



One More Step Forward for Palliative Care in Taiwan

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Written by **HFT secretariat**

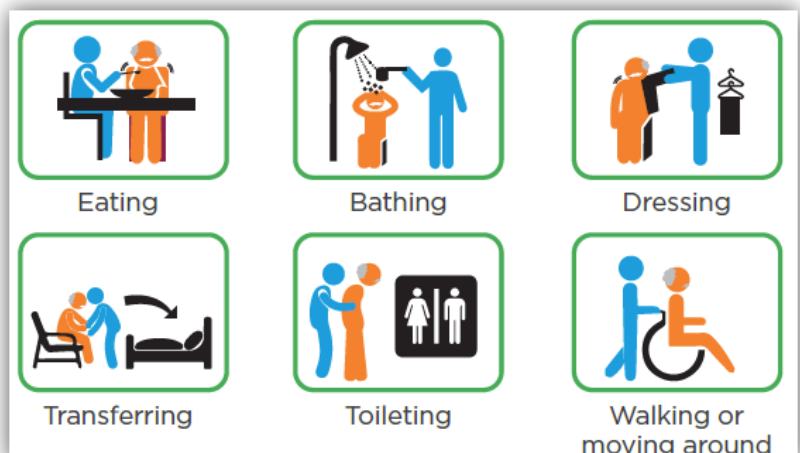
No matter if the patient is being cared at home or in a Long-term Care Facilities, the most important aspect is still the follow up.

Palliative care has been promoted in Taiwan for more than 20 years, and in those years, the idea and service of palliative care have received wide acceptance and recognition. And when it comes to clinical care, especially when a patient's acute symptoms are stabilized in the hospital's palliative wards, it is with increasing likelihood that the patient is transferred to the home environment or the elderly care facility. In such cases, the biggest concern for the patient and family is how to follow up on the situation.

Once the patient returns home, the palliative team can pay regular visits to provide palliative home care and ensure the patient receives continuous care. However, with the changing family structure and population, there is still a certain percentage of patients who cannot receive care at home, and thus, an elderly care facility becomes the common alternative for many. This also shows a new direction for community palliative care, that is, as it relates to bringing palliative care into Long-Term Care ("LTC") facilities. Therefore, we endeavor to provide quality palliative care access to patients and elderly who require palliative care in LTCs.

According to The Overview Statistics of Taiwan Elderly Long-term Care and Nursing Homes published in June 2016, there are a total of 1,081 LTC facilities with a capacity of 60,578 beds; currently, they are caring for 46,462 elders with an occupancy rate of 76.6%. Until June 2015, there were a total of 501 general nursing homes and veteran homes to provide 43,402 beds, and the occupancy rate was 85.4%.

Based on these statistics, we can estimate that there are currently more than 80,000 elderly residing in these facilities. With the trend of the general population growing





older, it is expected that this group of residency will continue to increase. Though these elderly are not necessarily terminally ill patients, but with inevitable aging and declining physical and mental functions, the palliative team should be involved at an early stage in order to effectively promote Advanced Care Planning. If the palliative team and LTC facilities can both build up a long-term partnership and start monitoring the physical and mental changes of the residents at early stages and interfere or refer proper resources and teams when needed, it would certainly benefit all parties.

However, actual clinical care is such that patients normally cannot receive proper care or have difficulties during the referral process to a new care facility. These are often due to the facilities' overloading and lacking of resources and actual experiences. How to assist these elderly care facilities to ease their loading and the access of proper resources is the most crucial issue when developing palliative care in LTC facilities.

Under the current circumstances, if the patients in these care facilities have professional palliative assistance, the staff would have a channel to professional counseling. With this shared care model, it also helps the care facility to build more trust into the relationship. As the nursing aides in the care facilities are often under great pressure, it is vital that the same amount of attention and resources are made readily available. By providing professional palliative care training and caring skills, it can effectively lower the stress and frustration that nursing aides face and increase their willingness to devote themselves into palliative care.

Looking at it from the other side, the elderly care facilities will encounter many challenges while trying to include palliative care into their services, for example, dealing with the public's acceptance of palliative care, devising the caring strategies, allocating resources, etc. Even the government and different policies will affect how far palliative care can reach within these facilities.

While palliative care is being promoted zealously into the community at homes and in elderly care facilities, the challenges that come along are often beyond expectations. Nevertheless, we hope with the participation of more professional teams and resources, we can push the development of palliative care in Taiwan one step forward, so that our beloved elderly can receive proper palliative care that provides for their bodies, minds, and souls.





The Ultimate Challenges while Promoting Palliative Care in Long-term Care Facilities

Written by **HFT secretariat**

Difficulties become obstacles that need to be overcome. The author would like to share her years of experiences of providing palliative care to the elderly who reside in care facilities and hope to see increased popularity of palliative care in these facilities.

Enabling the elderly who cannot stay home with the right of dying well is the primary reason for promoting palliative care in LTC facilities. Thanks to Hospice Foundation of Taiwan, I have the opportunity to share my experiences on promoting palliative care in elderly care facilities with many listeners. However, palliative care is still not popular in care facilities, and when we dig into the reasons, we can see that a lack of both resources and knowledge hinders its development.

Established in 1982, the Lauwulau Elderly Home I served at provided shelters for 15 dying destitute elderly. Every elderly was taken care of by nuns until each took his or her last breath. There was even one particular room that was used for post-mortem care. Compared to the current status of other care facilities, it was rather advanced. Now Lauwulau provides 79 beds and retains the spirit to assist these elderly to go on into their last journey in life by taking care of their needs and even funerals.

Caring for Dying Elderly Is a Heavy Burden

When providing EOL care, the elderly's senses and perceptions change, as do body circulation, breathing, urinary and bone systems. Such changes require comfort care like repositioning the elderly's bodies, massaging, drying bed sheets and clothes, and also cleaning their bodies and mouths, all of which require heavy man power. When the elderly eventually show difficulties of breathing that cause low oxygen levels in the blood stream, it indicates that the elderly are about to pass away. When



the family members are notified of the circumstances and request the staff to delay the dying process, staff can only apply high concentrations of oxygen into the patient. However, this often causes the elderly's breathing to become even more difficult, and staff are under enormous pressure to continuously check if the elderly are still breathing.

The best suggestion for this problem is for the elderly to die in the elderly care facilities with family members prepared and ready to accompany their loved ones at the end stage. This can both settle the elderly's spiritual and physical unease, and also effectively share the burdens and pressure of the staff.

Post-mortem Care Frightens Most Staff

Further, death still frightens many people, including staff. If death occurs during the daytime with more manpower available, including nurses, nursing aids, social workers and others, who are available to provide support and assistance, the pressure of facing death can be eliminated. However, if the elderly pass away during the nighttime with less manpower available, the staff may become fearful.

High Turnover Rate Poses a Challenge to Training Palliative Care Professionals

In advance, nurses must receive EOL care and pain management training, nursing aides must receive comfort care training, and social workers have to understand the meaning of Four Sayings of Life and how to guide the elderly to “say thanks, say sorry, say love and say good-bye”. Staff members in the care facilities can only receive these special palliative care skills once they have 1-2 years of experience serving the elderly. However, with the huge amount of workload and tiny sense of accomplishment, the turnover rate is always high except when staff members show strong initiative and actively devote themselves into palliative care; otherwise, it is very difficult to appoint

staff into such roles. Hence it is important for the senior staff members like administrators, supervisors, head nurses, and social workers to receive palliative care training and lead by example, and to enroll more junior level staff members to devote to palliative care.



Partner Hospitals Greatly Assist Home Care Nurses

The most important thing when promoting palliative care in elderly care facilities is to have a partner hospital to provide support. For example, physicians and home care nurses in the palliative team can visit the elderly regularly. Or when the elderly are at the end-of-life or are terminally ill, the staff in care facilities can consult palliative care nurses in the hospitals for proper care and advice. Or if the elderly require emergency hospitalization, the palliative team can also arrange for an available ward immediately to avoid the trouble of waiting for a bed in ER.

So far, eight non-cancer terminal diseases have already been included in the coverage of palliative care, and care facilities can also ask for palliative physicians to evaluate and apply for palliative coverage. However, for facilities in remote areas that may have difficulties to find a partner hospital, it is hard to find relevant support.

The environment provided for EOL elderly is very important, and it relates to the quality of palliative care as a whole. It is generally expected to be a quiet, soft lit, and independent space. Single rooms are preferred in order to meet the elderly's personal needs, like playing sacred music for Catholics and Christians or chanting for Buddhists, without distracting others. Thus, the elderly can be comforted spiritually while family members can feel safe to have private conversations with their loved ones. At the same time, this personal space can prevent other elderly roommates from witnessing and becoming fearful of the dying process.

Need for an Exclusive Area for Temporary Storage of the Deceased

Normally when an elderly passes away and there are other elderly residents in the same room, the elderly care facility should move the deceased body to a temporarily exclusive space immediately in order to wait for the family members, who can decide on important follow up matters, or for the funeral director to move the body.

In this exclusive space, religious music based on the deceased preference and any necessary religious rituals can be performed without concern of others' inconvenience. It is also a private space for the bereaved to express their feelings and bid farewell. Furthermore, it is also important to have this intermediate closed off area that allows more discretion when moving the deceased, so as not to disturb the emotions of other elderly residents. When Lau-wu-lau was built, the nuns had constructed a special room in the east wing for the deceased to be contained



temporarily and also an exclusive elevator for leaving the building without disturbing anyone. Thus, the deceased is quietly escorted to the ground floor and picked up by the emergency vehicle waiting by the elevator.

Difficulties with Performing Autopsies and Issuing Death Certificates

Many care facilities are reluctant to have the elderly pass away in the facilities. The reason for this is the trouble of issuing death certificates. Normally, if the elderly passes away due to diseases or declining health, a physician comes to perform an autopsy and issues a death certificate when the facility notifies the local health bureau. With complete medical records kept by the care facility, it is not difficult to issue a death certificate. However, the difficulty arrives when the day is on the weekend or a holiday and physicians cannot arrive in time to perform the autopsy. In which case, I suggest the facility to discuss with the local bureau to store the deceased in the funeral parlor and arrange an autopsy for the earliest working day; otherwise, it would be tremendously difficult to properly store the body.

Confirming DNR Orders to Avoid Lawsuits

What seems to frighten most facilities are the accusations from the family when the elderly passes away. The most common accusation tends to be negligence and not sending the elderly to the hospital in time. This often upsets and frustrates the staff. In order to avoid this situation, it is crucial to understand the will of the elderly and family members toward DNR. If the elderly or family members do not agree with DNR, then it is best for the elderly to pass away in the hospital. However, based on experience, even when the elderly or family members have signed DNR, it is still better to confirm again their willingness whether to allow the elderly to pass away in the facility when time actually comes.

Conclusion

There are still very few LTC facilities providing EOL care. Both what they believe and do and how the residents perceive them can affect the willingness of whether the elderly choose to pass away in the facility or in the hospital. At the end of life stage, the elderly need warmth, comfort, and companionship. If the institute can provide good EOL care environment and the family members can also be present, then it is the best scenario for both the living and the dying.





Building Diversified Long-term Palliative Resources

Written by **HFT secretariat**

The Hospice Foundation of Taiwan (“HFT”) started a series of palliative care in Long-term Care Facilities (LTCs) and has promoted it since 2014. This includes seminars throughout Taiwan and onsite visits to many LTCs to experience and understand firsthand the demands and difficulties. From the information collected, HFT has started the Long-term Care Palliative Workshop, hoping to provide professional educational courses to diverse professionals.

A Practical Workshop Combines Theory and Practice

The Ten-year Long-term Care Program 2.0 announced by the government clearly states the desire to “provide supporting services in communities to further the transition to palliative home care.” Hence, it is essential for LTC staff to equip professionals with palliative knowledge and skill. During the eight-hour course, it emphasizes what palliative care and Advance Care Planning are. The lecturers come from various palliative and long-term care backgrounds to share their professional knowledge and years of practical experiences, which appeal to the participants about the importance of palliative care in the LTC setting. Palliative care is an important trend, and thus, all LTCs and staff should start evaluating how they can also participate and provide the service within LTC.

The course design is based on different professional demands. For administrative managers, the course provides instructions to promote the concept of dying well and to take the initiative. For social workers, the course enhances their skills to better care and communicate with clients. For nursing staff, the course equips them with the necessary knowledge and skills to perform palliative services in the facilities; it also assists the nursing aides to build up their own awareness that they are also palliative care providers.

Each lecture is lead by professionals from that specific field, as they teach participants how to provide or promote palliative care in the facilities. With similar backgrounds, these participants are able to interact with each other on a more personal level and speak the same language.

Satisfaction rates 90% with the Course Design and Content

Part two of the course moves on to emphasize case studies. The participants gather actual caring experience when promoting palliative care in LTCs, including in care related to cancer, dementia, and chronic diseases. Participants are then divided into groups for discussion. Through the discussion topics related to the case background, physical and mental status and medical status, participants further share when they believe is the proper timing to receive palliative care and make medical decisions. Further, they share about how to accompany the case client at EOL, and how to offer spiritual guidance when needed under the three different premises as related to cancer, advanced dementia, and chronic diseases.

The two workshops had a total of 114 participants from 61 different facilities. The follow-up survey shows that more than 90% of the participants are “very satisfied” with the course content and lecturers. The case study design especially helps the participants to link what they have learned in their minds to what they feel in their hearts as an effective, experiential learning. Further feedback from participants indicate their desire to include ethical and law issues for terminally ill patients, grief and bereavement, spiritual care, and coping with unexpected death.

One thing worth mentioning is that palliative teams from local hospitals also attended the workshops and explained their available resources to LTCs. HFT has discovered that these workshops not only provides education, but also provides a link between local hospitals and facilities. LTCs can also gain more confidence once they understand that they are supported by hospital resources and further take the initiative to promote palliative care in LTC settings.

On-the-job Training and On-site Visits Proposed

Holding this practical workshop is merely one of HFT’s responses to the facilities’ needs. Clinical Bedside Teaching is the actual resolution HFT has proposed to fulfill LTCs’ demand. Professionals shall be invited to LTCs to provide face-to-face bedside teaching, so that LTC staff can learn palliative care skills directly from the professionals, and therefore, intensify the learning motives. Pingtung’s

Hsiao-ai Jen-ai Charity Home, Pingtung’s Genesis Social Welfare Foundation, and Taipei City’s Hao-ran Senior Citizens Home have all made this request and provided very positive feedback.

In addition, HFT has 86 contracted hospitals all over Taiwan, some of which have already set up cooperative palliative care agreements with LTCs. In the future, HFT will endeavor for more opportunities related to palliative on-the-job training and on-site hospice visits, so as to enhance the ability and confidence of the palliative professionals.

In response to the changes of medical surroundings and government policies like Long-term Care 2.0, aging in place, and home medical care, HFT's future plan will not be limited to LTCs only because many LTC professionals are not stationed at one facility only, but also actively take part in home care and community care. Thus, HFT has set its long-term vision on building up the patient-centered community palliative care network. In the meantime, HFT shall continue to enrich and diversify the available palliative resources so that palliative care in LTC settings shall grow in both quantity and quality.

