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JCEcc

Jockey Club End-of-Life Community Care Project

友愛伴行：社區照顧團隊的支援非癌症晚期疾病家庭的角色

「賽馬會安寧頌」計劃總監及香港大學思源基金講座教授(健康及社會工作學)
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「賽馬會安寧頌」計劃高級訓練主任馮曉青博士

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The Hong Kong Jockey Club Charities Trust
同心同步同建 RIDING HIGH TOGETHER

合作院校 Partner Institution:

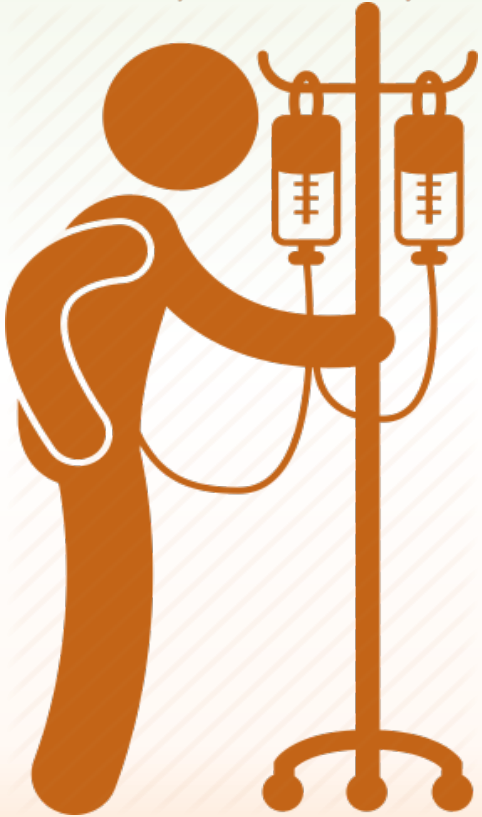
Faculty of Social Sciences
The University of Hong Kong
香港大學社會科學學院

香港長期病患者人口？

2013年，全港估計有

1 375 200名長期病患者

<15	15-39	40-59	60-69	>=79
2.8%	6.1%	32.8%	93.4%	75.7%



HKSAR (2014). Special Topics Report No. 62.

香港長期病患者的需要

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日常生活35萬人

打理家務
20.2萬人

交通出外
14.6萬人

醫療/復康
13.4萬人

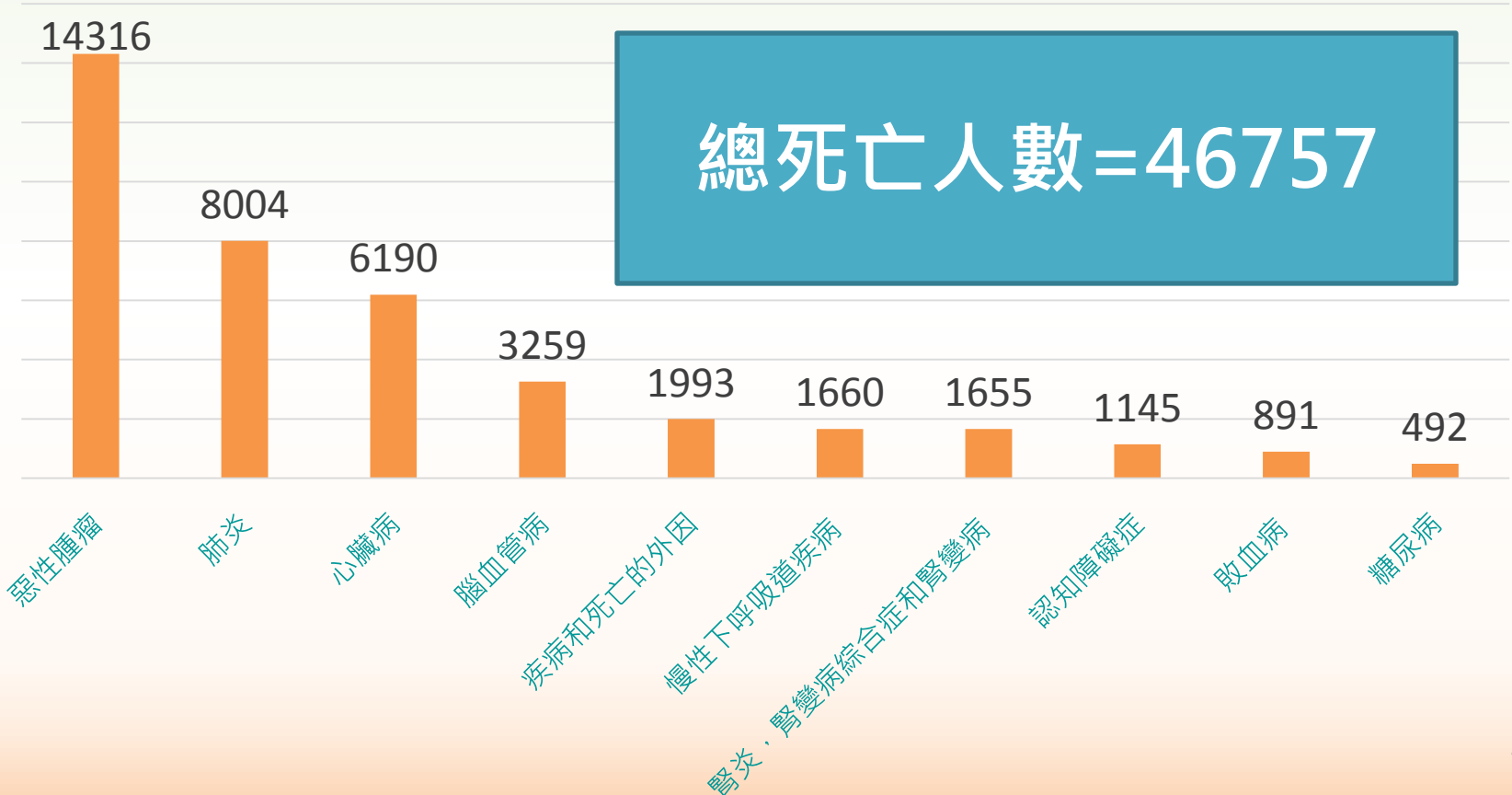
社區生活
11萬人

住宿5.6萬人

工作/學習
1.7萬人

HKSAR (2014). Special Topics Report No. 62.

香港大部份人死於...



總死亡人數=46757

安寧照顧

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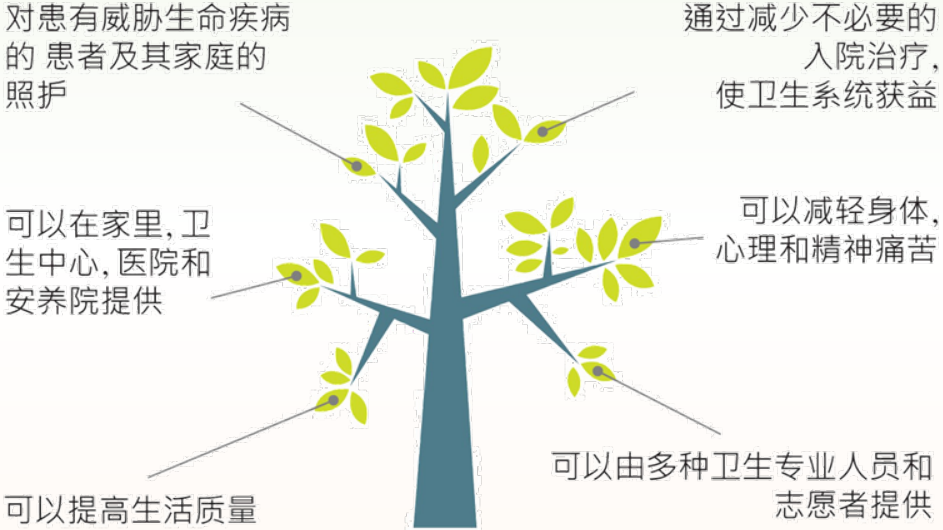
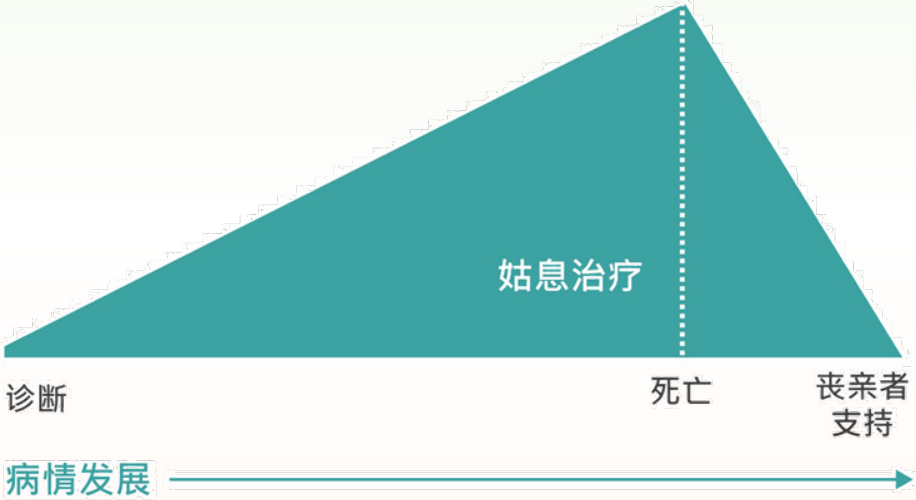
- 安寧照顧服務...由病人確診患有**不可逆轉的疾病**至過身的階段，大約**1年到6個月**的時間，透過**止痛、舒緩症狀治療、心理和精神支援**，改善**病人和家人**生活質素，從而令病人活得有尊嚴。

長期病患到晚期生命...





WHO (2017)

安寧照顧的需要

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wpca
worldwide palliative care alliance

World Health Organization

Global Atlas of Palliative Care at the End of Life

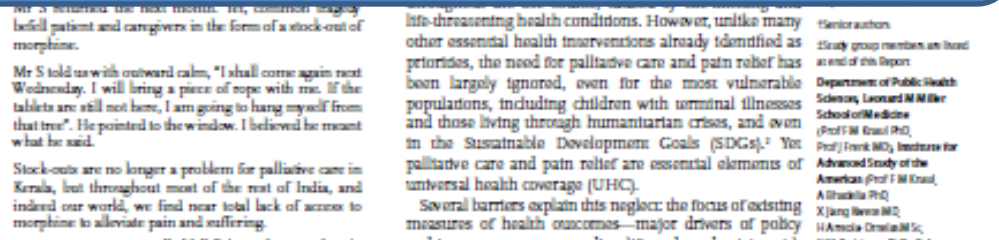
基於18種病類的疼痛出現率，估計有70%晚期人需要安寧照顧；而需要安寧照顧的長期病人人數估計為兩至三倍

The Lancet Commissions

Alleviating the access abyss in palliative care and pain relief—an imperative of universal health coverage: the *Lancet* Commission report

Felicia Marie Knaul, Paul E Farmer*, Eric L Krakauer*, Liliana De Lima, Afsan Bhadelia, Xiaoxiaojiang Kwete, Héctor Arreola-Ornelas, Octavio Gómez-Dantés, Natalia M Rodriguez, George A O Alleyne, Stephen R Connor, David J Hunter, Diederik Lohman, Lukas Radbruch, Maria del Rocío Sáenz Madrigal, Rifat Atun†, Kathleen M Foley†, Julio Frenk†, Dean T Jamison†, M R Rajagopal†, on behalf of the Lancet Commission on Palliative Care and Pain Relief Study Group‡

基於20種病類的健康相關痛苦出現率，估計2015年有45%玳亡個案需要安寧照顧；6100萬人出現健康相關痛苦



befell patient and caregivers in the form of a stock-out of morphine.

Mr S told us with outward calm, "I shall come again next Wednesday. I will bring a piece of rope with me. If the tablets are still not here, I am going to hang myself from that tree". He pointed to the window. I believed he meant what he said.

Stock-outs are no longer a problem for palliative care in Kerala, but throughout most of the rest of India, and indeed our world, we find near total lack of access to morphine to alleviate pain and suffering.

life-threatening health conditions. However, unlike many other essential health interventions already identified as priorities, the need for palliative care and pain relief has been largely ignored, even for the most vulnerable populations, including children with terminal illnesses and those living through humanitarian crises, and even in the Sustainable Development Goals (SDGs).[2] Yet palliative care and pain relief are essential elements of universal health coverage (UHC).

Several barriers explain this neglect: the focus of existing measures of health outcomes—major drivers of policy

†Senior authors

‡Study group members are listed at end of this Report

Department of Public Health Sciences, Leonard M Miller School of Medicine (Prof F M Knaul PhD, Prof J Frenk MD), Institute for Advanced Study of the Americas (Prof F M Knaul, A Bhadelia PhD, X Jiang Kwete MD, H Arreola-Ornelas MSc,

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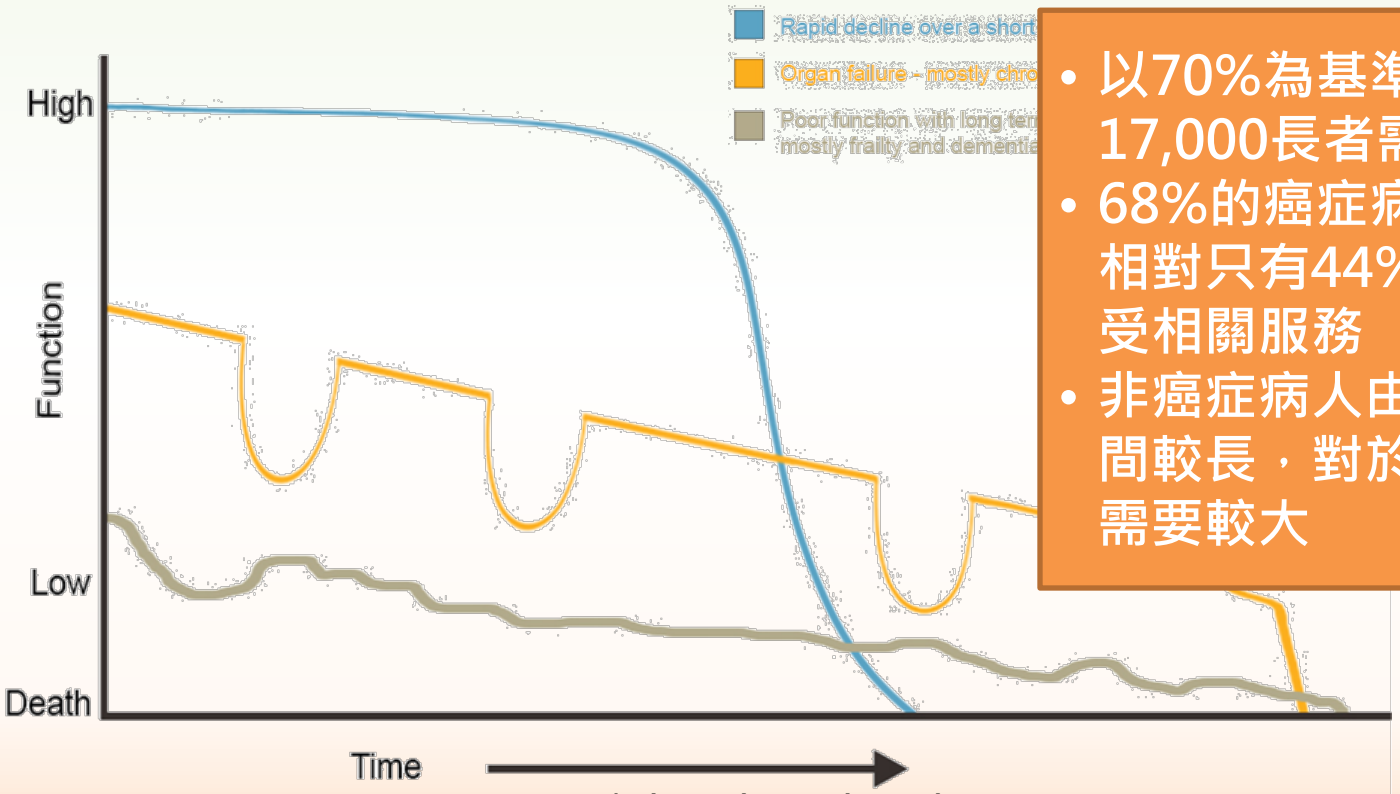

- 以70%為基準，香港每年有17,000長者需要安寧照
- 68%的癌症病人得到紓緩照顧，相對只有44%晚期腎病病人接受相關服務
- 非癌症病人由確診至死亡的時間較長，對於醫療及社區服務需要較大

Murray, et al. (2005); HA (2017). Strategic Service Framework for Palliative Care

全面的安寧照顧
Palliative Care for All

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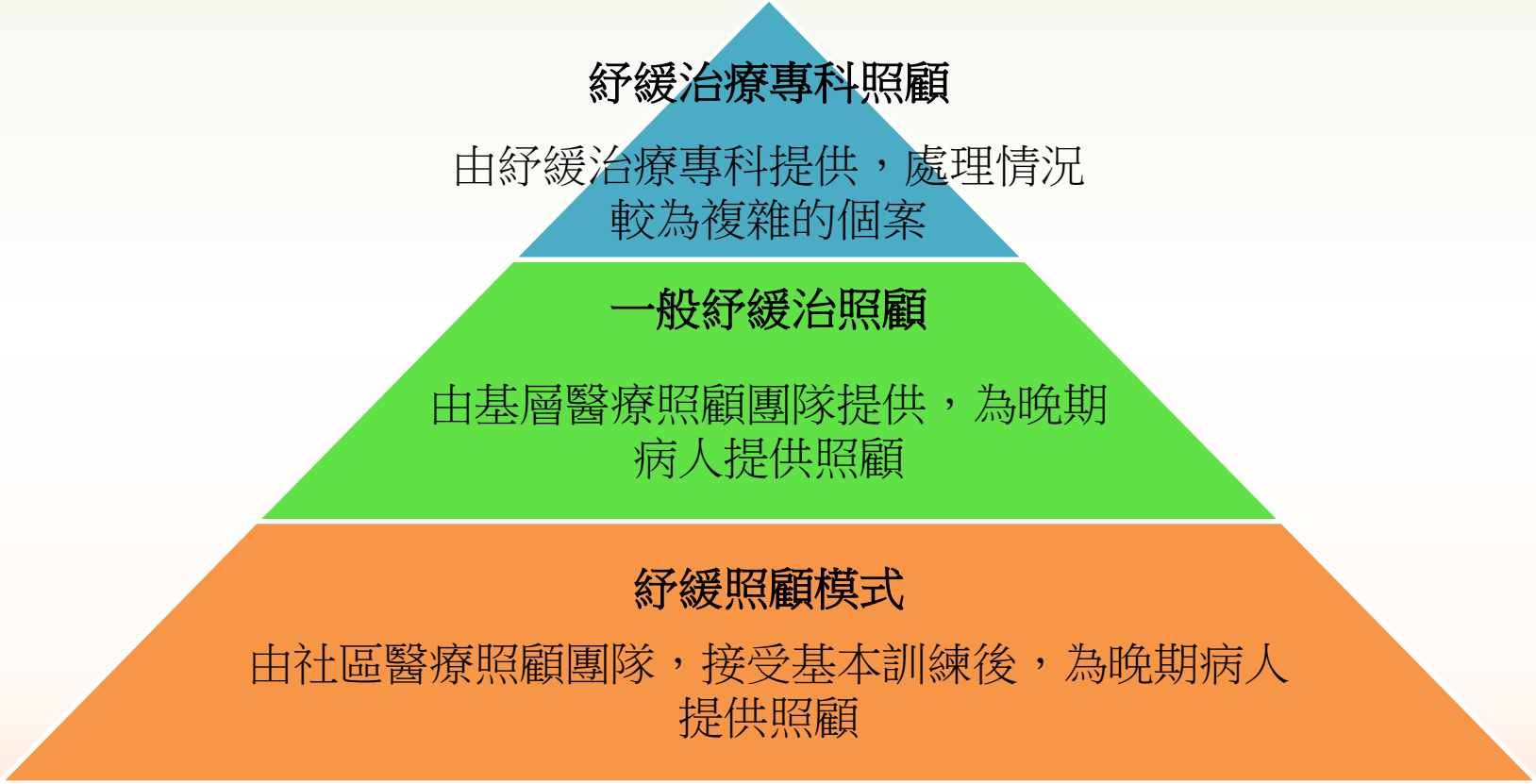

Gomez-Batiste & Connor (2017)

全面的安寧照顧
Palliative Care for All

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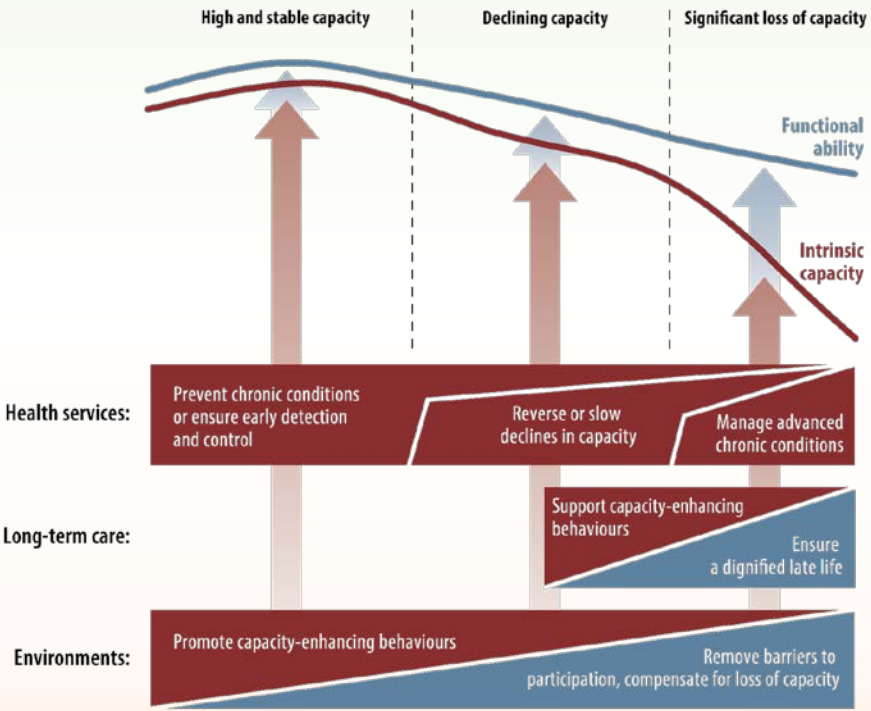
- Comprehensive Care
- Integrative community approach
- Team-based approach

Palliative Care Bow Tie Model

Hawley (2014). The Bow Tie Model of 21 Century Palliative Care



WHO (2017)

安寧照顧自主自決

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- 2015年的英國國民調查發現，晚期生命的抉擇主要圍繞七個主題：

在哪裡接受照顧？在哪裡過身？

自己可以參與照顧決定嗎？

自己可以選擇有質素的照顧服務？

自己可以選擇適合自己的服務嗎？

自己可以選擇身心社靈全人照顧嗎？

自己可以選擇讓誰人知道自己的意願嗎？

自己可以選擇誰人可以參與照顧決定嗎？

NHS England (2015)

安寧照顧自主自決

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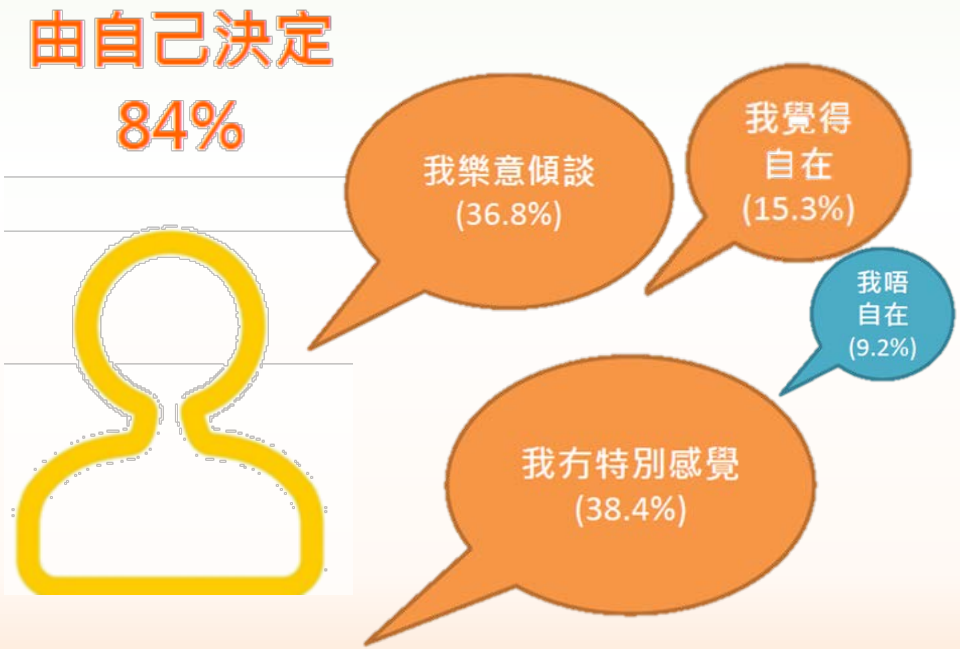
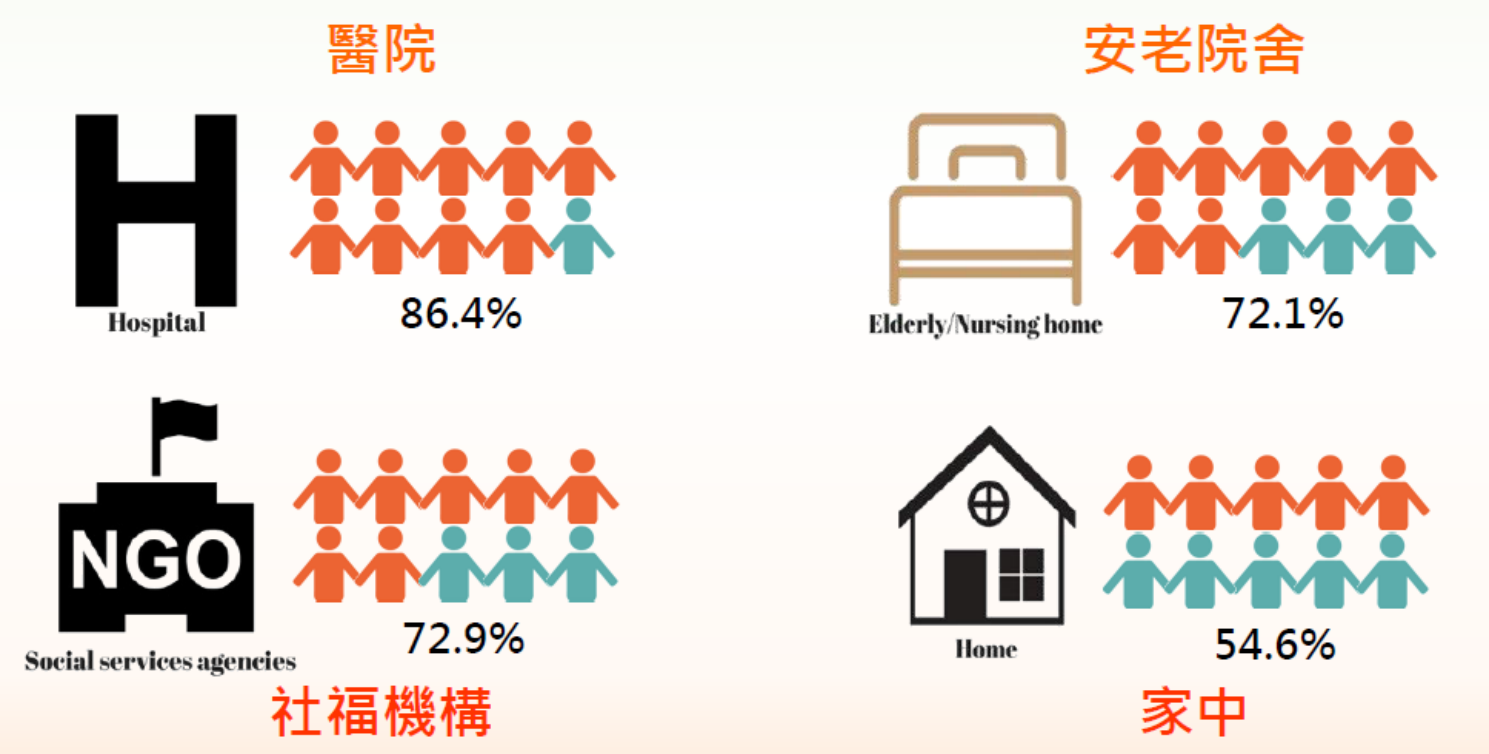
- 自在談死．自主自決



10人中有7人會選擇簽立預設醫療指示、接受安寧照顧及離世的地方

安寧照顧自主自決

- 安寧照顧在社區



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發展社區安寧照顧模式

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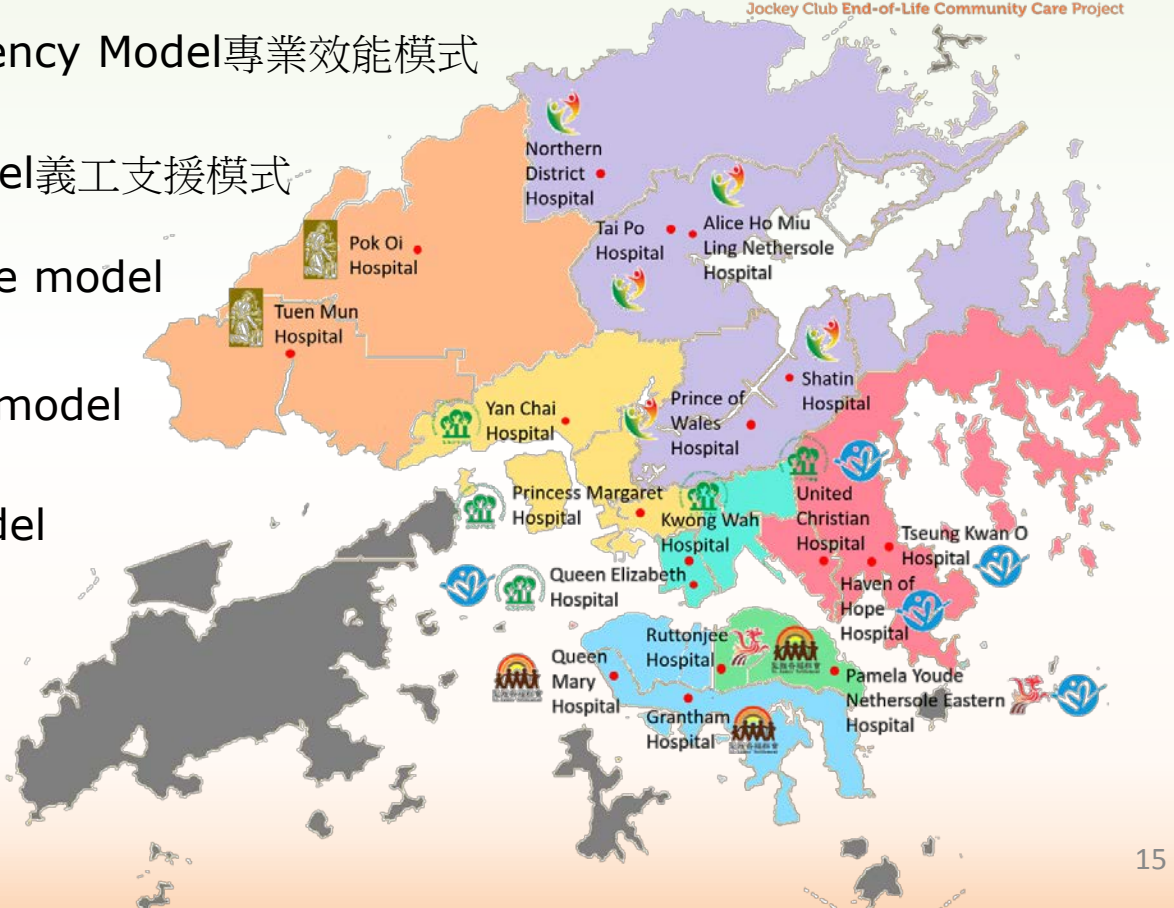
- Professional Competency Model專業效能模式
- Volunteer-based Model義工支援模式
- Residential home care model 院舍照顧模式
- Assisted family-care model 家庭協作模式
- Community-care model 社區照顧模式
- Non-cancer model 非癌症照顧模式



安寧照顧人力資源的重新理解

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家居安寧照顧：

- 每100,000 人口需要3位醫生、12位護士和6位照顧同工

住院照顧：

- 每10位病人需要1.5位醫生、15.5位護士和4位照顧同工

還有...額外25%的行政和管理同工

社區＝???

Gomez-Batiste & Connor (2017)

安寧照顧人力資源的重新理解

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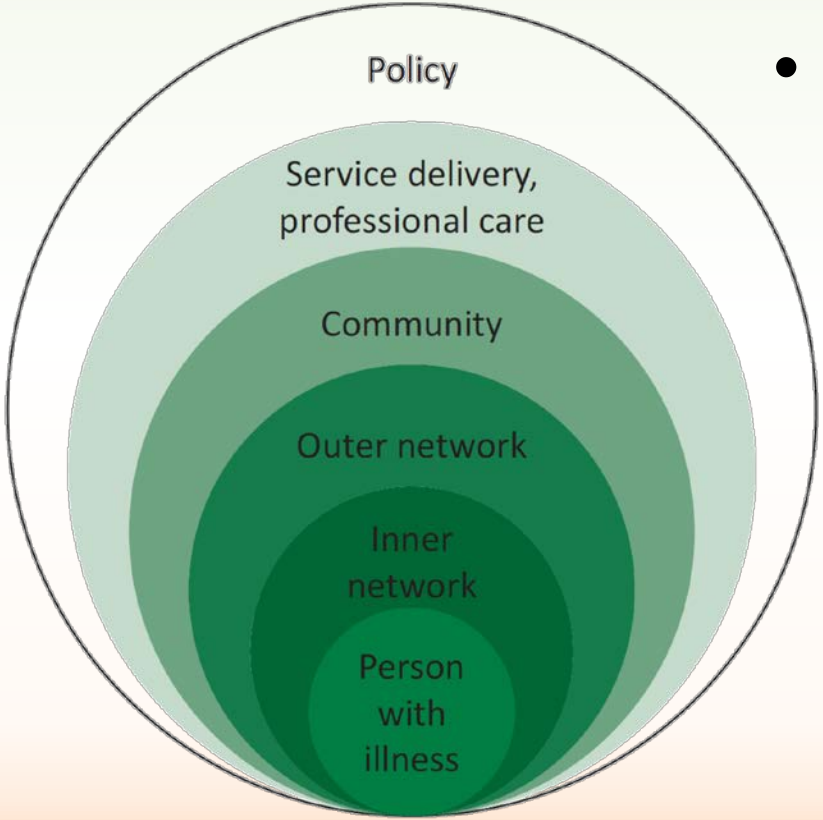
- 社區上人人都是資源，人人都是專家
  - 病人：自己身體狀況和照顧、生活意願的「專家」
  - 家人：最了解病人生活習慣，捍衛病人權益的「領導人」
  - 鄰里/社區/義工：提供社交支援，熟悉社區資源的「百寶袋」
- 安寧照顧「去專業化」

關愛社區，照顧網絡



- 建構關愛社區，強化照顧網絡
  - 內在照顧網絡：3至5位家人朋友，提供病生理需要、症狀管理、陪伴和情緒方面的照顧
  - 外在照顧網絡：支援內在照顧網絡，由其他家人朋友、專業照顧團隊組成，支援日常生活如家務等

人人都是專家

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Tier 1 — Those that require general end of life care awareness, focusing on a community development, asset based approach to care.

This tier outlines the knowledge and skills that will support individuals accessing end of life care, as well as their family, friends and carers, to ensure they are making the most of the support on offer and are able to plan effectively for their own current and future care needs. This tier is also relevant to those working in health and social care who have limited contact with individuals approaching the end of life.

A community development, asset-based approach to care encourages individuals to look beyond traditional care provision, ask 'what is important to me?' and how this could be achieved alongside care and support from health and social care professionals. This might include: the strengths and abilities of individuals approaching the end of life; the strengths and abilities of their family, friends, loved ones and carers; and the potential of the community to provide care and support.

The tier will be relevant to you if:

- You are a member of the public
- You have been diagnosed with a life limiting condition
- You support someone with a life limiting condition
- You work in the adult health and social care sector but have limited contact with anyone approaching the end of life. For instance, you might deliver care and support in ophthalmology or physiotherapy, or may be in a role that doesn't deliver care and support such as administration or maintenance.

End of Life Care
Core Skills Education and Training Framework

This framework was commissioned and funded by Health Education England and developed in collaboration with Skills for Health and Skills for Care.

Skills for Health
skillsforcare
NHS Health Education England

「專家」都有需要

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安寧照顧—共建關愛社區

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有您幫助的堅持

安寧照顧—共建關愛社區

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https://www.facebook.com/DeathFestHK/?fref=ts

國際學術會議

- 2017: 390位參加者
- 2018: 500+位參加者

專業培訓

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Policy roundtable & executive forum

Leadership Training Programme

Professional Training Workshops

出版刊物

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公眾/媒體活動

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心安·家寧

有您幫助的堅持

承諾·諾行

流動應用程式

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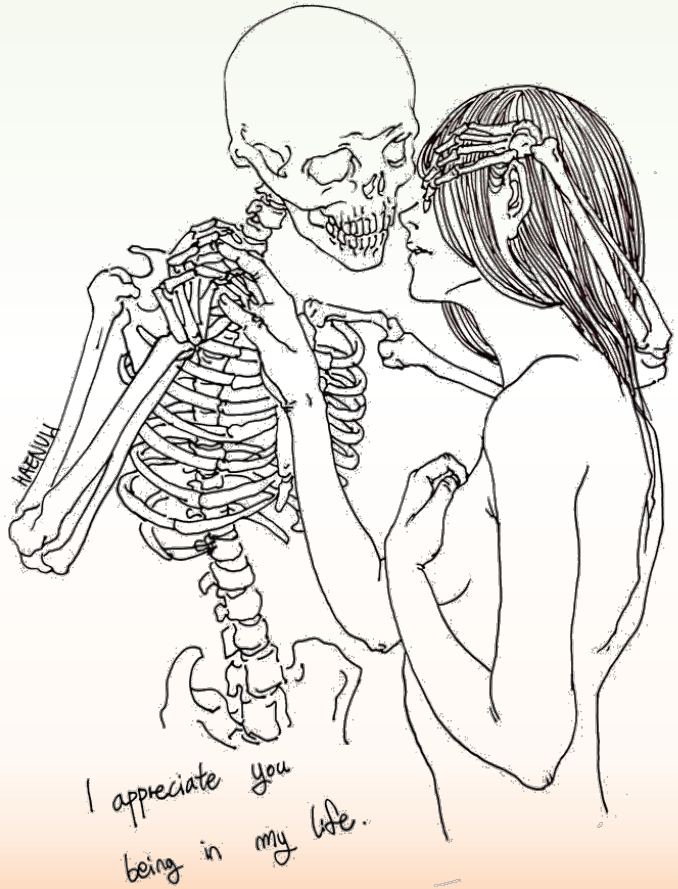

多謝！

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