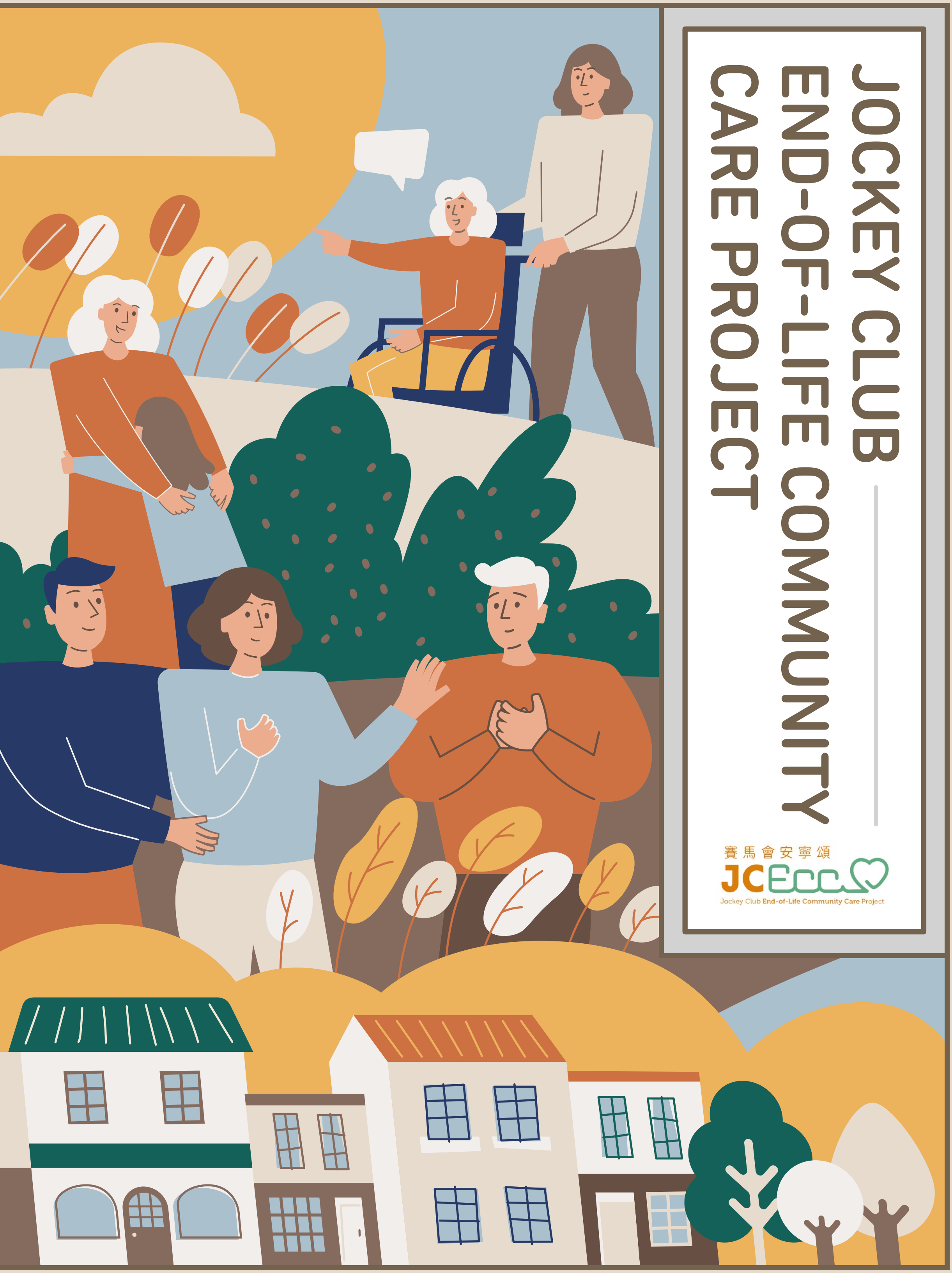


JOCKEY CLUB END-OF-LIFE COMMUNITY CARE PROJECT

賽馬會安寧頌

JCECC

Jockey Club End-of-Life Community Care Project

A PEACEFUL JOURNEY
IN THE FINAL STAGE OF LIFE

Jockey Club End-of-Life Community Care Project

When reaching the final stage of life, the greatest hope is to be able to walk away peacefully with dignity and choice.

People have a desire to return home with their families and friends, or to settle in an elderly home with more personalised care. Community end-of-life care service aims to minimise physical pain and psychological distress, fulfil practical needs, and support caregivers so that both patients and caregivers can maintain their quality of life.

The Hong Kong Jockey Club Charities Trust initiated a six-year project, the Jockey Club End-of-Life Community Care Project (JCECC) in 2016. The Project facilitates multi-disciplinary collaboration between medical and social sectors in order to strengthen the current end-of-life care services.

In 2019, the Project developed an "Integrated Community End-of-Life Care Support Team" model, which puts emphasis on providing need-based support to individual patients and their family members.

Everyone has different needs

We came into the world with a cry, learnt to walk as toddlers, and developed our personality throughout our adolescence. Throughout life we make choices that take us in different paths. Our journeys are varied as they bring us to our old age, making each of us unique. When we arrive at the end of our lives, we bring along our individual experiences, social values, family relations, and a diversity of needs.

Uncle Yam: Worrying about morphine dependency

Uncle Yam was diagnosed with colon cancer which later spread to his bones. As he developed lower limb oedema, it became extremely painful to walk. Although the doctor prescribed liquid morphine for pain relief, he refused to use it as he was afraid he would become addicted and end up like his wife who was in a delirious state before she passed away.

The JCECC Project Team made a great effort to understand Uncle Yam's concerns. They explained the benefits of liquid morphine and invited other patients with similar situations to share their experience. Eventually, he was willing to use the liquid morphine for pain relief and could enjoy his life in comfort.

Uncle Yau: Using a wheelchair without difficulty

Ten years ago, Uncle Yau was diagnosed with Parkinson's disease and gradually became dependent on crutches to move around. At the time he was living with his wife and a domestic helper, his living room was filled with rehabilitation equipment, including a wheelchair which he no longer used. In desperation, his daughter had bought a new wheelchair thinking it would help him, "I was distressed and exhausted and wasn't sure what to do, and so I randomly bought this online".

During a home visit, the JCECC Project Team social worker found that the wheels of this wheelchair were too small, and its body was not sturdy enough, which made it hard to push and unsafe to sit on it, so the social worker arranged a more appropriate wheelchair. Uncle Yau's daughter admitted that although the wheelchair was second-hand, they were happy with it and could easily use it.

Uncle Lam: Able to sleep tight with you

Uncle Lam fell into a deep slumber, holding on tightly to a family photo and a greeting card filled with grateful thoughts from his relatives. In the terminal stage of cancer, he was short of breath and his severe leg pain had long-deprived him from getting a good night's sleep. But that night, he was in dreamland.

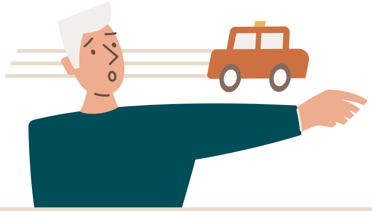
Uncle Lam spent most of his time working when he was young. He told the staff of the elderly home that he regretted not spending more time with his family. The JCECC Project Team wanted to help Uncle Lam reconcile with his family. The team organised a birthday party in the elderly home and invited all his family members.

At the party, his wife, children and in-laws, as well as grandchildren all reflected on the experiences with Uncle Lam and expressed their gratitude as they bid farewell. They also gave Uncle Lam a photograph of all of them together at the party, along with a greeting card filled with their thoughts and feelings about him.

Three types of needs of terminally ill patients

Physical Care

- Pain relief
- Symptom control
- Advance Care Planning



Practical Care

- Daily life
- Patient escort service
- Transportation arrangements
- Purchase or rental of rehabilitation equipment
- Caregiver support
- Respite service

Psychosocial Care

- Wish fulfilment
- Life review
- Recognising true value of lives
- Relationship reconciliation
- Social interactions
- Spiritual support for depression, anxiety and fear of death

Needs Assessment

WHAT KIND OF END-OF-LIFE CARE SERVICES ARE NEEDED?

The JCECC Project Team would conduct a detailed assessment on the physical, practical and psychological needs of terminally ill patients. Psychological needs could be subdivided into three parts: spiritual, social and family relationships. Based on the patient's unique needs, relevant services could then be designed and provided by the team's social workers, nurses, and volunteers, etc.

Assessment One : Physical needs

In the previous week, how much are the symptoms below affecting you?

	Not at all	Slightly	Moderately	Severely	Overwhelmingly
Pain	0	1	2	3	4
Shortness of breath	0	1	2	3	4
Weakness or lack of energy	0	1	2	3	4
Nausea	0	1	2	3	4
Vomiting	0	1	2	3	4
Poor appetite	0	1	2	3	4
Constipation	0	1	2	3	4
Sore or dry mouth	0	1	2	3	4
Drowsiness	0	1	2	3	4
Insomnia	0	1	2	3	4
Oedema	0	1	2	3	4
Dizziness	0	1	2	3	4

Every item having a score: A score of 3 or 4 = High physical need / A score of 1 or 2 = Low physical need / A score of 0 = No physical need

Assessment Two : Needs on Practical Care

The difficulties encountered in daily life over the previous week:

	Difficulties have not been resolved	Small portion of the difficulties have been resolved	Part of the difficulties have been resolved	Most of the difficulties have been resolved	All difficulties have been resolved/ No difficulty encountered
Have any practical problems resulting from your illness been addressed? (e.g. financial or personal problems)	4	3	2	1	0

A score of 3 or 4 = High need for practical support / A score of 1 = Low need for practical support / A score of 0 = No need for practical support

Assessment Three : Psychosocial-Spiritual Need Assessment

Have you come across the situations below in the previous week?

	Not at all	Rarely	Sometimes	Often	Always
1. Feel anxious about one's own illness situation and therapy	0	1	2	3	4
2. Feel depressed	0	1	2	3	4
3. Feel spiritually peaceful	4	3	2	1	0
4. Feel life is meaningful	4	3	2	1	0
5. Feel satisfied about life	4	3	2	1	0
6. Feel hopeful	4	3	2	1	0
7. Feel a sense of burden to the family	0	1	2	3	4
8. Feel worried about the world after death	0	1	2	3	4
9.Feel there are wishes to be fulfilled	0	1	2	3	4

Item Q1 and Q2 with the score of 2 to 4 = the emotional need arising from anxiety or depression is high /
Item Q1 and Q2 with the score of 1 = the emotional need arising from anxiety or depression is low /
Item Q1 and Q2 with the score of 0 = no emotions on anxiety or depression /
One of the items from Q3 to Q9 with the score of 3 or 4 = the psychological (spiritual) need is high /
One of the items from Q3 to Q9 with the score of 2 = the psychological (spiritual) need is low /
One of the items from Q3 to Q9 with the score of 0 or 1 = no psychological (spiritual) need

Assessment Four : Psychosocial-Social need assessment

Have you had any of the feelings below over the past week?

	Not at all	Rarely	Sometimes	Often	Always
Want to have companions	0	1	2	3	4
Feel there are many people they can rely on	4	3	2	1	0
Feel lonely	0	1	2	3	4

Any item with the score of 3 or 4 = the psychological (social) need is high /
Any item with the score of 2= the psychological (social) need is low /
All items with the score of 0 or 1 = no psychological (social) need

Assessment Five : Psychosocial - Need Assessment on Family Relationships

How was the overall interaction among your family members over the past week?

	Not at all	Rarely	Sometimes	Often	Always
Mutual care and support among family members	4	3	2	1	0
Able to express openly one's ideas and feelings among family members, including their own problems and dissatisfaction, even on sensitive topics	4	3	2	1	0
Blame and criticism among family members when disagreements arise	0	1	2	3	4

Average score for the three items 2 to 4 = psychosocial (family relationships) need is high /
Average score for the three items 0 to 1 = no psychosocial (family relationships) need

Community support fills the service gap

Project Director Professor Amy Chow

Professor Amy Chow, Project Director of JCECC, pointed out that "Integrated Community End-of-Life Care Support Teams help to fill in the gaps of existing services." "When the terminally ill patients' symptoms can be managed at home, they don't have to be hospitalised." She can empathise with the patients, "it is more comfortable to stay at home to get the care they need."

Professor Amy Chow
Project Director of JCECC

Since the 1980s, the Hospital Authority has started to provide palliative care services and patients could apply for home-based palliative care services. In the programme, a palliative care nurse conducts home visits once a week mainly to take care of patients' physical needs. And the nurse may also help with other issues relating to the patient and their family, despite the time constraints.

The Integrated Community End-of-Life Care Support Teams (ICESTs) of JCECC can also arrange home visits on Saturday or Sunday, when they will be able to communicate with the whole family. With the support of volunteers, they aim to address the psychological needs of the patients, through for example social outings including going to yum cha which are important to them.

"It may not be feasible for palliative care nurses of Hospital Authority to spare time during their regular home visits to address the patient's psychological needs. But these are just as important as managing the patients' symptoms." Professor Chow also adds that the team strives to help patients with their emotional and psychological needs particularly at the end of their lives.

They also take into account of issues the patient considers as unfinished business and enlists their family to help fulfil these wishes. It reassures the family members and makes them feel that they have done something to help, reducing distress when the loved one passes away.

The team is also tasked with facilitating communication among family members. "The patients and their family can get very emotional when facing death, making it a difficult topic to discuss. It often results in confusion and miscommunication." For example, out of concern a daughter tells her mother, "You should put on more clothes and eat more!" But it could upset her mother, who could take it the wrong way and feel like she is being criticised. Social workers could help them see and realise the love and care buried beneath the charged emotions. The social workers are skilled at picking up and highlighting the positive messages even though family members may try to "contain their emotions" in the presence of a social worker.

End-of-Life care services provided by the Hospital Authority and the Social Welfare Department

In Hong Kong, terminally ill patients who live at home could receive palliative care services through out-patient clinics or day-care services operated by the Hospital Authority. They may also receive palliative home care services provided by various hospitals. However, the services mostly focus on the medical needs of patients and there is limited support to address the psychosocial needs of patients and their families.

Integrated Family Service Centres, District Elderly Community Centres and the Integrated Community Centres for Mental Wellness currently offer services for patients with psychological problems, spiritual needs and/or family issues, as well as family members in need of bereavement counselling. But, these centres have their own service targets and rarely cover terminally ill patients and their families.

Like any elderly patients, terminally ill patients have practical needs such as arranging meals, escorting to clinics, and cleaning their homes. When they request a service, they are subject to the Standardised Care Need Assessment Mechanism for Elderly Services implemented by the Social Welfare Department, which will then put them on a Central Waiting List for Integrated Home Care Service (IHCS), Enhanced Home and Community Care Service (EHCCS), etc. Since the waiting time could be up to a year or longer, it may be too late for terminally ill patients by the time their turn comes.

Needs of terminally ill patients

Palliative day care service

Palliative home care service

Out-patient palliative care service

Integrated Home Care Service (IHCS)

Enhanced Home and Community Care Service (EHCCS)

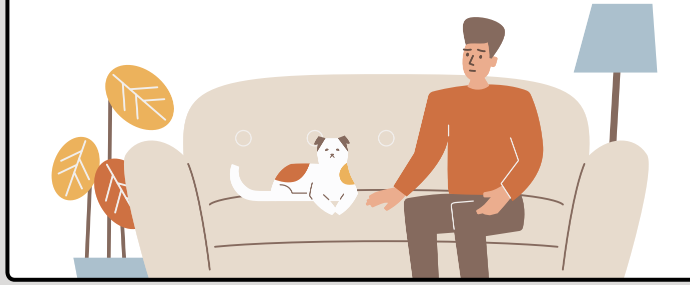
Community Care Service Voucher for the Elderly (CCSV)

Home Care Service for Persons with Severe Disabilities (HCSPSD)

Integrated Family Service Centre (IFSC)

District Elderly Community Centre (DECC)

Integrated Community Centre for Mental Wellness (ICCMW)



Bereavement Counselling

Integrated Family Service Centre (IFSC)

District Elderly Community Centre (DECC)

Integrated Community Centre for Mental Wellness (ICCMW)

Integrated Community End-of-Life Care Support Teams

The ICESTs of JCECC are community-based service teams which provide holistic care services for terminally ill patients and their family members in the community. The professional teams include social workers, nurses, programme/care workers and volunteers. They offer three types of support services, including physical care, psychosocial-spiritual care, and practical support. The services are tailored according to the needs of the patients and their family members which are identified via a standardised needs assessment.

Symptom management education

Caregiving skill training

Medical and rehabilitation equipment rental service

Psychological: emotional support and counselling for patients and caregivers

Social: facilitating family communication, arranging volunteer visits and social activities

Spiritual: life review, planning for future care

Home environment assessment

Navigation of community resources

Support service referrals

Organisations providing ICEST services

Organisation	Project Name	Service District	Contact
The Hong Kong Society for Rehabilitation	JCECC: "Life Rainbow" End-of-Life Care Services	Hong Kong East	2549-7744
St. James' Settlement	JCECC: Cheering@Home End-of-Life Care Services	Hong Kong Island	2831-3258
SKH Holy Carpenter Church District Elderly Community Centre	JCECC: "Hospice in Family" Home Care Support Services	Tuen Mun, Yuen Long, Tin Shui Wai	2242-2000
Haven of Hope Christian Service	JCECC: Hospice at Home	All over Hong Kong (mainly in Kowloon East, Kowloon Central and Hong Kong East)	2703-3000

Holistic Advance Care Planning

One of the most important tasks of the ICESTs is to facilitate terminally ill patients in making end-of-life decisions, including choice of end-of-life care, funeral arrangements, etc.

Professor Chow proposed the concept of Holistic Advance Care Planning (HACP) which classified patients into three distinct types based on their needs in five different stages. Against these 15 classifications in total, health and social care professionals can better identify the individual needs of patients and provide relevant services. "For instance, they may refer to the tools and guidelines of the Hospital Authority and discuss end-of-life care arrangements with a terminally ill patient. Since the patient is already at his/her end-of-life stage, it is important to facilitate them in making medical decisions based on their disease prognosis while also factoring in their personal values, for instance, should they be resuscitated at all costs?"

For the wider public with good health conditions, general topics like organ donation could be discussed. Those who lack knowledge about Advance Care Planning, or have no incentive to learn about it, may need life and death education. For those seeking to learn more, they can request more information or discuss matters with their friends. Taking a step forward, they can seek professional assistance in drafting Enduring Power of Attorney for early arrangements on financial matters.

"Service interventions should be adjusted for individuals with different care needs at different stages towards end of their lives." Professor Chow emphasised that she would not recommend initiating end-of-life care discussions with the general public, but instead targeting certain population segments, such as patients undergoing long-term dialysis. She stressed that it was essential to familiarise terminally ill patients with the concept of end-of-life care, and regularly provide them with the latest information, she believed that "a one-on-one approach should be adopted".

In addition to ICESTs, some public hospitals also have shown interest in HACP and are willing to try it out in the future.

INFO

Holistic Advance Care Planning (HACP)

	Universal Care	Selective Care	Indicated Care
			
Pre-contemplation No understanding of advance care planning and no motivation to learn	Deliver passive psychological education (Life and death education)	Deliver active psychological education (Sharing of real-life stories)	Clarify personal values, beliefs and missions. Conversation to spark interest
Contemplation No understanding of advance care planning at present but with incentive to know more	Offer information on community care services.	Offer information on health care and community care services	Offer information on health care services
Preparation Want to ask for information but have not yet sought the way to approach	Get the contact of professionals for community care services	Get the contact of professionals for health care and community care services	Obtain the contact of professionals for plans for medical care services
Action	Arrange referrals to appropriate professionals for community care services	Set up advance care plan	Set up advance care plan with family members and professionals, and sign related documents
Maintenance	Review the advance care plan when the situation changes	Review the advance care plan when the situation changes	Review the advance care plan with the professionals regularly

Key accomplishments in the first three years

5002	patients and family members served
36	elderly homes served
2256	staff of elderly homes trained
8192	professionals in the community and hospitals trained
586	volunteers engaged and trained
29025	public members participated in community education activities

Developing a Compassionate Community

During the first three-year pilot phase of JCECC, each of the four community end-of-life care service providers had showcased their unique services which were proved to be effective with positive outcomes.

Professor Chow highlighted the services' unique features, "St. James' Settlement applied a family-oriented approach that aims to improve family relationships among terminally ill patients; the Hong Kong Society for Rehabilitation emphasised the self-care management of patients; Haven of Hope Christian Service had a hospice centre that could provide respite care for relieving patients' symptoms and lessen the caregiving burden of family members; while the SKH Holy Carpenter Church District Elderly Community Centre focused on mobilising volunteers to support end-of-life care services".

The Integrated Community End-of-Life Care Support Team (ICEST) has combined the merits of all four services' features in the second phase of JCECC. It took a "need-based" approach to assess and identify the care needs of the patients and their family members in order to determine the most relevant service.

Apart from supporting terminally ill patients to receive care at home, the Project also covered residential care homes for the elderly. Professor Chow hoped that frail residents of elderly homes could be well cared for until their last moments so that unnecessary hospital admissions could be reduced. She also hoped that every district would have an end-of-life care support team consisting of social workers, nurses, programme/care workers, and volunteers to offer individualised care for terminally ill residents while facilitating HACP.

She pointed out that current end-of-life care services could not meet the growing demand especially for elderly living alone or those living in remote areas. "Besides volunteer visits, the whole community should be engaged so that neighbours could also offer help to terminally ill patients. She made reference to an overseas example where many volunteer drivers took patients for medical appointments. Patients and their family members in Hong Kong, however, found it hard to arrange transportation. In the long run, a compassionate community should be developed in order to provide well-rounded support for patients in their last days of life.

Significant impact in the first three years of service

By extrapolating from the data collected, it was estimated that patients who received home-based end-of-life care services under JCECC could reduce up to 3,784 hospital bed days, 62 Intensive Care Unit bed days, and 249 Accident & Emergency visits. It would be roughly equivalent to an estimated cost savings of HK$20 million from health care resources.

Regarding end-of-life care services in elderly homes, elderly residents who joined the Project could reduce up to 5,088 hospital bed days and 127 Accident & Emergency visits. It would be roughly equivalent to an estimated cost savings of HK$25 million from health care resources.

Professor Chow emphasised that the focus should not be on reducing costs, but to minimise unnecessary hospitalisation for effective use of health care resources.

It is worth noting that more than half of the patients interviewed had experienced fewer practical problems, while anxiety and depressive symptoms among patients and their family members had also been significantly reduced.

Change of general public

	2016	2017	2018
People who have heard about end-of-life care	30%	34.5%	39%
In case one gets terminal illness, one is willing to receive end-of-life care	81.7%	78.6%	83%

Change of patients and their family members

	Before the service	After the service	
Symptoms of physical discomfort	9.7	8.0	Reduced by 18%
Practical problems in the family	1.1	0.5	Reduced by 55%
Patients' symptoms of anxiety	1.2	0.8	Reduced by 31%
Patients' symptoms of depression	0.9	0.5	Reduced by 49%
Family members' symptoms of anxiety	1.7	1.2	Reduced by 27%
Family members' caregiving strain	12	9.7	Reduced by 19%

Better utilisation of health care resources

	Similar patients died in the hospitals in 2015	Patients received home-based end-of-life service of JCECC	
Number of hospital bed days six months before death	39.02	34.15	Reduced 4.87 days ▼12.5%
Numbers of Accident and Emergency visits six months before death	2.75	2.43	Reduced 0.32 times ▼11.6%
Numbers of Intensive Care Unit bed days six months before death	0.36	0.28	Reduced 0.08 day ▼22.2%

ST. JAMES' SETTLEMENT

CHEERING@HOME

JCECC: "Cheering@Home" End-of-Life Care Services provided by St James' Settlement mainly assist terminal cancer patients who are referred by Pamela Youde Nethersole Eastern Hospital, Ruttonjee Hospital and Grantham Hospital.

Project Manager, Mr Eric Yu, said the project is a "one-stop" service designed to cover the psychological, social, and spiritual needs of terminally ill patients and their families, so that they can live comfortably and with dignity in their final days.

Social workers would assess the needs of a patient (see P04-05 for details) before offering services such as cheer-up activities and personal care services to help the family.

"Emotions are charged when facing illness and death, often there are a lot of negative emotions among the patients and their family members. Our services in the CHEER model could help offer relief."

Service Target

End-of-life patients aged 60 or above.
Patients and family members living in Hong Kong Island who have agreed to take part in the programme

Scope of Service

*Additional charges may incur

Everyday Care	Smile Every Day	A Loving Home
Patient escorting services Personal care service* Meal services* Home environment improvement services* Medical and rehabilitation equipment rental service	Activities to help cheer-up patients and their families Life review Wish fulfilment* Spiritual support and networking Personal counselling	Support family caregivers Foster family relationships Inherit family wisdom Create memorable family moments Advance Care Planning Funeral planning and navigation Bereavement counselling

DAUGHTER: RELIEVING HER MOTHER'S LONELINESS

Daisy Lee placed pots of green plants along the window ledge to create a small indoor garden in her room. It made her happy to look at the plants, and because of that she preferred being in her room rather than sitting on the sofa in the living room.

Daisy Lee
Participant

Daisy Lee was a 71-year-old lady who had worked as a security guard in a supermarket and was responsible for catching shoplifters. She retired at the age of 60, but later was diagnosed with chronic obstructive pulmonary disease. Even in her old age, she was always on the move visiting places on her own, despite suffering from lung cancer, and having had a stroke.

In mid-2019, her lung cancer progressed to a terminal stage. She was hospitalised for two months, during which her health condition rapidly deteriorated.

"When she was home again, she could no longer walk," said Lee's daughter.

The hospital only provided eight weeks of out-patient support where an occupational therapist would visit Lee at home and teach her rehabilitation exercises. It was a relief for the family when Lee was later referred to JCECC: "Cheering@Home" End-of-Life Care Service which was run by St James' Settlement.

Easier for a non-family member to speak up

Daisy Lee has to rely on an oxygen concentrator to breathe for most of the day. When her cancer spread to her cranial nerves, she started having trouble recognising her family and communicating with them.

Her daughter described her as "impetuous" because she did not listen to anyone. She complained that Lee does whatever she wants, for instance, she rushes into the bathroom when she wants to take a shower and just leaves the house whenever she wants. Her daughter and domestic helper were often alarmed by her actions, and worried that she would fall and hurt herself.

The JCECC Project Team was able to quickly identify and understand what Lee needed and could benefit from. They organised a variety of social activities to keep her engaged. They also found out that she wanted to take some family photographs, so after she was discharged from the hospital they took her for a haircut. They then brought a camera crew with backdrop, lighting equipment and even a makeup artist to her home for the photo session. When Lee mentioned that she liked dogs, they arranged volunteers with dogs to visit her.

It was important to provide companionship and psychological support for Daisy Lee. Her daughter admitted that even though she took her mother for a walk nearby at the North Point Pier every afternoon, it was different when other people were accompanying them. "It made our outings more interesting," she said, "Having more people around us, it cheers me up too."

Her daughter admitted that she had been more focused on her mother's practical needs, such as her medication and nutrition intake, rather than her psychosocial needs. The social worker and volunteers played different roles and even discussed difficult topics like funeral arrangements in detail. Although Lee's daughter knew what her mother wanted for her funeral, she did not learn more details like the social worker did. "When my mother was lucid, she expressed certain ideas that were new to me. For instance, I found out which funeral ritual she preferred only after the social worker asked her."

As both her father and grandmother passed away quite suddenly, she was grateful that she had time to prepare for her mother's passing. "Everyone has to leave this world; it is just a matter of time. These things have to be dealt with eventually."

CHEER MODEL Five Elements:

① **C** Connect the family members as well as with the community

② **H** Heal the psychosocial wound of the family

③ **E** Express love and care

④ **E** Enhance family continuity through leaving legacy

⑤ **R** Replace sick role

VOLUNTEER

MS TIFFANY WONG: RESPECTING THE PATIENTS' DIGNITY

Tiffany Wong became a "Cheering@Home" volunteer in her 40's. She frequently visited Daisy Lee over a period of two to three months.

Ms Tiffany Wong
JCECC Volunteer

Mr Eric Yu
Project Manager
JCECC: "Cheering@Home"
End-of-Life Care Services
St James' Settlement

"One of the most unforgettable experiences was when I took Daisy Lee to the newly opened supermarket in North Point. We shopped around and tasted different foods. She was incredibly happy and excited." Wong said this experience gave her a different perspective: terminally ill patients are not weak and frail, but can be lively and cheerful.

She took care of another patient called Chun Chun who had terminal lung cancer. Surprisingly, she was rather chubby and relatively strong. Whenever they met, Wong would usually pat Chun Chun on her shoulder and she would respond by giving her a firm handshake.

Chun Chun enjoyed taking walks in the park. During these walks, they talked about flowers, plants and Chinese herbs. When she encouraged Chun Chun to exercise, she would hop onto the fitness equipment in the park and do squats, or walk back and forth. Wong realised that "her mood had an effect on Chun Chun's well-being. If Chun Chun was in a good mood, she was more willing to do exercise. I should visit her more often."

Deeper understanding of caregivers

The first time Wong made a home visit, she stood nervously behind a social worker and worried that she might say something inappropriate. She was also concerned that the patient might suddenly faint, or that they might run out of things to talk about. In reality, none of these worries ever happened. Patients and their family members were genuinely nice people.

"It's actually the other way round, during our visits it seems the patients are more concerned about us. They ask whether I'm hungry and if it's getting late, they remind me that it will be dark and may be windy outside."

Wong felt that trust is one of the most important factors in building the relationship. Volunteers are listeners and should not offer too much comment. "You should listen to what they want to say. You are there to make them happy."

Wong's husband was diagnosed with pancreatic cancer last year. Having seen her husband lying on the bed with various tubes attached to his body, she could easily share the stress of being a caregiver. "I felt the pain of a broken heart across my body. Not knowing what to do made me feel like I was being weighed down and crushed by an enormous sense of helplessness."

When her husband returned home from the hospital, she wanted volunteers to visit them. But her husband refused. Luckily, with his recovery he could gradually start taking care of himself, relieving some of the pressure on Wong so she could continue her volunteer work.

Leaving peacefully

No one wants to be forced to confront death, but it is a reality when taking care of terminal patients. Chun Chun started to feel very ill after taking a stroll through the park. As her condition worsened rapidly, she was immediately admitted to hospital. Wong was devastated, "She was walking and talking normally. But just an hour later, she couldn't speak, and I could see her life slipping away."

Wong felt that what she learnt most from her volunteer experience were not the cliché like "life is too short", rather, the value of being able to live with dignity, particularly for patients reaching the end of their lives.

Terminally ill patients know that there is little they can do to prevent their health from deteriorating. If we can uphold their dignity in their daily lives, they will be able to leave the world with a peace of mind. Wong says that it is important to "Accompany them in their final days and help them finish whatever needs to be done."

Social Worker: Adapting to changes together

A senior who was terminally ill, had a young daughter who was only in grade school. He was determined to undergo any possible treatment in order to be able to attend his daughter's primary school graduation ceremony. His unwavering desire to live made a big impression on Mr Yu, Project Manager of JCECC: "Cheering@Home" End-of Life Care Services. "I saw the 'Lion Rock Spirit' in him. Some terminal patients even strived against the odds of life."

It is difficult to discuss end-of-life care and medical decisions, not to mention funeral arrangements if patients have a will to live and fight. Yu said, "It's important for a terminally ill patient to have a strong desire to live, and I don't want to dampen their spirit." Mr Yu passionately says, "I could always keep them company as they adjust to the major changes in their life."

Initiating the talk at the right time

Yu is mindful when talking about Advance Care Planning with terminally ill patients and their

Advance Care Planning of the Hospital Authority

The information Yu discusses with patients takes reference from the Hospital Authority's Advance Care Planning which was developed in 2019. It covers the following topics:

- **Things valuable to me:** e.g. family, functional independence, spiritual or religious belief, legacy, funeral, pets, etc.
- **Things worrying me:** e.g. dying in pain, unpleasant past medical experience, unfinished business, being a burden, lingering death, after-death arrangements, etc.
- **My wishes or personal goals I would like to share with others;**
- **Preferred place of care if life expectancy is less than one year:** own home, moving to live with others, residential care home, or others.
- **Potential barriers to preferred place of care:** e.g. financial burden, availability of day-time/night-time caregivers, etc.
- **Preferences for personal care:** e.g. favourite food, companion, appearance, personal hygiene, social activities, hobbies, etc.
- **Preferences regarding limits on life-sustaining treatments for the terminally ill**

family members, particularly when their health conditions are stable. "If a patient is not ready to accept the reality, it's not possible and worth reasoning with them." Therefore, he would not insist on talking about it, but instead would spend the time to strengthen the relationships with the patient and family members.

Yu would initiate the conversations about Advance Care Planning when the patient's health is deteriorating and they need to start visiting the hospital regularly.

The first step to opening the dialogue is listening. After learning about the patient's thoughts on end-of-life care and medical decisions, further assessment on their level of understanding about advance care plans can be carried out.

"Many patients believe that their last days should be spent in the hospital. I would let them know of all their possible options, which includes spending their final days at home."

To clearly define the patient's preferences, social workers will conduct a further inquiry to avoid any misunderstandings. Social workers would note down issues or questions related to medical matters and remind them to seek clarification from their doctors. They may also accompany patients to visit doctors when needed. When the patient has decided to make an advance care plan, they would then seek formal support from a healthcare professional.

Being the go-between for family members

Yu recalls another incident when a patient's son unexpectedly received a phone call from the hospital saying his father needed to make an additional medical appointment. It made the son anxious as he felt it was because his father's condition was deteriorating. He worriedly called Yu asking for guidance. The three of them went to see the doctor together, only to find out that the extra session was for Advance Care Planning.

The nurse went through a host of possible life-sustaining treatments such as cardiopulmonary resuscitation, artificial ventilation, inserting nasogastric tubes, etc. and wanted an idea of the father's preferences. The son felt lost and asked the nurse, "what do you want from us?"

The nurse spent more than half an hour explaining further, and handed a booklet to the father at the end of their conversation. It consisted of two parts which required the father to complete: the philosophy of life and after-death arrangements, and necessary medical decisions corresponding to changes in health conditions. Yu helped explain some of the issues involved and the father filled out the booklet, but it was clear that the son was overwhelmed after the meeting.

Two months later, Yu attended another meeting with the father and the son, and this time it was with another nurse and a medical social worker. The nurse carefully read through the booklet the father had filled out, going through each instruction in detail. At the end, she suggested inviting a doctor's witness to sign off the advance care plan in the next consultation session.

His son did not join the meeting but he was concerned, asking, "Does putting down a care plan in advance mean my father wants to give up?"

Yu explained the concept of Advance Care Planning and encouraged the father to share his thoughts with his son so that they could make the decisions together.

Discovering strength through Life Review

The JCECC Project Team from St. James' Settlement can conduct life reviews for patients to preserve and pass on what is important to them to future generations as a legacy. The Project Manager, Mr Yu, showed two books, one of them was the life story of a grandpa which also documented his knowledge of Chinese medicine. Over the years, he collected Chinese medicine prescriptions which had been used for the treatment of his mother's illness. He wanted to leave this body of knowledge for other members of his family.

Another book he wanted to pass down was a collection of happy memories of his wife. Their daughter wanted people to remember the joyful moments in her mother's life. She later distributed this book to friends and relatives during the funeral.

Yu also stressed that life review is a form of narrative therapy, "it takes as long as half a year to complete a life review." He said, "telling their stories helps patients rediscover their strength, which is essential for them to face their current difficult situations."

THE HONG KONG SOCIETY FOR REHABILITATION

JCECC: "LIFE RAINBOW" END-OF-LIFE CARE SERVICES

JCECC: "Life Rainbow" End-of Life Care Services of The Hong Kong Society for Rehabilitation mainly receives cases of non-cancer patients referred from the Eastern Hospital and Ruttonjee Hospital.

The Project Team and volunteers must learn how to use specific medical equipment and deploy certain treatment methods for different illnesses. Social worker Ho Ying-ying pointed out that the life expectancy of non-cancer patients, although in their final days, could be longer than that of a cancer patient. During this time, their health condition fluctuates frequently.

In order to maintain a patient's quality of life, in which they can live with dignity and meaning, there are three critical skills they need to acquire: handling symptoms of illness, managing emotions and maintaining a daily routine.

"Although palliative care nurses would provide follow-up services, it is still difficult for elderly doubletons to take care of their spouse in their last days." Ho cited a case when a patient's pressure ulcer worsened on a Saturday. The patient's spouse was too weak to put him in his wheelchair to take him for seeing a doctor. They called for help from the JCECC Project Team nurse, who went to their home and showed them how to treat the pressure ulcer. At the same time, the project nurse called the hospital to arrange a community nurse to help clean the wound.

Service Target

End-of-life patients with chronic illness and their family members who live in Wan Chai or Eastern districts

Types of diseases included - advanced chronic obstructive pulmonary disease, end-stage renal failure, late-stage Parkinson's disease, and late-stage motor neuron diseases. In 2017, the service was extended to cover patients with heart failure.

Scope of Service

Symptom Management Support	Teach patients and their family members techniques to relieve physical discomfort (like shortness of breath, fatigue, insomnia)
Caregivers Support	Teach family caregivers skills in relaxation and stress management
Home Care Support	Match community resources with home care needs / Provide practical advice on the use of tools to help with patients' daily life
Personal and Family Counselling	Assist patients and their family members to reduce emotional distress / Foster family bonding and support
Volunteer Caring	Arrange phone calls and home visits by volunteers
Life Review Programme	Arrange wish-fulfilment activities / Conduct life review to recall and record happy moments
Holistic Life Empowerment	Assist patients and their family members to live positively in late-stage life / Assist patients to build a positive and active life model with appropriate symptoms relief exercises, dietary management, outings, and mapping out short-term goals

CHARACTERISTICS OF END-OF-LIFE CARE FOR DIFFERENT TERMINAL ILLNESSES

Chronic obstructive pulmonary disease

"Have you experienced shortness of breath this week?"

The most noticeable symptom of chronic obstructive pulmonary disease (COPD) is shortness of breath. "In our first home visit, I relied primarily on the project nurse to relieve symptoms of illness." Ho explained, "The nurse checked how the patient takes prescribed drugs, such as the number of times a patient should use an inhaler in a day, how much should be inhaled each time, and whether it is possible to relieve symptoms by changing their sitting posture or the way they breathe. Follow-up service will then be carried out by other colleagues or volunteers. "

The JCECC Project Team at The Hong Kong Society for Rehabilitation (HKSR), would teach caregivers ways to monitor a patient's health such as measuring body temperature and blood pressure, and checking blood oxygen levels via a clip-on oximeter. Caregivers were also taught how to maintain readings at a satisfactory level, or if needed, deploy remedies to improve the condition.

Currently, the COPD patients referred from hospitals are mainly male smokers. "Some of them are construction site workers who are not used to talking to people. 'Nothing is worth talking about. That's all I want to say' is their typical response."

Ho was concerned that many patients were not following the medication instructions accurately. For patients with inhalers, they should wait for a while between each puff. However, they often take several puffs at the same time. While nurses would remind patients, caregivers and volunteers can reinforce the correct practice repeatedly.

Ho observed that male patients are generally more reserved and harder to engage. For instance, they wanted to see their grandchildren but did not want to put pressure on their daughters-in-law. They would only share their real thoughts and feelings several months later after getting to know the volunteer better and establishing a closer relationship with them. They would ask, "Would it be possible for me to see my grandchildren on Sunday, when they don't have to go to school?"

Advance Care Planning is an even harder topic of discussion with male patients. "For example, when talking about cardiopulmonary resuscitation, they may avoid the topic by saying, 'I don't want to think about it.'"But the social workers would not give up, and instead carry on the conversation by giving them real-life examples to better gauge their thoughts. "Another patient who had the same illness eventually lost some of the functionality of his lung. When he arrived at the hospital, the doctor asked whether he wanted a ventilator to help him breathe. In torment, the patient wanted to end his life for immediate relief, 'Please, let me die now' he desperately said. What do you think about this case?"

After understanding the patients' thoughts, the Project Team would inform their family members and further discuss with them.

Kidney Failure "How's your current health condition?"

Since most of the end-stage kidney failure patients referred to HKSR have decided to discontinue dialysis treatment, they may experience different symptoms like chills, itchy skin, lower limb oedema, lower limb paralysis, mobility difficulty, fatigue, pain, dry mouth, loss of appetite, nausea, constipation, insomnia, and so on. The JCECC Project Team of HKSR would evaluate the patient's health every week. They would try to get more details of their condition, "have these symptoms been bothering you over the past week? How badly has it been affecting you?"

Ho said that the end-of-life care services helped terminally ill patients to sustain their daily lives, "patients chose to discontinue dialysis treatment because they want more freedom. These patients are, in fact, more proactive in managing their health conditions. When we meet, they would show me their notes and discuss the health record saying, 'readings have gone up quite a bit this time.'"

If the patient wanted to alleviate oedema, we would provide at least two possible solutions, such as cutting down salt intake; exercising and specifically, how much they should exercise in a week.

Not everyone is prepared to discuss Advance Care Planning. "I met an elderly man who showed me his health record booklet every time we met and would discuss the changes of some of his symptoms. When I attempted to talk about end-of-life medical decisions, he was hesitant and mumbled, "I don't really want to talk about this, it makes me anxious."

"Alright. We don't have to." Ho said, half a year later, the elderly man brought up this topic on his own, "Do you remember the issue you wanted to talk about the last time, what was it?"

"Are you referring to the decisions I have to make before I 'kick the bucket'?" Ho felt that the elderly man was aware of his health condition. He would wait until he felt very sick, but then he would not follow through with the decisions he had made involving the other people around him.

It is important to build reliable and trusted connections and relationships. As late-stage chronic disease patients could have a longer illness trajectory than expected, it is essential to maintain contact throughout this period despite what could appear to be insignificant changes in their symptoms.

The JCECC Project Team also helped patients fulfil their last wishes. Patients suffering from kidney failure found it hard to go out. A granny who suffered from both kidney failure and a stroke, wanted to attend lessons at HKSR. The Project Team arranged a car to take her to classes. A couple of days later, she was hospitalised and passed away.

Ms Ho Ying-ying
Social Worker

Dementia "Is your family doing well?"

During the final stage of dementia, patients may find it difficult to express their thoughts. The JCECC Project Team offers support to their caregivers as well.

Although palliative care teams of hospitals would discuss Advance Care Planning with families of terminally ill patients, dementia patients, even in their final stage, usually remained in the medical ward. Constrained by resources and manpower, there is relatively less time for medical staff to discuss end-of-life care plans with them.

"Even though medical staff may have explained the use of tube feeding when the patient can no longer eat and swallow properly, patients and their family still prefer to have our team involved in on-going communication."

Ho Ying-ying said, "we make every effort possible to try to understand the patient's needs and preference about end-of-life care by talking to their family members. We ask many questions and try to identify specific requests. Sometimes, family members tend to make decisions based on their interpretation which may not fully reflect the patient's needs and preference. Besides, opinions among family members are often diverse. "

Ho cited an example: The elder daughter was the caregiver but felt it was too much pressure to make end-of-life medical decisions for her mother on her own as her siblings did not see their mother frequently. So when the patient's other children came to visit their mother in hospital, the Project Team took the opportunity to engage them in discussion, "Everyone can take part in their mother's end-of-life care decision."

Sometimes medical staff could end up being too busy and may ask family members to make certain decisions without giving them sufficient information. "You have to decide whether resuscitation should be arranged." Social workers would follow up and provide further explanation like what resuscitation means, its risks, health implications and consequences.

Some doctors may invite the JCECC Project Team to help communicate with family members. Doctors feel that during these sessions the family members feel more obligated to participate in the discussions. When the family is unable to reach a consensus, social workers will follow up via phone call to get a clearer idea of their concerns and thoughts, and then initiate further discussion to try to work out an agreement.

Parkinson's disease

"Both of you are making a great effort!"

Patients with Parkinson's disease are mentally active. However, it is difficult for them to show facial expressions, making others hard to understand how they feel. Hence, they are also prone to depression.

"Most Parkinson's disease patients we've come across are men with low self-esteem. Since their speech has become slurred, caregivers may have trouble understanding them and feel frustrated, thus raising their voices and losing their temper with them. "It's because he never listens, and now he's fallen down again!", is the most common complaint among angry wives."

Ho said this could be the beginning of a vicious cycle where the husband wants to do more to show his capability, but it ends up being in vain. Instead, this has put pressure on their relationship and created more conflicts.

In this case, social workers could be involved to help the husband better understand his illness and symptoms. They can also help explain why the wife gets angry, so that both sides can recognise the efforts the other is making and appreciate each other more.

Sometimes, communication can go beyond words. The JCECC Project Team will customise experiential art workshops based on a patient's health condition, for couples to communicate and express themselves. For instance, if the patient can still move his fingers, Japanese Nagomi Art could be a healing experience for patients to create artwork with their fingertips.

Stroke

"Let's have a life with quality."

HKSR has been addressing the needs of stroke patients for many years and more recently, the organisation has offered even more comprehensive support to this group of terminally ill patients. "If the patient is mobile, volunteers will take them to rehabilitation centres for classes. For those less able, occupational therapists would be arranged to teach them appropriate home exercise, also involving the volunteers. They can then carry on exercising together regularly." Ho Ying-ying emphasises that patients could still do simple rehabilitation exercises under the guidance of therapists during their last days in a bid to slow down their health deterioration.

"Occupational therapists may recommend passive exercises to reduce stiffness, such as massage for patients who are bedridden. Aromatherapy, music therapy, etc, can also help improve a patients' quality of life and relieve pain."

Heart failure

"When death comes suddenly."

HKSR has long been promoting "self-health management" among chronic disease patients, including those with diabetes, high blood pressure, etc. Symptoms of heart failure are unpredictable and can worsen quickly. Advance Care Planning is usually discussed with these patients ahead of time.

"Heart failure patients may have experienced life-threatening heart attacks," Ho said that the JCECC Project Team would bring up end-of-life care discussions with them, "if you have a heart attack and your heart stops beating, do you want cardiopulmonary resuscitation to be performed? Your life might be saved, but you could end up in a coma where you must rely on a mechanical ventilator to breathe, etc. Would you be okay with that?" They also can share their thoughts candidly in group discussions with other patients with similar conditions.

"Some terminal patients referred to us are too frail and unstable and so it's too late to discuss what kind of care they would prefer. Therefore, we encourage terminal patients to think about and plan for their end-of-life care in advance."

MEDICAL-SOCIAL COLLABORATION ON ADVANCE CARE PLANNING

The Hong Kong Society for Rehabilitation produced a collection of booklets on symptom management for various illnesses, aiming to educate patients about self-care, and keep track of their health condition and how they are feeling. These booklets also serve as an entry point for families to discuss Advance Care Planning.

Ho pointed out that health care professionals might not have time and enough manpower to discuss Advance Care Planning with terminally ill patients and their family members. The Hospital Authority also developed a set of new guidelines on Advance Care Planning in 2019, which recommended discussions targeting matters important to the patient, their values and unfinished businesses. "These discussions could be lengthy. Doctors do not have time to go through these topics with patients, neither do they have the relevant experience."

HKSR is currently collaborating with Ruttonjee Hospital to initiate Advance Care Planning with terminally ill patients. In the project, the JCECC Project Team would lead the discussion with patients to gauge their preferences and needs while explaining the various options of end-of-life care and medical treatments. This would help the patients become more aware of their rights, and pave the way for future discussion with medical staff.

In the past few months, more than ten patients have signed the Advance Care Planning form in the hospital. Ho praised the collaboration for making it easy for patients and their families, while relieving the pressure on doctors and medical staff.

HAVEN OF HOPE CHRISTIAN SERVICE

JCECC: HOSPICE AT HOME

The team of Haven of Hope Sister Annie Skau Holistic Care Centre (SASHCC) includes specialists in palliative medicine and geriatrics, nurses, personal care workers, physiotherapists, occupational therapists, chaplain, social workers, volunteers and clinical psychologists. SASHCC has more medical professionals in comparison to other organisations.

Patients recruited to "JCECC: Hospice at Home" were referred by health care professionals or social workers. Their city-wide outreach service covered Hong Kong island, Kowloon and New Territories, except outlying islands. In partnership with referral organisations, end-of-life care services were provided using a case management approach to ease the burden on emergency services and reduce unnecessary hospital admission.

SASHCC also offers respite care services. "We provide short-term residential care service for terminally ill patients before they are able to return home." Dr Tracy Chen, Associate Consultant, believes that this service could also help caregivers. "For instance, if the caregiver needs to undergo a minor surgery and take rest for a week, the terminally ill patient could stay with us in the hospice temporarily."

Service Target

Patients aged 60 or above with terminal cancer or other chronic irreversible illnesses; those with an average life expectancy of up to 12 months.

Scope of Service

Health assessment, symptom management, guidance on medication,

home-based nursing care, teaching of related caring skills,

support services to address caregivers' emotional and spiritual needs, rehabilitation services and training,

specialist out-patient clinic and patient escort service,

facilitation of Advance Care Planning,

spiritual care and bereavement counselling.

NURSE: CASE MANAGEMENT AND REFERRAL

"After 90 years, it is normal for any machine to break down and malfunction."
"It could be more than just malfunctioning, long life could become a burden. "
"After working for more than 90 years, it's time to take a rest and let the young ones take over your work. When you are healthy, your children are most at ease. "

Ms Almond Cheung
Advanced
Practice Nurse

Almond Cheung, Advanced Practice Nurse of Haven of Hope Christian Service, and nurse Chan Lai-ming were comforting 92-year-old Granny Lam while noting down her blood pressure and body temperature.

A home visit usually lasts about 45 minutes to an hour. After the initial greetings, the nurse would start tracking vital signs and inquire about changes in physical conditions. When Granny Lam's daughter saw the oximeter, she immediately asked how to use it. Lai-ming showed her how it works and explained the difference in blood oxygen between an adult and an elderly person to reassure her about the fluctuations in her mother's blood oxygen.

Understand what matters

Granny Lam has been suffering from various chronic illnesses and keeping a plastic box full of medicine. Since she has been seeing private doctors, her medical records in public hospitals were incomplete. Almond Cheung admitted that it was hard to follow up on her case. Home visits can help identify and understand her real needs.

She had been suffering from back pain. The team arranged physiotherapists to teach her exercises and she also received acupuncture treatment, but both were unable to relieve her pain.

In a routine check-up, Cheung noticed swelling on Granny's back. She immediately reported the case to the doctor via a video call on her computer tablet. Granny's daughter also joined the discussion.

After an initial tele-consultation, the doctor referred Granny Lam to the Orthopaedics Department of Haven of Hope Hospital for a detailed check-up. Cheung supplemented information about the rehabilitation scheme and stressed the importance of finding out the root causes of the pain. "I will call again next Monday. In the meantime, feel free to call me if you need more information."

Non-medical care needs

Almond Cheung also prepared information on the nearby District Elderly Community Centre for Granny's family. It would give them access to community resources, like meals delivery, out-patient escorting service and volunteer visits, when needed.

Meanwhile, Chan Lai-ming taught Granny Lam's other daughter and their helper how to use food thickeners properly. Although Granny Lam had difficulty chewing and swallowing, her daughter knew that she would not like pureed meals. Chan showed her another way of preparing puree meals that she could add more water to make it like a soup instead. She patiently answered each of the daughters' questions.

At the end of their visit, Cheung asked for Granny's medicine box. She looked carefully and took pictures. This gave her additional information to discuss with the doctor.

DOCTOR: MEETING PATIENTS THROUGH TELE-MEDICINE

Associate Consultant Dr Tracy Chen is one of the key members of the JCECC Project Team at Haven of Hope Christian Service. She sees patients and provides medical consultation through video conferencing. "It is not merely patients pressing buttons and doctors prescribing medicine." Doctors are, in fact, backing nurses, social workers or healthcare staff in performing quality services. In a home visit, when they see a need for immediate medical advice, they can contact Dr Chen via tele-medicine.

"I would advise my colleagues on follow-up actions, such as taking blood pressure and examining various body parts before seeking my opinion. I would reach out to the attending physician of the patients to better understand the patient's needs."

For instance, a Granny with bowel cancer suffered from severe anal pain. Her family worried that it could be a symptom of cancer and asked a nurse to examine her at home. She found a rash around her anus, took photographs and discussed her findings with a doctor via video conference. Without going to hospital, Granny was diagnosed with shingles (herpes zoster) and prescribed with antiviral medication.

Nurses following up on different referrals

While other NGO partners of the JCECC project receive terminally ill patients referred from public hospitals, cases referred to Haven of Hope came from more than ten organisations, including public hospitals all over Hong Kong, as well as private doctors, and even social workers. Case follow-up is far more complicated and challenging.

"Some organisations asked us to handle physical symptoms; some doctors expected us to handle patients' and their family's emotions; others wanted us to arrange personal care services such as bathing..." Dr Chen expressed that the role of nurses was to act as case managers, assisting patients in accessing different community services.

SASHCC also provides short-term residential care for patients for up to a week. Apart from providing terminal patients with different medication and alternative treatments, the respite service also allows caregivers to take a short break when needed. In addition, volunteers of the team make regular home visits, and even take them out for outdoor activities such as yum-cha to foster relationships among family members.

Not easy to take care of advanced dementia patients

Currently, approximately 80% of terminally ill patients of "JCECC: Hospice at Home" are cancer patients. Dr Chen is particularly concerned about advanced dementia patients. She explains that "the fight against cancer is relatively quick and short, as most symptoms are severe and come suddenly. However, the fight against dementia can be long and arduous, with unpredictable symptoms. The pressure on the caregiver is tremendous."

Advanced dementia patients are usually not referred from hospitals or organisations, but by anxious caregivers who have made multiple enquiries.

On the day of the interview, Dr Chen told us about a 97-year-old granny that Almond Cheung visited on the same day. The elderly lady, who suffered from dementia, heart disease and several other chronic illnesses, could no longer stand upright due to osteoporosis. The severe pain prevented her from getting off the bed or going to the toilet. It became increasingly difficult for both the helper and her daughter to take care of her at home.

"We first tackled her symptoms by relieving her waist pain and correcting her sitting posture, so that she can regain her appetite. Pressure sores were the next issue we addressed ... and then we looked into getting extra help for the maid." The maid needed to attend to the routine household chores, but whenever she walked away, the granny fell down.

The Project Team recommended the maid to place a small bell next to Granny, which she could ring whenever she needed help.

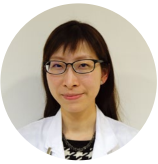
Mutual support in a Compassionate City

Advanced Practice Nurse Almond Cheung mentioned another granny who also suffered from dementia, but decided with her family's support that she did not want nasogastric tube feeding even if chewing and swallowing became difficult for her. Despite that, the hospital still insisted on using tube feeding. The Granny left the hospital as soon as her condition allowed.

"Her family turned to us for assistance and showed us the Advance Directive the Granny signed. We taught them how to use food thickeners and correct her seated posture. Cheung also arranged physiotherapists to visit Granny at home and taught her maid how to carry her, and help her take a bath, etc.

Dr Chen hoped that there would be more resources in the future to help advanced dementia patients. "The elderly resist going to elderly homes, yet their family members struggle and have trouble bringing them to see doctors. Staying at home could become a situation where they don't get the help they need."

Dr Chen has a bigger vision to achieve: to develop a compassionate city in which elderly with advanced dementia and those elderly living in rural



Dr Tracy Chen
Associate Consultant

places could be well supported by a closely-knit community network and through social-medical collaboration.

"We need better community planning and collaboration between the Social Welfare Department and the Hospital Authority to tackle issues stemming from the ageing population in an overarching and structured manner. Public education should be provided to the whole community to bring up their awareness and encourage them to support each other."

Documenting the patient's end-of-life heartfelt wishes

SASHCC developed an Advance Care Planning form to gauge how a terminally ill patient wants to be cared for in their last days.

- Is it the most important to minimise pain and discomfort?
- Would you accept palliative sedation?
- Would you want a doctor or your family members to tell you the truth about your clinical condition?
- At the end of life, would you prefer to receive cardiopulmonary resuscitation, use an artificial ventilator to sustain life, or continue futile treatments?

Dr Chen received training in the U.S. in 2010 to study ways of discussing Advance Care Planning with patients. "To my surprise, many participants were not doctors but social workers, pastors and therapists from different disciplines.

The professor admitted that when doctors talk to their patients about stopping certain medical treatment, it sounds like the doctor has given up on the patient. It might be more appropriate and natural for other trained professionals to facilitate the discussion, reaching out not only to terminal patients, but also those with chronic illnesses or even healthy people."

Dr Chen pointed at the form where a patient's last wishes were recorded" and said, "This page is optional, but we still have to cover this topic in our discussion."

S.K.H HOLY CARPENTER CHURCH DISTRICT ELDERLY COMMUNITY CENTRE

JCECC: "HOSPICE IN FAMILY" HOME CARE SUPPORT SERVICES

JCECC: "Hospice in Family" Home Care Support Services of S.K.H Holy Carpenter Church District Elderly Community Centre mainly provides services for terminally ill patients living in Tuen Mun, Yuen Long and Tin Shui Wai. According to the Project Manager, Ms Kimmy Lam, many new immigrant families and elderly live in the rural areas of these three districts. She says that the social support network is quite dispersed, which not only makes it difficult to access community resources, but also results in a long waiting time for social services. The home-based services are also hampered by an inconvenient transportation system.

JCECC: "Hospice in Family" Home Care Support Services has filled many of the service gaps by connecting patients and their family to relevant social service providers. The Project Team gives alternative support by outsourcing services for families who are on the waiting list.

Senior Service Manager, Mr Arnold Leung, emphasised that palliative care should also take into account a terminal patient's "Body-Mind-Social-Spirit" while focusing on their quality of life. He says it is crucial that the patients and their families' daily needs are met.

Service Target

Terminally ill patients aged 60 or above and their family members, living in Tuen Mun, Yuen Long and Tin Shui Wai

Scope of Service

Home-based End-of-life Care Service	Social workers are responsible for assessing needs and providing counselling, spiritual care, organising activities for patient's wish fulfillment, and rebuilding their social life, etc. There is also a nurse who can provide healthcare follow up and health-related enquiry services.
Mutual Support Group	Rebuilding social networks for patients and their family members to reduce stress.
Funeral Assistance and Bereavement Counselling	Assist family members of the deceased with funeral arrangements, provide professional bereavement counselling and help the family to lessen family grief and adjust to a new life.
Volunteer Training and Service	Volunteers make home visits to provide emotional and peer support, provide practical assistance and spiritual care for terminally ill patients and their family members.

Ms Hung Wai King
Participant

Singleton patient: I want to stay at home

61-year-old Hung Wai-king lives on her own in Sam Shing Estate in Tuen Mun. She keeps her medicines, papers, photo albums and medicine bags all on a folding table in her living room. Hung suffers from a number of chronic conditions, like heart disease, kidney and liver problems and high blood pressure etc. Since she lives on her own, she has managed to cut down her monthly household expenses to less than $1,000, her water bill only comes up to $19 and gas is $32.

Living alone, Hung is not concerned about her financial circumstances, but she is worried that she could end up in an elderly home due to her poor health.

Her husband was twenty years older than her. When he was diagnosed with terminal lung cancer, Hung became his main caregiver, taking care of his daily needs. She fed him meals, administered his medicine, helped him take baths, changed his diapers, and so on, until it became too much for her and she was burnt out. Unable to continue with his care, she sent him to an elderly home, but he did not like it and refused to eat.

Hung also heard that some of the staff members mistreated her husband and pinched him, leaving her with a terrible impression about old age homes. Her husband passed away in 2019, and as she was not close to her daughter, she ended up living on her own.

Tuen Mun Hospital referred Hung to the JCECC: "Hospice in Family" Home Care Support Services of Holy Carpenter Church. Hung insisted that she wanted to stay at home for as long as possible for her end-of-life care. "I don't want to leave my home unless I have no other option."

Volunteers discussed medical decisions and funeral arrangements with her. Hung chose to have the same end-of-life arrangement as her husband and opted for not having resuscitation, so she signed an advance care plan document in the Tuen Mun Hospital.

She wanted her funeral service to be arranged at the hospital like her husband's, and after cremation, she wanted her ashes placed in his shrine in the same columbarium.

"We have been a couple for more than forty years. I must not let him be a lonely spirit. We should "live" together again, under the same roof."

Ms Kimmy Lam
Project Manager

Lee Hin-tat and his wife
Participants

Patients living in rural area: Happy to have a visitor

82-year-old Lee Hin-tat and his wife lived on the second floor of a Yuen Long village house with a rooftop in Tai Tong. They did not have children and lived a carefree life with seven dogs and a cat.

As they got older, Lee's wife found it more difficult to walk up and down the stairs. So, they sold their flat and moved to Tseung Kong Wai, which was a 20-minute walk to the nearest bus stop. Fortunately, there was a shuttle bus service to Yuen Long town centre.

They both suffered from chronic illnesses and needed to see the doctor frequently. But each visit to the hospital was an arduous journey with a long walk to catch the shuttle bus to the town centre, where they then took a taxi to the hospital.

In mid-2019, the doctor suggested Lee to take his peritoneal dialysis treatments (a way to remove waste products from the blood when the kidneys could not function) at home. He refused, feeling that it would make his day too constrained and he would not be able to be flexible with his time. As a result, he was referred to the hospital's palliative care unit and a social worker further enlisted both him and his wife in the JCECC: "Hospice in Family" Home Care Support Services of Holy Carpenter Church.

As their health gradually deteriorated, they met up with their friends and relatives less often. And, after moving to their new flat, they completely lost contact with their old neighbours. The dogs and cats they once kept, also passed away. Watching TV became their only form of entertainment.

The couple looked forward to the home visits of social workers and volunteers from the project, which were some of their happiest moments.

Grandma: I want Buddhist rituals and chanting in her funeral

A grandma who refused to be hospitalised made a deep impression on the Project Manager of JCECC: "Hospice in Family" Home Care Support Services, Ms Kimmy Lam. "She was a devoted Buddhist. She believed that chanting to the deceased is an important ritual which needed to be performed within six hours after the person stopped breathing. She refused to be hospitalised knowing that her body would be sent to the mortuary and "refrigerated" immediately after she died.

Lam and her team made a huge effort to make sure the grandma's wish to stay at home for end-of-life care was fulfilled. But when she found out that the main reason she preferred to pass away at home was due to the chanting ritual, Lam asked, "If you pass away at home, who will come and lead the chant for you?" She then discussed with the hospital staff who agreed to give four additional hours for the chanting ritual before sending the grandma's body to the mortuary when she died.

Eventually, the grandma felt reassured and agreed to be hospitalised. In the last 12 hours of her life, fellow Buddhists were invited to lead the chants. Her family believed that the ritual was already performed well and enough during that period of time, and so they did not ask for extra time.

SOCIAL WORKER: FINDING A WAY TO TRAIN VOLUNTEERS

Mr Arnold Leung
Senior Service Manager

JCECC: "Hospice in Family" Home Care Support Services of S.K.H Holy Carpenter Church District Elderly Community Centre mainly provides services for terminally ill patients living in Tuen Mun, Yuen Long and Tin Shui Wai. The population of these three districts amounts to more than 1,100,000 people. Two hundred thousands of them live in rural areas and many are new immigrants.

"Many social services have a long waiting time typically ranging from 6 to 12 months. It can be too late for terminally ill patients by the time they get their turn," Lam explained. She was especially concerned about families with an older husband and a much younger wife. "When the husband is ill, his wife is usually preoccupied with taking care of their children. Since her friends are most likely young mothers, she may not know much about the elderly services in the district."

For cases like this, volunteers of JCECC: "Hospice in Family" Home Care Support Services may invite patients and their families living in the same housing estate to get together to help them build and expand their social support network, e.g. yum-cha together in neighbourhood restaurants.

Social workers will also assist in making applications for services like meal delivery and escorting patients. They will identify the needs of other family members and make referrals to relevant organisations for support when coming across cases such as isolated youths or pathological gamblers.

Patients living in remote rural areas have access to even fewer resources, Lam says, "the farther away they live, the fewer services available." For example, some service providers for cleaning or escorting patients can be reluctant to visit patients due to poor transportation networks, even if they are willing to pay.

Choosing the right people

Mr Arnold Leung, Senior Service Manager of S.K.H Holy Carpenter Church District Elderly Community Centre pointed out that patients and their family members had many daily issues which needed to be addressed.

He recommends expanding basic palliative care from "physical-psychological-social-spiritual"

to "practical-physical-psychological-social-spiritual" as end-of-life care should also address patients' practical needs in their everyday life.

The help and support of volunteers is important in remote areas. Currently, JCECC: "Hospice in Family" Home Care Support Services has about 200 volunteers, among them only 30-40 are actively involved in the New Territories West. The recruitment process of volunteers is stringent with 30 hours of training sessions and 20 hours of on-the-job practice.

"Finding an appropriate JCECC volunteer is not an easy job. The person shouldn't be too pessimistic and too negative about death. They should also have effectively managed any past situation in facing death." Leung explained that many volunteers had their own experience of facing death. If their emotions were not well-managed or fluctuated, it would be hard for them to take care of other patients and their family members.

Understanding patients in three perspectives

Mr Arnold Leung designed a 3L service model to help volunteers understand a terminally ill patient's Loss, Love and Legacy. Volunteers have to find out the patient's loss due to terminal illness; what would make the patient feel love; and things the patient wants to pass down to loved ones.

Volunteers will pass the information gathered to the social workers for service planning, such as arranging social activities, conducting life reviews, etc. Leung said that volunteers are both "informants" and service providers, tackling patients' needs pertaining to their social and everyday life.

Ms Lau Yuk
Volunteer

3L Service Model

LOSS

To understand what terminally ill patients may have lost owing to their illness, such as mobility, self-care ability, life goals, intimate family relationships, and social life, etc.

LOVE

To understand what else will enable patients to feel love, and explore what could be done accordingly.

LEGACY

To understand what patients want to pass down to their beloved.

Volunteer Ms Lau Yuk: Say no more

63-year-old volunteer, Lau Yuk, made regular visits to a grandma who loved knitting. The elderly lady was very talkative. She enjoyed telling stories of her past, but no one was interested in hearing them. Lau would patiently listen during home visits and even asked the granny to teach her how to knit, which made the grandma very happy.

Lau was also a volunteer of the "PARACLETE–Care and Comfort Angels" Project, another endeavour of the Holy Carpenter Church. She once attended a funeral of a baby. Unable to communicate with the ethnic minority parents due to the language barrier, Lau could only sit quietly next to the grieving parents. When she saw them kissing their child's dead body to bid farewell, she could not help but shed tears.

At the end of the funeral, the couple held Lau's hands tightly and kissed them. "At that moment, I realised the value in just keeping someone company and showing empathy. These gestures are far more powerful than words."

Ms Wong Po-yuk
Volunteer

Volunteer Ms Wong Po-yuk: Be able to learn more

65-year-old Wong Po-yuk has been a volunteer of the JCECC: "Hospice in Family" Home Care Support Services for more than three years. She gave an analogy comparing her volunteering experience to "a tree-hole", in which she sat still and listened, "Just let them vent, lend your ears to them and listen."

Wong once met an elderly man from her hometown during her home visits, who suffered from terminal cancer. Over two years of visits, he told her interesting stories and trivia about their hometown. Wong Po-yuk felt like she was travelling with him on a time machine.

When the elderly man passed away, she missed him a lot. "We got to know each other over the two years, starting from strangers to becoming friends. I saw many changes in him over that time. I think of him whenever I pass by where he once lived."

Wong Po-yuk admitted that it is hard for her to see patients die. Instead of suppressing her emotions, she allows herself to let her feelings out. After grieving, she would look back at the days she spent with the deceased fondly. "Actually, when the patient goes in peace and passes away with dignity, I feel happy for him."

Wong reflected that in fact she has learnt tremendously from the terminally ill patients whom she visited. Accompanying the patients in their last days has given her a new perspective of death.

HONG KONG ASSOCIATION OF GERONTOLOGY

END-OF LIFE CARE IN RESIDENTIAL CARE HOMES FOR THE ELDERLY

The Hong Kong Association of Gerontology provides JCECC: "End-of-Life Care in Residential Care Homes for the Elderly" in 48 subvented elderly homes situated in Kowloon East, Kowloon Central and Kowloon West. All the staff members of these elderly homes receive a six-month training on how to provide care to the terminally ill patients. It helps that elderly participants of the project would not have to travel back and forth to the hospital towards the end of their lives. Instead, they can stay in an "end-of-life care room" with regular doctor's visits and 24-hour nursing care, and the room is open for family members' visits round the clock.

Dr Edward Leung, President of the Hong Kong Association of Gerontology, hoped that the end-of-life care service model could be extended to all elderly homes in Hong Kong. Not only could it enhance a patient's quality of death, but also reduce the pressure on the public health care system.

Service Target

Terminally ill patients
in the 48 elderly homes
situated in Kowloon East,
Kowloon Central,
and Kowloon West

Scope of Service

Facilitation of End-of-Life Care Planning	The Project Team and staff of elderly homes will facilitate discussion on advance care planning and advance directives with patients and their family members	
Holistic Care	The Project Team, the Community Geriatric Assessment Teams of the Hospital Authority and staff of the elderly homes will join hands to provide care for terminally ill patients, addressing their psychological, social and spiritual needs	
Family Support Service	Intensive Care at Final Days	Bereavement Counselling

DAUGHTER: I HELD MY MOTHER'S HANDS IN RESIDENTIAL CARE HOME

Ms Lau Lai-ping
Participant

Lau Lai-ping gently kissed her mother on her forehead, just like her mother kissed her tenderly when she was born. Sensing that her mother's breath was fading, and with her face looking like she was falling asleep, Lau said, "I held my mother's hand, keeping her company till her very last moment.

Lau Lai-ping's mother had lived in Po Leung Kuk Comfort Court for Seniors for nearly ten years. About four or five years ago, she had a stroke and had been bedridden since then. In mid-2019, her mother went in and out of hospital for as many as six times in four months due to shortness of breath. Lau was traumatised.

When the superintendent of Comfort Court and the project nurse told her about the JCECC: "End-of-Life Care in Residential Care Homes for the Elderly" project of the Hong Kong Association of Gerontology, she immediately decided to enroll.

The best environment is one that feels familiar

When her mother was in hospital, only two people were allowed for each visit. The visiting period was too short to allow her to clean her mother's face and hands. It made her miserable to see the dirt between her mother's fingers, and later a big pressure sore developed on her arm. She could not help but comment, "Hospitals provide medical care, but they don't attend to personal hygiene and quality of life."

Lau also pointed out that hospitals could be "cold". Twenty years ago, when she was on the way home after visiting her father in hospital, she received a phone call from a relative. She rushed back to the hospital only to find the healthcare worker preparing to take the body to the mortuary, leaving her in deep regret that she was unable to say goodbye to her father. This was the main reason why Lau enrolled her mother in the JCECC: "End-of-Life Care in Residential Care Homes for the Elderly" project, so that she could pass away in a caring and familiar environment.

Lau Lai-ping said her family originally did worry that her mother could be deprived of proper medical care while staying in the elderly home. But she was reassured that, "the end-of-Life care room is not a path to death." She explains that it is a place where the care services are tailored according to the patient's health condition along with the needs of family members. In addition, doctor's visits and round-the-clock nursing care are also available.

Sharing heartfelt words in the end-of-life care room

When her mother's health deteriorated, Lau Lai-ping got the trust and consensus of all her siblings to sign the consent documents and agree to let their mother stay in the end-of-life care room.

End-of-Life care room of Po Leung Kuk Comfort Court for the Senior

Mr Dick Lee
Operation Manager
of Po Leung Kuk

During the five-day stay, family members could visit their mother anytime. Lau could spend time talking to her mother. They laughed and cried together.

This is something a hospital ward cannot provide, "It is not where one can open up and speak their mind. Every move we make could affect other patients."

When her mother fell into a coma, nurses encouraged Lau to keep talking to her. Lau was grateful for their kindness, "they reminded me to be in the moment and not to let go." She held her mother's hands, talked to her and kissed her forehead. Although Lau cried, she felt comforted knowing her mother was leaving them in peace.

Manager of residential care home: It is not lonely leaving the world

"Never have I thought that the elderly could have the option of spending their last days in a residential care home." Operation Manager of Po Leung Kuk, Mr Dick Lee adds, "I have worked in the emergency ward of the hospital. I know it is busy in hospitals with limited resources. The care that can be provided for an elderly patient is far less than that in an elderly home."

After joining the JCECC: "End-of- Life Care in Residential Care Homes for the Elderly" project, all staff members, including nurses, physiotherapists, care workers, health workers, general attendants and even the cooks, joined training sessions arranged by the Hong Kong Association of Gerontology. Apart from learning the practical skills in caring for terminally ill patients, they also joined experiential workshops and learnt how to face death.

Lee candidly said his colleagues were concerned about handling dying patients and had fears about the deceased body in the elderly

Three Options in
JCECC: "End-of-Life Care in Residential Care Homes for the Elderly" project

Option One	Option Two	Option Three
Residents are cared in the elderly home until expected dying within one to two days and then sent to the hospital.	Residents are cared in the elderly home until the last moment of life and then sent to the hospital.	Residents are cared in the elderly home until the last moment and certified death by Project Doctor in the elderly home (only applicable to Nursing Home and with prior arrangement made with funeral parlour)

home. Over the past three years, they handled 12 end-of-life patients who passed away in their residential care home.

Family members are part of the team

"End-of-Life care services in elderly homes is a team collaboration involving multidisciplinary professionals. However, family members form the most critical part of the team." Lee explained, "we cannot achieve much without the support of the family." The service usually starts with a meeting in which the person in charge of the elderly home, social worker, nurse and the family members all come together to discuss the direction of care and the medical options available for the elderly resident. It would be hard to proceed if there was disagreement among family members.

In one instance, a family member initially dismissed the option of receiving end-of-life care in an elderly home. But after witnessing the harrowing experience of the patient going in and out of hospital, she finally agreed to let her loved one stay at the elderly home for better comfort and end-of-life care.

Currently, the JCECC: "End-of-Life Care in Residential Care Homes for the Elderly" project provides three options. Family members can choose whether they want the elderly resident to be sent to hospital in the final stage. Some families may change their minds when the resident health condition deteriorates.

Staff members are not alone

Every time an elderly patient passes away, the team would hold a debriefing meeting. During the session, they would review the end-of-life care services provided, but it was even more important that they could share their feelings and emotions together.

Some colleagues initially were scared of having residents pass away in the elderly home. But in reality, they actually would miss the deceased resident. "I encouraged them to say goodbye in person and pay their respect." Lee admitted that mutual support is important. Whenever he was upset, he would talk to his colleagues for comfort.

HKAG PRESIDENT DR EDWARD LEUNG: MAKING GOOD USE OF MEDICAL RESOURCES

Dr Edward Leung
President, Hong Kong
Association of Gerontology

It is traumatic for terminally ill patients in elderly homes to go back and forth to the hospital. The Hong Kong Association of Gerontology (HKAG) surveyed about 500 residents from four elderly homes and found that more than 10% of them passed away within six months. Three months before they passed away, they were hospitalised for an average of three times with a maximum period of 25 days.

"If given a choice, elderly residents and their family members would prefer to stay in familiar surroundings." The President of HKAG, Dr Edward Leung pointed out that, "no one would want to go to hospital if there were appropriate medical care services in the elderly homes."

HKAG started to explore ways to introduce palliative care in elderly homes as early as 2007. In 2010, they collaborated with the Salvation Army on the Palliative Care Project, with an aim to take care of terminally ill residents in elderly homes until they died.

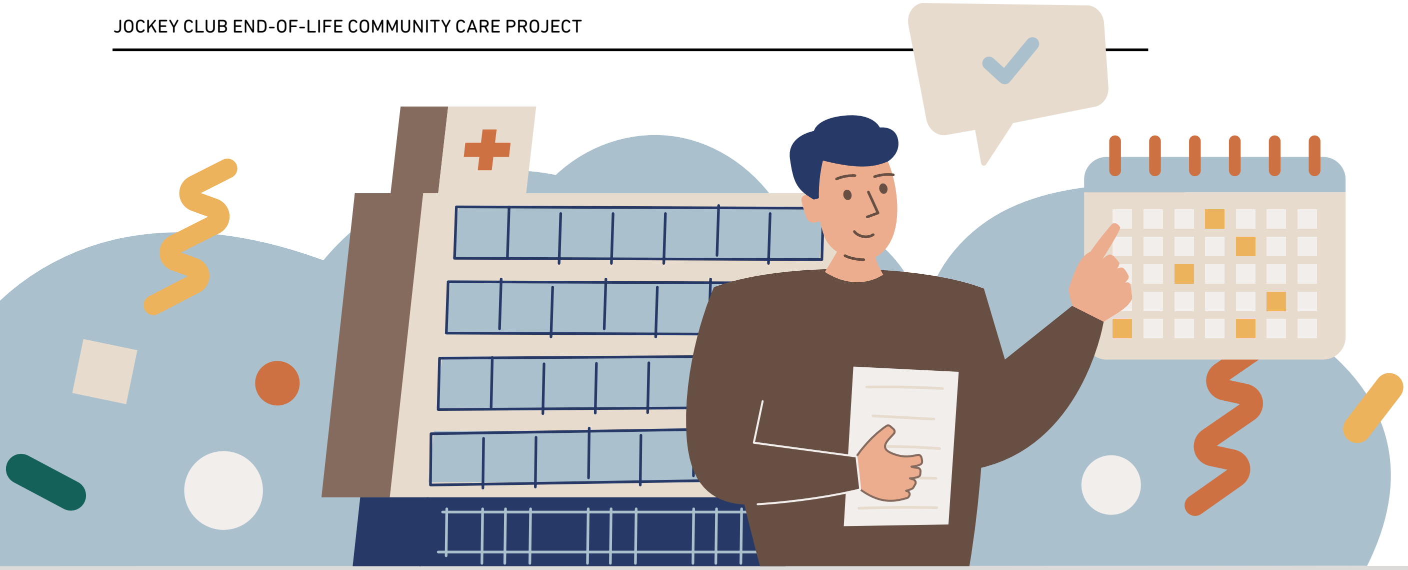
Since the launch of JCECC Project in 2016, HKAG has provided end-of-life care services in 48 subvented residential care homes for the elderly in Kowloon East, Kowloon Central and Kowloon West.

Training for all elderly home staff

In earlier years, HKAG only provided training to certain staff members of elderly homes, like social workers, nurses, health workers, etc. As a result, not all of the staff understood the whole issue which created barriers when promoting end-of-life care services in elderly homes.

Under JCECC, HKAG designated and trained up a team of nurses specialising in taking care of terminally ill patients. Each of these nurses is responsible for four elderly homes and visits them at least once a week in order to maintain a close collaboration. When needed, round-the-clock nursing support may be provided for the resident at imminent death in elderly home. These four elderly homes are usually under the same hospital cluster for effective cooperation with the respective hospitals.

Staff of the project's participating elderly homes will receive a six-month training, in which there will be a lot of discussions and case



illustrations to try to earn everyone's acceptance about engaging in end-of-life services. This approach has facilitated smooth implementation of such services in elderly homes.

JCECC has also supported participating homes to refurbish an end-of-life care room for residents to stay in their last days, where they can spend quality time with their families.

Gradually promoting the programme to all elderly homes

Dr Leung hopes that all government-subvented elderly homes in Hong Kong will be able to provide end-of-life care services in the future, similar to the JCECC: "End-of-Life Care in Residential Care Homes for the Elderly" project.

Leung estimated: Around 50,000 people die in Hong Kong every year and among them, more than 10,000 are elderly people living in residential care homes. If 20% among this group could reduce their time in hospital – there would be 2,000 fewer people staying in hospitals for an average period of a month, which amounts to 2,000 months' worth of hospital beds.

"This is going to generate a massive amount of savings with hospital beds being freed up every month!" Leung stressed that the project could substantially reduce the burden on the public healthcare system.

He believed that private elderly homes could also provide end-of-life care. Some private elderly homes have facilities and human resources. However, there are also those which have inadequate resources and are not even able to cover basic care services. It is important for the government to amend the legislation of elderly homes to enhance the environment and facilities of the less-equipped private elderly homes.

EXECUTIVE DIRECTOR MR LEONG CHEUNG: CONCLUDE ONE'S LIFE WITH DIGNITY

Mr Leong Cheung
Executive Director,
Charities and Community,
The Hong Kong Jockey Club

Hong Kong is facing a rapidly ageing population, and the number of terminally ill elderly patients has also escalated. Executive Director, Charities and Community at the Hong Kong Jockey Club, Mr Leong Cheung, pointed out that the JCECC is a project designed in response to the growing needs for end-of-life care services in the community which existing public services may not be able to cater.

The Hong Kong Jockey Club Charities Trust initiated the JCECC project in 2016 for a duration of six years with a total funding of HK$255 million, and it has now entered its second phase.

Providing choices for patients and family members

During the first three years of the pilot phase, JCECC partnered with five non-governmental organisations and 36 residential care homes for the elderly, in order to support terminally ill patients with different needs. In addition to helping patients relieve their physical symptoms, the Project Team also addressed their psychological, social, and spiritual needs.

Mr Leong Cheung hoped that "no matter where the terminally ill patients and their family members choose to stay, at home or in elderly home that they can truly enjoy quality time together."

Cheung explained that promoting end-of-life care in the community could offer more choices for terminally ill patients and their family members on caring options, while at the same time, allowing them to spend more time together. The Project Team also encouraged patients and family members to discuss advance care planning.

This would not only help the patients live the way they want in their final days, but also relieve some of the pressure on their family members and allow them to face the future in a more relaxed manner.

Hoping for more enhancement in the second phase

As JCECC enters its second phase, the project will continue to provide community-based end-of-life services and will extend its coverage to 48 elderly homes. It will also develop a standardised needs assessment tool to better facilitate the collaboration between the medical and social welfare sectors.

The project also aims to further raise public awareness on community end-of-life care so that people can make appropriate care choices for themselves.

Cheung stated that it was even more important for different stakeholders to have a better understanding of end-of-life care concepts so that they can then discuss openly about the issues, share their knowledge and manage the problems in the future with confidence.

Providing the Government with evidence-based reference for end-of-life care services development

Since its launch, the project has established close collaboration with 13 public hospitals in Hong Kong, and offered services to more than 5,000 patients and their family members.

When looking back, Cheung reckoned the many challenges the project had faced in the initial phase. Amongst all, the biggest challenge was the establishment and alignment of service mission with various collaborating organisations and hospitals, and exploring how the project's service programmes could complement existing services.

After consolidating the experience from the first phase, Cheung felt that the project managed to complement the policy direction of the government and the Hospital Authority. Through innovative community-based end-of-life care service models and close medical-social collaboration, the project was able to provide holistic support to terminally ill patients in the community and respect their wishes. These patients can choose to stay in the community where they are familiar with, and spend the last days of their life with dignity and in peace.

Lastly, Cheung expressed that the service data and experience gained from the JCECC project provides useful references for the government to consider developing and promoting end-of-life care services in the future.

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When reaching the final stage of life,
the greatest hope is
to be able to walk away peacefully and gracefully
with dignity and choice.
People have a desire to return home
and spend time with their families and friends,
or to settle in an elderly home
with more personalised care.

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

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The Hong Kong Jockey Club Charities Trust
RIDING HIGH TOGETHER