

Launch Ceremony and Press Conference

16 June, 2025

Quality end-of-life care benefits not only Hong Kong residents, but can also be extended to Chinese Mainland.



Mr Chris Sun
 Secretary for Labour and Welfare
 of HKSAR Government

Our Trust has expanded end-of-life care to include individuals with disabilities. The project, named "Unison," signifies a collaborative, multi-sector approach toward achieving this shared objective.



Mr Lincoln Leong
 Convener of the JCECC: Unison Advisory Committee



The ceremony was officiated by HKSAR Government Secretary for Labour and Welfare Mr Chris Sun, The Hong Kong Jockey Club Steward Dr Henry Chan, Director (Strategy and Planning) of Hospital Authority Dr Ching Wai Kuen, Dean of Faculty of Social Sciences of The University of Hong Kong Professor Ming Wen, and other guests, including more than 200 health and social care professionals from the city.



Dr Henry Chan
 Steward of The Hong Kong Jockey Club

Providing care for patients and families affected by terminal illness is a longstanding priority for the Jockey Club Charities Trust.



Professor Amy Chow
 Director and Principal Investigator of JCECC: Unison

Providing care for individuals with disabilities who are facing terminal illness requires more than just combining two service types. The HKD 290 million allocated over five years enables us to develop, implement, and evaluate an innovative, world-class care model that addresses these complex needs.



Professor Helen Chan
 Principal Investigator of JCECC: Unison

We understand that individuals at the end of life have diverse physical, psychological, social, and spiritual needs. Through Advance Care Planning, we help patients and families share their innermost feelings and wishes, ensuring they make the most of every remaining moment.

Professional Seminars: Gaps in End-of-Life Care Strategies for Providing Inclusive and Equitable Support to Persons with Disabilities

17 June, 2025

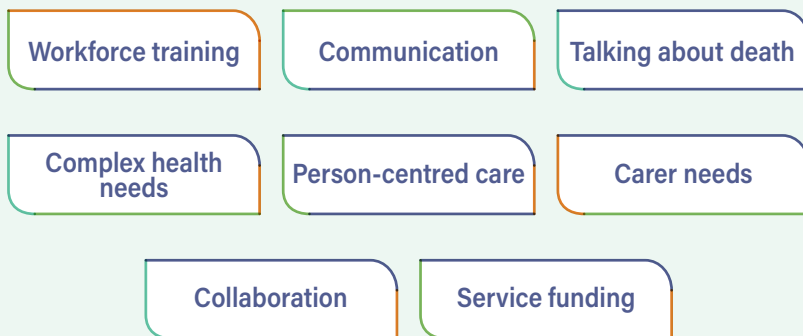
Persons with disabilities face distinct challenges at the end of life, underscoring the need for tailored care approaches. Advancing solutions that enhance the accessibility and inclusivity of palliative and end-of-life care is essential for moving forward. We invited a distinguished speaker from Australia to share insights on addressing the specific palliative care needs of persons with disabilities, while a local expert examined the challenges and practical strategies for delivering equitable, high-quality care in our community.

How to Meet the Palliative Care Needs of People with Disabilities



Scientia Professor Julian Trollor
The University of New South Wales

Challenges related to palliative care for people with intellectual disability 1-4



1. Adam, E., Sleeman, K. E., Brearley, S., Hunt, K., & Tuffrey-Wijne, I. (2020). The palliative care needs of adults with intellectual disabilities and their access to palliative care services: A systematic review. *Palliative Medicine*, 34(8), 1006-1018.
2. Tuffrey-Wijne, I. (2003). The palliative care needs of people with intellectual disabilities: A literature review. *Palliative Medicine*, 17(1), 55-62.
3. McKibben, L., Brazil, K., Hudson, P., & McLaughlin, D. (2019). Informational needs of family caregivers of people with intellectual disability who require palliative care: A two-phase integrative review of the literature. *International Journal of Palliative Nursing*, 25(1), 4-18.
4. Botsford, A. L. (2000). Integrating end of life care into services for people with an intellectual disability. *Social Work in Health Care*, 31(1), 35-48

Trollor, J. (2025, June 17)



Professor Julian Trollor shared Australia's palliative care system, which operates across three levels—primary, shared, and specialist care—and is adapted regionally with telehealth and outreach to support rural communities. People with intellectual disabilities face significantly earlier mortality and elevated cancer risks at younger ages compared to the general population. They frequently encounter barriers in receiving support service, including difficulty in accessing health information and low usage rate in specialist palliative care and pain management. To address these inequities, Professor Trollor recommended implementing co-designed care models and ensuring national health policies specifically include this population. He also introduced the development of service models which emphasizes rights-based, person-centred designs, ensuring equal access for people with disabilities through systemic reforms, workforce training, and reasonable adjustments. Cultural safety, diversity, and interdisciplinary collaboration are central to delivering inclusive, equitable, and dignified care that respects individual choice.

Equitable Palliative and End-of-Life Care for People with Disabilities: Challenges and Recommendations



Professor Helen Chan
The Chinese University of Hong Kong

Professor Helen Chan emphasized the UK concept of “reasonable adjustments”, which requires the removal of barriers that hinder access to palliative and end-of-life care for persons with disabilities. She highlighted the need for systemic, clinical, and environmental reforms, improved communication and person-centred approaches, and policy engagement to remove the barriers. She also stressed that the goal of building a compassionate community and fostering interdisciplinary collaboration is to deliver inclusive, equitable, and dignified care that respects individual choice.

Professional Training: End-of-life Communications with Persons with Disabilities and Their Families

21 March, 2025

Professor Amy Chow
The University of Hong Kong

In end-of-life situations, communication with patients and their families can be particularly challenging due to the sensitive and emotionally charged nature of these conversations.

In practice, individuals with different types of disabilities may experience various challenges in communication. Individuals with physical disabilities, particularly those with neurological conditions, may encounter difficulties in both processing information and expressing themselves. Persons with intellectual disabilities may have challenges in understanding complex language or instructions, often requiring additional time to process information and responses. Individuals in mental recovery may experience reduced concentration and, for those who have experienced psychosis, disorganized speech may also occur, potentially affecting the flow of communication. For persons with hearing impairment, barriers in receiving and comprehending auditory information may further complicate everyday interactions, highlighting the importance of adaptive and effective communication approaches.

Professor Chow emphasized that research has identified several key factors influencing these interactions, including trust, health literacy, the surrounding environment, and power imbalances. She also noted that distress during end-of-life care may be exacerbated by undesirable communication from others, underscoring that listening is often more valuable than speaking. It is crucial to treat persons with disabilities as adults, avoiding any patronizing or condescending attitudes during these critical moments.

Besides, a systematic review by Engel et al. (2022) identifies key elements that support meaningful communication, including providing open and honest information, aligning to the patient's and relative's communication process of uptake and coping with information, and demonstrating empathy. Also important are the use of clear, understandable language, leaving room for positive coping strategies, ensuring committed healthcare professionals take responsibility in consistency of information delivery, and recognizing relatives in their role as caregiver. Together, these elements highlight that, in end-of-life care, communication goes beyond conveying information to supporting patients and caregivers through trust, understanding, and compassionate care during this critical stage of life.

Engel, M., Kars, M. C., Teunissen, S. C. C. M., & van der Heide, A. (2023). Effective communication in palliative care from the perspectives of patients and relatives: A systematic review. *Palliative and Supportive Care*, 21(5), 890-913. doi:10.1017/S1478951523001165



Clinical Supervisions

27 February, 28 April, 20 June & 20 October 2025

Professor Amy Chow
The University of Hong Kong

Professor Helen Chan and Professor Angela Cui
The Chinese University of Hong Kong

Regular clinical supervision is offered by the Principal Investigators for the team members, aiming to enhance skill development, align intervention strategies, and facilitate ongoing support for practitioners. This process encourages continuous improvement by co-creating solutions to emerging challenges in the field. Particularly, streamlining the 3Ps model of the ICEST model for persons with disabilities. Additionally, interprofessional and interorganizational peer learning is promoted, ensuring that diverse perspectives contribute to a collaborative and adaptive practice environment.



HIGHLIGHTS OF LEARNING POINTS

FINISHING UNFINISHED BUSINESS AS A GOAL?

Patients facing end-of-life situations often carry unfinished business, ranging from personal goals to unresolved relationships. While some individuals may find ways to address these matters, others encounter practical, ethical, or deeply personal barriers that prevent resolution. Healthcare workers should avoid simply viewing tasks as "Done" or "Not done" and instead understand what unfinished issues mean to each patient. By exploring the underlying meanings and offering alternative approaches, practitioners can better support patients in meeting their true needs during this critical time.

DENIAL MIGHT HAVE FUNCTIONS

Health care professionals often believe that confronting the reality of impending death is essential for providing effective end-of-life care. However, patients and their families may require time to process this reality, and denial can sometimes serve as a protective shield. Abruptly removing this shield may be detrimental to the patient's well-being. Instead, practitioners should offer support that allows individuals to face the truth at their own pace, gradually and respectfully, ensuring emotional safety throughout the process.

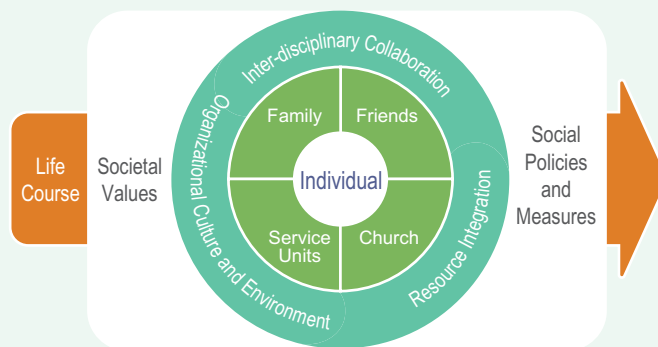
Workshop on Self-Determination of People with Intellectual Disabilities in Advance Care Planning

22 & 29 August 2025

Dr Wong King Shui, Phyllis
The Chinese University of Hong Kong

In recent years, the local intellectual disability services sector has placed significant emphasis on the issue of "self-determination" within "Advance Care Planning" (ACP). When discussing ACP with intellectual disability service users, how can practitioners understand the values, preferences, and expectations of people with intellectual disabilities? Practitioners can recognize and apply the "self-determination" of people with intellectual disabilities to support them in planning and implementing their "Advance Care Planning."

An Ecological Perspective on Advance Care Planning for People with Intellectual Disabilities



Wong, P.K.S. (2025, August 22 & 29)



HIGHLIGHTS OF LEARNING POINTS

SELF-DETERMINATION FOR INTELLECTUAL DISABILITY

The "self-determination" of people with intellectual disabilities refers to them acting as the leaders of their own lives, controlling their lives through autonomous choices, decisions, and actions to enhance independence and quality of life. People with intellectual disabilities enjoy the same respect and decision-making rights as the general population, free from excessive interference by others, enabling them to determine their personal wishes. It encompasses multiple core components, such as awareness, expression, and planning with implementation, to enhance their sense of autonomy, belonging, and competence.

ADVANCE CARE PLANNING FOR INTELLECTUAL DISABILITY

People with intellectual disabilities communicate with family members, caregivers, and professionals while they still have decision-making capacity to pre-plan care wishes for the late or end-of-life stages, ensuring appropriate support aligned with their personal values when they can no longer express themselves in the future. The plan covers lifestyle planning, medical choices, personal care preferences, financial and posthumous arrangements, as well as sharing of values and wishes. For people with intellectual disabilities, ACP emphasizes reframing it as "things to do while alive," rather than just "before death," and incorporates self-determination elements such as choice-making, decision-making, and self-advocacy.

Professional Training: Navigating the Grief and Bereavement Journey: From Diagnosis to Post-death

November, 2025

Professor Amy Chow
The University of Hong Kong

This professional training adopted a hybrid approach, consisting of 7 hours of online lectures and 7 hours of face-to-face workshops. During the sessions, participants were introduced to essential theories and practical skills in pre-death bereavement care, care at the moment of death, and post-death support. The program featured the ADAPTS model V4.0 and integrated HKU-ABC-RS and HKU-ABC-OS assessment tools to enhance understanding and application. A total of 62 health and social care professionals participated, fostering a collaborative learning environment.



Professional Training: ICEST Model for Persons with Disabilities

15 & 19 December, 2025

Training Teams of HKU and CUHK

The Integrated Community End-of-life Support Team (ICEST) model was initially developed for older adults and has since been adapted to address the specific needs of persons with disabilities. A dedicated 2-day workshop introduces participants to this model, covering the process systematically from assessment through to need-based intervention. The training incorporates mini-lectures, role-plays, and case studies, aiming to provide community partner teams with a standardized approach for implementing the unique ICEST model in their practice. This comprehensive orientation fosters consistency and effectiveness in community end-of-life care for people with disabilities.



Unison Ambassadors

October and November, 2025

HKU Training Team

End-of-life care is not solely the responsibility of professional staff; everyone in the community has a vital role to play. In this initiative, eighty-five community members participated in a hybrid training program combining online and offline elements. During the workshop on 22 November, 2025, participants worked together to share ideas and strategies for fostering compassionate and inclusive communities across Hong Kong, with a particular focus on supporting persons with disabilities at the end of life. The program culminates in an inspiring pledge ceremony, where attendees collectively commit to advancing end-of-life care and promoting dignity for all.

