HFT Newsletter

Forever Love, Endless Care

June 2026

PHPCI
Public Health Palliative Care International
2026
October 6-9
Pre-conference + Main conference
Location | Tamsui, New Taipei City, Taiwan

Bridging Culture, Building Compassion: Join us in Taiwan for the 9th PHPCI Conference

A New Era of Public Health Palliative Care

Allowing Them a Gentle Farewell

The Palliative Care Crisis for the People with Intellectual Disabilities

In Memoriam: Dr. Balfour M. Mount–

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

A New Era of Public Health Palliative Care

Bridging Culture, Building Compassion: Join us in Taiwan for the 9th PHPCI Conference

Dear distinguished guests, experts, partners, and colleagues in palliative care from around the world, greetings to you all.

On behalf of the Hospice Foundation of Taiwan and the Organizing Committee of the 9th PHPCI Conference, it is with great pleasure, sincerity, and honor that I warmly welcome you to this historic gathering.

The year 2026 marks a significant milestone for Taiwan. This year, the Hospice Foundation of Taiwan enters its 36th year of advancing hospice and palliative care. Over the past three decades, Taiwan has established a strong and enduring foundation in palliative care policy and legislation. From the implementation of the Hospice Palliative Care Act to the enactment of the Patient Right to Autonomy Act, we have built a comprehensive legal framework to safeguard dignity and autonomy of individuals at the end of life.

Yet as we confront the profound challenges of a super-aged society, we recognize that the efforts of the healthcare system alone are no longer sufficient to meet the growing demands of end-of-life care. The development of community-based initiatives, the integration of palliative care within long-term care facilities, and the cultivation of local support systems all remind us of the important mission still before us.

This year also marks a historic moment as PHPCI comes to Asia for the first time, with Taiwan honored to serve as the host country. It signifies a critical shift in our era: palliative care must move beyond the boundaries of terminal clinical care and be elevated to the level of national public health.

The core mission of this conference is to promote cross-sector integration and practical policy implementation. Together, we will explore how palliative care principles can be embedded within community public health systems, how Compassionate Communities can become a vital model for social governance, and how strengthening death literacy can empower individuals in advance care planning and decision-making. This is not only a healthcare issue, but also a reflection of social resilience and the values of human dignity and human rights.

In Tamsui, in northern Taiwan — a place rich in history and humanistic spirit — we look forward to meaning dialogue and collaboration with palliative care leaders from around the world. Together, we hope to explore how Taiwan's legislative experience and international public health models can be integrated and transformed into policy frameworks for Asia and the global community.

Thank you for joining us in Taiwan and for partnering together to move beyond the traditional boundaries of healthcare. Together, we can build a new vision of compassionate end-of-life care—one that is people-centered, policy-driven, and community-based.

We sincerely look forward to meeting you, exchanging ideas, and shaping the future together.

Shou-Chuan Shih
Chair of the 9th PHPCI Conference
Chairman, Hospice Foundation of Taiwan

Allowing Them a Gentle Farewell

The Palliative Care Crisis for the People With Intellectual Disabilities

At the end of life, people with intellectual disabilities are often unable to express their needs because of limited communication abilities, while systemic gaps further deprive them of meaningful choices about how they wish to spend their final days. Families bear the long-term pressures of caregiving, and medical teams frequently struggle to find consensus within the gray areas of law and ethics. Frontline professionals hope that understanding can begin through dialogue and that stronger institutional support can take root, creating a path toward dignity and peace for those whose final journey is too often overlooked.

How can we ensure that the final journey of those with intellectual disabilities is no longer one of isolated helplessness? Different roles reflect the same despair: social workers see the struggle between love and responsibility, while physicians feel the burden of accountability forced upon them by ambiguous regulations. These voices join in a common call: only when healthcare, social administration, and disability services are truly integrated can these individuals experience genuine peace in their final days.

The Voices Lost and the Needs Unspoken

Because of cognitive and communication limitations, people with intellectual disabilities are often labeled as "lacking decision-making capacity" during the course of illness. Chih-Ting Tseng, Head of the Social Service Department at Tamsui MacKay Memorial Hospital, observes that many terminally ill patients with intellectual disabilities may sense that “something is wrong” physically, yet lack the

language skills to explain it clearly. Instead, they may express distress through shouting, agitation, or restlessness. "Clinically, even when these patients are in unbearable pain, they are often not fully understood by medical staff," she says solemnly.

Even more concerning is that their needs are frequently ignored or considered unnecessary to acknowledge.

"He doesn't understand, so don't tell him." Tseng has heard this more than once in the hospice ward. Many families insist on withholding the diagnosis, believing that "knowing will only increase fear." However, in her view, this is a profound form of deprivation. Many people with intellectual disabilities have never been taught about death. They may be excluded from funerals and never invited to participate in or understand the process of losing loved ones. "As a result, when death finally comes for them, they are not only confused about what is happening but they also face fear and isolation alone."

In response, Tseng and her team seek alternative methods—through picture books, music, physical touch, and aromatherapy. Though seemingly simple, these forms of companionship can ease anxiety and bring a sense of familiarity and warmth into the unfamiliar hospital environment.

The Tug-of-War Between Love and Exhaustion: Families Reaching Their Limit

As a social worker, Tseng witnesses not only the silence of patients, but also the helplessness of families and the fractures within the system. "It’s not for lack of love, but lack of options."

Chih-Ting Tseng and her team strive to alleviate patients' anxiety through methods such as picture books, music, physical touch, and aromatherapy.

She recalled one patient with an intellectual disability who was brought to the hospital with a liver tumor already exceeding ten centimeters. "Only after questioning the family did the medical team discover that the patient’s mother had known about the illness for over a year, but chose not to pursue treatment and concealed the diagnosis from the residential facility." Tseng remembers that even when the patient was hospitalized, the mother refused paracentesis and antibiotics, insisting on "letting him go naturally."

Initially, the medical team felt anger and frustration, believing she was disregarding the patient’s rights. But after talking with her, Tseng understood the mother’s predicament: "She had been caring for her child alone for many years after her husband passed away early, and the financial burden was overwhelming. If she pursued treatment, the child would be evicted from the facility, and she would have to quit her job to provide care. The entire family’s livelihood world would collapse."

"In families of individuals with intellectual disabilities, this conflict between medical ethics and reality is common," Tseng says helplessly. Decisions that appear “cold-hearted” from the outside are often choices made in complete isolation and desperation.

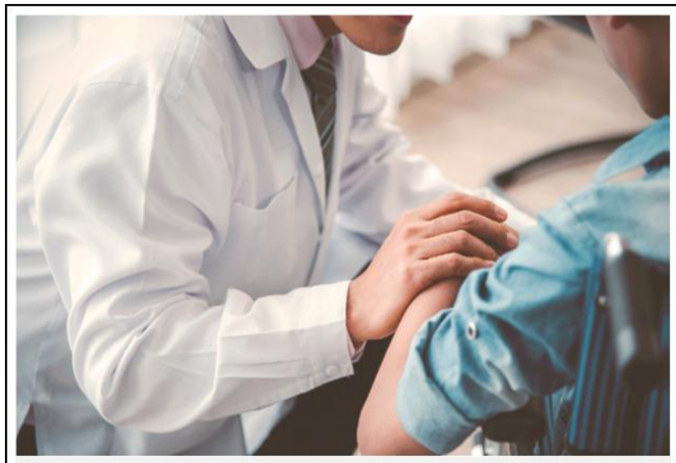
Dr. Tsung-Yu Yen, an attending physician at the Mackay Hospice and Palliative Care Center, shares this sentiment. "Even if we save him, he still still remain intellectually disabled." His words may sound blunt, but they represent a struggle many families dare not say aloud.

In clinical settings, he often sees these patients repeatedly admitted for infections, kidney failure, or bleeding. Families often flatly refuse intubation or antibiotics. These decisions are not made out of a lack of love, but out of the exhaustion and powerlessness accumulated over many years of providing care.

"In standard hospice consultations, physicians spend a long time communicating with families to persuade them to choose palliative care. However, in cases involving individuals with intellectual disabilities, families often decide faster than we do," Dr. Yen notes with empathy. This directness is actually a rational judgment formed after years of caregiving. "These families have already since seen the progression of the illness clearly, knowing that further treatment may only prolong suffering and financial hardship."

When love and responsibility collide, the "stop-loss point" for families of individuals with intellectual disabilities arrives earlier and more decisively than it does for other patients.

Medical Staff in a Dilemma When Consent Becomes a Void


When a patient lacks family support, physicians are frequently forced to bear the heavy burden of medical decision-making alone.

When asked about the most difficult challenge in caring for these patients with intellectual disabilities, Dr. Yen answers without hesitation: "Intellectually disabled patients are without family."

While "patient autonomy" is a fundamental principle of major treatment decisions, it is hard to implement here. Dr. Yen points out that most intellectually disabled patients are viewed as having "immature cognitive capacity," meaning medical decisions are typically made by guardians or family members. "The problem is that not everyone has a legally appointed guardian."

He recalled patients arriving at the hospital unable to understand their illness or communicate their wishes—and without any family members or guardians. This leaves medical teams facing an impossible question: Who is to sign the consent forms? "Some patients are long-term residents in institutions, but legally, these institutions lack authority to sign medical documents on their behalf."

Dr. Yen also described one patient with no known relatives whose identity was so unclear that even the name on the patient's identification card had been assigned by the Social Affairs Bureau. In situations like these, who should decide whether treatment continues?

Under Taiwan's revised regulations, life-sustaining treatment may be withdrawn if

two physicians determine that a patient is terminally ill. But this effectively forces physicians into the role of “temporary guardian,” placing a tremendous emotional burden on them.

"Not all doctors are willing to bear this," Dr. Yen admits. While the Hospice Palliative Care Act provides a legal basis, in practice the burden often falls upon the few physicians willing to shoulder the responsibility.

Therefore, he calls for a more seamless integration of the system. The medical sector needs to establish stable cooperative models with social welfare and disability services, ensuring that the link between institutions and hospitals is no longer just a one-way street of "sending and receiving patients," but a partnership that can collaboratively plan end-of-life care. The government should also clarify the responsibilities regarding guardianship and signing authority to prevent hospital directors or social workers from being trapped in legal gray areas. At the same time, support for medical teams is indispensable, as these decisions are not merely legal matters, but they concern how a human life reaches its end.

A Vision for Integration Amid Systemic Fragmentation

As a medical social worker specializing in end-of-life care, Chih-Ting Tseng deeply understands the fragmentation between different service systems. On the medical side, staffing shortages often force healthcare teams to simply defer to the family’s wishes when a patient is dying. On the institutional side, residential facilities are often paralyzed by regulatory constraints, leaving them with no choice but to discharge patients as their conditions worsen. Meanwhile, social administration and disability services often lack the resources for long-term

Only through education, integration, and systemic reform can we ensure that they are no longer forgotten in life’s final journey, but can instead experience true dignity, gentleness, and peace within a palliative setting.

support. These systemic gaps leave people with intellectual disabilities into "isolated islands" during the most vulnerable stages of life.

Tseng believes the key to improvement is not to wait until a patient reaches the end of life to rush a remedy. Instead, life education must begin much earlier, allowing facility staff, families, and even the individuals themselves to gradually encounter the concepts of "death and grief" within everyday life, learning how to talk about them and face them together.

She also emphasized the importance of institutionalizing cross-sector collaboration. Healthcare, social welfare, and disability services need a permanent platform for cooperation, ensuring that support systems remain connected when patients move between services and settings.

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.

She also points out that the government should invest more resources to ensure that

medical and social work teams have sufficient personnel to handle complex cases. Such support would also reduce the pressure and fear experienced by institutions caring for terminal residents. "We must first learn to hold our own fears before we can accompany them through their grief and helplessness," Tseng says. In her eyes, this is no longer a simple medical issue, but a lesson that society as a whole must learn to face together.

"It is not that they cannot understand; it is that we haven't helped them understand." This statement by Tseng points directly to the blind spot of the current system. In the face of major illness and terminal stages, individuals with intellectual disabilities should not remain passive recipients of decisions. They need others to translate their needs, and more importantly, they need systems capable of building a network of support around them. Only through education, integration, and systemic reform can we ensure that they are no longer forgotten in life’s final journey, but can instead experience true dignity, gentleness, and peace within a palliative setting.

In Memoriam: Dr. Balfour M. Mount—A Humanistic Pioneer of Palliative Care

It is with profound respect and heavy hearts that we commemorate the passing of Dr. Balfour M. Mount. Dr. Mount was not only the founding father and global leader in palliative care but also a humanistic visionary who elevated spiritual care to a central position in medicine. His passing on September 29, 2025 (Canada time), is an immeasurable loss to the international palliative care community.

A Global Pioneer and Visionary

Dr. Mount's academic contributions established milestones recognized around the world. Ag McGill University in Canada, he founded the Palliative Care McGill Program and the Spiritual Care Academy. He is also credited with coining the term "Palliative Care Medicine," which became foundational to the discipline as we know it today.

Beyond his professional accolades, his character itself testified to his greatness. He was a giant of his era—brimming with positive energy, passion, and unwavering conviction, yet possessing a heart of immense tenderness

and peace. Even while facing illness himself, he remained radiant and full of grace, embodying the maturity and wisdom refined through life's journey. In many ways, he truly lived out the very essence of the spiritual care he championed.

A Lasting Legacy in Taiwan's Hospice Movement

Dr. Mount's influence is deeply rooted in the history of palliative care in Taiwan:

- Sowing the Seeds of Spirituality: On June 4, 1989, during the summer meeting of the Academy of Hospice Physicians in the United States, Dr. Mount shared the concept of the "Spiritual Care Academy" with Professor Yin-Liang Lai. That conversation profoundly inspired Taiwan's emerging hospice and palliative care movement.
- Laying the Foundation for Professional Training: Inspired by this vision, the Hospice Foundation of Taiwan launched the "Spiritual Caregiver Training Program" in late 2001 and established its own "Spiritual Care Academy."
- Teaching and Mentoring in Person: Around the year 2000, when Taiwan first invited internationally renowned scholars to conduct spiritual care education and training, Dr. Mount personally accepted the invitation to visit. He became a key mentor in cultivating the first generation of local spiritual care educators.

A Twenty-Five-Year Bond of Mentorship and Friendship

The friendship between Professor Yin-Liang Lai and Dr. Mount began with their first meeting in 1989 and later deepened into a "mentor-and-friend" relationship during Professor Lai's advanced studies in the United States. In September 1991, Professor Lai traveled to the Royal Victoria Hospital in Montreal, Canada, to learn

directly from Dr. Mount about the development of spiritual care.

This bond extended far beyond professional life into their family life. Dr. Mount affectionately nicknamed Professor Lai’s two sons "American Buffalos." Furthermore, his own adoption of a child from China further showcased his humanistic compassion that transcended race and culture.

Even during their final meeting at a commemorative conference in Montreal in 2004, Dr. Mount, despite being physically frail, continued to embody the true meaning of compassionate humanism through his characteristic gentle humor, warmth, and encouraging words. In the years that followed, the friendship endured through annual Christmas e-cards exchanged over nearly 25 years.

We offer this tribute with the deepest respect and remembrance for a truly remarkable humanistic pioneer. Dr. Mount’s spirit and his vision of "Whole-Person Care" will continue to inspire generations to come.