



From Hospital to community -

**Bridging the Gap to Enhance Life Rainbow for
Terminal Dialysis Patients & Their Family Members**
「醫社互補 – 為晚期病人帶來美麗的告別」

The Hong Kong Society for Rehabilitation

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

合作夥伴 Project Partner:



Background

- Support by the Hong Kong Jockey Club Charities Trust Fund
- Aimed to
 - Improve the quality of end-of-life care patients and families
 - Enhance the capacity of service providers
 - Raise public awareness of this issue



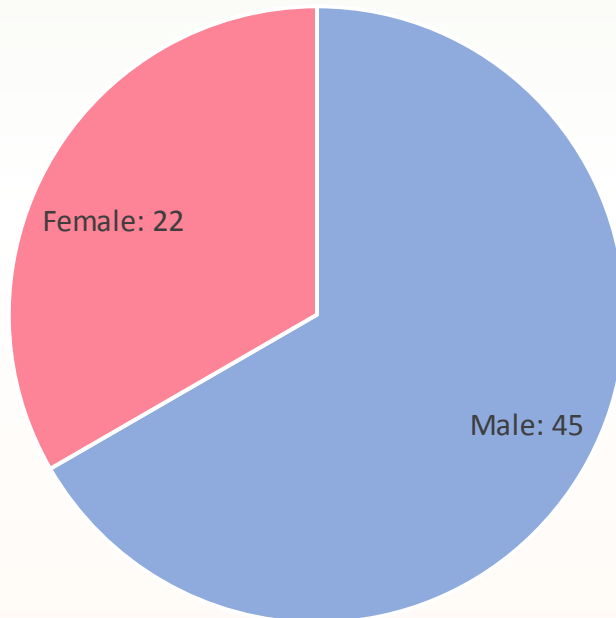
Target Groups of HKSR

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

Progress

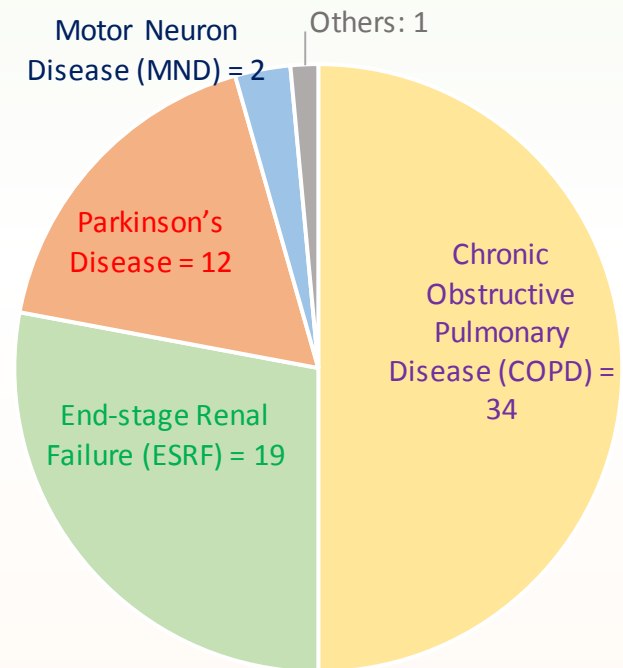
No. of beneficiaries:

No. of patients served: 67



No. of caregivers served: 99

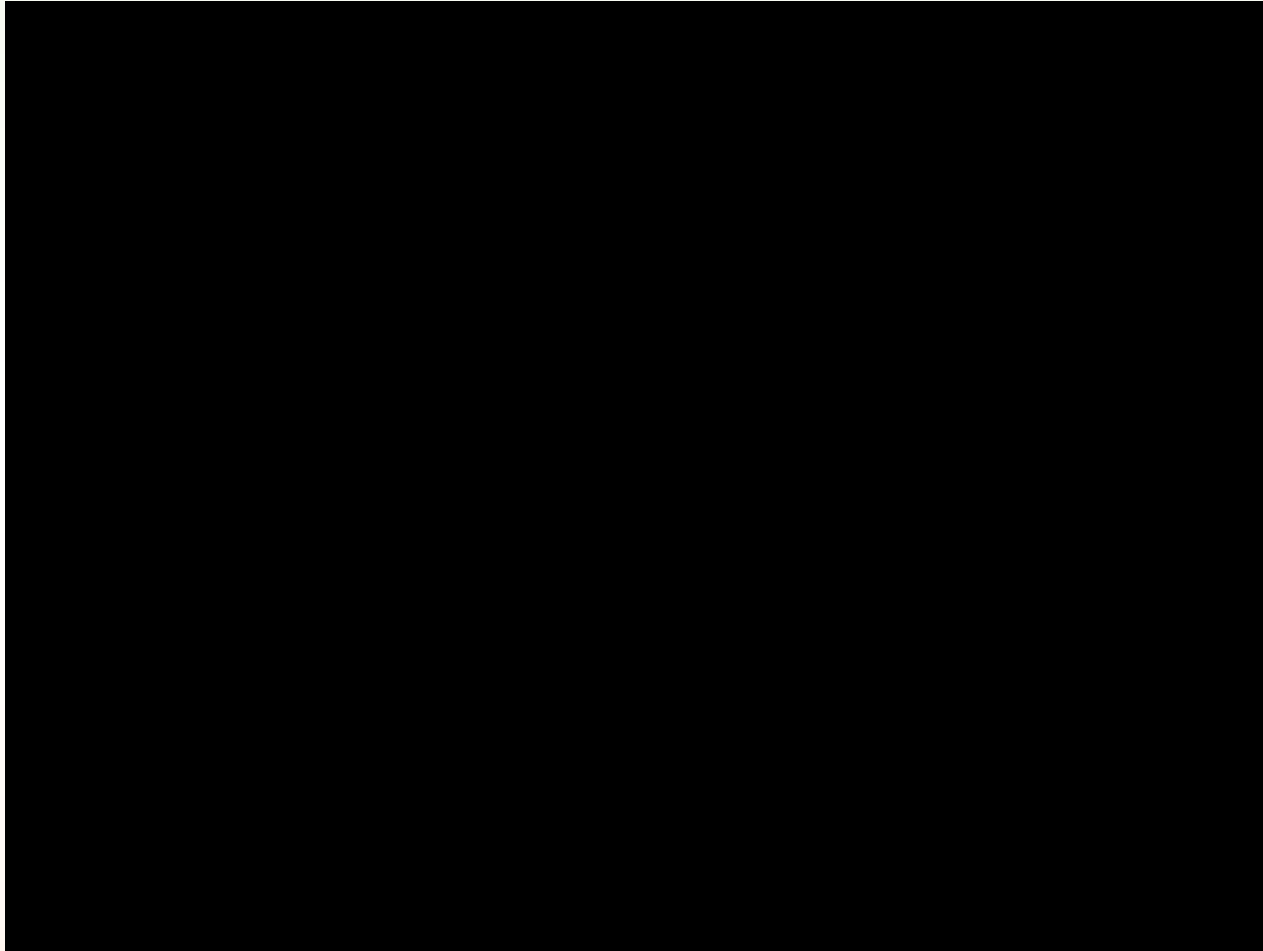
Types of chronic diseases



Most patients were referred from PYNEH, Department of Medicine. Few were referred from other NGOs or self referral.

生活就是等？

Life Count Down



Characteristics of Target Groups

- *Patients referred from **Department of Medicine**, rarely receive hospital's Palliative Care Service*
- *What kind of medical & healthcare services they receive?*
 - ***Follow-up in SOPD***
 - ***Admit to A&E for emergency need***
- ***Less than 10%** are users of Enhanced Home & Community Care Services (**EHCCS**)*
- ***Age: 40%** of patients are ≤ 69*



Features of Service Model

Four Intervention Focus

*Symptom
Management
Education & Optimize
Health Functioning*

*Psychosocial Spiritual
Support*

*Positive Death
Preparation*

*Connecting to
Community Resources*

Symptom Management Education & Optimize Health Functioning

- **Why?**

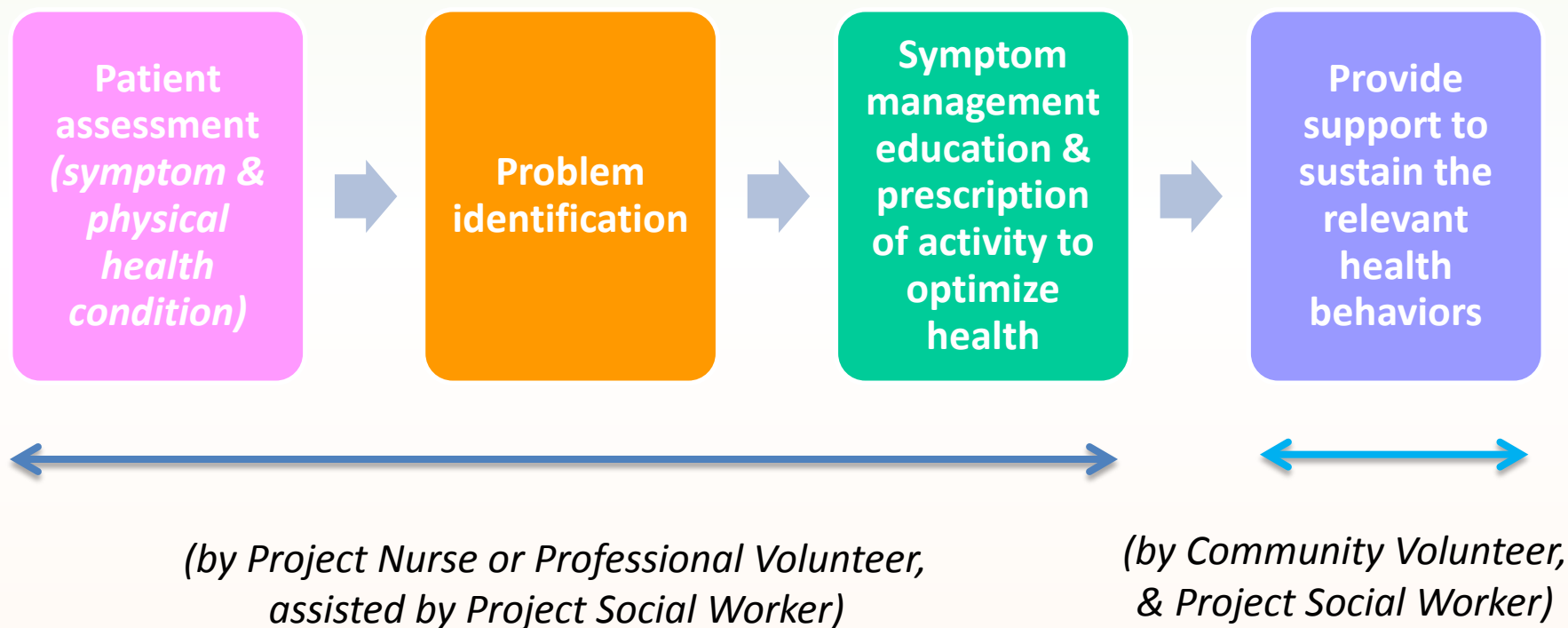
Patients & Caregivers:

- *Lack of relevant knowledge and skills*
- *Lack of self-efficacy*
- *Unexpected difficulties encountered in home environment*
- *Related home-based support is insufficient*

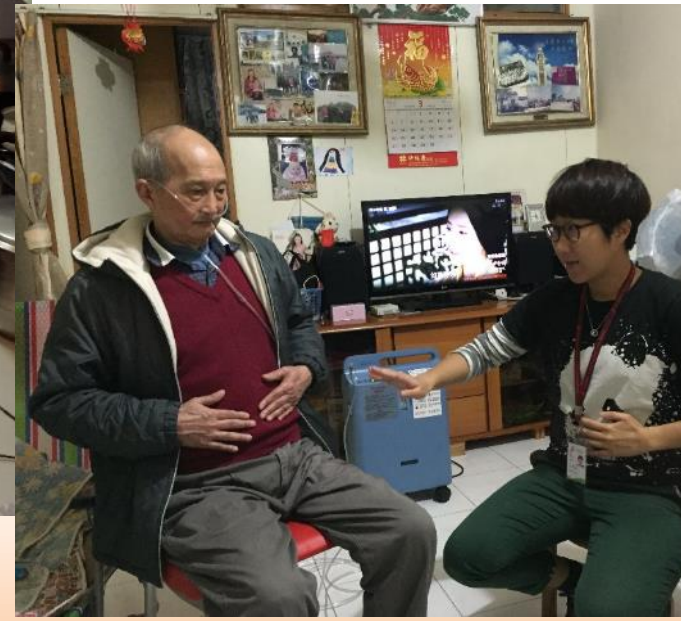
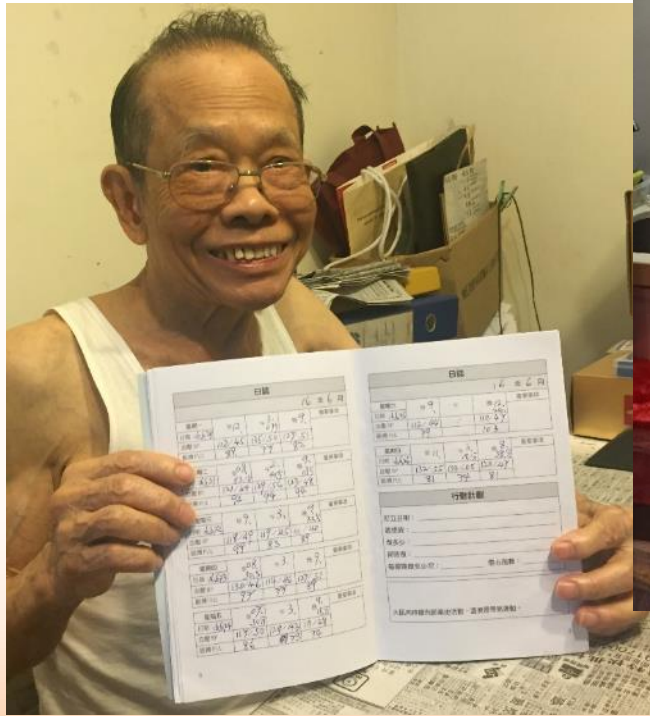
EMPOWERMENT



- *How & Who will Provide?*



Symptom Management Education & Optimize Health Functioning



Psychosocial Spiritual Support

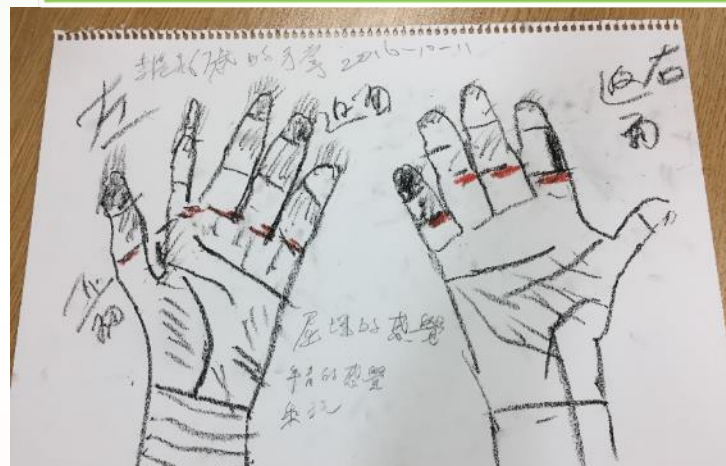
- Celebrate life and reconstruct meaning
- Relationship reconciliation
- Prescribe joyful activity
- Prescribe activity to optimize social participation

Psychosocial Spiritual Support

賽馬會安寧頌

JCECC

Jockey Club End-of-Life Community Care Project



Positive Death Preparation

- Provide anticipatory guidance in coping with patient's progressive deterioration
- Communicate on care preference & wish
- Address unfinished business
- Leave a legacy

Positive Death Preparation

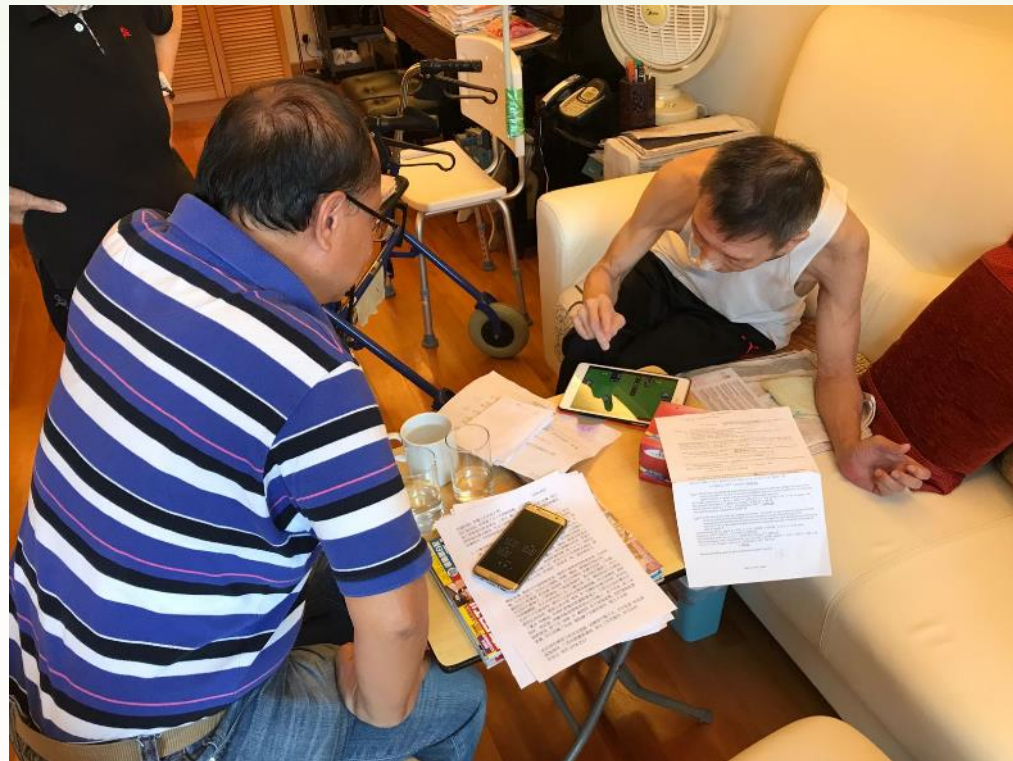
賽馬會安寧頌



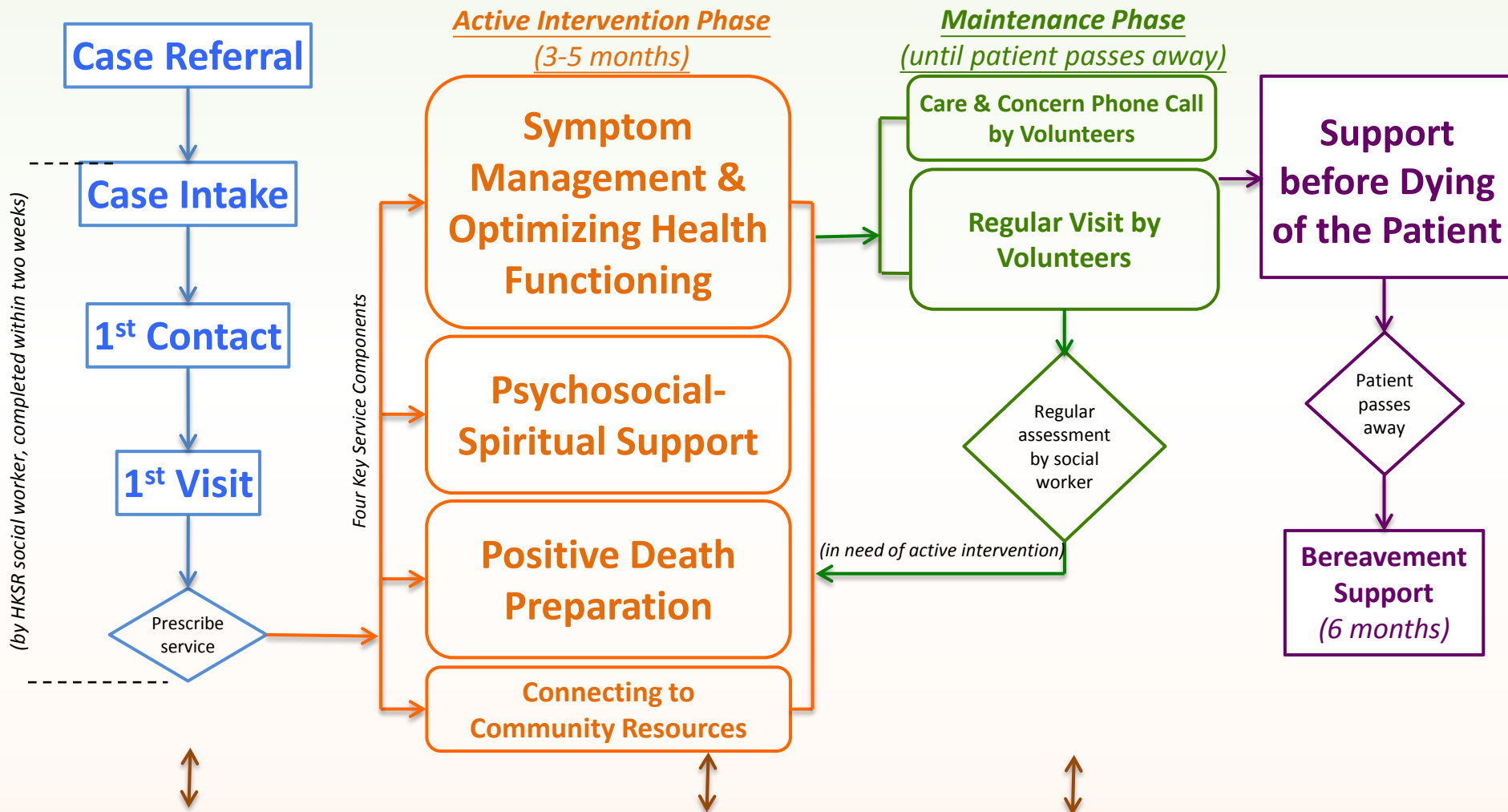
Jockey Club End-of-Life Community Care Project



Connecting to Community Resources



Service Pathway



Collaboration between HKSR & Hospital (Pamela Youde Nethersole Eastern Hospital, PYNEH)
Case discussion, Seek advice, Refer back to better utilize existing service provided by hospital

Medical & Healthcare Sector:

- Pamela Youde Nethersole Eastern Hospital (HA-HKEC)
- Formation of Clinical Advisory Team:
 - *“Early” identification of related patients*
 - *Case discussion & giving advice on intervention*
 - *Better utilize existing hospital services*
 - *Developing Hospital-Community “Complementary Model”*

誰適合被轉介？

Referral Criteria

- Late / End stage of disease
 - late stage COPD with long term-home O2 therapy
 - ESRF on dialysis with poor prognosis
- Presents of complications/ comorbid diseases
- Affected quality of life
- Advance dementia

致：香港復康會「安晴·生命彩虹」社區安寧照顧計劃
傳真: 2549 5727 電話: 2549 7744

主辦機構:

策略伙伴:



香港復康會
The Hong Kong Society
for Rehabilitation



香港紅十字會
The Hong Kong Red Cross



香港社會工作者總工會
The Hong Kong Association
of Social Workers

寧頌



Life Community Care Project

香港復康會



「安晴·生命彩虹」社區安寧照顧計劃

東區尤德夫人那打素醫院 醫護人員轉介表

請於適當方格內加上✓號

由：☐呼吸科 ☐腎科 ☐腦科 ☐物理治療部 ☐職業治療部
☐社康護理部 ☐醫務社會服務部 ☐病人資源中心 ☐其他：_____

患者 資料	姓名：_____ 性別： <input type="checkbox"/> 男 <input type="checkbox"/> 女 年齡：_____
	聯絡電話：(手提)_____ (住宅)_____
	* 患者轉介時必須為在家居住 (居於安老院舍者不符合)
	* 患者居住地點必須為港島東聯網 (包括灣仔區及東區)
	診 斷： <input type="checkbox"/> 慢性阻塞性肺病 (正使用家用氧氣機)
	<input type="checkbox"/> 末期腎衰竭 (<input type="checkbox"/> 腹膜透析 <input type="checkbox"/> 血液透析)
<input type="checkbox"/> 帕金森症 (中後期)	
<input type="checkbox"/> 運動神經元病 (中後期)	
<input type="checkbox"/> 其他 (請註明)：_____	
<input type="checkbox"/> 已轉介其他服務跟進情況 (請註明)：_____	

照顧者 資料	姓名：_____ 性別： <input type="checkbox"/> 男 <input type="checkbox"/> 女 與患者關係：_____
	年齡：_____ 聯絡電話：(手提)_____ (住宅)_____

補充資料：_____

建議提供之服務：

☐情緒輔導 ☐照顧壓力處理 ☐身體症狀舒緩 ☐照顧技巧訓練 ☐家庭溝通改善
☐義工關懷 ☐社區資源轉介 ☐心願實現行動 ☐其他 (請註明)：_____

轉介者資料：

姓名：_____

職位：_____

Case sharing

- Mr. Lam, M/72
- PMH:
 - Type II DM, AF, severe OSA, ESRD on dialysis for > 10 yrs. (CAPD for 7 yrs. but complicated with PD peritonitis, changed to hemodialysis since 2014)
- Social background: divorced, lives with daughter & domestic helper
- Admission in July 2016 for management of fluid overload due to poor diet compliance
 - Developed chest infection, type II respiratory failure requiring BIPAP, fast AF, line sepsis, AVF thrombosis, Ryle's tube feeding

- Poor prognosis with meeting the referral criteria:
 - Question 'Would I be surprised if this patient died in the next year? Answer → No
 - Functional impairment: Karnofsky Performance Status score < 40
- Prepared patient and daughter for end of life care
- Relieving daughter's anxiety for taking patient care

Benefit to clinical team

- Established rapport between patient's daughter & medical team → more understanding in patient care management → less complaints to hospital staff
- Showed appreciation to ward staff
- Nice ward atmosphere in patient care → enhance patient quality of care



Benefit to patient & family

Strengthen communication with daughter



More control of life



Enjoy life

Optimize social connection



假如去到疾病「晚期」你的選擇是：

1. 避免痛苦？

2. 「盡量救」？