



# 實踐在院舍離世 – 同行者的經驗

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同心同步同進 RIDING HIGH TOGETHER

合作夥伴 Project Partner:



香港老年學會  
Hong Kong Association of Gerontology

# End-of-Life care in Residential Care Homes for the Elderly (RCHEs)

## 有關「賽馬會安寧頌」

隨著香港人口老化，晚期病患老人數不斷攀升，公眾對社區晚期病人護理服務的需求亦日漸增加。為此，賽馬會慈善信託基金會撥款二億五千五百萬港元，於2016年開展推行為期六年的「賽馬會安寧頌」計劃，協助改善社區晚期護理服務的質素，以及為相關服務的專業人員提供培訓，並舉辦公眾教育活動。

「賽馬會安寧頌」結合跨界別力量，聯繫社區及醫療系統，強化現有臨終護理服務。計劃會在社區及安老院舍推行安寧服務，為晚期病患長者提供全面的支援，讓他們可以在充裕知情下作出合適的臨終護理選擇，提升他們的生活質素。計劃合作夥伴包括：香港大學社會科學學院、香港中文大學醫務老年學研究所、香港老年學會、基督教靈恩協會、香港復康會、聖保羅修會、及聖公會聖長者地區中心。詳情請瀏覽 <http://www.jcecc.hk/>

**賽馬會安寧頌 - 「安寧在院舍」計劃查詢：**

香港老年學會  
 Hong Kong Association of Gerontology  
 電話：(852) 2775 5156 傳真：(852) 2775 5586  
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## 賽馬會安寧頌 - 「安寧在院舍」計劃

JCECC:  
 End-of-Life Care in Residential Care Homes for the Elderly



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### 計劃背景

賽馬會安寧頌「安寧在院舍」計劃獲香港賽馬會慈善信託基金會資助。計劃為期六年，為院舍內患有末期病患的院友提供舒緩及臨終照顧服務，讓他們圓滿地走完人生旅程。

### 計劃目的

透過此計劃所成立之「安寧在院舍」專業團隊，支援及協助40餘位於九龍東、九龍中及九龍西的政府資助院舍，發展一貫院舍臨終照顧服務模式，讓參與計劃的院友及下稱「院友」在最後的日子能獲得適切的全人照顧。

### 一站式之關懷建立支援服務

由專業人員組成之「安寧在院舍」專業團隊，與院舍、院舍與院舍、為院友提供適切之照顧計劃。同時，團隊會與支援院舍員工之活動，加強團隊合作精神，推廣善待自己的概念，減輕照顧工作上面對之壓力。

### 持續學習培訓 - 推廣生死教育

- 「安寧在院舍」專業團隊會為參與院舍之線層及專業同工提供臨終照顧培訓，在臨終及專業服務提供支援，協助參與院舍的員工掌握應用相關知識與技巧，履行臨終照顧服務。
- 於社區層推廣舒緩及臨終照顧概念、「預設照顧計劃」及「預設醫療指示」內容等等，旨在提升大眾對死亡及臨終照顧服務的認識。

### 支援家屬照顧者

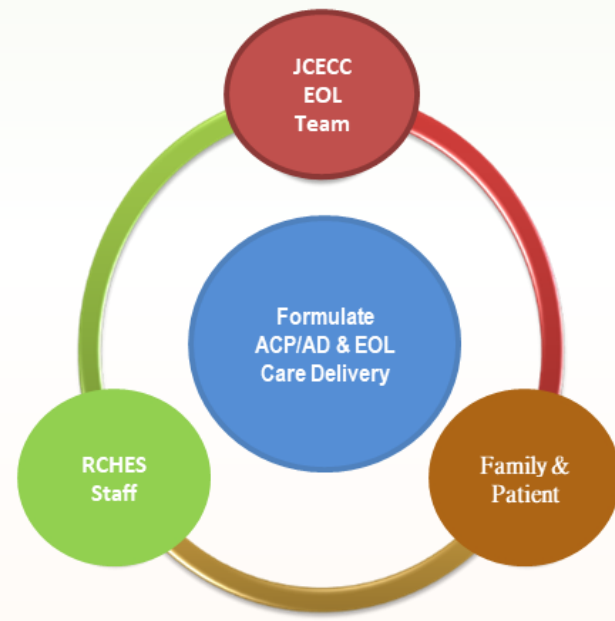
「安寧在院舍」專業團隊將從旁支援家屬/照顧者，協助其表達及面對親人/院友離世，掌握相關資訊，與親人/院友好好話別。

### 臨終照顧

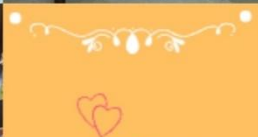
當院友進入生命倒數時刻，「安寧在院舍」專業團隊及院舍同工會繼續提供舒適的照顧，並讓院友入住「安寧房」，由親友陪伴在旁並予支援，讓院友安詳圓滿地走完人生旅程。

如欲了解計劃詳情，可瀏覽以下網址：  
 JCECC End of Life Care in Residential Care Home for Elders in Hong Kong  
<https://youtu.be/bMvMAsR0tg>





# End-of-Life care in Residential Care Homes for the Elderly (RCHEs)



## 計劃流程

開展籌備階段，為院舍職員提供培訓，設立「安寧房間」，為院友及家屬舉辦講座介紹計劃

初步評估院友及其家屬意願，轉介有需要的院友，接受臨終照顧服務

簽訂「參與計劃同意書」後，正式為院友提供臨終照顧服務，提供及執行「預設圓願計劃」

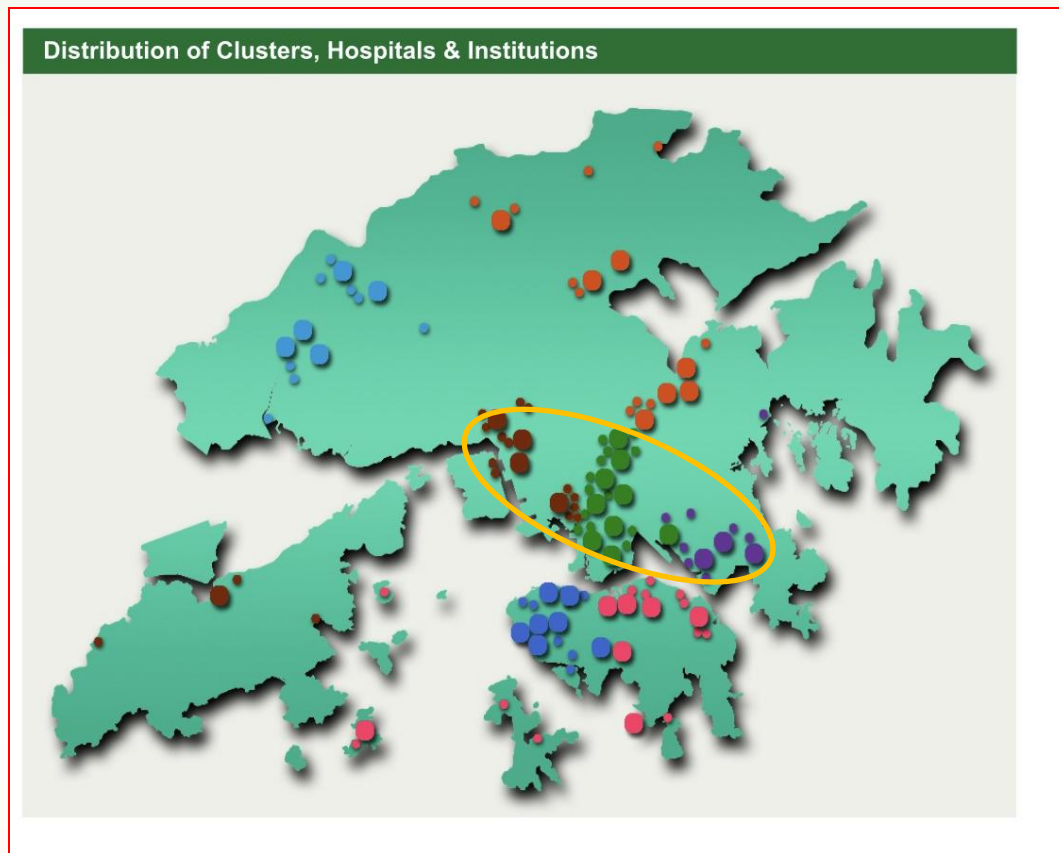
當院友病情轉差 (出現瀕死症狀)

- 院友及家屬意願到醫院接受治療
- 院舍安排院友入住安寧房間，提供完備的臨終護理，讓家屬陪伴院友，直到出現瀕死症狀，轉送個案前往急症室
- 院舍安排院友入住安寧房間，提供完備的臨終護理，讓家屬陪伴院友，在院友家屬同意及院舍情況許可下，由計劃醫生證實個案死亡，並事前已聯絡殮葬商安排處理身後事








院友離世後，為家屬提供哀傷輔導及協助處理殮葬事宜

為院舍職員安排解說會  
安排解說會予家屬及其他院友  
按院舍需要舉辦追思會

# End-of-Life care in Residential Care Homes for the Elderly (RCHEs)



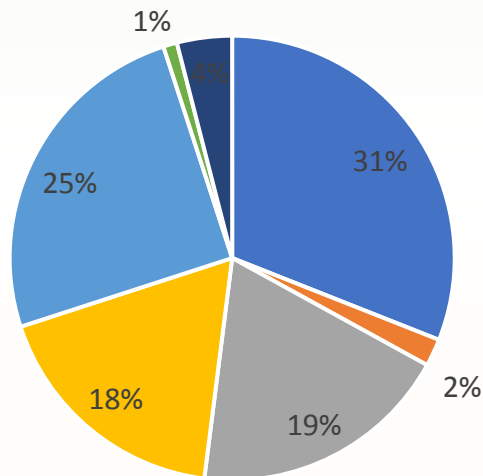
- Phase 2 (2019-2021) project
- 01/2019- 03/2020
- Served Kowloon Central, East and West clusters
- Total **48** sub-vented C&A home and contract homes joined the program
- These homes under the care of **8** (KWH, QEH, OLMH, UCH, HHH, CMC, YCH & PMH )CGAT teams

 HKEC	 KHWC	
 KCC	 KEC	 KWC
 NTEC	 NTWC	

# End-of-Life care in Residential Care Homes for the Elderly (RCHEs)

01/2019-03/2020, **180** residents received EOL care in these RCHEs under this project

principle diagnosis for residents recruited in EOL care



- Dementia
- Malignancy
- Others
- Parkinson's disease
- End organ failure
- Major stroke
- Haematological disease

Mean Age:  
90.29 (7.35)  
Years old

Gender:  
F:M  
76%:24%

68.89% has  
dementia

Received EOL care :  
2.88(2.997) months

# Story of Madam Cheng

- F/93
- Bedbound, BADL totally dependent, double incontinence
- 1 son and 1 daughter, who was the main carer
- Recruited into EOL program due to advanced dementia in 11/2018
- ACP: opted for comfort hand feeding, DNACPR in case of futile resuscitation
- During 02- 03/2019, 4 admissions into TKO for pneumonia, UTI, complicated by renal and liver failure
- 4<sup>th</sup> admission into TKO on 17/03/2020 for UTI and then discharge back to RCHEs
- Has been visited by project nurse and prepared daughter about anticipatory leaving of patient
- Daughter preferred the EOL care at RCHEs and ACP reconfirmed, psychosocial support provided to daughter for carer stress

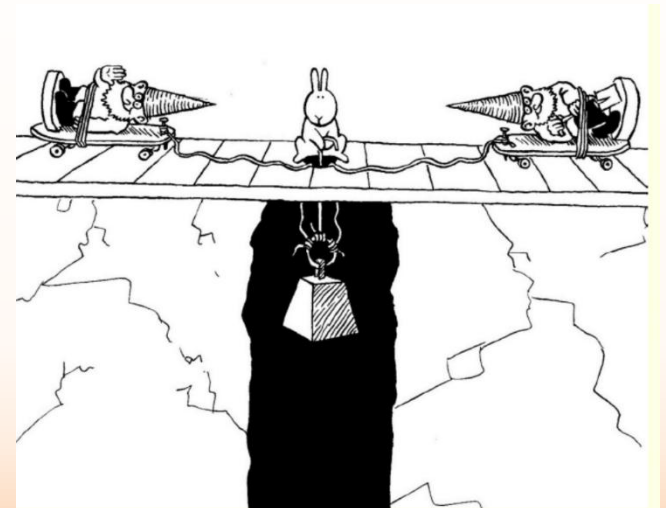
# Story of Madam Cheng

- **28/03/2019**, being called by project nurse to assess patient's condition since further deterioration
- Oral intake fair, low grade fever, tired looking, generalized odema over limbs and body
- Put on oral antibiotic for underlying chest infection
- Parent CGAT team was informed about the poor condition of patient
- Prepare to start EOL room service in next day
- **29/03/2020** morning, her condition further deteriorated, clinical picture suggested that she was in final day
- Daughter and son-in-law interviewed in RCHEs , preferred EOL care at RCHEs and reconfirmed the ACP, guarded prognosis informed



# Story of Madam Cheng

- Then son turned up and requested transferred out for further management
- Family conference held immediately at RCHEs, updated condition explained in detail, poor prognosis informed
- After prolong discussion, son insisted his decisions and we found that he did not turn up before and rarely visited patient in past
- This was a Chiu chow family, he was the only son
- He even declined option of clinical admission by CGAT team
- Sent to A&E at noon
- Patient passed away on **05/04/2019**





# The Daughter from California Syndrome (天邊孝子症候群)

- Described by Molley in his article “Decision making in the incompetent elderly”

*J Am Geriatr Soc 1991;39:396-399*

- Not uncommon seen in daily practice especially in Geriatric/PC setting
- SUGAR
  1. Surprised by the scale of deterioration
  2. Unrealistic expectation
  3. Guilty feeling
  4. Absent from life or care of the patient
  5. Reassert role as an involved caregiver

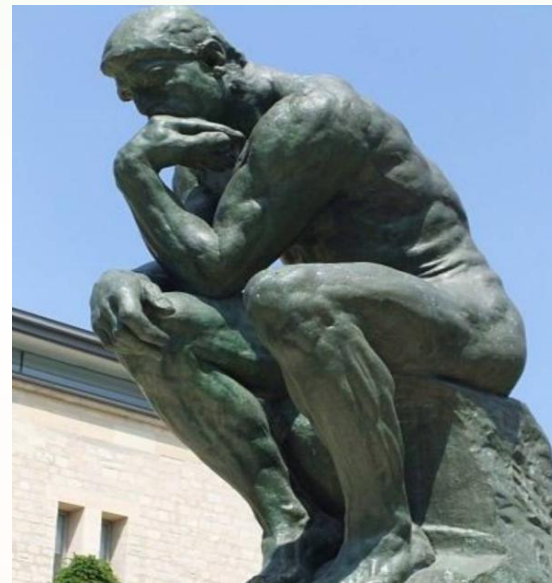
# Story of Madam Chan



- F/93, HT on drug,
- 8 children, walked unaided, ADL independent
- Family conference held at RCHes with staff and her 4 children on **04/06/2019**
- AD signed and Opted for comfort hand feeding, DNACPR and not for NIPPV in case of futile resuscitation
- Photos and video taken by younger son since this was a big life event for her family and patient
- All the AD/ACP conversation conducted in Chiu chow (潮州)dialect
  
- **20/05/2020**, major brainstem stroke, bedbound, unable for communication, put on artificial feeding due to brain stem stroke
- Family requested comfort care and DNACPR order was made during in-patient care
- Visited by our project nurse recently, family felt very grateful since patient signed AD already

## Family conference

- to provide a platform for communication between family members
- to understand patient's condition
- to solve the conflicts
- to reach consensus on care plan
- allied realistic expectation
- The importance of Advance Directives
- Amazing of language
- Meaning of “good death”



# Story of Mr. Cheng



「心無罣礙，無罣礙故，無有恐怖」  
《心經》

*“See no more obstacles in their mind,  
and because there are no more obstacles  
in their mind, they can overcome fear.....”*

Heart Sutra (translated by Thich Nhat  
Hanh 一行禪師)

Amitabha Looking Back ( Mikaeri Amida)

回首阿彌佻佛立像

Eikando Zenrinji, Kyoto, Japan

# Story of Mr. Cheng

- M/87
- ESRF, not for renal replacement therapy, IHD, dementia, FU at renal OPD
- Lived in self financed home for around 2 years
- 10 children, Buddhist
- In 11/2019, referred by RCHEs staff for EOL care since had 3 admissions within recent 6 months, just referred to PC team, await the appointment few weeks later
- Seen by project nurse on **09/11/2019**, family conference held at RCHEs and ACP discussed, family opted for DNACPR and not for NIPPV in case of futile resuscitation, for comfort hand feeding
- **26/11/2019**, being called to assess patient since condition deteriorated
- Restless, dyspnea, oliguria
- Clinically in fluid overload, grave prognosis informed
- Family conference held at RCHEs with nurse and RCHEs staff
- ACP discussed in detail

# Story of Mr. Cheng

- Family preferred last journey cared at RCHES, opted for comfort care, not for tube feeding, not for IV fluid/IV medications
- Wish: “Chu-Nien” chanting (助念)
- Clinical condition suggested in final days, risk of sudden death due to hyperkalaemia informed
- EOL conversation was well documented in note
- EOL room service initiated immediately, accompanied by family member
- Sent out to A&E in the early morning on **27/11/2019**

# Story of Mr. Cheng

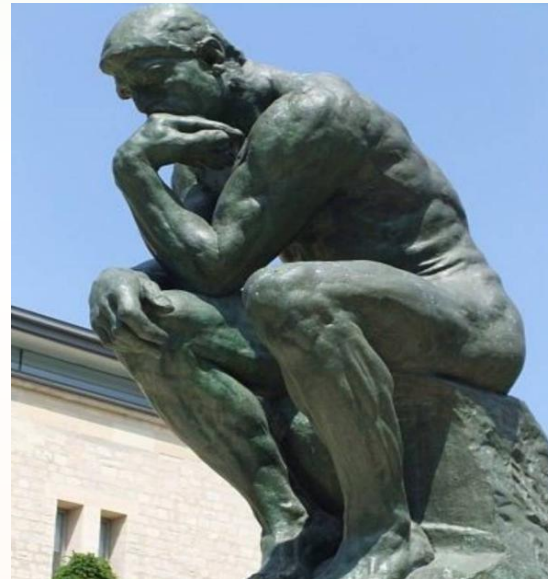


- CPR not performed in A&E since clinical notes were brought at same time and A&E doctor confirmed the decision of DNACPR with family and project nurse
- All family members had chance to say good-bye to Mr. Cheng before sent out
- “Chu-Nien” chanting (助念) performed more than 5 hours
- Family felt grateful since no CPR and they were able to do the “Chu-Nien” chanting



I think therefore I am  
我思故我在 ~ *Rene Descartes*

- Would it be different if he receive PC service earlier?
- Importance of well documented ACP and EOL conversation
- Know little about different religious value
- 適時釋安



# Story of Madam Liu

- F/92, RCHEs since 09/2006
- Only son lived in Canada
- Remote relationship
- DM, HT, ?pancreatic neoplasm in 2019, not for further work up
- AD signed on 27/11/2018 under this project, opted for comfort hand feeding, DNACPR in case of futile resuscitation
- Repeated admission and son came back to visit her in 2019
- EOL care since 07/2019, bedbound, BADL dependent
- 24/01/2020 evening, being called to assess patient, just discharged from hospital at noon
- Generalized odema, jaundice and tired looking, fair oral intake, vital sign still stable
- Patient clearly expressed to stay in RCHEs instead of back to hospital and preferred DNACPR in case of futile resuscitation
- Son contacted and condition and care plan updated by email, facetime to patient
- EOL room service initiated, developed aspiration pneumonia and needed O2 therapy but able to be settle down by oral antibiotic
- Discharged from EOL room on 03/02/2020

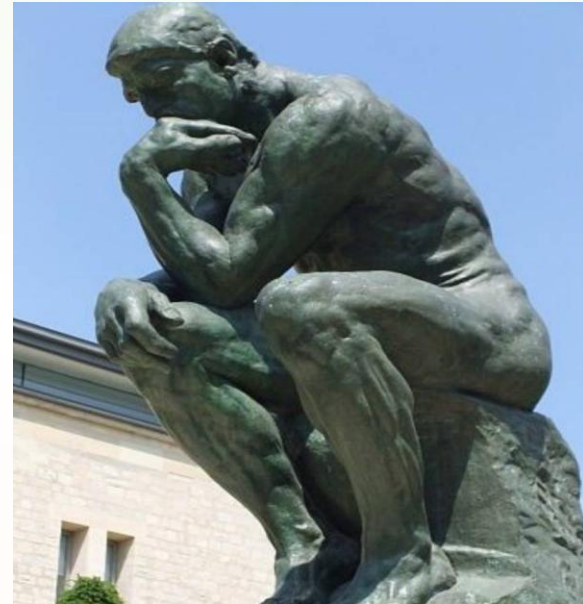
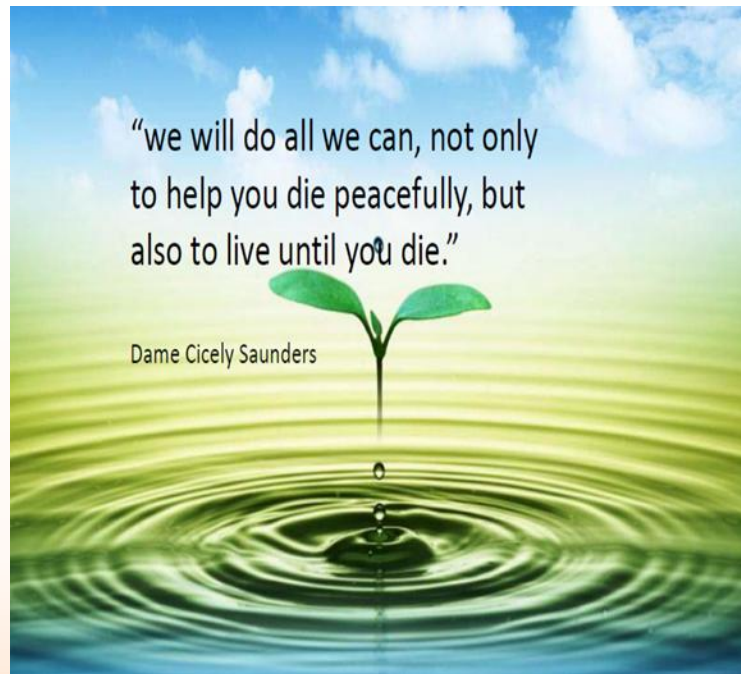
# Story of Madam Liu



- **30/09/2020**, being called to assess patient again since BP drop(95/55mmHg), drowsy and GC downhill
- Chest wall herpes zoster wound infection and multiple sacral sores
- EOL room service initiated again
- Insulin was off due to poor oral intake and borderline h'stix
- Oral antibiotic prescribed, wound care advise given
- Optimized drug for pain management
- Discharged again from EOL room **06/10/2020**
- Primed RCHE staff, her condition might fluctuate again
- **11/10/2020**, being called again due to change in condition, developed hypothermia temp=34.6°C
- Discussion with project team and RCHEs staff about the available resources, decided to send out
- Visited by project nurse in hospital on 14/10/2020, looked comfortable
- Patient succumbed on **20/10/2020**

# I think therefore I am 我思故我在 ~ *Rene Descartes*

- Do not harm
- Beneficial to patient
- EOL ≠ deprived medical care
- DNACPR ≠ Do Not Care
- Know your limitation, choose right patient to be cared in right place





# COVID-19 pandemic



# Story of Madam Lam

致：香港老年學會

## 感謝信

我是  安院 (石圍角) 院友  恩臨 (已故) 的女兒  彩

在沉重心情送別母親之時，也更特別，感謝貴會“安寧在舍”的黃惠英姑娘，長期以來如似家人般愛惜及關懷，照顧母親。在母親臨終之最後階段，黃惠英姑娘、沈南珠醫生、鄭姑娘、陳姑娘和林姑娘，各人都大大的表現出，樂業敬業的專業精神，無時無刻的護理及照顧著媽媽的需要。同時也無微不至的關心家人的情緒，及身後事的安排經驗分享。

感恩有你們的辛勤付出，及大愛之精神！我代表全體家族同人，致萬分感謝！

致謝人： 彩

2020年10月15日

- F/92
- Widowed with 2 daughters and 1 son, younger daughter was the main carer
- Christian
- Hai-nam dialect
- Recruited into EOL program since 10/2018 for advanced dementia and frequent admissions
- RCHEs resident for more than 10 years
- Bedbound, BADL dependent, assisted oral feeding
- 2 admissions during 09/2020 for pneumonia and poor oral feeding, failed to wean off O2 upon discharge on 24/09/2020
- Being call to see patient on 04/10/2020 for poor oral intake
- Family conference held and family aware of patient's poor condition
- Preferred to receive EOL care at RCHEs, opted for comforted hand feeding, not for iv fluid, DNACPR and not for NIPPV in case of futile resuscitation

# Story of Madam Lam

- EOL room service initiated
- Family met daily to update her condition
- On-line reverend service arranged for last blessing
- Accompanied by project nurse to A&E when no vital sign on **08/10/2020**
- Project nurse attended her funeral service



# Story of Madam Cheung

賽馬會安寧頌



Jockey Club End-of-Life Community Care Project

沈南珠醫生

您好.我們是張鑽女士的家人.她的安息禮拜及火葬已在9月5日辦妥了。

在此我們非常感激您照顧家母的健康及疾病.定當銘記於心。

祝安康愉快

家人 李志明  
李小姐  
9/10/2020

THANKS  
A special note of appreciation



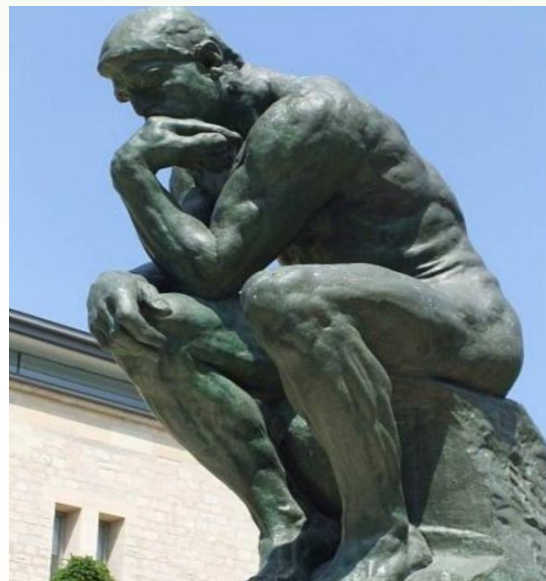
# Story of Ms. CHEUNG

- F/90, sub-vented home resident
- Widowed, 5 children, relationship, good family support
- Recruited into JCECC EOL program in 11/2017 due to advanced dementia
- Bedbound, BADL dependent, assisted oral feeding
- Family opted for comfort hand feeding and DNACPR/not for NIPPV in case of futile resuscitation
- On 15/11/2019, being called to see Ms. Cheung in RCHEs since decrease oral intake and fluctuating mental state
- Family conference held in RCHEs, ACP confirmed and preferred to receive care at RCHEs instead of admission
- EOL service initiated, psychiatric drugs and unnecessary drugs were off
- GC improved and discharged from EOL room on 17/11/2019
- 2 admissions in 03/2020 and finally admitted on 21/07/2020 and pass away on 12/08/2020

## 醫生

“幫助病人善終本來就是醫師的責任之一”

黃勝堅醫生



## 顧死

I think therefore I am  
我思故我在 ~ *Rene Descartes*

*Faith*  
makes all things possible.

*Hope*  
makes all things work.

*Love*  
makes all things beautiful.

So now faith, hope, and love abide, these three;  
but the greatest of these is love.

Corinthians 13:13

所以現在常存的有信、望、愛這三樣; 而其中  
更大的是愛。(哥林多前書 13:13)

I think therefore I am  
我思故我在 ~ *Rene Descartes*



**Every good conversation starts with good listening.**



Listen with your...

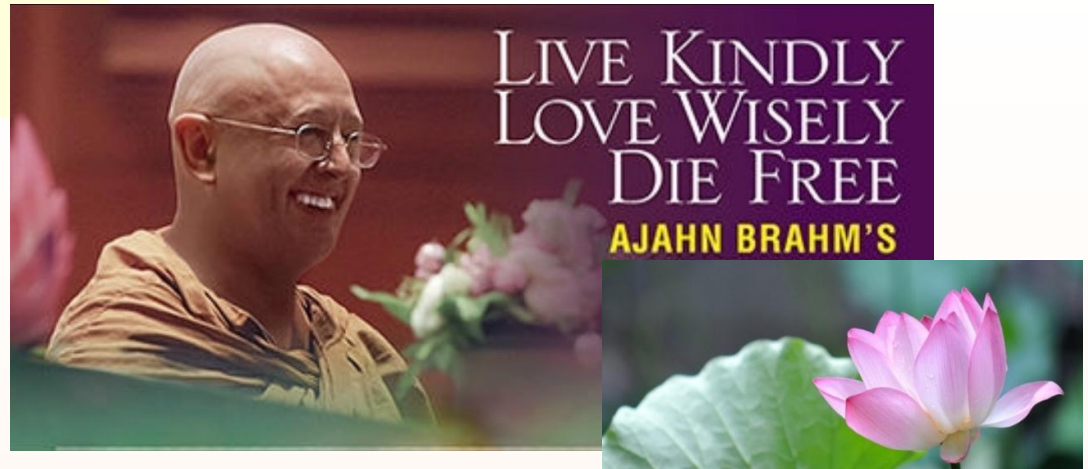




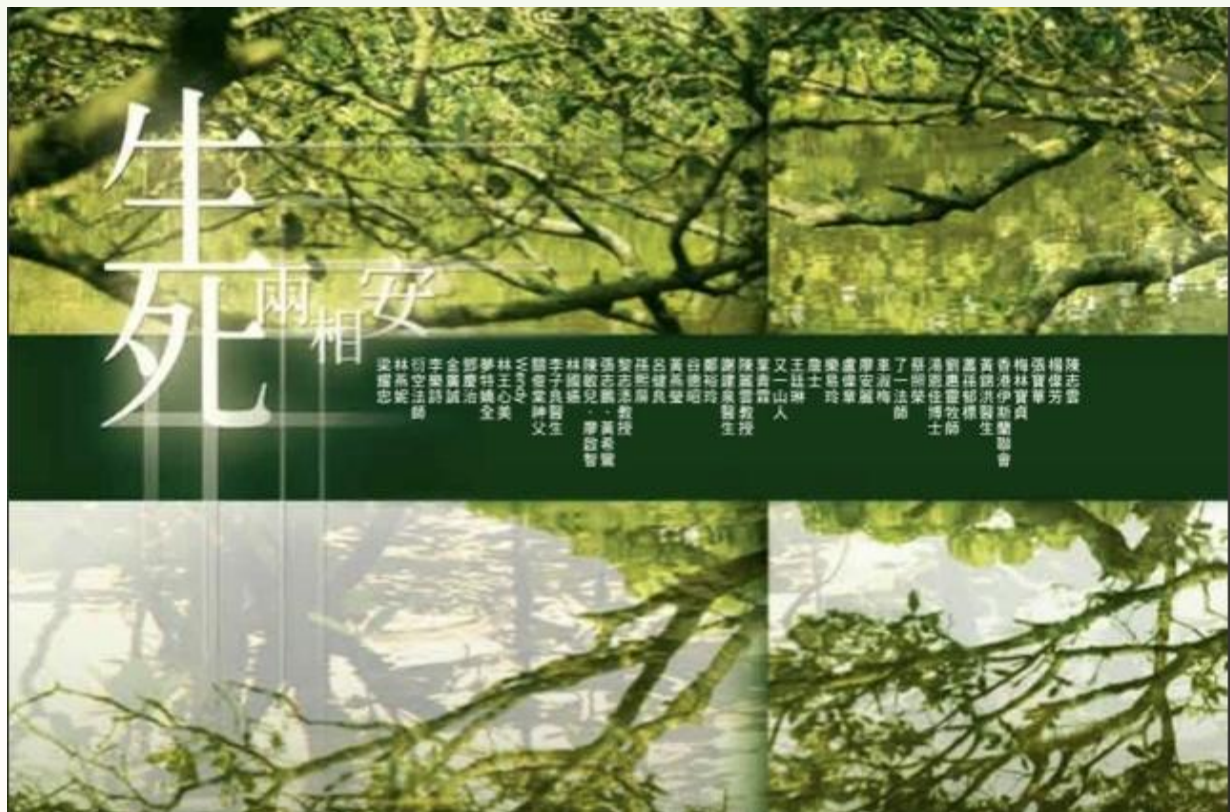
# I think therefore I am 我思故我在 ~ *Rene Descartes*

Don't let go too soon  
but don't hold on too long

-Tuesdays with Morrie-  
*miseriadulce.tumblr*



# I think therefore I am 我思故我在 ~ Rene Descartes



黃勝堅說，  
安寧其實是「生死兩相安」，臨走時道歉、道謝、道愛、道別，修補生命裂痕、化解恩怨情仇，病人帶著微笑安心地走，活著的人也沒有遺憾，這樣的死亡照護更能激發社會正能量。



# Thank you



此圖摘自幾米《奔向春天的下午》

## Acknowledgement

1. Hong Kong Jockey club Charities Trust
2. HKAG
3. HA CGAT teams
4. RCHEs staff
5. Patients and their family

