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Adding Life to Years: Comprehensive End-of-Life Care for All

April 2024

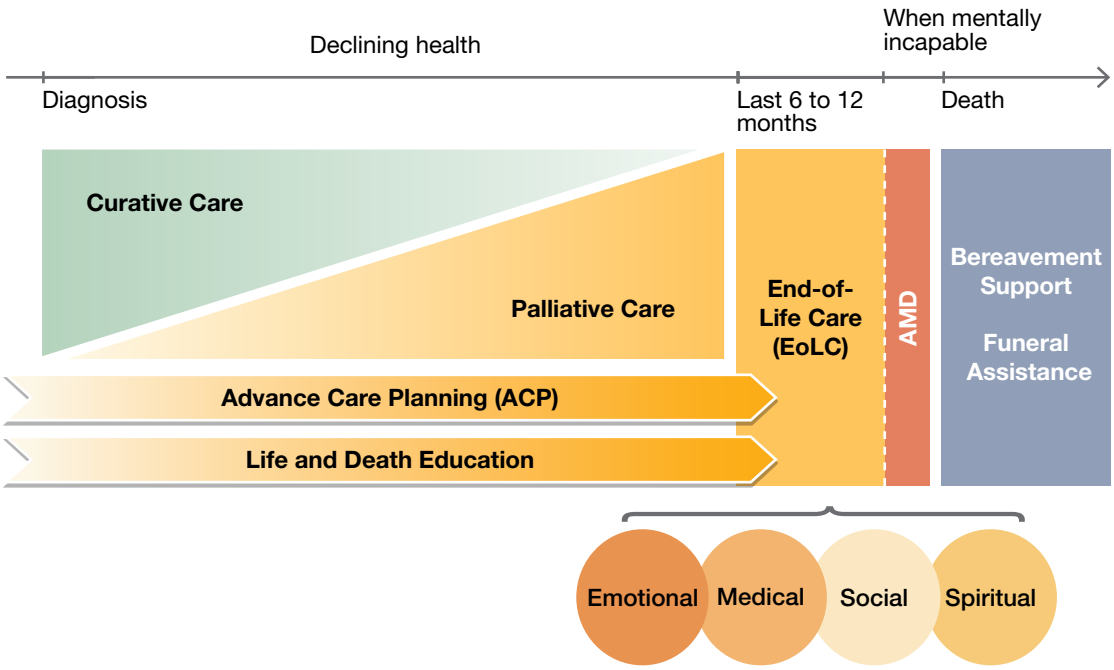
Introduction

Under Hong Kong's Advance Decision on Life-sustaining Treatment Bill, individuals aged 18 or above are allowed to make an Advance Medical Directive (AMD), legally supporting their choices of the medical treatments they wish to decline when no longer capable of decision-making. The associated law amendments also aim to remove existing legal barriers for healthcare professionals in following AMD.[1] While commendable, this bill alone may not be able to address the full spectrum of care needs beyond medical care. Additionally, individuals should be empowered to make informed decisions about AMD through facilitated discussions regarding individuals' needs and the available options.

Hong Kong Demands Comprehensive End-of-Life Care

End-of-life care (EoLC) plays a pivotal role in respecting an individual's desire for a peaceful death. It encompasses a comprehensive approach to address medical, social, emotional, and spiritual needs in the final 6 to 12 months of people's life.[2]

Figure 1. Spectrum of care



EoLC not only benefits individuals, including patients, carers, and families, but also has a positive impact on the healthcare system. Data reveals a notable surge in medical service utilisation during the last 6 months of people's life,[3] exerting a considerable strain on hospitals and healthcare resources. As hospital services are costly and highly specialised, diverting the demand for EoLC from hospitals to community can optimise resource allocation, while catering to the preference of 90% citizens to remain in community at the final stage of their lives.[4-5]

Building upon the insights from our 2019 EoLC study titled *Fostering Medical-Social Collaboration in Achieving Quality End-of-Life Care*, which offers a comprehensive analysis of EoLC landscape in Hong Kong. Leveraging on the insights of diverse stakeholders across different sectors and disciplines, this report provides recommendations at the system, service, and education levels.

System Level: ACP Framework

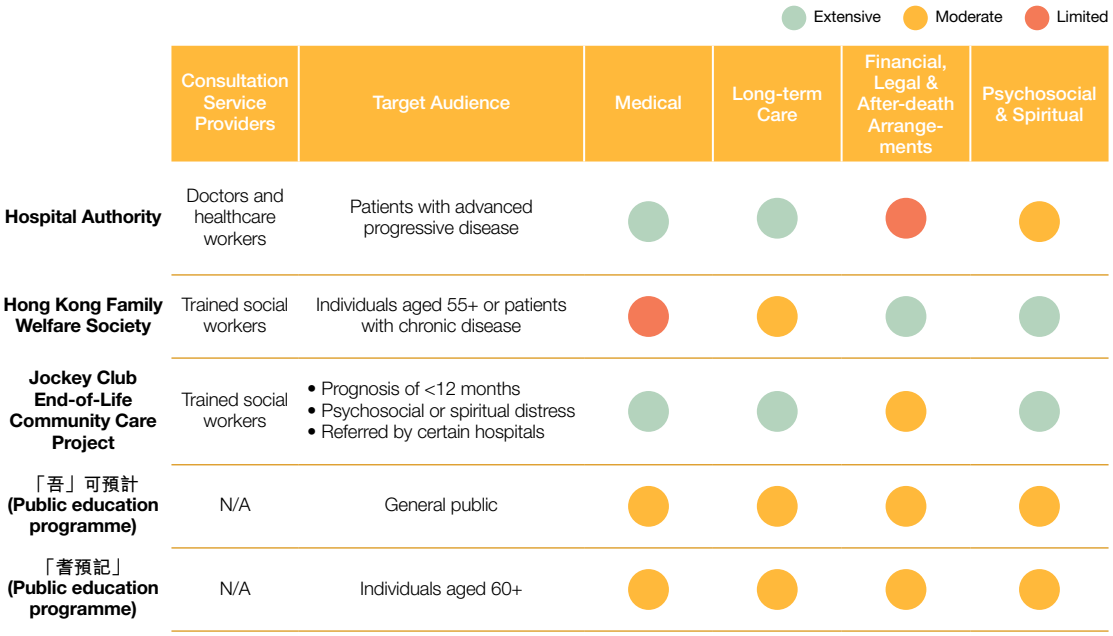
Recommendation 1: Develop a Territory-wide Standardised ACP Framework

To address the issue where AMD cannot address the full spectrum of care, a territory-wide standardised ACP framework offers a solution. While AMD is a legally binding document that focuses on medical treatments during incapacity, ACP serves as a vital communication process through which individuals can express their values, beliefs, and preferences, facilitating the creation of personalised plans for medical, personal, and social care.[6]

In Taiwan, ACP consultation is mandatory before establishing an AMD under the "Patient Right to Autonomy Act".[7] Besides, Singapore's national ACP programme, "Living Matters", effectively normalised conversations about EoLC in an Asian context, reducing cultural taboos and enhancing accessibility for ACP services in over 60 healthcare and social care institutions.[8-9] ACP enables individuals to create legally binding documents (e.g., AMD) and facilitates discussion among family members on EoLC that incorporates individuals' values and preferences.

However, ACP does not have a formal status in Hong Kong. There is a lack of standardised care focus, service providers, and target audiences in different ACP programmes,[10-14] resulting in varying levels of support and coverage. Therefore, the Government should develop a territory-wide standardised ACP framework to guide the design of ACP programmes and set a formal status for ACP in Hong Kong.

Figure 2. The framework of existing ACP programmes in Hong Kong

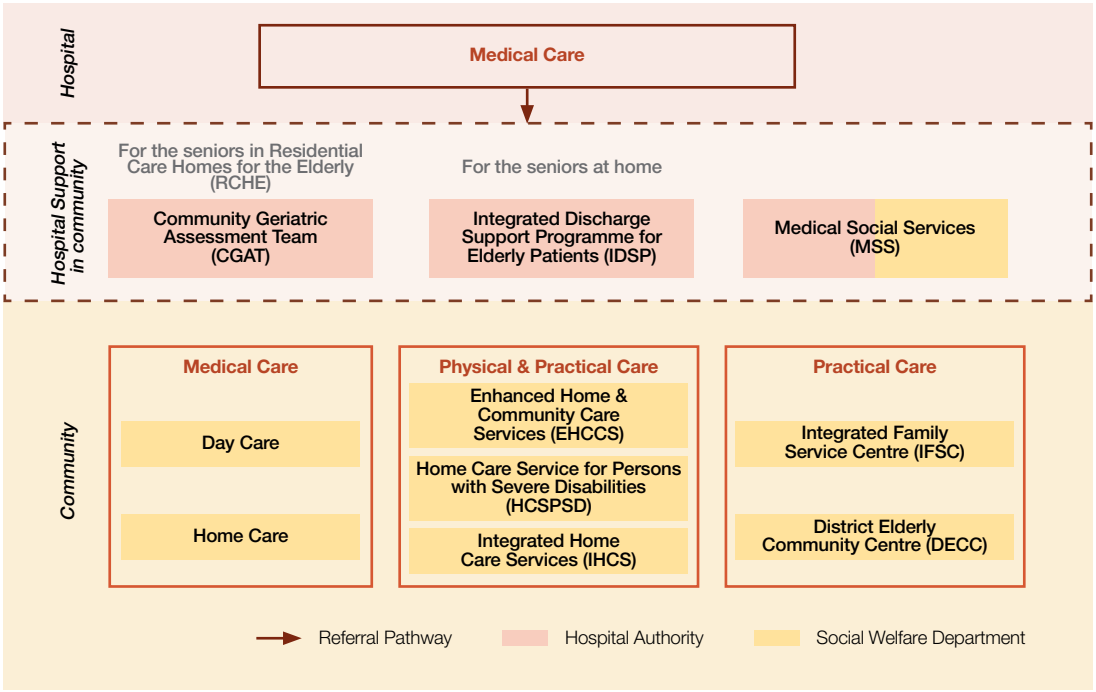


Drawing on the successful models in the United Kingdom, Singapore, and Australia[15-18], the recommended ACP framework should consider both system infrastructure and an individual's journey. System infrastructure should incorporate the training of professionals and the inclusion of ACP information in the existing electronic health record system (i.e. eHRSS for Hong Kong), while the individual's ACP journey should encompass public education, active engagement, proper documentation, and regular review and implementation of ACP documents. The documentation of ACP should be effectively communicated with different units in hospitals, especially the Accident and Emergency Department, and other health and social care institutions.

Service Level: Holistic EoLC Services

In the current service landscape, while providing medical care in public hospitals, the Hospital Authority (HA) extends support for the patients to the community level through programmes such as "Enhanced Community Geriatric Assessment Team for EoLC in Residential Care Homes for the Elderly" (Enhanced CGAT), Integrated Discharge Support Programme for Elderly Patients (IDSP) and Medical Social Services (MSS). These services aim to connect patients to community-level services provided by the Social Welfare Department (SWD) and community partners, covering medical care, physical and practical care, and psychosocial care.

Figure 3. Current service delivery pathway in Hong Kong



Although both HA and SWD provide various medical-social transition support for patients and their carers, the lack of coordination leads to service fragmentation. Individuals may need to navigate the community service system by themselves and consult multiple service providers separately, resulting in a high threshold for accessing suitable services.

Nevertheless, this service gap is now bridged by community efforts. Jockey Club End-of-Life Community Care Project (JCECC) was launched in 2016 to improve the quality of EoLC. It introduced two community-based EoLC models, the Integrated Community End-of-Life Care Support Teams (ICEST) and EoLC in Residential Care Homes for the Elderly (RCHEs). These models foster collaboration between public hospitals, RCHEs, and different sectors, promoting holistic support for terminally ill patients in the community.

JCECC has presented significant impact. Patients who had the EoLC at home or in RCHEs services for three months experienced both physical and mental improvements, accompanied by fewer hospital bed days and A&E attendances.[19] Nonetheless, JCECC was set to conclude in 2026, raising concerns about the future of the established medical-social network.

In Singapore, a national care integrator called Agency of Integrated Care (AIC) was established in 2009 under the Ministry of Health. As a single agency, AIC manages referrals, coordinates aged care services, and enhances service development and capability-building across the medical-social domains. By fostering medical-social collaboration, AIC enhances service accessibility and continuity of care.[20]

Recommendation 2: Formulate an EoLC Service Strategy

To better coordinate EoLC services, it is imperative to establish a clear role delineation and collaboration model among organisations and professionals. An EoLC service strategy that connects existing medical and social services is therefore crucial to ensure coordinated and comprehensive EoLC.

Drawing from examples in the United Kingdom and Australia,[21-23] the Government should consider common themes present in overseas models, including the emphasis on ACP, holistic care, care coordination and utilisation of technology.

To better deliver EoLC in a coordinated manner, it is crucial to expand the focus beyond the last 12 months of life to encompass palliative care (PC). Incorporating elements of early PC into curative care can ensure that individuals receive holistic care, including symptom relief and emotional support, while still pursuing curative treatments.

A local study featured a structured ACP programme introduced by a hospital PC unit in collaboration with various specialties. It reduced acute admission and length of stay of patients by 35% and 39% respectively, while ensuring the concordance of patients' wishes with end-of-life and funeral arrangements.[24] Better incorporating early PC into the care continuum can raise awareness towards EoLC and facilitate patients in making informed decisions, ensuring that their wishes are respected and fulfilled.

By formulating an EoLC service strategy that incorporates these elements, Hong Kong can work towards establishing coordinated services that cater to the diverse and evolving needs of individuals requiring EoLC.

> *"Many doctors and medical social workers outside Palliative Care Unit are not fully aware of community EoLC resources."*
>
> Consultant of palliative care in a public hospital

Recommendation 3: Establish a Clear and Consistent Communication Pathway to Connect EoLC Services and Facilitate Medical-Social Collaboration

To provide patients with integrated medical-social care, it is crucial to establish a clear and consistent communication pathway to connect EoLC services between hospital and community, facilitating medical-social collaboration. This communication pathway should integrate existing service referral links, streamlining the process of connecting patients with suitable services.

Drawing references from the examples of JCECC and AIC in Singapore, the Government should put in place a mechanism to coordinate with hospitals, holistically assess patients' needs, match them with existing social services, and follow up regularly. This can ensure that patients receive integrated EoLC across hospitals and the community.

Education Level: Strategies to Raise Awareness

There is a palpable disparity in awareness and information dissemination among the population. Although a substantial percentage of individuals (75%) felt comfortable or did not experience any discomfort discussing life and death issues, a staggering 70% lacked awareness of EoLC, underscoring the opportunity to enhance education in this domain.[25]

Furthermore, it has been observed that citizens prefer to receive EoLC information from relatives and non-religious acquaintances (e.g., carers) (55%), healthcare professionals (HCP) in the community (41%), and HCP in hospitals (40%).[26] It is concerning, however, that the actual flow of information does not align with these preferences—most information is transmitted through hospital-based healthcare professionals (32%), while fewer individuals receive guidance from their preferred sources, —only 29% and 9% of individuals receive information from relatives and non-religious acquaintances (e.g., carers) and HCP in the community respectively.

Therefore, it is crucial to provide EoLC education strategically. For EoLC service users, promoting life and death education should be prioritised, while for EoLC service providers, the Government should empower health and social care professionals through enhanced university curriculum and on-the-job training, as well as ACP training.

> *"We should empower doctors across specialties, as well as health and social care professionals, to initiate difficult but necessary conversations, making EoLC more accessible."*
>
> Professor engaged in EoLC training and education

Recommendation 4: Promote Public Life and Death Education

Hong Kong can strategically promote public life and death education by adopting a three-step approach targeting individuals at different stages of life and with varying levels of preparedness, which involves raising awareness, facilitating discussion, and taking actions.

To enhance awareness among students and the public from an early age, the Government may draw reference from Taiwan's approach of integrating life and death education into school curriculum. Taiwan's initiative serves as a comprehensive model that emphasises policy establishment, teacher training, enriching curricula with relevant activities, and extending education into the community.[27]

For individuals facing deteriorating health conditions and their families, health and social care professionals should provide information on ACP, tailored to the severity of health conditions and preparedness level. This can encourage patients and their families to participate in discussions related to EoLC and take action in ACP and AMD for the later stage. Additionally, terminally ill patients and their families should actively participate in ACP and AMD, as well as receiving bereavement support when needed.

> *"The Government should strategically plan for life and death education targeting citizens of different ages and care needs."*
>
> Programme director of community care service

Recommendation 5: Equip Community Professionals and Volunteers with ACP Training

Community professionals and volunteers who are delivering services to individuals with declining health should be incentivised to undertake ACP training and become ACP facilitators. Through providing ACP to all age groups across different service settings by these trained personnel, EoLC information can be disseminated to a wider population. This is also aligned with people's preference, considering that HCP in the community, and relatives and non-religious acquaintances (e.g., carers) are preferred as the top two EoLC information sources.

Such training should extend beyond working professionals to include volunteers and laypeople. This practice is also evident in the "Respecting Choices" model in the United States, which offers a robust training protocol for participants of different backgrounds. This model is comprehensive, encompassing an array of ACP skills tailored for different health statuses.[28]

Moreover, Singapore's national ACP programme "Living Matters" also illustrates the benefits of training ACP facilitators for both clinical and social care settings.[29] A network of over 5,000 certified and proficient ACP facilitators has been created to effectively disseminate accurate and compassionate EoLC information to the public.[30] The Government may reference these models in promoting ACP training in Hong Kong.

Recommendation 6: Enhance University Curriculum and On-the-Job Training in Health and Social Care

Currently, university curriculum and on-the-job training for healthcare professionals in EoLC tend to be fundamental, which may only include hospice visits. This may not fully prepare them for the complexities of providing comprehensive and quality EoLC, sometimes leading to a greater emphasis on curative treatments which may come at the expense of a patient's overall quality of life. Hence, the relevant institutions should enhance EoLC elements in the curriculum and training, emphasising the importance of striking a balance between disease management and improving a patient's quality of life.

In addition, there is a need to enhance communication skills among health and social care professionals, particularly in conveying prognosis and conducting sensitive EoLC discussions. Ethical training for healthcare professionals should prioritise the shift of focus from treating diseases to considering the patient's overall well-being, promoting a more compassionate and patient-centred approach. Extending trainings beyond healthcare professionals to other social care professionals is equally critical, to ensure that a multidisciplinary team is well-equipped to provide holistic care, engage in meaningful discussions about death, and meet the unique needs of patients and their families who face end-of-life issues.

Conclusion

In conjunction, these recommendations support the vision where EoLC is delivered in a person-centred, dignified, and coordinated manner in Hong Kong. The implementation of policies and programmes at all levels—system, service, and education—would create synergy and contribute to the development of comprehensive EoLC. This ensures EoLC is well-integrated into the care continuum, respecting and responding to people's preferences and rights to compassion and care at the final stage of life.

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