立法會衞生事務委員會 2019 年 12 月 13 日會議

晚期照顧:有關預設醫療指示和病人在居處離世的立法建議

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首先,對政府提出改善晚期照顧的上述兩項立法建議是肯定的,並已提交具体的立法諮詢事項的回應,立法建議的重點是病者對臨終治療和照顧的意願能被尊重和貫徹執行,臨終者可以選擇不在醫院,在居處離世,所以祇提出改善法律架構是不足夠,以下提出三方面立法以外的建議以達至實現立法原意:

1. <u>成立一個中央登記系統儲存晚期照顧的預設醫療指示和日後推出的持續授權書</u> 參考英國和星加坡的做法,設立一個方便使用者及其親屬或受托,以及跨服務系統,公、私服務提供者使用的登記系統。

2. 貫徹服務配套、強化社區善終照顧

- 2.1 建立醫、社協作的善終服務模式和系統 請參考附件 Appendix: Aligning Medical and Social Care to Deliver Quality, Effective and Compassionate End-of-life Care for the Dying in Residential Care Homes for the Elderly
- 2.2 將**臨終照顧納入為資助安老院舍持續照顧**的核心服務一環,配備設施和人力資源,結合延展社區安老醫療和紓緩治療,為院舍長者提供身、心、社、靈的全面臨終照顧。另附一份改善在院舍離世的行政措施和法例,當中提及在安老院舍离世者的遺體處理、儲存、運送亦涉及配套的設施和政策修訂•Appendix: Overview of the Legal and Administrative Barriers to Caring and Dying-in-place in Residential Care Homes for the Elderly
- 2.3 要買徹「居家安老」的政策目標需要讓長者能盡量留在熟悉的家居環境 獲得適切的照顧以至**居家終老**。首先,改善家居照顧服務應加入善終支援, 教導及支援家人照顧臨終長者,讓長者能盡量留在熟悉的家居環境,獲得適切 的照顧,以至延遲入住院舍,及減少進出醫院對臨終者及其家人所帶來的勞累 和壓力。另外,必須協調醫管局或社區基層醫療服務,提供到戶的紓緩治療和 護理。最後,加強輔導服務,協助臨終者作心理和靈性準備,交託社會責任和 惜別親友。

3. 制定善終政策和服務規劃

不少國家有制定整全的善終政策,協調各有關公共服務提升臨終者的生活質素。 2008年,英國制定的善終照顧策略提出四個「好死」目標,包括為臨終者:(1)提供適切、有尊嚴和優質的死前和死後支援服務;(2)控制和減少臨終痛楚和折騰的症狀;(3)有選擇地在一個熟悉的環境離世和(4)離世時有親友陪伴。

香港需要一套全方位的善終政策以滿足社會需求,範疇可包括:

- · 生死教育 納入各級學校正規課程,以及在社區推行公眾教育
- **醫社結合的紓緩治療和護理,照顧臨終者身、心、社、靈的需要**,按他的意願定 出照顧計劃,包括預設醫療指示
- 修訂法例(包括法醫、救護車條例等)讓臨終者能留在社區終老
- 強化及支援非正規社區照顧者,組織及培訓義工和家人
- 監管及優化殯葬服務和設施
- 喪親及後事支援服務
- 照顧人員的專業培訓和配套設施



Aligning Medical and Social Care to Deliver Quality, Effective and Compassionate End of Life Care for the Dying in Residential Care Homes for the Elderly (RCHEs)

Fang, M.S., Lou, W.V. & Kong, S.T.

End-of-Life Care Policy Issue Brief 3

ABSTRACT

The Issue

- RCHEs have become the last place of residence for many elders until their deaths and the trend is increasing.
- Living and dying well in RCHEs rely on co-ordinated medical and services, to provide holistic, personcentred and integrated care that is grounded in comfort and dignity.

The Barriers

- Inadequate medical support, unable to access physicians for emergency consultations, lack of on-site trained nursing and personal care capacity to manage the dying process, affect the quality of end of life care.
- Gaps in care co-ordination and communication frustrate the dying elders and their families with inappropriate care, repeated assessments and inconsistencies in implementing the advance care plan and delayed care.

The Solutions

- Measures to improve care system <u>structures</u> include (i) increase the medical and nursing care capacity in care homes; (ii) develop a shared IT system; (iii) establish a facilitated pathway to streamline care transitions and expedite hospitalization for imminently dying elders.
- Align <u>processes</u> of care as in identification of target service recipients, jointly conducting holistic care
 assessment and engaging families in care planning, division of roles in managing the dying moment,
 post death certification and finally, support to bereaved families.
- Enhancement of structures and processes of partnership is grounded on <u>a common driving value, a shared goal and trusting relationships</u>

Citation: Fang, M.S., Lou, W.V. & Kong, S.T. (2016). Aligning Medical and Social Care to Deliver Quality, Effective and Compassionate End of Life Care for the Dying in Residential Care Homes for the Elderly (Policy No. 3). Hong Kong: Faculty of Social Sciences & Sau Po Centre on Ageing, University of Hong Kong. Retrieved from www.socsc.hku.hk/pp/end-of-life-care-3/

Introduction

As older and frail elders become care-dependent, many have no choice but to move into long term care facilities. 7% of the elderly in Hong Kong live in care institutionsⁱ, among which 68% are over 80 years old; 81% are living with co-morbidities of two or more kinds of chronic illnesses (hypertension, stroke and dementia being the top three chronic illnesses) and 44.6% suffers the highest level of impairment in managing activities of daily living (ADL), needing help in mobility, eating, toileting, bathing, dressing and transferringⁱⁱ. To many of these frail elderlies, the elderly homes are their last place of residence before their deaths. Hence, it is important to consider the dying experience, the availability and quality of end of life care in long term care facilities.

The aims of end of life care is to improve the quality of life of the dying in four core aspects: physical, social, psychological, social and spiritualⁱⁱⁱ. And, a good working definition of what constitutes a "good death", as identified by patients and families across the developed world has been summarized as "maintaining control, good symptom management, an opportunity for closure, affirmation of the dying person, recognition of and preparation for impending death and not being a burden as being crucial"^{iv}. It is essential that medical and social services are coordinated to provide holistic and person-centred end of life care for the dying elders, that is grounded in comfort and dignity.

Based on a quantitative survey of care home managers and a qualitative study of four medical-social partnership care models, this issue brief looks at the **structure**, **process** and outcomes of integrated care that could be put in place

to ensure older people can live and die well in residential care homes.

Perceived Challenges and Critical Areas Needing Improvement

98% of one hundred surveyed subvented care home managers have identified the followings as important or very important issues of inadequate medical support and co-ordination between medical and social care that need to be addressed:

Issues of Inadequate	(%) Very	(%)
Medical Support	Important	Important
24 hour consultation/onsite	71.0	28.0
support by either		
hospitals/CGAT		
Registered medical	56.0	40.0
practitioners to arrive at the		
site to certify death		
Training to enable them to	54.0	44.0
handle dying residents'		
discomfort		
Regular weekly visits to the ill	50.0	43.0
residents		
Issues of Medical-Social		
Care Co-ordination		
Consistency in implementing	50.0	48.0
the advance care plan,		
advance directives and the		
post-transition care		
Standardized assessment	45.0	52.0
mechanism		





3.

Common understanding in	40.0	54.0
when to start End of Life care		
Include AD and ACP in e-	40.0	54.0
medical records		
communication		
Improve the channels for	37.0	61.0
information exchange		

Improving Structures to Enhance Care Systems Capacity

Increase the medical and nursing care capacity in care homes. Access to extended hours, if possible round-the-clock, medical advice and support are important. Fluctuating and sudden health deteriorations in the dying process are great stressors to the nursing and care staff in the homes, especially at night time or after office hours. Without immediate assurance and guidance from physicians and experienced nursing staff, dying patients would be transferred to hospitals to avoid risks and liabilities.

<u>Training and equipping staff</u> in care homes with the nursing knowledge and skills to handle dying discomforts are essential. This should be supplemented by the provision of necessary medical equipment and drugs to be administered in the Homes.

2. Shared information technology (IT) system is essential to co-ordinate care. Different parties of care have to be well informed of the wishes and health status of the dying elders. The existing electronic health record sharing system (eHRSS) should be enhanced. The ability to capture and, crucially, share information across all facets of care is important to integrated end of life care. Carers in RCHEs need to know and can assist to record changes in health situations and preference of care of the dying resident.

Facilitated pathway or mechanism for direct public hospital clinical admission minimize can unnecessary procedures and interventions, thus improving the quality of care transitions for the dying elders from RCHEs^{vi}. The care homes are supported by the Community Geriatric Assessment Team (CGAT) providing on-site care to the dying resident and the non-acute extended health care facility provide timely direct admission when death is imminent. These proven effective pilot models should be replicated, and be made the standard practice and not the exception. The facilitated clinical admission pathway should also be extended to EoL cases identified by private visiting medical officers (VMOs) and onsite medical officers responsible for primary health care in RCHEs.

Aligning Processes to provide Appropriate Care

A joined up approach to on-going holistic assessment of their needs across the physiological, social, psychological and spiritual domains. Psychosocial needs assessment, carer and family assessments and the existing interRAI (Resident Assessment Instrument) from the social care system, should be adapted for end of life care and integrated with the medical palliative care assessments. There

should be agreement on when to start the assessment, who to conduct the initial and on-going assessments, how to update and access the documentation.

5. Advance care planning (ACP) should be a personcentred and co-ordinated process. The concerns and wishes of the dying elders and their families are core and they need to be informed, involved and supported in making decisions in both social and medical care.

The social care workers in the elderly care homes are well placed to identify triggers and start the "death talk", they know the elders and their families and are experienced in handling relationships and practical livelihood matters for the elders. Home workers are responsible for the daily care, and nurses in RCHEs are at the frontline of managing the discomforts of the dying process. Medical practitioners play the critical role of informing the elders and their families of the prognosis, the possible deterioration process and options of treatment, symptom management and comfort measures. All parties should work together in conducting comprehensive advance care planning, that straddles medical and social care for the dying elders.

6. Formal mechanisms of care co-ordination, like the use of a case manager. There should also be clear protocols, communication procedures and roles in care transitions. Last but not least is to provide a

supportive work environment conducive to collaboration and mutual support for frontline carers and mangers of care across systems.

Outcomes of Care

To the dying elders and their families, the following four outcomes of co-ordinated care have been iterated: (i) to be able to relief pain and discomforts; (ii) effective communication and shared decision-making, to be informed and involved; (iii) reduce unnecessary hospital transfers; (iv) respectful of wishes and compassionate care^{vii}.

Conclusion

Structures prescribe the capacity of the care system and aligned processes ensure the appropriateness of care to meet needs. Adequate structure and processes are grounded on core value foundations of medical – social partnership. These three foundation pillars are:

- Respect dignity and holistic well-being of the dying elders as the driving value
- 2. A shared optimal goal of dying well, balancing quality of life and quality of care to achieve care-inplace until death and eventually dying in the place of choice
- 3. **Trust** as a core foundation, with the elderly at the centre, building trust among formal, informal carers and the care systems. The four "I"s for building trust is to Inform, Involve, share Intention (shared goal) and Insist on value (driving value) in the process of care for the dying.





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Fang, M. S., Lou, V. W. Q., & Kong, S. T. (2015b). Four Medical-Social Shared Care Models Providing End-of-Life Care in Residential Care Homes. Hong Kong: Salvation Army. Retrieved from http://www.socsc.hku.hk/pp/wp-content/uploads/2015/10/Attachment-8.pdf

vi Luk, J.K.H., Liu,A., Ng, W.C., Beh, P., Chan, F.H.W. (2011). End-of-life care in Hong Kong. Asian Journal of Gerontology & Geriatric, 6(2):103-106.

Hui, E., Ma, H. M., Tang, W. H., Lai, W. S., Au, K. M., Leung, M. T., ... & Woo, J. (2014). A new model for end-of-life care in nursing homes. *Journal of the American Medical Directors Association*, 15(4), 287-289.

vii Fang, M. S., Lou, V. W. Q., & Kong, S. T. (2015b). Four Medical-Social Shared Care Models Providing End-of-Life Care in Residential Care Homes. Hong Kong: Salvation Army. Retrieved from http://www.socsc.hku.hk/pp/wp-content/uploads/2015/10/Attachment-8.pdf



Overview of the Legal and Administrative Barriers to Caring and Dying in Place in Residential Care Hones for the Elderly (RCHEs) Fang, M.S., Lou, W.V. & Kong, S.T.

End-of-Life Care Policy Issue Brief 4

ABSTRACT

The Issue

- Currently there is no policy in Hong Kong to align and coordinate different care systems in the provision
 of End of life (EoL) care, in specific there is no mandate supporting dying-in-place in RCHEs
- Improving relevant legal provisions and removing administrative barriers are a priority, if we are to provide more options in the place of care and death for an ageing population

The Concerns

Legal and administrative barriers to caring and dying in place in RCHEs are identified across four key
phases of end of life care: (i) the preparation of death and advance care planning; (ii) the care delivery
to ensure consistency and continuity in honouring the dying persons preference of care; (iii) the dying
process, including the certification of death and the cause of death; (iii) the registration of death and the
handling of the body

The Solutions

- Legislate on Advance Directives (AD) and Do-Not-Apply-Cardiopulmonary-Resuscitation (DNACPR) in order to give mandate to both hospital and non-hospital care systems to consistently acknowledge and honour the medical and care preferences of the dying
- Enduring Powers of Attorney in personal care (EPA-personal care) should include the use and non-use
 of life sustaining treatments, as well as post-mortem funeral and burial arrangements
- Amend the Coroner's Ordinance (Cap 504) to exempt RCHEs from reportable death given that the dying elders is registered in a recognized EoL program and a medical practitioner has attended the dying person within 14 days prior to his death, can issue the medical certificate on the cause of death
- Align and share information of AD and care plans through electronic health system, to ensure synchronization of the dying residents' care preferences across systems
- Enhance the physical, people and medical capacities of RCHEs to support caring and dying in place

Citation: Fang, M.S., Lou, W.V. & Kong, S.T. (2016). Overview of the Legal and Administrative Barriers to Caring and Dying in Place in Residential Care Hones for the Elderly (RCHEs) (Policy No. 4). Hong Kong: Faculty of Social Sciences & Sau Po Centre on Ageing, University of Hong Kong. Retrieved from www.socsc.hku.hk/pp/end-of-life-care-3/



Sau Po Centre on Ageing The University of Hong Kong *** 大學社會科學等院 Overview of the Legal and Administrative Barriers to Caring and Dying in place in RCHEs Note 1

	Anticipatory & Preparation of	Care Delivery	Death	Post Death
	Death	(Consistency & Continuity in care)		
Presenting Problems	 Wishes of the dying elders not respected, no choice, care decisions dominated by professionals resulting in frustrations & complaints Care systems working in silos, duplicate & disjointed efforts in soliciting care preferences& planning. Confusing & distressing to the dying elders & families Increasing dementia cases, too late for ACP & AD HA too many forms (hospitalized/ nonhospitalized/) and guidelines (review periods, revocation) on DNACPR, AD & ACP. Confusing to patients & RCHEs 	 Gaps in following care preferences of the dying elders in care transitions, especially during emergencies. Ambulances (FSD) cannot follow HA patient-signed DNACPR & can only deliver patients to HA A&E admission RCHEs limited access & usage of eHealth system, affect delivery of timely & appropriate care RCHEs wary of liabilities & lack care capacities to follow ACPs & ADs 	 Cultural taboos & social considerations not conducive to dying-in-place in RCHEs Avoid death in RCHEs, due to cumbersome reporting & police investigation for "reportable death" Families, at a time of grief, want to avoid autopsy & investigation, Difficult for RCHEs to access physician to certify death & cause of death onsite 	cold storage facilities to hold bodies
Legal Barriers	 AD no legislative backing. Concerned about HA AD model forms do not cover care decisions in RCHEs. Increasing dementia cases cannot sign ADs before losing cognitive capacity AD cannot assign proxy and the future EPA (personal care) will not include life sustaining treatment(LST), thus creating a gap in care decisions 	 Ambulance under FSD do not follow HA DNACPR and have no knowledge of dying patients ADs on the use of LST 	(Cap504) classification of deaths in non-nursing home RCHEs as "reportable death" deters dying-in place	 Death in RCHEs unable to use public and hospital mortuaries for certified natural deaths, hence only those that can afford private funeral parlours can die in place License requirement for body storage facilities in RCHEs





Administrative Barriers & Practice Issues

- No understanding & established protocols between RCHEs and HA on when to start death preparation with frail elders and how to collaborate in conducting ACP & making AD
- HA guidelines on administration/review of ACP and ADs are not known and not binding on RCHEs, hence no protection if complained
- RCHEs not aware of and difficult to follow ACP and ADs signed by patients in hospitals, e.g. Comfort feeding needs additional manpower

- Cumbersome procedures to extend patient's consent and allow RCHEs to access and use the shared eHealth records
- Problem with transportation to extended care facility for clinical admission of EoL cases
- EoL cases identified by non-HA physicians have problem aligning CGAT support & public hospital clinical admission
- Code of Practice (Cap459) on storage of non-designated drugs in RCHEs, affect timely relief of symptoms

- Inadequate physician support to attend to imminently dying elders & to certify death on-site, especially when death occurs off office hours.
- Extra work for staff in RCHEs to counsel bereaved families and accompany them to handle death registration
- Cumbersome administrative reporting on certified deaths in nursing homes

- No provision of facilities in RCHEs for holding place of bodies for at least 24 hrs after death
- No after office hours issuing of death registration & cert for removal of bodies, to allow for transportation of bodies to holding places / mortuaries
- Unaware & limited use of non-office hour burial permit issued by Police, for certified natural death by a registered medical practitioner (Type 2)



Suggestions for Improvements

- 1. Legislative Improvements
- 1.1 Legislate to give a clear scope and legal status on the application of Advanced Directives (ADs). To ensure individual's care preference at the end of life in the use and non-use of life sustaining treatment, is known and followed by all care providers, including RCHEs and Ambulances under Fire Services Department. The legislation should be coupled with efforts in public education to promote public awareness and usage of ADs and the training of different care disciplines in conducting Advanced Care Planning and the administration of Ads
- 1.2 The future Enduring Powers of Attorney in personal care (EPA-personal care) should include in its scope: (i) use and non-use of Life Sustaining Treatments and (ii) post-death funeral and burial arrangements. Reduce the cost administration of assigning an EPA-personal care to meet the needs of growing population of single elders or couples without children, as well as for the increasing number of dementia cases to designate proxies for care decisions. Reference can be taken from the UK Lasting Powers of Attorney – personal welfare, which is now an online service.
- 1.3 Consider <u>one</u> of the followings in the amendment to the **Coroner's Ordinance** (Cap 504):
- (i) Include in the Type 16 exemption under Reportable Death to include RCHEs operated by non-profit making charitable organizations registered under Section 88 of the Inland Revenue Ordinance.
- (ii) Include deaths in RCHEs in the Type 2 exemption under Reportable Death to include " any death of a person (before his death, joined a recognized end of life programme, which can be defined in the

- Ordinance) & when a registered medical practitioner has attended the person within 14 days prior to his death will issue the medical cause of death
- (iii) Non-legislative version of (ii) is for the Coroner to accept the certification of the medical cause of death by a registered medical practitioner that has attended the person within 14 days prior to his death in the RCHE and create a fast track of no autopsy and release for death registration. The certification of Form 18 (medical cause of death) can be amended to accommodate situations where the Form can be signed by doctors under a recognized end of life programme. These doctors may include both primary care doctors and hospital doctors.
- 2 Administrative and Practice Improvements
- 2.1 Collaboration between medical and social care practitioners in conducting Advance Care Planning and signing of Advanced Directives. Develop common understanding of the criteria of when to start the EoL programme and division of responsibilities in care, clear protocols of care transitions and communication of changes in health status.
- 2.2 Clear and timely documentation in a shared IT system, recording ADs and care plans(if not the full medical records through the eHRSS), accessible to all care providers, including emergency services, with consent from the dying person
- 2.3 Align the work of CGAT teams with the RCHEs' visiting/onsite medical officers (V/OMOs), who may need to be resourced and include duties for EoL care for dying elders in RCHEs. Set up simple referral protocols by these V/OMOs for direct clinical admission of the dying elders, if situations require.





- 2.4 Transportation for emergency direct clinical admission and transportation for removal of bodies, after death in RCHEs.
- 2.5 Enhancement of the physical(PC room, access to mortuary), people (additional staff, training, support) and medical capacities (access to medical advice, training in nursing & symptom management, availability of drugs & equipment) of RCHEs to support caring and dying in place Note 2.
- 2.6 Provisions for Hospital Authority registered patients that have ADs and ACP in the public hospital, that eventually die in RCHEs can use the hospital mortuary and CGAT doctors can outreach to RCHEs to certify deaths on-site.
- 2.7 Streamline procedures for permit to remove body from RCHEs to funeral homes, esp. after office hours, to relief time pressure on families & staff.







The Dying Processes in RCHEs

1. The feasibility of dying-in-place is restricted by the **legal capacity** of the home to allow for dying-in-place.

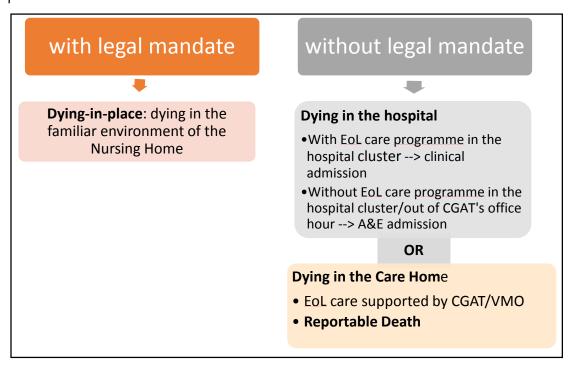


Fig 1: The Dying Process in RCHEs With & Without Legal mandate for Certified Natural Death

The Coroner Ordinance (Cap 504) states that deaths in nursing homes can be exempted from being categorized as reportable death.

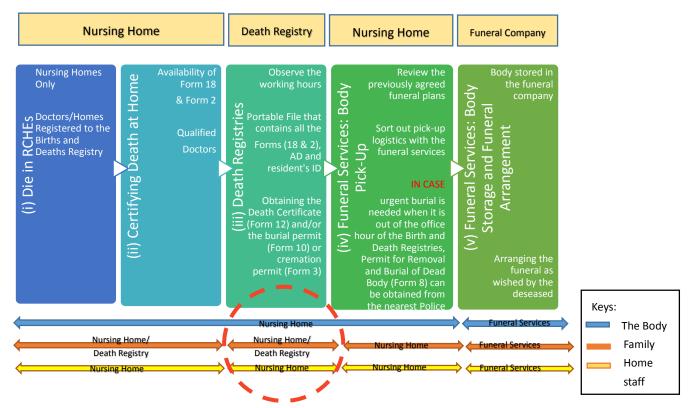
'Any death of a person where the death occurred in any premises in which the care of persons is carried on for reward or other financial consideration (other than in any premises which comprise a hospital, nursing home or maternity home registered under the Hospitals, Nursing Homes and Maternity Homes Registration Ordinance (Cap 165))'

Dying in other types of residential care homes is otherwise categorized as 'reportable death', which requires an investigation by the Police and subject to the Coroner's decision on whether an autopsy is required to determine the cause of death. This is a big deterrence to the dying elders and their families, who do not want autopsies, as well as to the care homes that have to handle cumbersome investigations and reporting.



1.1 The Dying Process in Nursing Homes

Fig. 2 Process of dying-in-place for Nursing Homes



*Notes: Form 18— Medical Certificate of the Cause of Death

Form 2—Medical Certificate (Cremation)

1.2 The Dying Process in Non-nursing home registered RCHEs

For those RCHEs NOT registered under Cap 165, including Care and Attention Homes, Homes for the Aged, Hostels for the Elderly, Contract Homes and Private Care and Attention Homes, they have to go through other dying pathways, i.e. clinical admission, the normal A&E transfer and reportable death if the resident dies at home.

The **dying in hospital experience** can be improved through direct clinical admission to geriatric ward or an extended care facilityⁱ. First of all, it honours and is aligned with the medical choices of the residents. Medical staff in the extended care facility is equipped with necessary knowledge and skills in pain and symptom management. The ward is designed to allow family care, such as manual feeding, in the last few days of life. As compared to dying in the care homes, the presence of hospital mortuary allows family members more time to digest the bad news, instead of rushing through the post-death logistics. The pre-death collaboration and communication between RCHEs,



the extended facility and CGATs are crucial. For example, CGAT was involved in the initial ACP meeting and also some ACP reviews held by the residential care homes, that it was then able to communicate the residents' spiritual needs to the extended care facility EoL ward in the last few days of the resident's life. The resident was offered a direct pass to go to the EoL extended care facility, but the problem remains in transportation in the care transition.



The Physical, People and Medical capacities necessary to support dying-in-place in RCHEs

For physical capacity, it is important for the care homes to be equipped with a Palliative Care (PC) room to allow family members to accompany the dying resident in the last few days. The space ensures privacy and close personal care, without disturbing other residents, in the communal living environment of RCHEs. The access to mortuary facility for body storage is a serious concern for hygienic reasons and the absence of mortuary creates time pressure and extra costs for transporting the body to the funeral services where cooling facilities are available.

People Capacity means **extra staff** for the extra workload involved in taking care of the dying residents and their families; **basic training** for all staff in carrying out EoL care and proper after death debriefing and **emotional/psychological support** for staff members.

Medical capacity requires round-the-clock **access to physician,** for consultation and advice and also certification of deaths on site in the RCHE. **Training in nursing and personal care** to handle pain and dying symptoms are essential to equip staff in RCHEs to manage the dying process with provisions of end of life care **drugs and special medical equipment** be added to the RCHEs facilities.

Luk J.K.H., Liu, A., Ng, WC, Beh, P., & Chan, F.H.W. (2011). End-of-life care in Hong Kong. Asian Journal of Gerontology & Geriatrics, 6(2):103-106

Hui, E., Ma, H. M., Tang, W. H., Lai, W. S., Au, K. M., Leung, M. T., ... & Woo, J. (2014). A new model for end-of-life care in nursing homes. *Journal of the American Medical Directors Association*, 15(4), 287-289.