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香港中文大學
 賽馬會老年學研究所
 CUHK Jockey Club Institute of Ageing



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媽媽媽媽和我的小事

My Little Story with Mom : About the inevitable Goodbyes in life



Everyone will eventually go through the end of life, including you and your beloved family members and friends. The seemingly small moments and decisions made in the end-of-life care are in fact significant issues affecting family relationships and quality of life.

Jockey Club End-of-Life Community Care Project ("JCECC") produced a mini-movie: "My Little Story with Mom". The premiere of the mini-movie launched on November 1, 2017, at The University of Hong Kong. More than one thousand audience members attended. The story is about Jane (Ms Susan Shaw) living with end-stage cancer and the time spent with her daughter, Iris (Miss Catherine Chau). The story incorporates the final journey of life, and how they had made end-of-life care (EoLC) decisions together. Could they express their thoughts and wishes to each other, and cherish the time they spend together?



Nearly all seats were occupied in the premiere; the audiences were touched by the mini-movie. The forum after the movie was divided into two parts. The first part was the main actors and the director sharing their experience. The second part was led by Dr Chow Yin Man Amy, the Project Director of the JCECC Project. Dr Leung Man Fuk Edward, President of Hong Kong Association of Gerontology, and Dr Leung Chi Tat Antony, Medical Superintendent of Haven of Hope Sister Annie Skau Holistic Care Centre, engaged the audience in discussing life and death issues.



Joining Hand to Create a Compassionate Community for Patients and Families



The mini-movie showed an ideal picture of quality EoLC in the community. During the forum, a caregiver from the audience shared his experience and challenges in taking care of his mother with a terminal illness at home. This highlighted how difficult it could be for the caregivers. Dr Leung Chi Tat Antony acknowledged the caregiver's struggle, "It (Care at home) is indeed a great challenge to the caregiver, regarding physical strength, knowledge and emotions. We have to support the caregivers with appropriate facilities and services. The living environment in Hong Kong is too crowded for facilities installation, and home care services are also limited." One solution might be promoting close collaboration between the health and social care sectors to establish a community EoLC network.

All parties are joining hand to hand to work together to improve community EoLC in Hong Kong. In mid-2017, The Hospital Authority released a "Strategic Service Framework for Palliative Care." The framework proposes future strategies and directions for palliative care development in Hong Kong in the coming five to ten years. The strategies include "enhancing the collaboration of medical and oncology palliative care specialists", "promoting a shared care model according to the patients' needs", "enhancing palliative care in the ambulatory and community settings" and "strengthening performance monitoring for continuous quality improvement". Dr Leung Man Fuk Edward called for the collaborative efforts of different parties. He believes that Hong Kong can turn into a compassionate community for patients and families at the end of life.

Living a Normal and Dignified Life



Dr Chow Yin Man Amy said that patients in end of life are not only coping with physical symptoms but also encountering various psychological, spiritual and social needs. Instead of wasting valuable time handling conflicts and arguments, it is worthwhile to think of ways to cherish every moment together to create sweet and beautiful memories.

Just like the lyrics of the mini-movies theme song: "It is never too late to embrace our beloved ones in everyday life. We are creating our own little stories together……"

Wonderful memories are created in daily life. By engaging in "little" daily life stuff with family, the patients can feel the joy and happiness of living, maintain connections with others, continue social and familial roles and pass on life wisdom. They can also express love, gratitude and forgiveness to their beloved, and eventually leave with a sense of relationship closure.



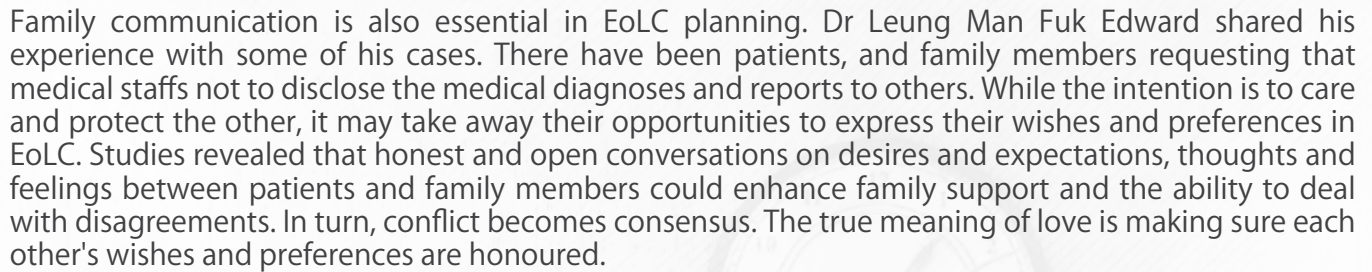
Communication: A Pathway to Better EoLC Planning



Dr Leung Man Fuk Edward pointed out that the conditions and preferences of every patient vary, and there is no single solution in making EoLC planning decisions. Doctors should explain clearly to patients and family members about the patients' condition and treatment progress. They should provide support for patients, instead of putting all the burden on family members. Indeed, there is no right or wrong in EoLC decisions. What important is that patients' preferences are respected, and a family consensus is reached. Communication is the bridge connecting the EoLC team, patients and family members to understand and eventually reach an agreement.

However, previous research revealed that communication problems existed in 84% to 94% of clinical encounters. Life and death issues are one of the most challenging topics that healthcare teams do not know how to handle, and often worry that they might not be able to manage the emotions of patients and families.

In reality, patients and their families can sense when something is not right. They know, sometimes even earlier than the report, that they are not going to recover from the disease. Many of them can accept the diagnosis and understand that getting sick and dying is an inevitable fact for everyone. They do not blame the healthcare team, and they are not afraid of discussing death-related topics. Thus, if the healthcare team takes the opportunity to initiate the discussion, patients' wishes and preferences can be made known to the family and healthcare teams much earlier. Thereby, EoLC planning can be carried out in an orderly manner.



<http://www.socsc.hku.hk/JCECC/mini-movie>

Cheering
Practitioner:

**Play with
patients, help
caregivers to
relax**



Many people bear caregiving responsibilities when there is someone in the family diagnosed with a severe illness. Caregiving burden is often so heavy; it can be unbearable. Miss Wong is one of the examples. Recently retired, her everyday life is to take care of her 89-year-old father who is living with her. Her father was diagnosed with heart failure and dementia.

Since Uncle Wong's diagnosis, the family have tried to arrange three domestic workers to take care of him. Unfortunately, the workers were not professionally trained in taking care of severe patients and were very stressed out ultimately. Uncle Wong fell down a couple of times and got hurt at home. The family was anxious about his

condition, but they are also fully engaged with their work and family. Miss Wong has therefore decided to retire early to take care of her father.

Miss Wong was very tense taking care of Uncle Wong. She had to stay very alert every moment. She was worried that her father might get injured or was at risk of under-nutrition. These concerns made her difficult to rest well at night. "I had fallen asleep when I heard a huge 'bang'. I woke up and discovered that my father was lying on the ground, hurt. I was terrified and called the ambulance immediately." Miss Wong has lost ten pounds and developed acid reflux since she took up the caregiving role. She had thought of sending Uncle Wong to the elderly home, but he was very reluctant.

Miss Wong was referred to JCECC: "Cheering@Home End-of-Life Care Services". St. James' Settlement introduced their "Cheering Practitioners" services to them. Caregiving officer and cheering practitioners paid a visit to them, to plan and organise different cheering activities for Mr Wong and family members. Miss Wong was amazed at the abilities and creativity of her father. He was still capable of playing chess, making crafts, playing mahjong, singing, etc. These were discoveries for her, "Since my father was diagnosed with dementia, we seldom talked and engaged in such activities. I only noticed his decline and loss of abilities. Now I realise his abilities, and it seems that his situation is not as poor as I thought."

During the volunteers' visits, Miss Wong was temporarily relieved from her routine caregiving tasks. This enabled her to take a break to go shopping, have afternoon tea and relax. Miss Wong treasured her time to refresh herself so that she could be recharged to continue her caregiving work.

"In the past, we were very quiet at home, but now we are actively thinking of new ideas to play, planning for outings and activities such as going out for meals, visiting Béthanie, having a party with the neighbours etc." Miss Wong felt that the relationship with her father has become closer. Even though they will separate from each other in the future, the daughter can still have enjoyable and relaxing memories.





Go with love, freedom and peace

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Madam Lam is an 89-year-old lady with Chronic Obstructive Pulmonary Disease (COPD). Her pulmonary function was only 30%. She needed 24-hour oxygen therapy. However, Madam Lam was a tough and autonomous woman. She insisted on going to the elderly home to visit her husband who was diagnosed with dementia. This meant that she had to walk up and down stairs, but she needed to take breaks every few steps. Her toughness may be related to her experience of supporting her family solely, raising her children and taking care of her long-term-ill husband.

Madam Lam came from a rich family. Shortly after marriage, her husband was diagnosed with a severe illness, and Madam Lam became the sole supporter of the family for years. It is

commendable that the couple still loves each after decades: "My husband remembers that he has three children but does not recall their names. He puts a piece of paper in his pocket to remind himself. However, he never forgets my name. I told him 'you can forget the others, but not me!'"

In the past, Madam Lam did not bring along the traditional oxygen tank when she visited her husband, because it was too heavy. It would be quite risky if she encountered dyspnea on her way to the elderly home. Under JCECC: "Life Rainbow End-of-life Care Service", The Hong Kong Society for Rehabilitation arranged Miss Fong, a volunteer who is also a retired nurse, to give Madam Lam advice on daily life and outings. "I would help Madam Lam to check whether she is administering her medicine, and using the oxygen machines properly." With the help of volunteers, Madam Lam is using a portable oxygen generator, so that she can go out more easily.

Miss Fong also provided Madam Lam with some tips on home care: "Madam Lam prepares nutritious food for her husband every day, but she only eats simple food such as congee. I reminded her to stay aware of her nutrition, and that she has to take care of herself so that she can take care of her husband. I have also taught Madam Lam deep breath exercises, skills to handle cramps and correct usage of suitable chairs for bathing."

The team also facilitated Madam Lam to discuss advance care planning with her son. They have signed Advance Directives, documenting EoLC decisions such as tube feeding and cardiopulmonary resuscitation (CPR): "My bones are weak and fragile, it would be excruciating if I receive CPR." She stated her preferences clearly and felt secure and peaceful after signing the Advance Directives. Madam Lam loves freedom; she articulated that she would like to have a sea burial after her death. With her openness, the volunteers conducted a life review with Madam Lam and produced a life storybook for her as a legacy. She learnt to appreciate herself and to express her emotions or needs in the process.

With the help of professional volunteers, Madam Lam continued her wish to visit her husband living in the elderly home. Advance Directives enabled her to choose and articulate preferences on EoLC and after-death arrangement. Retaining her autonomy and perseverance, Madam Lam lives wonderfully, dignifiedly and meaningfully in her end of life.

The story of Madam Lam is now available on the JCECC website at: <http://www.socsc.hku.hk/JCECC/e-cases/>



A 1.5-meter Tall Christmas Tree Made by a Nasopharyngeal Cancer Patients Illuminated The University of Hong Kong



Chi-Hung is 62 years old and has been suffering from nasopharyngeal cancer (NPC) for the last 16 years. While he stayed in the hospital, the occupational therapist encouraged him to learn the paper handicraft the "Triangle Plug", which has become the good friend of Chi-Hung. When he is making the paper handicraft, he forgets all his troubles and pains caused by the end-stage disease.

Chi-Hung has been in home care for years. He borrowed books as references and made his own paper design products such as dragon boats, rattan baskets and animals. He also worked as a mentor for volunteers and patients, teaching them how to make "Triangle Plug" paper handicraft. His works have been exhibited in hospitals.

Chi-Hung has been receiving JCECC: "Cheering@Home End-of-Life Care Services" for nearly one and a half years. "Triangle Plug" has been a frequent topic for him and the St. James' Settlement caregiving officer. One day, the officer read a news article about a Taiwanese artist making a giant work using tens of thousands of "Triangle Plugs". She invited Chi-Hung to design and create a 1.5-meter giant Christmas tree. Chi-Hung was very excited to take this challenge, with the help of other volunteers.

Chi-Hung designed the overall structure, number of levels, and decoration of the giant Christmas tree. Starting from early December, he worked with a group of volunteers to fold nearly 3000 "Triangle Plugs" in about ten days. They then spent two more days to assemble and decorate the Christmas tree.

The exhibition of this hand-made Christmas tree displayed from December 19 to 27, 2017 at the lift lobby of the ground floor of the Jockey Club Tower at the University of Hong Kong. The tree brought Christmas joy, happiness and blessings to HKU teachers and students.





The JCECC: "Hospice in Family" Home Care Support Services mainly supports the end-of-life patients and families in Tuen Mun, Yuen Long, and Tin Shui Wai District. The project aims to promote entire families to live with care, love and dignity when facing end-of-life situations with regular support by social workers and volunteers. The project also organises different workshops regarding aromatherapy and expressive arts therapy for the families. As of November 30, 2017, the project has supported 127 families, and over 1,600 people have received volunteer and professional training by our project staff.



香港復康會
The Hong Kong Society
for Rehabilitation

The JCECC: "Life Rainbow" End-of-Life Care Services kicked off the "End-of-Life Care Movement for Self-Help Organisations" in September 2017. It aimed to enhance the awareness for members of Self Help Organisations (SHOs) to care for end-of-life (EOL) patients and to equip them with relevant knowledge, skills and emotional preparation. Two training workshops and a public seminar were held. As one of the key stakeholders in providing EoLC, members of SHOs can understand more about the needs of patients and their families by sharing similar experiences and providing mutual support. The public seminar held on November 12, 2017, received a good response. Over 150 participants have joined the three events; more similar activities will be organised.



The JCECC: Cheering@Home End-of-Life Care Services provides the community with in-home end-of-life care to families and patients with life-threatening illnesses. In July 2017, the Project completed the second batch of "Cheering Practitioner Training." Eighteen cheering practitioners (volunteers with individual talent) were recruited. The cheering practitioners are companions and playmates with the clients creating fun moments with families facing end-of-life issues. They help to relieve the pain brought by illnesses and allow the patients and their loved ones to enjoy every moment without being occupied by the disease.





香港中文大學
賽馬會老年學研究所
CUHK Jockey Club Institute of Ageing



Under JCECC, the CUHK Jockey Club Institute of Ageing (IoA) has worked closely with the hospital network in the Hospital Authority (HA) New Territories East Cluster (NTEC); Residential Care Homes for the Elderly (RCHEs); Community Organisations and Patients' Association. As of October 31, 2017, 181 information sessions and workshops for healthcare staff, patients and their relatives, volunteer and public have been held with more than 6,300 attendees.

A "Casebook on Ethical Decision-Making in End-of-Life Care of Older Adults", was developed in collaboration with the CUHK Centre for Bioethics. The healthcare training manual provides an open-access online resource for healthcare professionals who face

ethical issues when caring for older adults at the end of life (EoL). For access, please go to <http://www.ioa.cuhk.edu.hk/en-gb/casebook>

A second public event on EoLC education was held on August 12, 2017, to serve the community at Tai Po. There was an enthusiastic response. The event attracted over 220 participants that attended the talks on knowledge of EoLC. Over 200 participants joined the five interactive workshops. Tied in with the Senior Citizen Day, IoA was invited by the Hong Kong Public Libraries to give two EOL care talks and exhibitions in the Shatin and Tai Po Public libraries. Forty participants joined the interactive talk, and the event attracted over 10,000 viewers to the exhibition.



The "JCECC: End-of-Life Care in Residential Care Homes for the Elderly (RCHEs)" organised 317 pieces of training in 34 RCHEs with over 1,700 RCHE staff participating since November 2017. Starting from July 2016 to October 2017, the project provided holistic end-of-life care services to 42 elderly people in RCHEs and helped 50 elderly people to sign advance directives. The project has also organised forty public seminars for 1,500 elderly since April 2016. A mid-term seminar titled: 在安老院舍推行臨終照顧服務的實踐分享會 was held on June 23, 2017, 180 participants from NGOs attended. Positive feedback was received from the NGOs colleagues. Participants wanted to know more about the detailed execution of the service inside the RCHEs, collaboration with Community Geriatric Assessment Teams (CGATs) and how to implement the advanced care planning.



基督教
靈實
協會
HAVEN
OF HOPE
CHRISTIAN SERVICE

尊重生命 • 改變生命



The JCECC: "Hospice at Home" has performed service provisions for two years and has served more than 120 patients with life-limiting illness and their families. With the aim of "Respecting Life, Impact Life", the Haven of Hope Sister Annie Skau Holistic Care Centre continues to serve patients and their families by providing holistic care, rehabilitation and spiritual care. By using a case management system model and referrals from service partners, we bring the EoLC service from hospital to home. Therefore, the patients can stay at the places where they are familiar with and treasure their last moments with care and peace.



From June to December of 2017, the JCECC project team has invited 28 renowned local and international experts to conduct 18 professional workshops and 16 public seminars, to enhance professional competence on psychosocial and spiritual care, communication and EoL decision making, and increase public awareness on EoLC.

International Speaker



Professor Elizabeth Lobb

Professor of Palliative Care (Allied Health),
Calvary Health Care Sydney



Professor Elizabeth Lobb shared the following 6 components in patient-centered EoLC in a series of educational activities:

1. Education and shared knowledge;
2. Involvement of family and patient in EoLC decision;
3. Collaboration and communication among care team members;
4. Sensitivity to non-medical and spiritual dimensions of care;
5. Respect for patient needs and preferences and
6. Free flow and accessibility of information.

Professor Lobb emphasized that communication is the key to achieve the above 6 components, and encouraged participants to initiate EoLC discussion.



Professional Trainings

June 6, 2017

Workshops on Advancing Psychosocial Clinical Skills in End-of-Life Care: Enhancing Therapeutic Effectiveness and Facilitating Couple Communication



Public Seminars

June 10, 2017

Public Seminar on End-of-Life Care: Everyone's Business



Reference:

Palliative & End-of-Life Care: A Blueprint for Improvement
<https://www.aci.health.nsw.gov.au/palliative-care-blueprint>



Past Event

International Speaker



Professor Richard Harding

Professor of Palliative Care
Cicely Saunders Institute King's College London

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Professor Richard Harding pointed out that assessment tools can help to better understand patients' need, to track changes on their physical and psycho-social-spiritual well-being, and to evaluate the effectiveness of EoLC services. He introduced Palliative Care Outcome Scale (POS), a tool developed and validated by the King's College London, and its research evidence and clinical application.



Professional Trainings

July 24, 2017

Workshop on The Integration of Valid Outcome Measures in Clinical Practice to Improve End-of-Life Care



Reference:

Palliative Outcome Scale
<https://pos-pal.org/>





Past Event

International Speaker



Professor Carl Becker

Professor of Medical Ethics and Policy
Kyoto University



Professor Carl Becker has extensive research experience on Japanese elderly culture and life and death issues. He shared that Asian wisdom and practices can help patients and family cope with death. For example, calligraphy and dance allow elderly to find meaning in life and feel joy and happiness; religious activities like praying, chanting and other rituals can bring sense of spiritual peace to patients, and help family members to relieve their grief. He also analysed the connections between living and deceased persons from multiple religious perspectives, and concluded that such connection can improve patients' and family members' quality of life and reduce professional burnout.



Professional Trainings

December 5, 2017

Workshop on Identifying and Reducing
Burnout in Health and Social Care



Public Seminars

December 7, 2017

Seminar on Western and Asian Wisdom
in End-of-life Care, Death and Grief



Past Event

International Speaker

**Dr Patricia Bomba**

Vice President & Medical Director
Excellus BlueCross BlueShield



Dr Patricia Bomba is an international expert of Palliative Care. She shared that Advance Care Planning (ACP) is a process for patients to make their own EoLC decisions. There is no absolute right or wrong in EoLC decisions, but the only important thing is to make sure that patients' preferences and values are being respected and understood. She provided 5 easy steps to initiate ACP discussions:

1. Learn more about advance directives (AD);
2. Remove barriers and myths in EoLC;
3. Be motivated to discuss on the benefits of EoLC;
4. Complete healthcare proxy and living will and
5. Review and update the EoLC planning regularly.

**Professional Trainings**

November 14&15, 2017

Workshop on Advance Care Planning (ACP):
A Population Health Approach

November 16, 2017

Seminar on Improving End-of-life
Care: Honest and Compassionate
Conversations

**Public Seminars**

November 17, 2017

Seminar on Conversations Change Lives:
Know Your Choices • Share Your Wishes

**Reference:**

<http://www.compassionandsupport.org/>





Past Event

International Speaker



Professor David Kissane

Chairman,
Department of Psychiatry
Monash University, Australia



Professor David Kissane is the expert of Demoralization research in EoLC. He explained demoralization is a mental state of lowered morale and poor coping, characterised by feelings of hopelessness, helplessness, and loss of meaning and purpose in life. Demoralization is associated with depression and suicidal risk. He concluded from research that 15% of advanced cancer patients have demoralization symptoms. Relevant assessment tools for demoralization and Meaning and Purpose Therapy (MaP) were also introduced.



Professional Trainings

September 25, 2017

Workshop on Demoralization and the Application of Meaning and Purpose Therapy in EoLC Settings



September 27, 2017

Family as a Whole: Family-Focused Grief Therapy as a Versatile Intervention in End-of-Life Care



Public Seminars

September 30, 2017

Seminar on Demoralization among Patients with Cancer: A New Diagnosis or Another Form of Depression?



Reference:

Book: Management of Clinical Depression and Anxiety, written by Maggie Watson, David Kissane. (2017).



賽馬會安寧頌義工感謝日

JCECC Volunteer Sharing and Appreciation Event

2017年12月2日 December 2, 2017



「媽媽和我的小事」微電影首映禮 暨 導演、演員分享會及公眾座談會

Gala Premiere: "My Little Story with Mom" and End-of-Life Care Public Seminar

2017年11月1日 November 1, 2017





May 2018

Workshop on Spiritually Sensitive Assessment and Interventions in End-of-Life Care: Theory, Practice, and Experience

日期: 2018年5月16日 上午十時正至下午五時三十分

Date: May 16, 2018 10:00am – 5:30pm

地點: 香港薄扶林道香港大學百周年校園賽馬會教學樓11樓社會科學活動室

Venue: Social Sciences Function Room, 11/F, The Jockey Club Tower, Centennial Campus, The University of Hong Kong

Workshop on Preventing Burnout and Promoting Well-Being for Helpers in End-of-life Settings

日期: 2018年5月17日 上午十時正至下午五時三十分

Date: May 17, 2018 10:00am – 5:30pm

地點: 香港薄扶林道香港大學百周年校園賽馬會教學樓11樓社會科學活動室

Venue: Social Sciences Function Room, 11/F, The Jockey Club Tower, Centennial Campus, The University of Hong Kong

安寧照顧講座：生命晚期的心靈成長和轉化 Seminar on Spiritual Growth at the End of Life

日期: 2018年5月19日 下午二時正至四時正

Date: May 19, 2018 2:00pm – 4:00pm

地點: 香港薄扶林道香港大學百周年校園賽馬會教學樓11樓社會科學會議廳

Venue: Social Sciences Function Room, 11/F, The Jockey Club Tower, Centennial Campus, The University of Hong Kong

June 2018

Conference on Innovation · Impact

The Review and Vision of Community End-of-Life Care

安寧照顧研討會：創新·成效 - 社區安寧照顧的回顧與前瞻

日期: 2018年6月20-21日

Date: June 20-21, 2018

地點: 香港大學百周年校園李兆基會議中心大會堂

Venue: Hall II, Lee Shau Kee Lecture Centre, Centennial Campus, HKU



International Keynote Speakers



Dr Stephen Connor



Professor David Currow



Professor Irene Higginson



Professor Wang Ying-wei



Details and Registration: www.jcecc.hk/conf2018