic development:

- Golden Age economy
- Wellness and health
- Productivity and engagement
- Technological application
- Social cohesion and inclusion

Above all, GAF has been promoting life-and-death-education over the years. We emphasize empathetic and human-centred approach to elderly and end-of-life care. GAF welcomes FHB's public engagement exercise to uphold patient self-determination.

GAF has arranged an interactive consultation session on November 28, 2019 to exchange ideas and collect comments from our members across different sectors and professions to discuss their views on the aforesaid issue. This response paper serves to provide a summary of the collective opinions and views of our members.

II. Advance Directives (AD) – A person indicates, usually in writing that when mentally competent, what medical treatment he or she would refuse at a future time when he or she is no longer mentally competent.

Generally, the acceptance of AD among the elderly population is increasing. Many people preferred to have an advance directive regarding medical treatment under certain circumstances.

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Apart from the issues outlined in the questionnaire, our members are particularly concerned about the adequacy of the system in providing sufficient channels for:

a. Elderly people to get more information on this subject. Most of them have limited knowledge and awareness of the pros and cons of making an AD. Open discussion on this subject is also limited. Therefore, it is more realistic to promote AD and 'Dying in Place' on a wider and continuous basis while striving to establish a clear and consistent legal framework.

b. Elderly living alone have difficulties in finding witnesses for AD. It is suggested to have "mutual witnesses" between elderly within their peer groups.

c. There were cases when the elders had already been suffering from chronic diseases and started to become unconscious. But they were still able to indicate clearly that they would refuse invasive medical procedures even though they had not signed any AD. It is suggested to have clear legal provisions on verbal AD request.

d. Sons/daughters to learn more and find ways to discuss with their elderly parents. Clear understanding between family members is extremely important because this issue does not only affect the patient himself. It may involve several generations within the family who may hold different views toward 'life and death'. Such disparity may lead to very different interpretation towards the execution of AD. Furthermore, family members and care-givers normally lack medical knowledge and could be easily confused by the seriousness of diseases/situations that may trigger the AD. Unanimous agreement within the family is deemed necessary.

e. Young people to learn more at a younger age to change their mindsets on issues related to death. The young and middle-aged population in their 20s to 40s will become the elderly population 40 years later. We should incorporate respect to our parents, senior citizens, family support and social responsibility to take care of our seniors as part of the education programmes. It is suggested that now is a proper time for the Government to promote "life-and-death education" at schools.

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f. Medical staff, e.g. medical practitioners, first responders and emergency rescue personnel etc, should be well-trained with the latest legislation. First responders and emergency rescue personnel should be allowed to accept signed DNACPR forms as AD. In reality, medical staff may have difficulties in making decisions to ignore AD based on the best interest principle and requests from family members which may affect a patient's self-determination right. Medical staff should guide family members to understand the patient's situation e.g. the chance of recovering after critical medical treatment; defining chronic disease that may lead to AD arrangement or whether AD is suitable.

g. A central electronic registry for storing all ADs, as part of the Electronic Health Record Sharing System (eHRSS), is deemed necessary when the original AD would not be available.

III. 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 and not necessarily in the hospital.

Generally, with family's support and a suitable environment, 'Dying in Place' is better than dying in hospital surrounded by life-sustaining equipment and with minimal privacy. Both family members and the patient will have more intimate space and feel calm at the place of choice of the patient.

Apart from the issues outlined in the questionnaire, our members are particularly concerned about the adequacy of the system on the followings:

a. Clear legal provisions should be provided on the followings: How to define the suitability of 'Dying in Place'? What sort of support/resources will the Government provide to family members and care-givers?

b. Elderly living alone: How can care-givers help elders without families or staying at nursing homes to implement 'Dying in Place'? The Government should clearly define the role of care-givers who help the patients to implement 'Dying in Place', e.g. financial arrangement. How can care-givers be legally protected while taking care of the patient outside the hospital?

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c. It is suggested that the government should allocate more resources to implement hospice and palliative care services to support 'Dying in Place'. As the Government has plans to spend billions of dollars in building hospitals, it is suggested to build a palliative care hospital.

d. In general, members agree that dying in place will not affect a property's price as long as the elders die 'naturally'. However, it is suggested to promote the right concept to the business sector, especially the real estate and funeral industries as their views will affect the attitude of the elders and their family members.

e. In practice there is still a lot of work to be done in the community to allow the concept of "Dying in Place" to be rolled out on a large scale. We opine that the Government should explore more opportunities to co-organize training courses or public talks with various professional institutions or associations with a view to reaching out to, not only NGOs, but also a wider community including SMEs.

f. GAF believes that public education is key to mindset and behavioural changes, which is at the centre of any drive to adopt innovative solutions to ageing. The public needs to know and discuss more about life-and-death issues with their families and friends before they will choose to make changes and to support such legislation. It is also important that in encouraging mindset and behavioural change in this regard, there are choices for members of the public to uphold patient self-determination and the quality of life as well as a harmonious relationship with their family members. The Government should work with academic or educational institutions to change the mindset of students on life-and-death at a younger age.

IV. Conclusion

The proposed legislation forms a core part of our preparation for a smart ageing society. Yet there are various unmet needs and multiple issues, both horizontally and vertically, related to our current education system, healthcare system, on top of the current elderly care support system. GAF welcomes the legislative proposal, and hope that this is not the end but just the beginning of the HKSAR government's lead in nurturing and developing a more "human-centred" approach to build a vibrant and healthy ageing community but ever smart at heart. We commit to continue to work closely together with the HKSAR government.

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QUESTIONNAIRE

		Agree	Disagree	Remarks
Advance Directives				
1.	Do you think that the public at large is ready to accept the concept of advance directives?	☑	☐	
2.	Do you think that there should be clear legal provisions for advance directives, or Hong Kong should continue to rely on the common law framework?	☑	☐	
3.	Do you agree with the fundamental principles set out in paragraph 4.8?	☑	☐	
4.	Do you agree that an advance directive must be made by a mentally competent person who is aged 18 or above to be legally valid?	☑	☐	
5.	Do you agree that artificial nutrition and hydration should be covered under an advance directive and can be withheld or withdrawn according to the patient's wish?	☑	☐	
6.	Do you agree that the primary objective of an advance directive should be for advance refusal of life-sustaining treatments to minimise distress or indignity when the patient faces a serious irreversible illness?	☑	☐	

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7.	Legally, there is no limitation for healthy individuals signing an advance directive. Do you agree that the public is sufficiently aware of the pros and cons of making an advance directive when healthy?	☐	☑	
8.	Do you agree that a person may revoke or modify an advance directive at any time?	☑	☐	
9.	Do you agree that an advance directive must be made or modified in writing?	☑	☐	
10.	Do you agree that both verbal and written revocation of an advance directive should be accepted?	☑	☐	
11.	Do you agree that a legally-valid advance directive must be witnessed as safeguard?	☑	☐	
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?	☑	☐	
13.	Do you agree that written revocation of advance directive need not be witnessed to avoid imposing unnecessary hurdles?	☐	☑	

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14.	Do you agree that, when a single family member/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?	☐	☑	
15.	Do you agree to the use of a model form for making advance directives, rather than a statutory prescribed form, to be legally valid?	☑	☐	
16.	Do you think that the proposed safeguards to ensure validity of an advance directive are sufficient?	☑	☐	
17.	Do you think that the "prespecified conditions" in the proposed non-statutory advance directive 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, or any conditions as pre-specified by the person?	☑	☐	
18.	Do you think that the proposed safeguards to ensure the applicability of advance directives are sufficient?	☑	☐	
19.	Do you agree to allow emergency rescue personnel to accept advance directives with signed DNACPR forms attached and not attempt CPR?	☑	☐	

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20.	Do you agree to the use of a model DNACPR form, rather than a statutory prescribed form?	☑	☐	
21.	Do you agree to allow emergency rescue personnel to accept DNACPR form without an advance directive and not attempt CPR for the reason that there is consensus between the healthcare team and family members that this is in the best interests of the patient who is unable to make an advance directive?	☑	☐	
22.	Do you agree that the advance directive document may be recorded in eHRSS?	☑	☐	
23.	Given the possibility of a time lag between the latest status of advance directives and records in eHRSS, eHRSS may not contain the most up-to-date and accurate records. Do you agree to the proposal that storage of advance directive records in eHRSS should be voluntary?	☑	☐	
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?	☑	☐	
25.	Do you agree that it is the responsibility of the individual/family to draw the attention of emergency rescue personnel to the existence of an advance directive?	☑	☐	

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26.	Do you agree with the proposed arrangements on liability?	☑	☐	
27.	Do you think that medical professionals should also be exempted from disciplinary proceedings for professional misconduct for a decision made by him/her in good faith and with reasonable care?	☑	☐	
28.	Do you agree with the proposed consequential change to the Mental Health Ordinance to remove the potential conflict?	☑	☐	
Dying in place				
29.	Do you agree that, as a prerequisite to promote dying in place, the relevant provisions of the Coroners Ordinance should be amended to exempt certain deaths in RCHEs from reportable deaths?	☑	☐	
30.	Do you think that the proposed safeguard for RCHE residents is sufficient if deaths in RCHEs may be exempted from reportable deaths?	☐	☑	

Other views:
Please read other views from P.3 to P.6 of this Response Paper

THANK YOU FOR YOUR FEEDBACK.

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Please provide your written submission on the consultation issues or complete the Questionnaire and return to us on or before 16 December 2019 through the contact below:

Address:	Food and Health Bureau (Attn: Assistant Secretary for Food and Health (Health) 6B) 19/F, East Wing, Central Government Offices 2 Tim Mei Avenue, Tamar Hong Kong (Re: End-of-life Care: Legislative Proposals on Advance Directives and Dying in Place)
Fax:	2840 0467
Email:	eolcare@fhb.gov.hk

PERSONAL DATA COLLECTION STATEMENT

1. It is voluntary for any member of the public to supply his/her personal data upon providing views on the consultation document. Any personal data provided with a submission will only be used for this consultation exercise. The submissions and personal data collected may be transferred to the relevant Government bureaux, departments or agencies for purposes directly related to this consultation exercise. The relevant parties receiving the data are bound by such purposes in their subsequent use of such data.

2. The names and views of individuals and organisations which put forth submissions in response to the consultation document (senders) may be published for public viewing after conclusion of the consultation exercise. FHB may, either in discussion with others or in any subsequent report, whether privately or publicly, attribute comments submitted in response to the consultation document. We will respect the wish of senders to remain anonymous and / or keep the views confidential in relation to all or part of a submission; but if no such wish is indicated, it will be assumed that the sender can be named and his/her views be published for public information.

3. Any sender providing personal data to FHB in the submission will have the right of access and correction with respect to such personal data. Any request for data access or correction of personal data should be made in writing to the contact specified above.

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