



Hospice  
Foundation of  
Taiwan

# HFT Newsletter

Forever Love, Endless Care

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# Immediate Palliative Care - Fulfilling Life's Expectations


## From Early to Timely Intervention

*Many people misunderstand palliative care as “doing nothing” or “waiting for death.” In fact, palliative care is far from being passive; it emphasizes proactive care, helping patients live well throughout the course of their illness.*



At the end of last year, Grandma A-Chun was diagnosed with colon cancer, which had already metastasized. Encouraged by her family, she fought the cancer aggressively. However, the discomfort caused by chemotherapy was unbearable. Dr. Huang-Ren Lin, Director of the Palliative Care Center at Lotung Poh-Ai Hospital, visited her to adjust her medication and alleviate her symptoms. He also took time to understand her and her family's thoughts during this process.

After three months of treatment, the hematology and oncology team found that Grandma A-Chun's chemotherapy results were not as expected. She was sent to the emergency room again due to severe nausea and vomiting. The medical team and her family urged her to try another form of chemotherapy. However, the suffering caused by chemotherapy was too much for her, and she longed for less pain. Having the support of the palliative care team, Grandma A-Chun felt she had fought hard enough and expressed her wish to transfer to the hospice ward.



That morning, after discussions with her family and the medical team, they decided to respect Grandma A-Chun's wishes and transfer her to hospice care. Dr. Lin believed she would overcome this crisis and be discharged stably. “After that, the home hospice team will take over her care.” Dr. Lin had accompanied her for more than three months and witnessed her pain during the treatments. Through full communication, he saw how she and her family moved from conflict to gradual understanding. “To outsiders, palliative care may seem like ‘doing nothing,’ but it actually fulfills the patient’s and family’s expectations for life.”

## **The Initial Motivation for Engaging in Palliative Care**

As a resident, attending physician, and later the director of the hospice ward, Dr. Huang-Ren Lin often asked himself if he had done enough or done things right. He frequently reflected on what he truly cared about and pursued. “My mentor, Dr. Ying-Wei Wang, told me: ‘Whatever can help the patient and doesn’t cause harm, we must do our best to achieve it.’” Helping patients lead a complete and fulfilling life is what all advocates of hospice care strive to do throughout their careers.

More than four years ago, Dr. Huang-Ren Lin transitioned from Hualien Tzu Chi Hospital to the Palliative Care Center at Lotung Poh-Ai Hospital in Yilan. He found that while palliative care in Taiwan had been developing for nearly 30 years, Yilan lagged behind in holistic palliative care compared to Hualien. He attributed this to the lack of a large medical center in Yilan and the traditional mindset still prevalent among some of the elderly population. This also motivated him to promote palliative care in his hometown.

Dr. Lin offered a compelling explanation of palliative care: “We aim to enable patients to live the life they want, even at the end.” He pointed out that some people






mistakenly equate palliative care with “giving up treatment.” In reality, palliative care allows patients to continue receiving treatment for other illnesses, regardless of their age or the severity of their condition. “Palliative care is not about doing nothing or doing less; it’s about being even more proactive. Anything that benefits the patient, where the pros outweigh the cons, should be pursued with greater effort.” The ultimate goal of palliative care is always to help patients live well.



## **The Essence of Immediate Palliative Care**

In late 2022, Dr. Huang-Ren Lin launched the project “Comprehensive Provision of Immediate Palliative Care to Improve the Quality of Life for Patients with Advanced Cancer and Non-Cancer Diseases.” Through systematic evaluation, the goal was to include both advanced cancer and non-cancer patients in palliative care earlier, thereby improving their quality of life at the end of life. This project received funding from the Hospice Foundation of Taiwan, providing more research opportunities and resources for the team.

What exactly is proactive palliative care? Dr. Lin believes it involves “caring for patients who are not yet at death's door, giving them a period of quality life.” Unlike past hospice care, palliative care focuses on patients in the later stages of their illness. It’s not just about waiting for the final days but ensuring that patients can live with dignity and confidence while they still have time.



In summary, the palliative care team's most distinct feature is its holistic approach to patient care. This involves a team of doctors, nurses, social workers, psychologists, and spiritual care personnel providing physical, emotional, and spiritual support to both the patient and their family. "Our goal is not only to ensure that the patient receives the highest quality of medical care but also to be a support system for their family and primary caregivers, providing comprehensive assistance and consultation."


Given that immediate palliative care is time-sensitive, how should the intervention point be determined? Dr. Lin explained that the concept of immediate palliative care involves shifting from "Early" intervention to "Timely" intervention. This means that palliative care can be introduced as soon as a disease enters its advanced stage while treatments are still ongoing, allowing for timely intervention at any stage.

## **Immediate Intervention Enhances Quality of Life**

The concept of immediate palliative care has been around for some time. Ten years ago, Lotung Poh-Ai Hospital established a Palliative Care Center to provide hospice and palliative services. However, many families, patients, and even healthcare professionals still believed that palliative care was only meant for the end-of-life stage. This perception gradually changed with the implementation of the project "Comprehensive Provision of Immediate Palliative Care to Improve the Quality of Life for Patients with Advanced Cancer and Non-Cancer Diseases."

This project was planned in 2020 and officially began systematic patient intake in August 2022, running until the end of November 2023. Over the 15-month period, Dr. Lin evaluated the project's impact, noting that "in the past, the average time from when patients began hospice care to their passing was 1.5 months. However,






with the intervention of palliative care, this time has been extended by an additional month.” In other words, on average, patients now have 3 to 4 months after palliative care intervention to arrange their remaining lives, which is an improvement from the previous 1 to 2 months under hospice care alone. Furthermore, the immediate palliative care model has encouraged more patients to accept hospice care, increased the proportion of home care, and reduced unexpected hospitalizations and deaths.

Currently, Lotung Poh-Ai Hospital's immediate palliative care program targets both cancer and non-cancer patients. Initially, it includes patients with hematologic malignancies, breast cancer, and gastrointestinal cancers. For non-cancer patients, the focus is primarily on those with heart failure and chronic obstructive pulmonary disease, with plans to expand to other wards in the future.

## **Realizing the True Meaning of Holistic Care**

Dr. Lin believes that, although advances in medicine have provided doctors with more sophisticated treatment tools, over-medication and unnecessary routine treatments that do not improve quality of life are not what patients want. The key is not simply surviving but dying peacefully while maintaining quality of life and dignity, allowing patients to make autonomous decisions about how they wish to live. “I believe the trend of palliative care is here to stay, but there is still room for improvement.” He emphasized that palliative care has evolved from hospice care and that the next challenge is to fully integrate patient autonomy into the care model.

He shared a story of a grandfather with prostate cancer who, after receiving palliative care, found new meaning and purpose in life. He decided to accept home care, and seven years later, he is still alive. His wife, who had originally helped care for him, passed away earlier due to a stroke and pneumonia. This example shows



that patients who receive palliative care can live well and for a long time. “Grandfather often expressed his gratitude to us. Sometimes, I would jokingly ask him, ‘How do you plan to arrange things when your time comes?’ He would always smile and reply, ‘Of course, I’ll follow my wife’s example and pass away peacefully at home.’”

Dr. Lin firmly believes that palliative care is not just about medical treatment; it is about the human connection. This, he says, is the true meaning of holistic care.



# **Palliative Care Queries: Enhancing Doctor-Patient Communication**

## **Utilizing Question Prompt List: Supporting Hospice Care with Compassion**

*Research from abroad shows that purposeful and meaningful conversations are crucial for patients with limited time. Effectively using a Question Prompt List (QPL) can significantly reduce decision-making difficulties for patients.*

Entering the field of hospice care often means stepping into confusion. This sentiment resonates deeply with Ya-Chun Cheng, a supervisor in the Nursing Department of Hualien Tzu Chi Hospital. Despite over two decades of the Palliative Care Act being in effect, Cheng observes that challenges still persist, making it difficult for families and medical teams to navigate this path smoothly. One of the most significant hurdles remains effective communication.

### **Communication Barriers in Hospice Care**

A family member of a patient who received hospice care shared with Cheng that, even long after their loved one passed away, they felt more confusion than gratitude when reflecting on that period. “At the time, we couldn’t fully understand the information provided by the medical team,” the family member admitted.

They expressed that although they had many questions, they didn’t know how to ask them or even how to articulate their concerns clearly.

Another family member told Cheng that if they had better understood the hospice care’s philosophy and processes before receiving it, the hospice team could have



provided more assistance with managing the patient's symptoms and preparing the family mentally.

Cheng recalls instances where she observed family members nodding repeatedly in agreement with the doctor's explanations during consultations, only to quickly ask a nurse afterwards, "What did the doctor just mean?" Although the nurse patiently explained, the family had already missed the best opportunity to voice their doubts.

Cheng explains that the communication gap arises from several factors, such as the patient's health literacy and the limited time available during consultations. Furthermore, hospice care carries stigmas for some people, such as being associated with "waiting to die" or "being abandoned," which leads the medical team to vaguely suggest options like, "Let's see if another doctor can help," or "Maybe we can try another approach."



The difficulties in hospice care became more apparent to Cheng after she took on the role of supervisor for hospice care and adult oncology. While she was pleased to see some cancer patients receiving shared care with hospice, she also

noticed that many patients and their families did not fully understand the role of the hospice team. Instead of being gently referred, they often felt forced into accepting hospice care, which led to less-than-ideal outcomes. Unwilling to see this cycle repeat, Cheng resolved to make a change.



## **Question Prompt Lists: Bridging Doctor-Patient Communication**

In recent years, doctor-patient communication in Taiwan's healthcare system has improved significantly, thanks to various efforts. Specifically, the Health Promotion Administration and the Joint Commission of Taiwan have introduced various Question Prompt Lists (QPLs) to facilitate shared decision-making in medical care. These lists are available for surgeries, medications, cancer treatments, and more. Patients can review these lists before consultations to think about what questions they need to ask, alleviating some of their concerns.

“However, there currently isn't a relevant prompt list for hospice care in Taiwan,” Cheng noted. This led her to consider, “When patients and their families enter this unfamiliar field of hospice care, can we provide them with some guidance to help alleviate their confusion and understand what questions to ask?” With the support of her two PhD advisors and funding from the Hospice Foundation of Taiwan, Cheng began researching a “Question Prompt List for Advanced Cancer Patients and Their Families in Hospice Care.”

“In the clinical setting, good communication and listening are important, but asking the right questions is the key,” Cheng emphasizes. She believes that although Taiwan is moving towards precision medicine, the time available during consultations is still very limited. A QPL can help get to the heart of the matter quickly, “allowing patients to directly ask about their concerns and the medical team to respond to their needs.”

During the development of the QPL, a patient offered Cheng valuable feedback. He recalled that when hospice care was first initiated, he was simply told, “We can ask another team to assist you, and we’ll see if this can make you feel more comfortable.” But he didn’t understand what “we’ll see” meant and he felt lost until a doctor clearly stated, “Shortness of breath is your most uncomfortable symptom right now; let’s address that first.” This direct approach helped him understand how the hospice team could assist him.

“Clearly stating the primary goal of the treatment helps patients receive the most effective care,” Cheng concludes. She believes that the design of a QPL must be straightforward and concise, helping patients and medical teams focus on the key issues. This approach avoids vague questions such as, “Do you have any questions?” which often leave patients unsure of where to begin.

In her review of the literature, Cheng also discovered that the development of QPLs for hospice care abroad is already quite advanced. After obtaining a QPL, patients can prepare their questions before the next appointment, with case managers providing guidance before they meet with the doctor.

However, after considering the differences in cultural practices, health literacy, and medical systems between Taiwan and other countries, Cheng realized that foreign QPLs were not suitable for use in Taiwan. She concluded that there is an urgent need to develop localized QPLs specifically for advanced cancer patients and their families in Taiwan’s hospice and palliative care settings.



## Enhancing Quality of Life on the Final Journey

After a year of interviews and surveys, Cheng completed a QPL containing 25 questions. Preliminary results revealed that patients and families who used the QPL experienced significantly reduced anxiety after their consultations.

This outcome convinced Cheng of the necessity of QPLs in hospice care. She believes that patients who lack critical information for making treatment decisions may experience poor care and quality of life at the end of life. On the other hand, early communication and proactive guidance from medical teams can increase the acceptance of hospice care among patients with advanced cancer.

Cheng explained that her current QPL is focused on advanced cancer patients rather than terminal cancer patients due to her extensive clinical experience.

“In the past, we often encountered patients who passed away the day after being admitted to the hospice ward. We don’t want to see that happen,” she recalled. Cheng shared the story of a patient who not only received shared hospice care early but also continued with home hospice care. Even when he was readmitted, he was smoothly transferred from the acute care ward to the hospice ward. “This means that many patients can go home and spend more time with their families if they receive proper hospice care,” she said. “This is why we want to promote early palliative care for advanced cancer patients.”

“Although the initial draft of the QPL is completed, I hope to refine it even further,” Cheng said. She plans to collaborate with hospice care experts and make any necessary adjustments before applying the QPL in clinical settings. “I hope to complete it within a year so that advanced cancer patients can benefit!”



# Precision Identification of Palliative Care Needs for a Peaceful End of Life

## Palliative Care for Elderly Veterans at Veterans Homes

*The home hospice care team at Taipei Veterans General Hospital has been dedicated to providing palliative care for residents of Veterans Homes during the final stages of their lives. To date, the team has facilitated dignified end-of-life care for over 100 residents.*

*With the support of the Hospice Foundation of Taiwan's palliative care advocacy, education, and research programs, the team has reviewed and analyzed past medical records. The goal is to develop a scale more aligned with the practical care needs in long-term care institutions, enabling the early identification of patients approaching the end of life or requiring palliative care, thereby providing timely and appropriate care.*

In long-term care institutions, the sound of ambulances transporting residents to the hospital is a common occurrence. Whenever a resident experiences a health emergency, they are promptly sent to the hospital for treatment. However, when medical interventions no longer align with the resident's needs and instead place an additional burden on them, we must pause and consider: what kind of care does the resident truly desire? Would they prefer to remain in the comfort of their familiar surroundings with caregivers they know? Medical training often focuses on relieving patients' suffering and extending their lives, but seldom teaches us how to balance these when prolonging life may also extend the dying process.

Currently, Taiwan has 16 Veterans Homes, which for many residents serve as their second home. These veterans, who have dedicated their lives to serving the country,

often wish to spend their remaining years at the Veterans Home and pass away there with dignity. This makes the promotion of palliative care within long-term care facilities especially significant. The goal is not merely to allow residents to die at the Veterans Home, but to help them reduce suffering in their final days, achieve physical, mental, and spiritual peace, and ensure that their families can say their farewells in a meaningful way—attaining peace for both the living and the deceased.


As of now, about 50 residents at the Taipei Veterans Home are receiving palliative care, with an average admission age of over 90. The Taipei Veterans General Hospital's home hospice care team provides regular visits by doctors and nurses, assists with comfort care, and conducts palliative care family meetings to understand the resident's preferences and set end-of-life care goals.

## Comprehensive Care Through Family Meetings

The promotion of palliative care has faced many obstacles, particularly with frontline institutional staff who often hold misconceptions about caring for terminally ill patients. These staff



members may lack experience in end-of-life care and fear the unpredictability of the dying process. This makes palliative care education all the more essential. It is of utmost importance to provide practical training courses in palliative care to Veterans Home staff, covering aspects such as addressing common psychosocial and spiritual needs of terminal patients, managing end-of-life symptoms, and assessing signs in the final stages of life.



In the staff training courses, learning to identify residents in need of palliative care is the first step. In addition to terminal cancer patients, many elderly residents with non-cancer conditions often suffer from dementia or multiple chronic comorbidities. Although they may seem stable in their daily lives, issues like weight loss or a single severe infection or fall can significantly reduce their functional abilities. This makes it difficult for staff to recognize the appropriate time for early palliative care intervention.

Family meetings have always been a cornerstone of palliative care. At various stages of a resident's illness, all concerned parties, including family members, Veterans Home supervisors, ward leaders, nurses, and the Taipei Veterans General Hospital's home hospice care team participate in family meetings. The team explains the resident's current conditions, potential developments, and recommended medical care plans. If the residents are conscious, they also participate, discussing their values, wishes, and the family's perspectives, which include preferred end-of-life settings and the extent of life-saving measures like CPR. Every family meeting reveals a unique life story, with the experiences and wisdom shared by the Veterans Home residents and their families helping the team to provide care that best aligns with the residents' needs. Family meetings may occur multiple times, allowing for adjustments to the medical and care goals as the residents' condition evolves.

## Skillful Use of “Comfort Packs” for Peaceful End-of-Life Care




The Taipei Veterans General Hospital’s home hospice care team conducts regular visits, integrating palliative care into daily routines. This approach is like adding a partner that works together to improve the resident’s quality of

life. The team provides comprehensive comfort care, including wound care, lymphatic massage, oral hygiene, and hand and foot care. Doctors also prescribe preventive medications tailored to the resident’s condition to quickly and effectively relieve discomfort. These medications are collectively referred to as “Comfort Packs,” which helps reduce emergency room visits and hospital admissions for terminally ill residents, improving their quality of life and allowing them to peacefully pass away at the Veterans Home.

Supported by the Hospice Foundation of Taiwan’s palliative care advocacy, education, and research programs, the Taipei Veterans General Hospital’s home hospice care team reviewed data from November 2018 to September 2022. A total of 90 residents passed away at the Veterans Home during this period, with the data showing:

- 96.7% were male, with an average age of 92, and 27.8% were single veterans.
- 28.9% had a cancer diagnosis, while 48.9% were diagnosed with dementia.
- 7.8% had signed advance healthcare directives.
- The average duration from palliative care admission to death was 144.9 days.





The analysis revealed that, regardless of whether residents had cancer or not, respiratory distress was the most common terminal symptom among the elderly, affecting approximately 67.8% of residents before death. Oral morphine was the most frequently prescribed and used medication in the Comfort Packs, primarily for alleviating respiratory distress and pain. All Comfort Pack medications were prescribed in advance during regular doctor visits, aimed to alleviate potential discomforts such as:

- Fever: antipyretics or antibiotics prescribed
- Respiratory distress or pain: morphine prescribed
- Agitation or delirium: sedatives or antipsychotics prescribed

The study also highlighted the importance of respiratory care skills for long-term care facility staff in end-of-life care. Proper use and timing of Comfort Pack medications are essential components of staff education and training.

## **Enhancing Care Quality by Integrating Palliative Care with Long-Term Care**

Ms. Chia-Miao Hong, a supervisor at Taipei Veterans Home, once said, "Caring is like a relay race; the facility is the resident's final stop. When the family hands over the baton to us, we need to help them run to the finish line of life." Families expect the facility to provide better care and quality of life for the residents. By integrating palliative care into long-term care, the quality of care can be enhanced, but families often have limited understanding of palliative care. Promoting palliative care requires teamwork: long-term care staff need to receive on-the-job training in palliative care, while residents and their families should engage in life education to learn how to take responsibility for their own lives.



If long-term care facilities can combine palliative care and proactively communicate care goals with residents or their families, it will not only improve the quality of end-of-life care for residents but also increase family satisfaction with the facility's services. This allows residents to say their goodbyes in a meaningful way, making the end of life a moment filled with blessings and emotion, rather than a sudden, unprepared event.

I'll never forget the profound impact of witnessing the first resident pass away peacefully at the Veterans Home. Though it may seem like a small step, it was a significant leap forward for both our home hospice care team and the facility. The small, seemingly trivial things we do can bring immense satisfaction to residents. Simple acts like daily cleaning, comforting massages, and other forms of care become great sources of enjoyment for them. The anticipation of a bowl of corn soup or the joy of sipping a beer with a side dish brings smiles to the veterans' faces, which gives us tremendous encouragement and the motivation to keep going.

There is never a perfect time to say goodbye to a loved one. There will always be feelings of sadness and reluctance. What matters most is how we accompany them through this journey—expressing gratitude, offering apologies, showing love, and bidding farewell. Walking this final path with residents and their families is the most precious part of our work. We are deeply grateful to every resident who has entrusted us with their last days at the Veterans Home. The Taipei Veterans General Hospital's home hospice care team will continue to strive to assist more people in need.

