



公眾教育講座- 心安家寧循證系列
同行安寧照顧路：探索與啟示
講題：愛自己 = 愛家人

賽馬會安寧頌講師
馮廣榮先生(MSW, RSW, FT)
21/6/2023 2:30-3:30 pm



策劃及捐助 Initiated and funded by:



香港賽馬會慈善信託基金
The Hong Kong Jockey Club Charities Trust

合作夥伴 Project Partner:



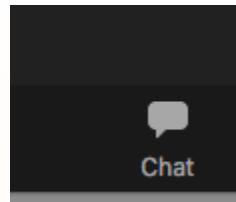
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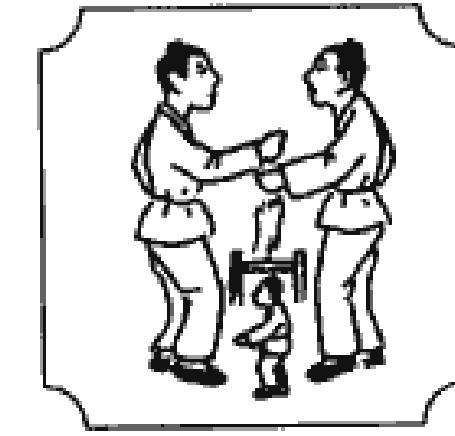
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講座目標

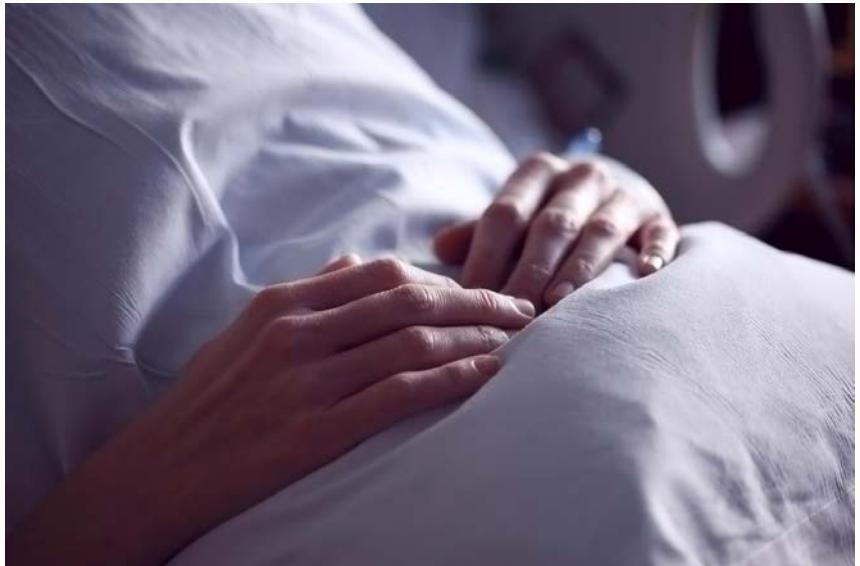
晚期病人與家人的情緒互為影響，有效地溝通和回應雙方的關注，可減輕兩者在安寧照顧歷程上的壓力。從簡介本計劃研究，提出如何回應家庭中彼此的關注，達至心安家寧。



講座流程

- 簡介部分本計劃研究內容重點
- 回應照顧者的關注：做什麼？講什麼？
- 晚晴溝通小貼士

正面的臨終關懷的因素？



這麼近？

那麼遠？

就欠一點點

Pic @ Pixabay

促進社區臨終關懷正面成果的因素：

對病人和家庭照顧者的橫斷面質性研究

Original Article

**Factors facilitating positive outcomes in community-based end-of-life care:
A cross-sectional qualitative study of patients and family caregivers**



Palliative Medicine
2021, Vol. 35(6) 1181–1190
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DOI: 10.1177/02692163211007376
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Keyuan Jiao¹ , Amy YM Chow^{1,2}, Juan Wang¹ and Iris IK Chan²

目的：從病人和家庭照顧者的角度探討在社區環境中促進正面的臨終關懷的因素以及如何在實踐中實現這些因素。

結果：確定了七個核心主題：

- 1. 對關係的積極情緒
 - 2. 對關係的積極評價
 - 3. 通過**詢問受援者**的情況進行護理
 - 4. 護理的**工具性**（即資訊、護理指導、實際說明、心理支持，多種活動）
 - 5. 護理的**全面性**（即多樣性，死亡后的照顧，家庭層面的福祉）
 - 6. 護理的**結構**（即及時跟進，完善的系統）
 - 7. 工作者的質素
-
- 1. positive emotions about the relationship
 - 2. positive appraisals of the relationship
 - 3. care through inquiring about recipients' circumstances
 - 4. instrumentality of care (i.e. information, coaching on care, practical help, psychological support, multiple activities)
 - 5. comprehensiveness of care (i.e. diversity, post-death care, family-level wellbeing)
 - 6. structure of care (i.e. timely follow-up, well-developed system)
 - 7. qualities of workers

研究內容啟示 - 1

- Service recipients' emotional reactions and cognitive perceptions toward the relationship with care providers, rather than the relationship, are expected to have positive impact.
- 服務接受者對與護理提供者的關係的情緒反應和認知感知，而不是關係，預計會產生正面影響。

研究內容啟示 - 2

- The instrumentality, comprehensiveness and the structure of care are considered as important components of care facilitating positive outcomes.
- 工具性、全面性和護理結構被視為促進護理積極成果的重要組成部分。

研究內容啟示 - 3

- Holistic inquiries by service providers about service recipients' circumstances are not considered as a burden but are perceived as a major factor contributing to high quality care.
- 服務提供者對服務接受者情況的全面詢問不被視為負擔，而是被視為促進高質量護理的主要因素。

- 什麼是照顧者壓力？



Pic @ Pinterest

重新定義香港臨終關懷家庭照顧者的照顧壓力



Palliative and Supportive Care

cambridge.org/pax

Original Article

*This article has been updated since its original publication. See <https://doi.org/10.1017/S147895152300072X>.

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End-of-life care; Modified caregiver strain index; Caregiver strain; Family caregivers; Caregivers' burden

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Redefining caregiver strain for family caregivers in end-of-life care in Hong Kong

Amy Yin Man Chow, PH.D.^{1,2} , Genevieve Ataa Fordjour, PH.D.² , Keyuan Jiao, M.A.P., PH.D. CANDIDATE¹, Nahri Jung, PH.D.², Iris Kwan Ning Chan, B.S.W.² and Chak Nam Kuok, B.SOC.SC. (HONS) IN SOCIOLOGY²

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Abstract

Objectives. Caregiving for family members at their end of life is stressful. Caregivers' strain, burden, or stress has been measured in various geographical and sociodemographic contexts. The concept of stress, burden, and strain are sometimes used interchangeably. By analysing the factor structure of the Chinese version of the Modified Caregiver Strain Index (C-M-CSI), this study aimed to examine the caregiving strain concept and its demographic correlates.

Methods. A sample of 453 family caregivers of patients with a terminal illness in Hong Kong was employed. Exploratory factor analysis (EFA) and confirmatory factor analysis (CFA) were performed. In addition, generalized linear models (GLM) were used to examine the demographic correlates.

Results. The EFA yielded a 3-factor model termed "Perception of Caregiving," "Empathetic Strain," and "Adjustment Demand." This 3-factor model explained 50% of the variance and showed good internal consistency. The CFA confirmed the 3-factor construct with satisfactory internal reliability ($\chi^2 [61, N = 226] = 108.86, p < 0.001$, CFI = 0.96, TLI = 0.95, SRMR = 0.04, and RMSEA = 0.06). Inspired by this factor structure and concepts of stress and strain from engineering discipline, a new model of caregiver strain is proposed. Additionally, family caregivers of non-cancer patients, who were not living with the patient, or younger were associated negatively with different dimensions of caregiver strain.

Significance of results. The results gave insights into the advancement of the conceptualization of caregiver strain, its multidimensional nature, and process of change, which inform directions for future research and practices.

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stress

noun

B1 [C or U]

great worry caused by a difficult situation, or something that causes this condition

緊張，壓力；造成緊張的因素

賽馬會安寧頌



burden

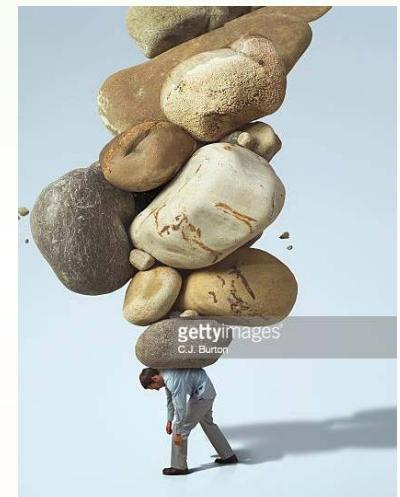
noun [C]

a heavy load that you carry

負荷，重負

C1

something difficult or unpleasant that you have to deal with or worry about



strain

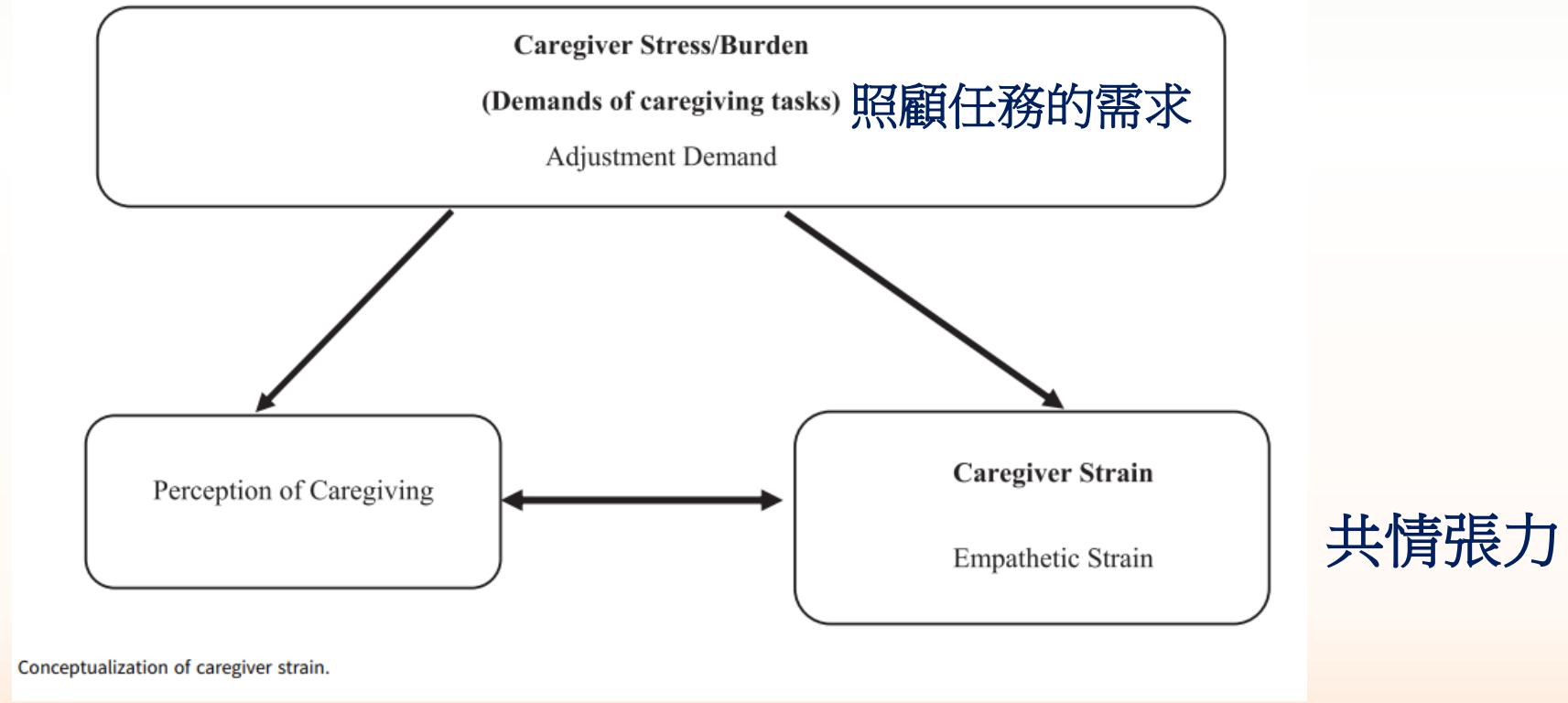
noun

a force or influence that stretches, pulls, or puts pressure on something, sometimes causing damage

壓力；拉力，張力；作用力



- caregiver stress as the external force, which brings about the changes in various forms of caregiver strain and consequently affects the health outcomes and quality of life of the caregiver.
- 照顧者壓力作為外力，會帶來照顧者各種形式的應變變化，從而影響照顧者的健康狀況和生活質量



- Family caregivers of ages below 60 years were more likely to experience adjustment demand, as they often have to fulfill other family duties (e.g., childrearing) or work-related responsibilities, which may generate inter-role conflicts
- 60 歲以下的家庭照顧者更有可能經歷調整需求，因為他們經常需要履行其他家庭責任和工作相關的責任，這可能會產生角色間衝突

(Boumans and Dorant 2021).

- If the definition of caregiver strain is the change in the individual after resuming the caregiver role, then this study postulates that caregiver strain would have negative, neutral, and positive dimensions.**(壓力具有負面、中性和正面維度)**
- feeling of being torn, or other positive ones, such as contentment
(負面感覺：例如被撕裂的感覺，其他積極的感覺：例如滿足感覺)

- caregivers share a universal empathetic strain. there is universal emotional suffering faced by the caregivers of patients with a terminal illness, which should not be overlooked.
- 照顧者都有一種普遍的同理心壓力。照顧者普遍面臨著情感上的痛苦，這一點不容忽視。

為何要自我照顧

- 照顧病人身心靈的需要，亦可令我們身心靈乾竭。
- 我們及我們身邊的人都應該有愉快的生活。
- 令我們能繼續敏銳地聆聽到病人。

壓力與身體疾患

系統	症狀
神經系統	頭痛、頭暈、耳鳴、怕聲浪、手震、手腳麻痺、手汗、無力、易倦、失眠、身體各部分的神經痛。
心臟系統	心跳急促、心跳不規則、心跳力大、胸口痛、血壓上升、血壓下降。
呼吸系統	呼吸急促、胸口痛。
腸胃系統	食慾不振、口乾、哽咽、胃痛、胃氣、作悶、嘔吐、肚痛、肚瀉、便秘、頻便、排便不清。
腎系統	頻尿、排尿困難、排尿不清。
生殖系統	經期失調、性機能失調。

香港心理衛生會 (2006)

照 顧 者 壓 力 自 我 測 驗



請您在看了下列**14**項敘述後，就您實際上照顧的情況，圈選後面的分數。
(如：若您很少感到疲倦，就圈**1**分的位置)

	從 未	很 少	有 時	常 常
1. 您覺得身體不舒服(不爽快)時還是要照顧他	0	1	2	3
2. 感到疲倦	0	1	2	3
3. 體力上負擔重	0	1	2	3
4. 我會受到他的情緒影響	0	1	2	3
5. 睡眠被干擾(因為病人在夜裡無法安睡)	0	1	2	3
6. 因為照顧他讓您的健康變壞了	0	1	2	3
7. 感到心力交瘁	0	1	2	3
8. 照顧他讓您精神上覺得痛苦	0	1	2	3
9. 當您和他在一起時，會感到生氣	0	1	2	3
10. 因為照顧家人影響到您原先的旅行計畫	0	1	2	3
11. 與親朋好友交往受影響	0	1	2	3
12. 您必須時時刻刻都要注意他	0	1	2	3
13. 照顧他的花費大，造成負擔	0	1	2	3
14. 不能外出工作家庭收入受影響	0	1	2	3

總 分



【沙氏負荷量表 - 簡化版】

照顧者壓力評估

請把最正確形容你的感受的空格內打✓。

* 1. 你有沒有感到因花了時間在這親人身上，而使自己時間不足夠呢？

- 從沒有 很少 間中 頗多 經常

* 2. 你有沒有因為要照料這親人，又同時要應付家庭和工作上的種種責任而感到有壓力呢？

- 從沒有 很少 間中 頗多 經常

* 3. 當你親人在你左右時，你會否感到緊張呢？

- 從沒有 很少 間中 頗多 經常

* 4. 你有沒有感到不能肯定你能為你的親人做什麼事呢？

- 從沒有 很少 間中 頗多 經常

先照顧自己，再照顧家屬



回應照顧者的關注



1. 促進病人與家人間的正面關係 → 病人與家人共創美好時光-
→ 我們可以一起**做什麼**？

2. 促進病人理解自己不是家庭中的負累 → 拉近彼此的溝通方
法 → 我們可以一起**講什麼**？

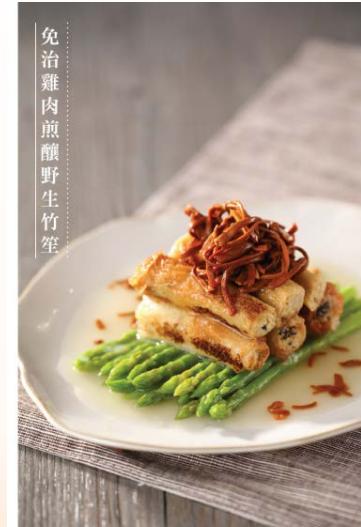
- 食
- 玩
- 傾



(Kinder網頁圖片)

食

- 嘳起美好回憶
- 慶祝的方式
- 表達關懷的媒介
- 安慰能手(comfort food)



賽馬會安寧頌
JCEccc
Jockey Club End-of-Life Community Care Project

晚晴心語
✿ 餵饌日常 ✿

食譜及心情故事分享

策劃及捐助:

香港賽馬會慈善信託基金

合作院校:

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

讓吞嚥困難者吃得有尊嚴



日本製照護軟餐

日本通用設計食品(UDF)分類

等級1	牙齒易咬碎類：咀嚼較大塊和堅硬的食物有點困難、正常吞嚥的長者
等級2	牙齦可壓碎類：咀嚼較大塊和堅硬的食物十分困難、吞嚥部分食物會有點困難的長者
等級3	舌頭可壓碎類：只能咀嚼細碎及柔軟食物、吞嚥水或茶時有點困難的長者
等級4	毋須咀嚼類：咀嚼細碎及柔軟食物，以及吞嚥水或茶時感困難的長者

(明報製圖)

五味人生

- 甜
- 酸
- 苦
- 辣
- 甘



愛之語
測驗

真心的禮物

透過送禮物來表達愛

精心的時刻

專屬於愛人的陪伴時間

服務的行動

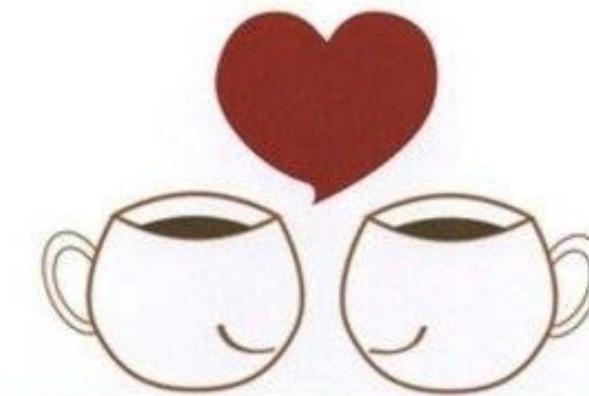
為對方做事情，比如幫忙分擔家務、跑腿等

肯定的言語

說出正向和肯定的話語給對方聽

身體的接觸

以實際的肢體碰觸溝通彼此的愛



The Five
love languages

How to Express Heartfelt Commitment to Your Mate

兩性溝通的雙贏策略

5

種愛的言語：

肯定的言詞

精心的時刻

接受禮物

服務的行動

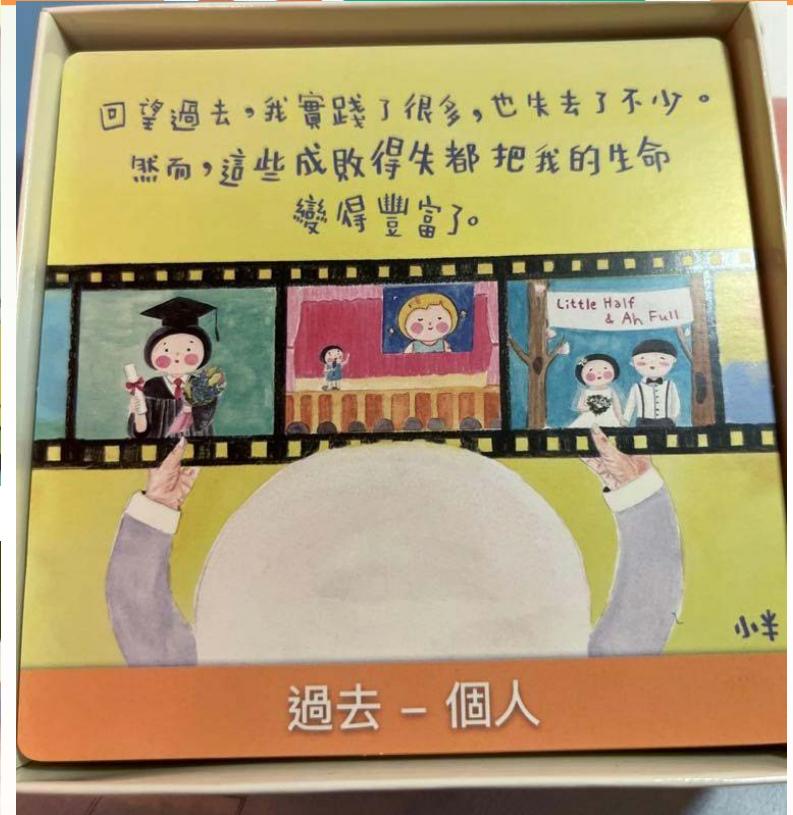
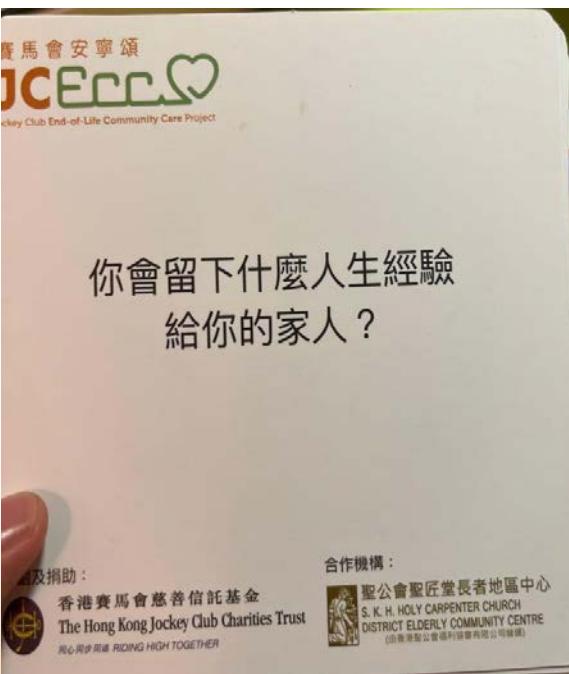
身體的接觸

桌上小遊戲



@東華三院圓滿人生服務

我的時光寶盒



賽馬會安寧頌
JCECC

【照顧者快樂時光】卡片集 "Happy Times Card" Set



照顧途中**需要**小確幸

We **NEED** "little happiness" when taking care

照顧途中**選擇**小確幸

We **CHOOSE** "little happiness" when taking care

照顧途中**實現**小確幸

We **ACHIEVE** "little happiness" when taking care



Hosted by : Sau Po Centre on Ageing

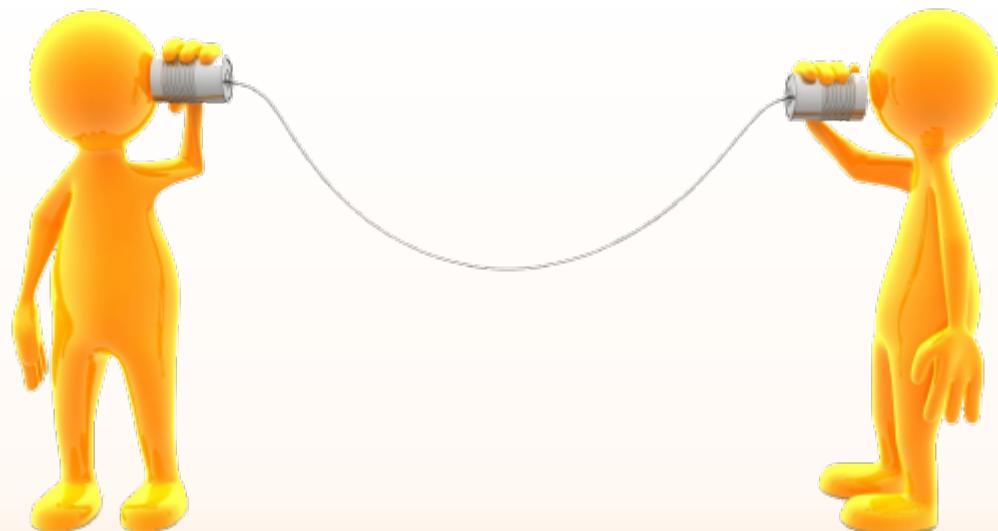
<https://onlinepytsysprd.feo.hku.hk/event/110259>



<https://www.caregiving.hku.hk/>

晚晴溝通小貼士

- 照顧意願
- 照顧評估
- 時、地、人，事、情



為無法言說的人說話SPEAK for the Unspeakable

- 我知道
- 我記到
- 我揀到
- 我講到



溫馨提示(一)

- 情緒本身不分好與壞，沒有應該與不應該，只是有或沒有出現。
- 情緒不是一項工程，沒有先後次序，有時會同時出現，有時會反覆來回。

溫馨提示(二)

- 理解每位家屬有着自己的經歷及成長背景，接受他們有着不同的情緒反應、表達方式及時間的長短。
- 同樣，照顧者也有着自己的感受，可透過不同渠道去紓發，以增加及延續自己的正能量。

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預設照顧計劃—「預」埋您： 真人圖書館故事分享

第三回

Advance Care Planning in End-of-Life Care: Human Library Sharing Session

Episode 3

預設照顧計劃 (Advance Care Planning - ACP) 是指病人在仍有決定能力時，與家人和醫護人員溝通，商討日後不能自決時所採用的醫療和照顧計劃。制定預設照顧計劃，病人便可按照自己的價值觀和意願，選擇要接受怎樣的治療和護理。雖然預設照顧計劃主要由醫護人員/社工與家人/病人溝通而制定，然而安寧義工在協調溝通以及照顧病人身心靈需要方面亦同樣重要。「真人圖書館故事分享」第三回邀請了「賽馬會安寧頌」「安寧在家」居家照顧支援服務安寧義工周女士Maggie以及服務使用者鳳雲分享安寧照顧經驗和討論預設照顧計劃的心路歷程，亦邀請了香港聖公會福利協會安寧服務總監陳慕寧女士作分享。

2023
30/6
星期五

① 正午12時至下午1時正

講座將以網上形式  及 Facebook Live 舉行



專家分享：
香港聖公會福利協會
安寧服務總監
陳慕寧女士



詳情及報名
www.jcecc.hk/humanlibrary3
活動將以廣東話進行
The event will be conducted in Cantonese



公眾教育

預設照顧計劃—「預」埋您：真人圖書館故事分享（第三回）

日期: 2023年6月30日（星期五）

時間: 正午12時 – 下午1時正

活動簡介：

- 真人圖書館故事分享

「賽馬會安寧頌」「安寧在家」居家照顧支援服務安寧義工及服務使用者

- 專家分享

香港聖公會福利協會安寧服務總監 陳慕寧女士

模式：座談會將以網上直播形式 Zoom 及
JCECC Facebook Live

舉行語言：廣東話

社區安寧全人照顧課程

以網上學習模式輔以面授工作坊
由嘉賓講者教授安寧照顧知識及技巧

基礎單元
進階單元
高階單元

現已推出，請即報名



詳情及登記：

www.JCECC.hk/onlinelearning



證書



CME/CNE/CPD
學分



檢討問卷



https://hku.au1.qualtrics.com/jfe/form/SV_3lw5RP8wlejSCc6



Thank you!

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