Hospice Foundation of Taiwan

HFT Newsletter

Forever Love, Endless Care

February 2026

PHPCI
Public Health Palliative Care International

BRIDGING CULTURE,
BUILDING COMPASSION:
INNOVATIONS IN
PUBLIC HEALTH PALLIATIVE CARE

2026
October 6-9
Pre-conference + Main conference

Location | Tamsui, New Taipei City, Taiwan

- **Public Health Palliative Care International**
- **Who Says they Don't Understand Death?**
  Bridging the Gap in Understanding: Love and Farewell Among People with Intellctual Disabilities
- **Accompany Them on the Last Mile in Famailiar Surrounding**
  End-of-Life Care for People with Intellectual Disabilities in Care Facilities

Hospice Foundation of Taiwan
www.hospice.org.tw

No. 45, Minsheng Road ,Danshui District, New Taipei City 25160 Taiwan
Tel: +886-2-28081130 Fax: +886-2-28081137 Email: hospice@hospice.org.tw

Like us on Facebook Like us on Instagram

Public Health Palliative Care International

By Prof. Luc Deliens, President of PHPCI

Over the past five, ten, and twenty years, an enormous amount of work has been devoted to developing public health palliative care as a distinct domain within palliative care. This movement began with the publication of Allan Kellehear's Health Promoting Palliative Care in 1999, followed by Compassionate Cities in 2005. Both books are built on a simple yet innovative and mobilizing idea: dying is a social event with a medical component—not a medical event with a social component.

However, the way many societies have developed and implemented palliative care suggests the opposite. Almost exclusive attention has been given to expanding professional palliative care services, while community-based approaches and societal capacity have been largely neglected by policymakers. As palliative care has become increasingly professionalized and medicalized, communities have had less and less involvement in the dying process. In response to these trends, Kellehear's books focus on applying health promotion methods to palliative care and on mobilizing social networks around people facing serious illness, loss, and death.

The 8th Public Health Palliative Care International (PHPCI) Conference held in Bern, the capital of Switzerland.

A speaker shares insights on how healthcare professionals can maintain their own well-being and humanity within clinical practice.

These ideas quickly spread across the globe, and since then, the field of Public Health Palliative Care has continued to mature. This is reflected in the worldwide compassionate communities movement, the biennial World Conference on Public Health Palliative Care, the creation of the specialized journal Palliative Care and Social Practice, the establishment of Public Health Palliative Care summer schools, the publication of textbooks, the founding of Academic Centres of Expertise on Compassionate Communities, and, last but not least, the creation of the international association Public Health Palliative Care International (PHPCI) – https://www.phpci.org

PHPCI views death, dying, loss, and care as everyone's responsibility—at least for those with the capacity to participate. A public health approach to end-of-life care sees the community as an equal partner in the long and complex task of providing high-quality care at the end of life. All PHPCI members hold this principle as true and commit their respective organizations to this shared vision. The association was inaugurated during the 3rd International Conference on Public Health and Palliative Care in Limerick, Ireland. Its mission is to promote public health principles and approaches in palliative care on a global scale by encouraging practice-based learning, providing professional support, and facilitating local and international communication between members working to embed public health perspectives into palliative care practice.

PHPCI fosters community engagement and mobilizes social capacity through various events and initiatives.

Our upcoming 9th International Conference on Public Health and Palliative Care, to be held 6-9 October 2026 in Taipei, Taiwan, presents a major opportunity to engage with Asia and support initiatives in Taiwan and beyond. This conference will promote the philosophy, values, concepts, and methods of compassionate communities, and help equip people with the educational and practical resources they need to advance the goals of health-promoting palliative care.

🌐 Conference Information & Key Dates

Join us in Taipei for the upcoming 9th International Conference. For more details and participation, please visit our official website: **PHPCI 2026**.

Event	**Date**
Abstract Submission Opens	**January 31, 2026**
Workshop/Symposium Submission Closes	**March 31, 2026**
Online Registration Opens	**April 2026**
Abstract Submission Closes	**April 30, 2026**
Early Bird Registration Deadline	**June 30, 2026**
Online Registration Closes	**September 28, 2026**

Who Says They Don’t Understand Death?

Bridging the Gap in Understanding: Love and Farewell Among People with Intellectual Disabilities

> *Separation is a life lesson that no one can avoid. In Chinese culture, conversations about life and death are difficult enough; for individuals with intellectual disabilities and their families, this journey presents even deeper challenges.*

As life expectancy continues to rise, people with intellectual disabilities—like any of us—must confront the loss of family members and friends, the illness of peers, and even the death of loved ones. When grief, anxiety, and helplessness arise, they may struggle to express their feelings due to limitations in language or cognition, which can affect their daily motivation and psychological stability.

Many people mistakenly believe that individuals with intellectual disabilities “do not understand” death, or that they are “unable” to make medical decisions. In reality, the concept of death is not entirely abstract to them. Through experiences such as the passing of relatives, the loss of pets, or even their own physical discomfort, they can gradually form an awareness of life’s end.

Hui-Fang Lin, Secretary-General of the Parents’ Association for Persons with Intellectual Disability in Taiwan, observes: “We cannot make decisions for them based on our own values. What we can do is lay out the information, help them sense and imagine, and give them the opportunity to choose.” Therefore, establishing a system of life-and-death education and medical decision-making

support that is understandable, participatory, and expressive has become an urgent issue in the field of palliative care.

Life-and-Death Education Beginning with Emotional Experience

Yijun (right) and her mother pose for a photo at a community event.

Yijun is a young woman with a mild intellectual disability. When she speaks about missing her late uncle and grandmother, she pauses and softly says, “I look at their photos, listen to the music they liked, and watch the TV shows they used to enjoy.” Having experienced the death of a family member as early as sixth grade, she has developed a unique sensitivity and awareness regarding life and death.

Life-and-death education should never be limited to the transmission of knowledge alone; it must begin with life experience. Yijun’s mother recalled that the family never deliberately avoided talking about death with her. When Yijun’s uncle passed away, she was still young and resisted visiting the hospital because she was frightened by the sight of medical tubes. As she grew older, however, she began to proactively raise questions about death with her family and teachers.

Later, when her grandmother passed away, the entire family folded paper lotus flowers together for a whole year. Yijun, who had been very close to her grandmother, participated throughout the process despite learning more slowly. This shared journey of remembrance and healing not only taught her to turn love

Through shared daily rituals, death is no longer a taboo, but a practice in learning how to say goodbye.

into action, but also helped her learn how to face separation.

Over the years, Yijun has learned to explore life-and-death issues on her own—searching for information online and asking friends, gradually finding her own answers. This active learning has eased her fear of death. She candidly shared, “I’m slowly finding some answers, and I’m less afraid now.” If there were life-and-death courses designed specifically for people with intellectual disabilities, she said she would be eager to participate because “I want to learn and prepare myself.”

Reaching Consensus on Medical Choices Through Communication

When asked whether she would be willing to sign an Advance Decision (AD) for herself, Yijun replied without hesitation, “Yes, I want to.” However, she also raised a critical question: “If I sign it and my family disagrees, who will the doctor listen to?”

Yijun’s concern reflects the practical challenges of Taiwan’s Patient Right to

Autonomy Act. Although the law is intended to safeguard individual wishes, in clinical practice medical professionals still tend to defer to family opinions. She stated clearly, “I hope doctors listen to the patient, not only to the family.” Medical autonomy can only be realized when consensus is reached with family members before signing the document.

For most families, discussing life-and-death issues is already difficult; for families of people with intellectual disabilities, it is even more so. Hui-Fang Lin noted that the Act includes five clinical conditions under which it can be activated, but for people with moderate to severe intellectual disabilities, understanding these complex scenarios can be challenging. It requires additional time, extensive explanation, and personal life experiences to support comprehension.

They often need concrete examples—such as terminal cancer or the inability to eat—to build understanding. Moreover, even individuals with relatively good expressive abilities, like Yijun, are often excluded because the medical system does not understand their communication styles, such as non-verbal expression. Future policy design must prioritize the establishment of “understandable dialogue mechanisms” and provide “tangible links to life experiences.”

The Caregiver’s Dilemma Between Holding on and Letting Go

From Yijun’s story, it becomes evident that her mother is a highly disciplined and forward-planning caregiver—and this is indeed true. “I keep a family information binder with all our important records, plus digital backups,” she explains. Her determination grew from witnessing the confusion a friend’s family faced after a sudden fatal car accident: “No one even knew where the bankbooks were. I never

want to experience that kind of chaos." By contrast, Yijun's father tends to avoid conversations about death, often saying, "Don't talk to me about these things—just talk to our son." This difference in attitudes reflects how many families vary in their approach to end-of-life issues.

Yet the greatest inner struggle for caregivers is often their own difficulty in letting go when confronting mortality. Hui-Fang Lin shares that, in most cases she has encountered, parents facing serious illness find decision-making even harder because of their concern for a child with intellectual disabilities. This "bond of love" ironically becomes the very barrier that prevents them from choosing a peaceful and dignified end.

She emphasizes that different families and age groups need different forms of preparation. For older adults and "double-aging" families, early planning that integrates health, financial, and care considerations is crucial. For younger individuals with intellectual disabilities, guidance should start from the understanding that "parents cannot be there forever," using everyday experiences and teachable moments to help them recognize the realities of aging and decline, and gradually build the capacity and desire for self-determination.

Medical choices need to be translated into understandable visual formats, giving people with intellectual disabilities opportunities to access and understand them.

For young people with intellectual disabilities, education should begin with the understanding that “parents cannot be there forever,” using life experiences and teachable moments to guide them in recognizing the inevitability of aging and functional decline, and gradually develop the capacity and willingness for self-determination.

Helping Everyone Walk the Final Mile with Dignity

Although the Patient Right to Autonomy Act still limits the ability of people with moderate to severe disabilities to sign independently, “education about death can no longer wait,” Hui-Fang Lin emphasizes. “Understanding death is not a single lesson, but an accumulation of lived experiences.” From witnessing a pet’s aging and passing to the loss of family members, being gently guided through everyday experiences may take time, but proves far more effective than one-time lectures on life and death.

Caregivers and institutions must also devote greater effort to helping individuals develop ways to express their wishes beyond spoken language, ensuring that the question, “How do you want to complete this final stretch?” is not a privilege reserved only for those without disabilities.

Hui-Fang Lin stresses that people with intellectual disabilities deserve medical autonomy as well. Even when their ability to express or judge is limited, they should be respected, supported, and provided with appropriate assistance in decision-making. “This is not merely a matter of policy design, but one of human dignity and the right to choose.” In practice, promoting easy-to-read resources is essential. When medical decision-making information is presented through visuals, simplified text, or scenario-based simulations, individuals with intellectual disabilities can better understand procedures such as intubation or cardiopulmonary resuscitation (CPR), and more clearly express their own preferences.

Everyone deserves to complete their life journey with care and dignity, regardless of verbal ability or intellectual capacity. When we are willing to listen and to walk alongside them, we discover that they understand love—and they also understand how to say farewell.

Accompany Them on the Last Mile in Familiar Surroundings

End-of-Life Care for People with Intellectual Disabilities in Care Facilities

When individuals with intellectual disabilities approach the end of their lives, what they need most is not the cold presence of medical equipment, but the comfort of familiar surroundings and the warmth of trusted companionship. In recent years, Chiayi Francis Home and Changhua County Erlin Happy Christian Home have begun exploring how palliative care can be practiced within residential care facilities. Moving beyond the fear caused by unfamiliar hospital settings, and gradually building interdisciplinary care teams within their facilities, these institutions—guided by courage and faith—are creating the possibility for residents to spend their final days in a place they can truly call home.

In Taiwan, most palliative care still takes place in hospital wards. For people with intellectual disabilities, however, unfamiliar environments are often more frightening than physical suffering itself. In response to the natural course of aging, illness, and death, a small number of institutions have begun offering “home-based palliative care” within their facilities.

Among these pioneers are Chiayi Francis Home and Erlin Happy Christian Home. Many of their residents have lived there since childhood, spending decades with their caregivers and peers, and have come to regard the institution as their home. When death approaches, these facilities choose not to send them away from their familiar environment, but instead allow them to complete the final mile of life at home, accompanied by caregivers and peers.

Unfamiliar Hospital Wards Take Away a Sense of Safety

For residents, the institution is not a place of custody, but the home they know best.

“For people with intellectual disabilities, unfamiliar hospitals can be even more frightening than the illness itself,” reflected Hui-Tang Tsou, former Director of Chiayi Francis Home (now Executive Director of disability service institutions under the Catholic Diocese of Taichung). In the past, when residents’ conditions worsened, they were typically transferred to hospitals for end-of-life care. Yet for many, this sudden change of environment caused deep distress.

“In the hospital, they face constantly changing medical staff, cold surroundings, and the loneliness of being unable to express themselves,” Tsou explained. He recalled a cheerful and independent young man who, after being diagnosed with cancer and hospitalized, begged every day to return to the institution for a simple reason: “That’s where the nuns and caregivers he knew were.”

For these residents, Tsou emphasized, a sense of safety is often more important than treatment itself. Because they cannot always express their fear in words, their restlessness and anxious glances become the clearest cries for help.

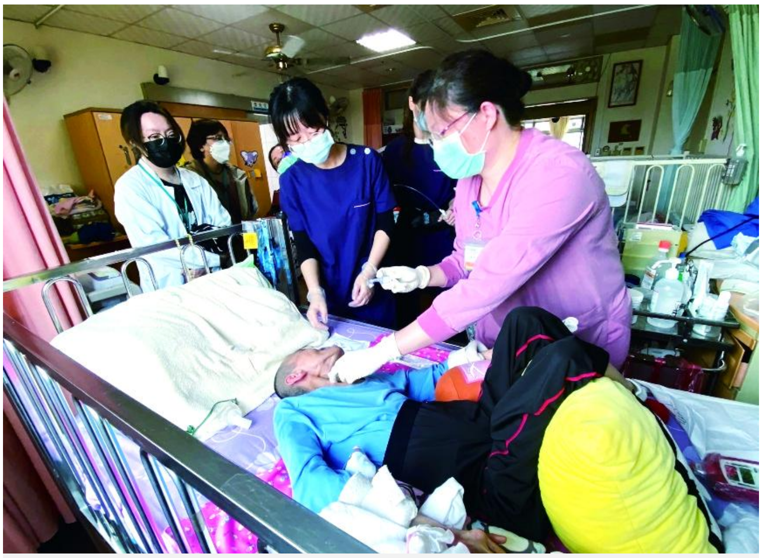
Even brief environmental changes can have a powerful impact. Tsou noted, “Each summer, when the facility undergoes disinfection and residents must return home or stay temporarily in another institution, even a two-week separation can lead to emotional instability—and in some cases, a higher mortality rate." These experiences led Francis Home to realize that truly protecting residents in their final journey means allowing palliative care to take place in the setting they know best: their own home within the institution.

A Courageous First Step

In 2015, Francis Home began exploring palliative care within the institution, with a young resident diagnosed with terminal cancer becoming their first case.

Tsou acknowledged that, at the time, the facility lacked both the knowledge and equipment for end-of-life care, leaving staff anxious and uncertain. Yet driven by the resident's strong wish to remain in the home, the team held what Tsou called a "painful meeting." "We were confronting the unknown—deciding whether to courageously accompany him through life's final stage within the institution."

Ultimately, they chose to "take on the responsibility." The home invited the palliative care team from St. Martin De Porres Hospital, a long-term partner, to provide support while also training internal staff. The nuns, many with nursing experience, took the lead in caregiving, modeling care for the other staff to follow.



The palliative care team from St. Martin De Porres Hospital visits Chiayi Francis Home to provide guidance and support.

"At first, many colleagues

resisted—it is a tremendous weight to bear,” Tsou recalled. “But our supervisors stepped forward first, and gradually, fear gave way to action.”

Following the resident’s peaceful passing, the team gained both confidence and practical experience: learning how to gently touch sensitive skin during bathing, how to calm anxiety with words and smiles, and, importantly, understanding “what not to say.” Tsou recounted once remarking, “You’ve lost so much weight,” only to see the resident’s expression instantly change. He realized that the resident had not yet come to terms with their declining condition, and that even seemingly casual comments could cause emotional pain.

From One Courtyard to Society at Large

The palliative care journey at Francis Home did not start with a fully developed system—it began with a single resident’s wish to “go home.” That simple desire inspired the team to build an in-house palliative care program from the ground up.

Tsou notes that many institutions in Taiwan still operate with a “just send them to the hospital” mindset, lacking both the willingness and resources to accompany residents through life’s final stage. He believes that government policies and incentives are needed to encourage facilities to honor residents’ right to “grow old and pass away at home.”

At Francis Home, palliative care is more than a medical service; it is a practice of human rights and dignity. Supporting residents to spend their final days in a familiar environment reflects the institution’s commitment—and sends a broader message to society: the end of life should not be defined by the cold sterility of hospital wards, but by the warmth and companionship of home.

Erlin Happy Christian Home shares a similar approach. Its history reflects the broader evolution of disability care in Taiwan: from initially serving children with polio to later supporting individuals with intellectual and multiple disabilities.

“Our residents are getting older,” explained Esther Lin, Superintendent of Erlin Happy Christian Home. Of the 198 residents, 57 are over 45 years old—nearly 30 percent of the population—and more than 100 have lived at the institution for over two decades.

These figures highlight a dual challenge: residents are entering high-risk stages for aging-related illnesses such as cancer and heart failure, while their families are also aging and less able to provide care. Consequently, death and palliative care have shifted from abstract medical concerns to unavoidable daily realities.

In 2018, Erlin applied to the Ministry of Health and Welfare to establish an “Aging Care Unit,” reorganizing space, staffing, and daily routines. By placing nursing staff at the forefront of daily care, the institution was better prepared when its first terminal cancer resident reached the end of life in 2019, marking the beginning of its structured palliative care practice.

Care Centered on Fulfilling Final Wishes

Jane’s story is one of the most profound chapters in Erlin Happy Christian Home’s palliative care journey. She had lived at the institution for over 20 years, and in 2023, she was diagnosed with terminal liver cancer. Tumors occupied two-thirds of her liver, and doctors cautioned that she could pass away at any moment.

An interdisciplinary team—comprising caregivers, nurses, social workers, and a pastor—launched a Person-Centered Planning (PCP) process. Despite Jane’s limited cognitive abilities, the team made a concerted effort to listen to her wishes.

"She wanted to buy beautiful jewelry, enjoy oyster soup, and go shopping with her daughter," recalled Heng-Yu Tian, Team Leader of the Nursing Care Department. Caregivers pushed her wheelchair through bustling markets to savor the hot soup, and accompanied her and her daughter as they picked out new clothes. These seemingly simple moments brought light and joy back into her fading life.

As her condition worsened, Jane became restless at night, often crying between 1 and 3 a.m., saying she saw deceased relatives and friends. Through prayer and pastoral support, her emotions gradually calmed, bringing comfort to both her and the staff.

On the night before she passed, despite the cold weather, Jane insisted on going to the night market for a bowl of vermicelli soup. Wrapped in a scarf and surrounded by caregivers, she smiled like a child as she ate. The next day at noon, she passed away peacefully in her sleep.

"Though it was challenging, we are grateful to Jane," Tian said. "She taught us how to help someone with intellectual disabilities leave this world with dignity and

Caregivers at Erlin Happy Christian Home accompany Jane in fulfilling her final wishes.

A caregiver at Erlin Happy Christian Home wraps a scarf around Jane and pushes her wheelchair through the night market, helping her realize her wish to visit it one last time.

fulfillment, even with limited resources."

Systemic Gaps That Constrain Palliative Care

Despite these experiences, institutional palliative care continues to face significant systemic barriers. Yi-Lin Kuo, Professional Associate Dean, highlighted the most urgent issue: insufficient medical linkage. Located in a rural area, Erlin has limited access to home-based palliative services, hospital beds, and hospice physicians. As a result, even when residents reach the terminal stage, timely medical support is often unavailable.

"When a resident dies without being officially enrolled in a hospice program, hospitals cannot issue a death certificate. The institution is then forced to involve the police for administrative verification or call in a local health center physician at short notice to issue the certificate," Kuo explained. These complex procedures not only add stress to staff but also compel grieving families to navigate bureaucratic hurdles at a difficult time.

At Chiayi Francis Home, nuns, nurses, and caregivers gather to offer end-of-life prayers and companionship to a resident.

Legal responsibility poses an additional challenge. Kuo elaborated: if a resident experiences sudden massive bleeding, should caregivers perform CPR, even if it only prolongs suffering? Institutions must conduct multiple family meetings, obtain signed Do Not

Resuscitate (DNR) consent, and secure physicians’ documentation before they can safely “accompany without intervention.”

“We care and we pray,” Kuo admitted. “Delivering palliative care in a residential setting is never easy, but our faith gives us strength. Out of compassion and familiarity, we choose not to send residents to unfamiliar hospital wards, but to let them remain with those they know well.”and heritage to create a sustainable path for rural communities.

Faith-Based Grief Support

At Erlin Happy Christian Home, palliative care is not only about caring for those who are dying, but also about supporting those who remain. When a resident passes away, the institution holds memorial and comfort services where peers sing hymns and share memories. These rituals serve both as grief counseling and as gentle education about death.

“We don’t shy away from talking about death,” emphasized Superintendent Esther Lin. Residents openly discuss death and heaven, and come to understand that departure and passing away are not something to fear. For peers with especially deep emotional bonds, social workers and pastors provide one-on-one support to help them through their grief. This approach not only helps residents gradually come to terms with death, but also enables staff, through each farewell, to find the strength to continue accompanying others on the next stage of their journey.

Chiayi Francis Home places equal care in grief support. When a resident reaches their final moments, nuns, nurses, and caregivers gather at the bedside, praying

At Erlin Happy Christian Home, palliative care is not only about caring for those who are dying, but also about supporting and educating those who remain.

softly and singing until the heartbeat slowly comes to rest. Afterwards, residents living on the same floor line the corridor to see their friend off. In the days that follow, memorial gatherings and annual remembrance services, led by the nuns, continue the process of healing.

“Farewell rituals are also a form of grief counseling,” Tsou believes that only by remembering and honoring can death become a shared journey rather than a hidden taboo.

Returning Palliative Care to the Essence of Life

Whether at Chiayi Francis Home or Erlin Happy Christian Home, the journey of palliative care has been difficult, yet steadfast. Without strong medical backing, they rely on interdisciplinary teamwork and faith to sustain one another. In the absence of clear legal protections, they build understanding and trust through repeated dialogue and careful coordination. This challenging yet deeply compassionate path is taken for one purpose: to fulfill the vision that people with intellectual disabilities may “grow old and pass away at home.”

This is not only a display of courage by two institutions but also a shared responsibility for society as a whole, because every life deserves to be respected and accompanied until the very last moment. Along the way, these homes carry the weight of limited medical resources and systemic gaps, yet through each farewell they also discover the deeper meaning of life education: death is no longer a forbidden topic, but an invitation to learn, to accompany, and to grow.

“This is their home. We can’t bear to send them away.” These simple words capture the shared conviction of both Francis Home and Erlin Happy Christian Home. It expresses a hope that palliative care will not remain a privilege for the few, but a right for all—and the most peaceful resting place for every life.