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Jockey Club End-of-Life Community Care Project

"Life Rainbow" End-of-life Care Services

Care at Home: Empowerment Approach in End of Life Care Service for Non-cancer Patients and Their Family Members

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捐助機構 **Funded by:**
香港賽馬會慈善信託基金
The Hong Kong Jockey Club Charities Trust
同心同步同進 RIDING HIGH TOGETHER

主辦機構 **Organized by:**
香港復康會
The Hong Kong Society for Rehabilitation

策略伙伴 **Strategic Partners:**
HONG KONG EAST CLUSTER
港島東醫院聯網
東區尤德夫人那打素醫院
內科部、社區及病人資源部

Project Background

香港復康會
The Hong Kong Society for Rehabilitation

抱負 Vision

我們致力成為一所具效能、影響力以及關懷的全人照顧及復康機構。

We aspire to be an effective, impactful and caring organisation in holistic care and rehabilitation.

使命 Mission

透過創新復康服務及賦權殘疾或面對健康挑戰的人士，倡議全人健康、社會參與以及共融有利的環境。

Through innovation in rehabilitation and empowering persons with disabilities or health conditions, we advocate holistic well-being, social participation, and an inclusive and enabling environment.

價值觀 Values

我們信守

We strive to uphold the following values in every one of our actions and interactions:

尊重人 Value People	信任、尊嚴、尊重、平等參與及溝通 trust, dignity, respect, equal participation and communication
專業精神 Professionalism	同理心、優質服務、持續發展、勇於承擔及力臻至善 empathy, quality service, continuous development, commitment and in search of excellence
誠信 Integrity	忠誠、信實及問責 honesty, truthfulness and accountability
充能 Empowerment	自主、自強及參與公共政策 having control, self-management and participation in public policy
共融 Inclusiveness	尊重多元化、以權責為本 respect diversity and right-based approach

"Life Rainbow" End-of-Life Care Services
「安晴・生命彩虹」社區安寧照顧計劃

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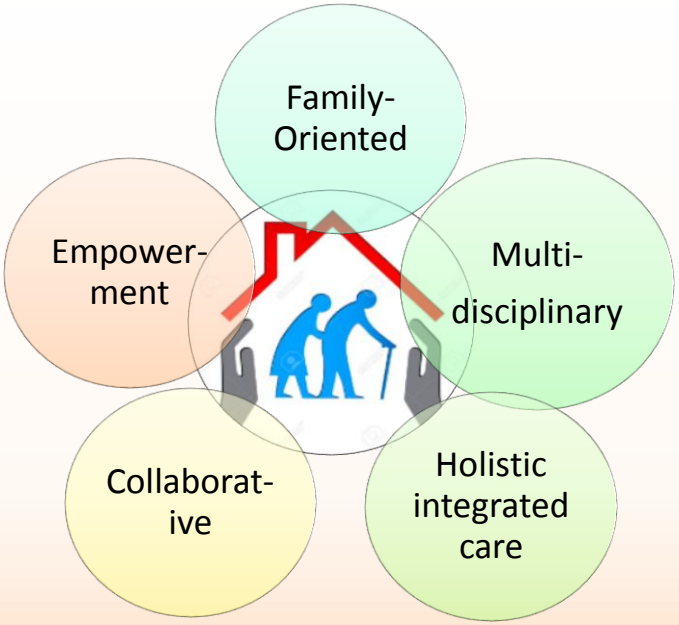
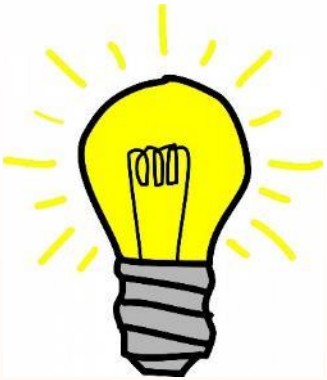
- Funded by **The Hong Kong Jockey Club Charities Trust**
- Strategic partnership with **The Hong Kong East Cluster of the Hospital Authority**
- Research and model building support by **The University of Hong Kong**
- Organized by **The Hong Kong Society for Rehabilitation (HKSR)**
- Pilot project has been stated since 2016





Community EoL Care Model for patients and family with late stage chronic illness

Project Objectives

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- Enabling the patients to **live as fully as possible** and with dignity in the community despite their illness.
- **Empowering** family members' capacity in performing their caring role and reduce their distress and sense of burden.
- Facilitating the patients to **transform the experience** of loss into self-integration and positive death preparation.
- Enhancing **family communication** on care preferences and wishes.

Home-based community care model

Team Combination

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Project Nurse

Social Workers

Freelance Professionals

Community Supports

Peer Supporters

Professional Volunteers

Service Targets

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- Referred by the **Medical Team** of the **Hong Kong East Cluster of the Hospital Authority**

- Patients with ***Late-Stage Non-Cancer Diseases***, including:
  - *Chronic Obstructive Pulmonary Disease (COPD)*
  - *End-Stage Renal Failure*
  - *Heart Failure*
  - *Neurological Diseases (such as Parkinson's Disease, Motor Neuron Disease, Dementia)*

- Priority to aged 60 or above

Service Statistics (Jan 2016 – May 2021)

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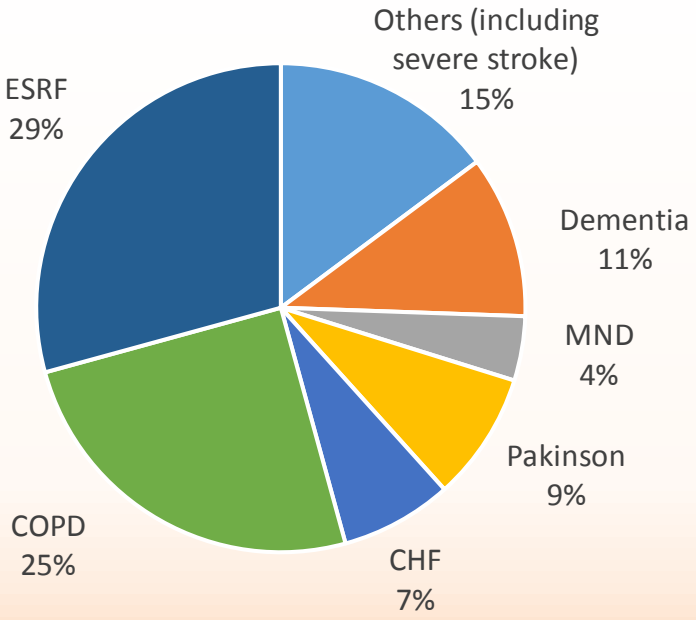
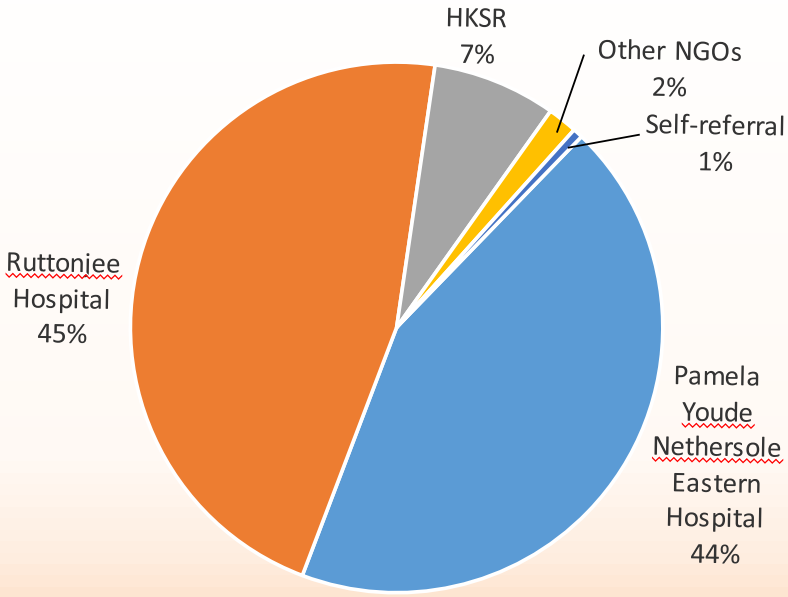
CASE SERVICE

No. of Beneficiaries	Cumulative Total
Patients	505
Family members	903

Disease Types



Referral Sources



Assessment – Plan – Intervention

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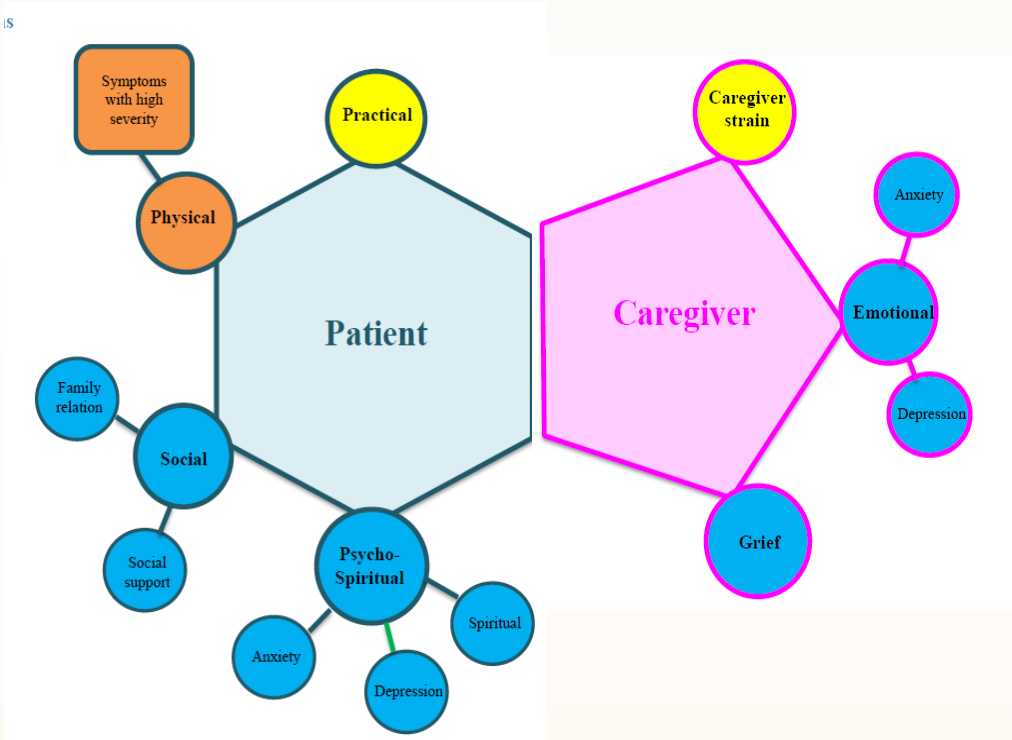
- Service tools and research study back up by HKU



Condition of non-cancer patients

Condition of non-malignant chronic illnesses patients

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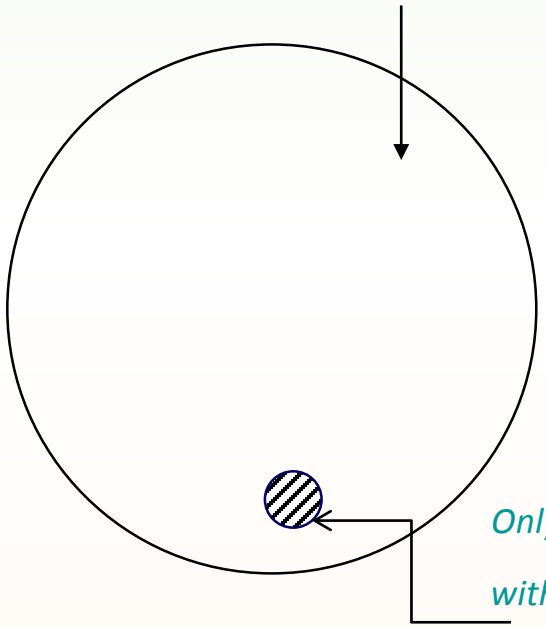
- Nearly **67%** of death in HK is from non-malignant chronic illnesses (HKSR Department of Health , 2020)

- Only around **1.4%** of them received palliative care (compared with that of 80% in cancer patients) (Lau, et al, 2010)

*Most of the patients with End-stage Organ Failures receive **NO SERVICE***



*Only **1.4%** of people with end-stage organ failures receive **"specialist" palliative care***

Disease trajectories of late stage non-malignant chronic illnesses

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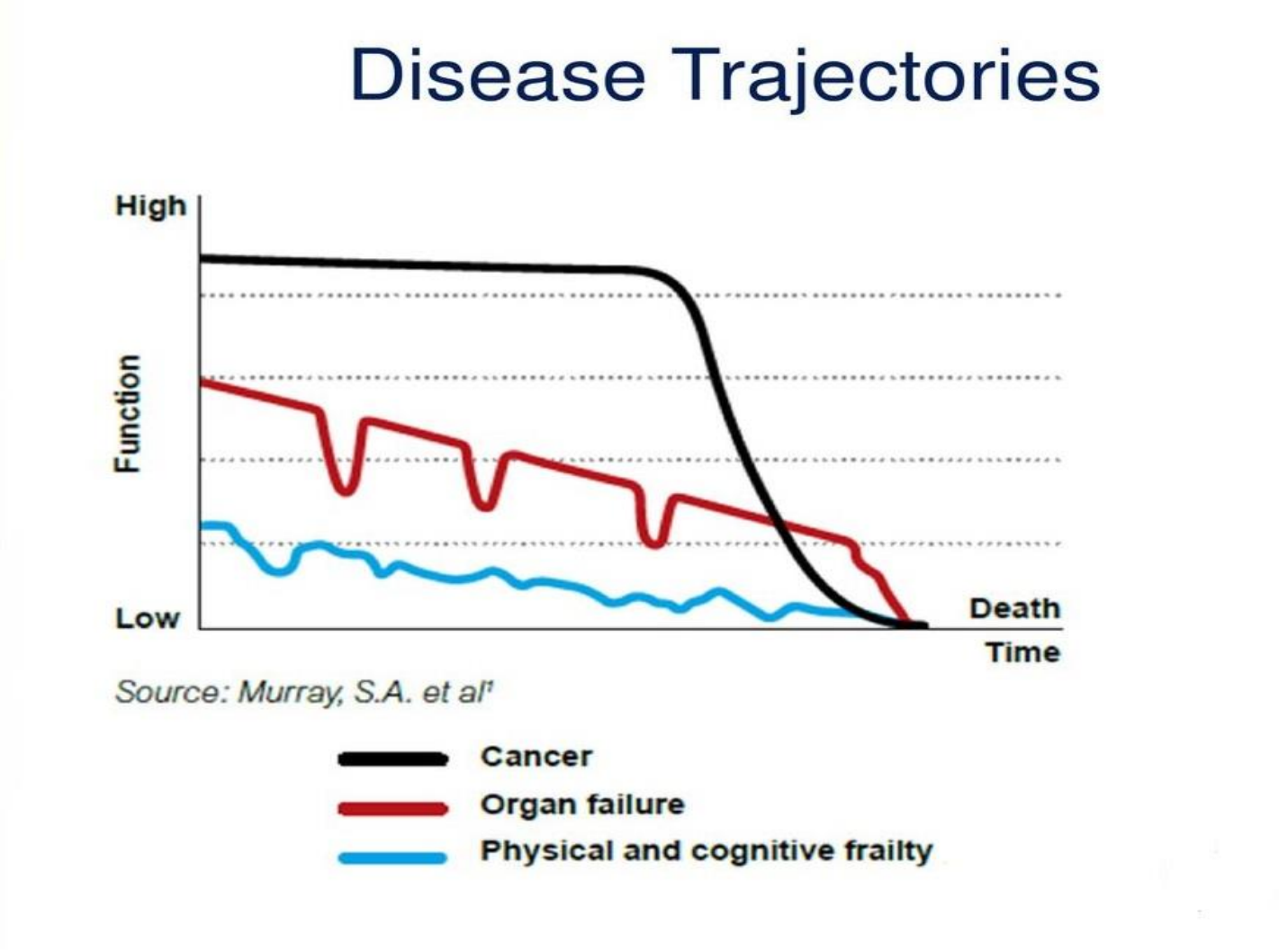

Empowerment approach

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Empowerment (Lorraine and Robert, 1991) :

- process of awareness and capacity building
- participation to greater decision making , control and to transformative action

1.Empowerment on managing symptoms & optimizing health functioning

2. Psychological & spiritual support to reduce death anxiety & future regret

3. Family-oriented discussion on advance care planning

Image: Freepik.com, stories

Empowerment approach

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Personalized and Holistic Care for patients and their families

- Physical care → 1.Empowerment on managing symptoms & optimizing health functioning
- Psychosocial Spiritual Care → 2. Psychological & spiritual support to reduce death anxiety & future regret
- Practical Care → 3. Family-oriented discussion on advance care planning

Empowerment component:

1. Empowerment on managing symptoms & optimizing health functioning

Empowerment on Managing Symptoms & Optimizing Health Functioning

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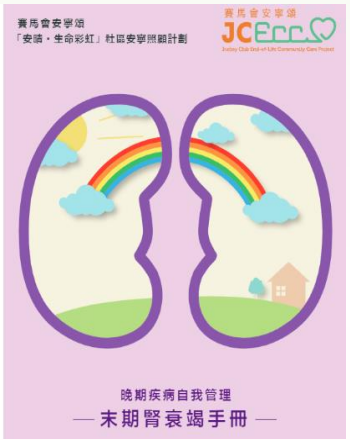
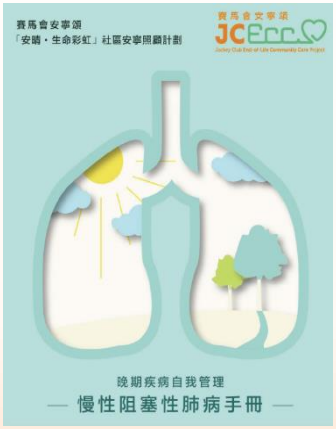
✓ Self Management of chronic illness

Symptom management skills



Self-monitoring



Service planning and goal setting

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維持日常生活

1. 按時用藥
2. 適量運動
   - 呼吸肌力運動練習
   - 心肺運動練習
   - 上下肢肌力練習
3. 均衡飲食
4. 足夠睡眠
5. 調適身心
   - 保持正常社交
   - 培養興趣
   - 學習保健養生 (按摩)

為自己定立目標，維持日常生活

我的目標我做得到

目標訂立日期：_____

(一) 我的目標：_____

(二) 達至目標的方法

方法1

做什麼？_____

做多少？_____

何時做？_____

每週做多少次？_____

方法2

做什麼？_____

做多少？_____

何時做？_____

每週做多少次？_____

ACTION PLAN

Objectives

Methods

What? When?
How?
How many?

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Empowerment component:

2. Psychological Spiritual Support to Reduce Death Anxiety

Psycho-spiritual Support – *Caregiver: Care for Yourself*

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2.自我照顧原則

- 接受世事並非完美，按自己能力去承擔照顧工作，在自己承受不到前要找幫手
- 訂立實際可行的照顧計劃
- 避免把煩瑣的照顧工作填滿一整天，爭取足夠休息
- 照顧自己的身心健康，保留一點私人空間，做一些自己享受的活動，例如：運動、聽音樂
- 給自己短暫的假期，可尋求家務助理、日間護理中心或幾天的暫託服務來幫助自己
- 與其他照顧者聯繫，交流照顧心得及困難，互相支持和鼓勵
- 與專業人士（如：醫護人員、社工）保持聯絡，在有需要時求助
- 欣賞自己為家人的付出

3.如何減輕您的身體疲勞

疲勞的警號

- 在長期的照顧壓力之下，您的身體定會出現某處位置有疲勞酸痛的現象及精神疲累不堪
- 當您感覺到身體及精神缺乏力量時，便需要休息，使身心再補充能量

引致疲勞的原因

- 不良姿勢、環境因素、缺乏優質休息及合適運動、性格因素、心理壓力等

疲勞的影響

- 令自己減少不同的活動，引致心情沮喪、灰心喪志，形成身心壓力難以應付，加劇疲勞的情況

應用有效的疲勞處理方法在日常生活中

- 使用不同方法去儲存體能，例如：鬆弛練習、伸展運動、飲用湯水、按摩穴位等等
- 安排多些簡短休息時間、或找人代勞照顧患者三數天：讓自己歇一歇、鬆一鬆
- 使用不同的輔助器材，以減低體能上的消耗
- 量力而為，主動求助

Psycho-spiritual Support

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- In-depth Counselling
- Regular Review & Strength-Perspective
- Simple Means
- Action-based

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Empowerment component:

3. Family-oriented discussion on advance care planning

Advance Care Planning

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晚期的醫療需要及方式

心願交托

- [ ] 舒服及少痛
- [ ] 保持身體整潔
- [ ] 希望醫生及家人向我如實告知病情
- [ ] 由醫生及家人為我決定，不需要如實告知
- [ ] 其他：_____

（香港大學行為健康教研中心，2008）

預設醫療指示 I

- [ ] 當病情到了末期，我仍然希望繼續用各種醫療及搶救方法嘗試延續生命
- [ ] 當病情到了末期，除了基本護理和紓緩治療，我選擇不接受任何維持生命治療（如人工營養及流體餵養），讓生命自然結束。
- [ ] 到時由醫生及家人代我作最適當的決定。

預設醫療指示 II

當病情到了末期，我不想接受以下的維生治療：

- [ ] 心肺復甦法
- [ ] 以呼吸機維持生命
- [ ] 人工導管餵養
- [ ] 其他：_____

（香港大學行為健康教研中心，2008）

（善寧會，2016）

我的後事選擇

我會選擇以下的安葬方法：

- [ ] 土葬，安葬地點：_____
- [ ] 火葬，骨灰安葬地點：_____
- [ ] 海葬，骨灰散落地點：_____
- [ ] 花園葬，骨灰散落地點：_____
- [ ] 器官捐贈
- [ ] 捐贈以作大體老師或無言老師（作醫學教學用途）
- [ ] 骨灰製成晶石，供後人紀念
- [ ] 其他：_____

我的殯葬選擇

我選擇的儀式是：

- [ ] 天主教
- [ ] 基督教
- [ ] 道教
- [ ] 佛教
- [ ] 醫院遺體告別儀式
- [ ] 舉辦追思會
- [ ] 不需儀式
- [ ] 其他：_____

我心中快樂的晚期生活

人生一路走來，想做的事都做了嗎？
未了的心願：

- [ ] 多見見親人及朋友
- [ ] 多聽自己喜歡的歌
- [ ] 多做自己喜歡做的事，例如：_____
- [ ] 維持身體活動機能
- [ ] 其他：_____

Medical and Social Collaboration of Co-join ACP Signing

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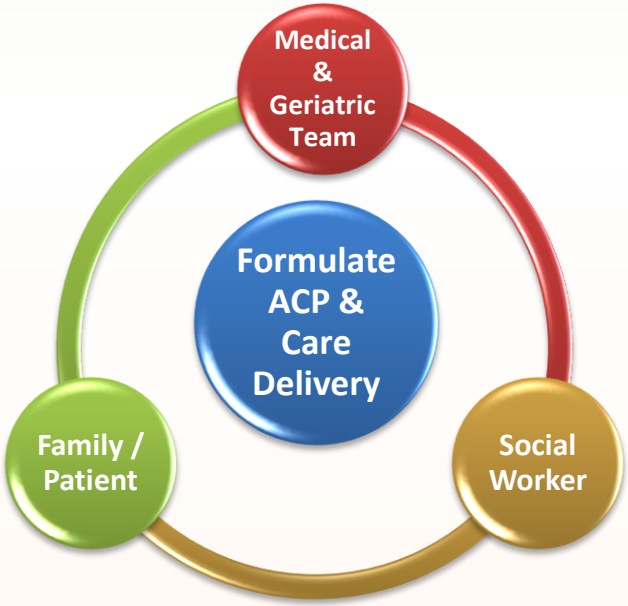
- A new medical social collaboration mode was developed with the Geriatric Team of RTSKH to facilitate ACP signing.



Patient Identification & Initiation of ACP Conversation

Case referral to HKSR

ACP Discussion (Psycho-social Part)

Schedule Appointment for ACP signing

ACP Discussion (Medical Part) + Signing of ACP

Execution & Review of ACP

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The Hong Kong Society for Rehabilitation

Conclusion

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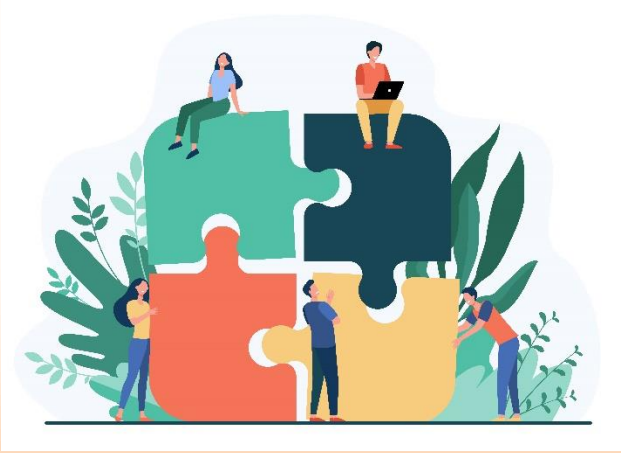
- Project shows significance in empowering non-cancers patients and their family member
- Community Care End-of-Life Care approach has a promising prospect in the future local palliative care to meet the huge service demand
- Lack of service for young & middle aged late stage non cancer patients and the families
- Engaging different stakeholders of community to build care networks



Our Wish

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COMMUNITY EOL CARE AS
REGULAR SERVICE

References

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