



Hospice  
Foundation of  
Taiwan

# HFT Newsletter

Forever Love, Endless Care

November 2018

## 2018 International Conference on Palliative Care in Long-Term Care Settings – Integration of Palliative and Long-Term Care

Along with the increasing awareness of patient autonomy, the desire for dying well in the place of choice and dying in the place one calls home is also on the rise. The elderly desire not only to live long, but more importantly to live well, and to die well. Hence, it is imperative to fortify palliative care capabilities and resources to provide people with easy access regardless of where they are, be it a community care unit, long-term care facility or hospital. This would ensure that quality care is available to the elderly where they reside and improve the quality of death. It serves as an important basis allowing for the elderly to enjoy the last days of their lives in a familiar setting where they call home.

Motivated to explore ways to meet this increasing demand, the Hospice Foundation of Taiwan held an international conference on World Hospice Day, 13th October 2018. A total of 546 participants joined the event and a number of international and local scholars and experts from both the public and private sectors with expertise in long-term care, education and clinical work were invited to share their knowledge on these topics.

*Prof. David Currow: The Integration of  
palliative Care with Other Health Services*

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*Prof. Chia-Chin Lin: Care and Die in Place of  
Choice-Improving Palliative Care within Long-Term  
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# Conference Program at a Glance

**Date: 2018/10/13    Location: HNBK International Convention Center**

## Policy Navigation

Topic	Speaker
The Integration of Long-term Care, Home Care and Palliative Care in Taiwan	<ul style="list-style-type: none"><li>• Dr. Jui-Yuen Hsueh, Administrative Deputy Minister, Ministry of Health and Welfare</li></ul>
The Integration of Palliative Care with Other Health Services	<ul style="list-style-type: none"><li>• Prof. David Currow from University of Technology Sydney</li></ul>
Care & Die in Place of Choice – Improving Palliative Care within Long-Term Care (LTC) Facilities	<ul style="list-style-type: none"><li>• Prof. Chia-Chin Lin from University of Hong Kong</li></ul>

## Current Worldwide Trends (JKT Research Project)

Topic	Speaker
The Current Situation of Japan's Palliative Care in Long-term Care and Home Care Setting	<ul style="list-style-type: none"><li>• Assist. Prof. Jun Hamano from University of Tsukuba</li></ul>
The Current Status of Korea's Palliative Care in Long-term Care	<ul style="list-style-type: none"><li>• Dr. Jeanno Park from Bobath Hospital</li></ul>
Community Hospice Care – A Significant Puzzle of Long-term Care	<ul style="list-style-type: none"><li>• Prof. Hui-Zi Chen from Fu Jen Catholic University</li></ul>

## Practical Challenges

Topic	Speaker
Obstacles Facing Long-term Care Facilities in Providing Services to Ensure a Good Death for its Residents	<ul style="list-style-type: none"><li>• Dr. Ming-Hwai Lin from Taipei Veterans General Hospital</li></ul>
A Discussion on the Care of Long-term Care Facility Residents that Meet the Five Specific Clinical Conditions under the Patient Right to Autonomy Act	<ul style="list-style-type: none"><li>• Dr. Sheau-Feng Hwang from Taichung Veterans General Hospital</li><li>• Dr. Ming-Hwai Lin from Taipei Veterans General Hospital</li><li>• Dr. Wen-Jung Sun from Taipei City Hospital</li><li>• Dr. Yih-Chyang Weng from MOHW Nantou Hospital</li><li>• Representative from Taipei City Hang-An Seniors' Home Multiple Long-Term Care Services</li><li>• Representative from Suang-Lien Elderly Center</li><li>• Representative from St. Joseph Home for Alzheimer's Disease and Related Dementia</li></ul>



More conference-related articles to come in the next HFT newsletter

# The Integration of Palliative Care with Other Health Services

Written by the **HFT Secretariat**

*Based on the content of Prof. David Currow's presentation in the 2018 International Conference on Palliative Care in Long-Term Care Settings - Integration of Palliative and Long-Term Care*

*Prof. David Currow currently holds positions as the Professor of Palliative Medicine at the University of Technology Sydney, the Matthew Flinders Distinguished Professor of Palliative and Supportive Care at Flinders University, and the Associate Director (Research) at the Wolfson Palliative Care Research Centre at the University of Hull in England.*

The main focus of Prof. Currow's talk is to demonstrate how palliative care is essential across all categories and why initiative should be taken to integrate palliative care with other health services. He divides his talk into three parts: First, the need to hear from patients; to understand what they have to tell us about care at the end-of-life. Secondly, how we can provide needs-based palliative care, and finally he suggest ways to integrate palliative care with other health services.

At the beginning of his talk, Dr. Currow shares his reflections from his recent trip to Paris, where he visited Hôtel Dieu, the oldest hospital in Paris on the banks of the Seine. Dr. Currow says that this was the hospital that changed clinical practice when a group of doctors had stressed that health should no longer be a privilege, but something to be enjoyed by everyone.

Further, Prof. Currow points out that the life expectancy



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rate has steadily increased since 1870. In high income countries like Taiwan, Australia, Japan, and Korea, there has been a steady increase of three months added to the life expectancy rate every year over the last 160 years. This drastic change needs to be put into consideration as we consider how to integrate palliative care with other health services, and how we should meet this population in their needs. Professor Currow suggests that we do this by starting to listen to the patients' needs and elaborates on why palliative care should be integrated with other health services.

## **What do Patients Value at the End of Life?**

First, what do people value at the end of life? By conducting a survey that interviewed terminally-ill patients, the needs that came on top are controlling pain and symptoms, avoiding prolongation of the dying process, and relieving burdens. These needs can be viewed as the ability for one to carry out one's personal and financial affairs as one would want.

Personal care also includes a broader concept of self-independence. Though symptom control is the most frequently-discussed issue, being independent as long as possible is also on top of the list when patients are asked what they want. The fear of being a burden to other people and of losing one's independence and dignity are the most common worries. Optimizing one's function and physical comfort is considered the ultimate goal for most patients.

Professor Currow further demonstrates his point of view via the Australia-modified Karnofsky Performance Scale (AKPS), that is, if patients' function and AKPS can be maintained above 70 for longer periods of time, they will have sufficient ability to live longer independently. By simply maintaining patients' function, the shape of death is changed without changing the date of death.

## **Needs-Based Palliative Care**

Second, Prof. Currow aims to answer what needs-based palliative care looks like for both patients and caregivers. He stresses the universal demand for palliative care across different diagnosis categories and mentions that patients with lung cancer and COPD often suffer from breathlessness at the end-of-life stage. For multi-morbidity and frailty patients, the decreased self-care functioning is also evident. The predominant symptom control concerns and loss of function concerns both lead to the same issue of one losing one's physical function, and thus, imply that better physical symptom control allows patients to live with dignity and function normally without being a burden to others.

A survey consisting of 27,000 interviews focused on caregivers' needs indicates that regardless of the disease diagnosed, caregivers are in need of physical care, information, and emotional and spiritual support. When caregivers who recently experienced the death of a patient are asked if they would offer care again, 7.4% caregivers responded they would not provide care again, and 16.5% remained undecided.

If people are not willing to take on this role again, the lack of caregivers will no longer be a problem affecting just a small group of people, but will become a widespread problem. How caregivers can be cared for is now a challenge that lies ahead. By facing this challenge, we must reflect on whether society is paying enough respect to these caregivers rather than taking them for granted.

### **How Palliative Care can be Integrated with Other Health Services**

Last but not least, how do we find ways to integrate palliative care with other health services? Prof. Currow suggests that we can approach this through primary care, other sub-specialist services, and all health care providers regardless of health system structures.

For primary care, when palliative care is introduced in time, a 23 minutes case conference with GP and health providers to address the immediate issues and future contingencies will greatly improve the mutual communication on what the patients' core values are, and what can be done to help patients achieve them. Topics could be about what three major things may happen in the coming week or month, and what can be done in anticipation. Having a direct and candid conversation can increase patients' self-care function, and enable them to cope with expected symptoms.

When the Karnofsky performance score was used to serve as an effectiveness measure for case conferences, the Karnofsky scores for patients receiving case conferences are on average 57.3 higher than patients who only receive routine care, scoring at 51.7. Hospitalization is also reduced to 1.26 when compared to those receiving routine care, at 1.7. Hospitalization is also reduced to 1.26 when compared to those receiving routine care, at 1.7.

For sub-specialist services like end-stage renal diseases patients who need dialysis treatment, palliative care teams can also intervene to achieve an optimum result of symptom management with renal professionals. It is a difficult decision whether to undergo dialysis treatment or not, but if both quantity and quality of life are considered, the answer becomes clearer.

For all health providers regardless of what their health systems are--whether special services, family physicians, community nurses or allied health practitioners--a single

needs-assessment tool for palliative care is needed. For example, the Needs Assessment Tool: Progressive Disease (NAT:PD) can be introduced as a medium to identify patients with high levels of needs that might require referrals for full assessment by specialist services. This tool can assist caregivers to identify if the patients' needs are beyond caregivers' capabilities and also serve as a base evaluation for the specialist services that are necessary.

When we think about how to integrate palliative care into long-term care setting, we are actually putting all the expectations on caregivers. Therefore, how caregivers can receive a better support on EOL care knowledge and skill is another issue to look into.

## The Privilege of Being a Palliative Professional

Prof. Currow concludes his speech with a quote from Oliver Sacks:

*I cannot pretend I am without fear. But my predominant feeling is one of gratitude. I have loved and been loved; I have been given much and I have given much something in return; I have read and travelled and thought and written. I have had an intercourse with the world, the special intercourse of writers and readers.*

*Above all, I have been a sentient being, a thinking animal, on this beautiful planet, and that in itself has been an enormous privilege and adventure.*

— Oliver Sacks, *Gratitude*

Prof. Currow urges us to remember that palliative care is about individuals facing their mortality. Palliative professionals and allied health practitioners like us, who are all sentient beings, have this enormous privilege to reach out to others and participate in their adventures of life. We are making a difference with our daily work, but let's try to make these differences greater in the years ahead by not becoming complacent.

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Integration of Palliative and  
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# Care and Die in Place of Choice-Improving Palliative Care within Long-Term Care Facilities

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*Written by the **HFT Secretariat***

*Based on the content of Prof. Chia-Chin Lin presentation in the 2018 International Conference on Palliative Care in Long-Term Care Settings - Integration of Palliative and Long-Term Care*

*Professor Chia-Chin Lin is currently the Professor of Alice Ho Miu Ling Nethersole Charity Foundation in Nursing, and Head at HKU School of Nursing. Prior to joining HKU, Professor Lin served as Dean at the College of Nursing in Taipei Medical University*

*between 2011 and 2017. She is a Fellow of the American Academy of Nursing; and received her Bachelor of Science in Nursing from Taipei Medical University, her Master of Science and Doctor of Philosophy from the University of Wisconsin-Madison School of Nursing and Educational Psychology. She has also obtained an EMBA from National Taiwan University.*

Prof. Lin is originally from Taiwan and now serves in Hong Kong University, where she opens her speech by indicating how thrilled she is of Taiwan's progressive palliative care. First she presents the global picture of how people die, then focuses on the current status of Taiwan, and finally, explains Hong Kong's elderly situation compared to Taiwan's.

She reports that the world population is aging rapidly with decreased birthrates, and this has changed the family structure drastically. For example, Taiwan's life expectancy is now 79.8 years old, and the disability rate for people above 65 is 12.7-16.3%, which implies one in every six elderly is disabled and requires care. Additionally, the number of family members per Taiwanese household now is 2.77 persons; we can interpret from this number to be two adults and less than one child. Prof. Lin adds that it is foreseeable this will be the last generation to take care of its parents and the first generation to be abandoned by its children.

## **Choosing Where to Die**

In an international study comparing the percentage of deaths occurring in hospitals and residential aged care settings in 45 populations around the world, whether people die in hospitals, LTC facilities, in their own homes, or elsewhere, varies across different cultures. However, when the results are restricted to people over 65, the number of people who die in hospitals grows significantly.

Dying at home is often viewed as the ideal scenario, but Prof. Lin said this might not be the case due to where the interviewees take place. That is, most participants choose their current locations as their preferred place to die, but as the question is asked closer to their death, the percentage of participants who choose to die in hospitals rise significantly. According to a study done by Eng-Kiong Yeoh

In Hong Kong, due to the government's regulations on how it issues the death certificate, people often choose to die in hospitals and check-in 24 hours prior to avoid prolongation of body storage and official autopsy procedures.

For people to choose nursing homes, it is important to ensure nursing homes adequately provides for people's needs. According to N. Greenwood's research in 2017, dying elderlies in nursing homes often experience physical discomfort associated with the dying process, negative psychosocial experiences, unmet support with spiritual needs, inadequate care received and unsupportive physical environment.

## **Palliative Care Policies in the EU and the US**

In the European Union, in order to integrate palliative care with long-term care facilities across Europe, a protocol of a cluster randomized controlled trial of the "PACE Steps to Success" is used. The goals are to evaluate the effectiveness and cost-effectiveness of the "PACE Steps to Success" palliative care intervention for older people in long-term care facilities, to assess the implementation process, and to identify facilitators and barriers for implementation in different countries. PACE adopts train-the-trainer methodology to train the core facilitators and support them to implement it in various countries.

In the United States, there are three models of nursing homes: partnership with hospice services, partnership with external palliative care teams (or medical palliative professionals), and facility-based professional teams. 27% of nursing homes in the United States have special programs or specially trained staff to provide hospice and palliative care.

## **Hong Kong: CGAT team and DIN Project**

In Hong Kong, the Hong Kong Hospital Authority (HA) has published a Strategic Plan for



Palliative Care in 2017 to set goals of expanding palliative home care and enhancing palliative care support to elderly residents in Residential Care Home for the Elderly (RCHE). There were 93,600 elderly who lived in RCHEs in 2016 and most had chronic diseases. 10% of these elderly pass away in hospitals yearly with average stays of 28 days and 3 submissions into hospitals six months before their deaths. Providing good quality end-of-life care is recognized by the Hong Kong government as vital to RCHEs.

There are currently two programs that aim to enhance RCHEs' ability in providing quality palliative care. They are the Community Geriatric Assessment Team (CGAT) outreach service led by HK Hospital Authority and Dying In Nursing Home (DIN) led by Haven of Hope.

The CGAT team has provided EOL care for RCHEs in the eastern cluster of Hong Kong since January 2014, and became stronger by collaborating with palliative teams in October 2015. As of August 2018, 58% of RCHEs have joined CGAT services and received training. There were 151 patients who participated and received 4.6 months of services before death. They averaged 90 years old and 95% were wheelchair bound or bedridden. 82% of ACP was signed in at RCHEs and their ACP intentions were 100% performed in Emergency department without resuscitation.

The DIN service is a program led by Haven of Hope. It aims to offer an option for residents to choose if they wish to die in the nursing homes so as to be taken care of by familiar staff in familiar surroundings. This program has divided its operation into three key stages: preparation, long-term care during imminent death, and support after the resident passes away. Since 2000, the DIN service has served 111 residents to die in the nursing homes. When comparing medical costs, DIN residents who died in RCHEs totaled HK\$299,867 and non-DIN residents in RCHEs totaled HK\$384,565. It is clear that the DIN service reduced hospital admissions, hospital stays, and cost of EOL care. Assuming the DIN service model is adopted in all RCHEs, a potential cost of HK\$347,184,320 can be saved by the government a year before death.



## TAIWAN's Next Move – Reducing Disease Disparity

In a survey conducted by Prof. Lin targeting six veteran homes, 89% of residents who participated did not wish to prolong their life, but only 12% of the residents made ADs. When asked the reason why they did not have ADs, residents responded that they were unaware of it, and did not know how or where to proceed. Thus, it seems residents' willingness toward AD has no association with staff's knowledge and attitude. In fact, up to 60% of residents would sign ADs after hearing more about them.

Taiwan's palliative care includes patients with cancer, dementia, and many other illnesses. Based on statistics collected during 2000-2013 on Taiwan's palliative care trend for patients with dementia, there is increased usage of palliative care for both dementia and cancer patients in the last six months of life. However, dementia patients still receive more cardiopulmonary resuscitation, invasive mechanical ventilation, and tube feeding than cancer patients. This survey shows that there is still much room for improvement and in reducing disparity.

## Developing a Sustainable System for Growing Palliative Demands

Considering future development, Prof. Lin lists five major issues including: (1) Financial Sustainability - increasing tax for alcohol, tobacco and sugary drinks to increase government funding has been adopted by many; (2) Human Resources and Education - increasing manpower with proper staff training is a prerequisite for implementation of long-term care policy; (3) Caregiver Support - providing caregivers with ACP/ EOL knowledge, practical skills, and psychosocial support; (4) Environmental Design - major environmental factors can reduce total suffering by providing privacy, social interaction, positive distraction, and personalized environment; and (5) LTC Policy and Quality of Care - encouraging partnership between medical-social professionals, and LTC facilities with palliative care services, building resources platform and the continuing support of NHI reimbursement policy.

### Integration of Palliative and Long-Term Care

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These above issues implicate the need to increase the availability of palliative care services in LTC facilities; to advocate for more resources to support services for quality of EOL care in places like LTC facilities; to support living and dying well with choices available; and to initiate ACP discussion as well as to conduct more research in such services to evaluate effectiveness.

Finally, Prof. Lin congratulates Taiwan on its number six ranking in the 2015 Quality of Death report. Regardless of whether the participants feel Taiwan deserved this high accreditation or not, there is still much to do to make palliative care in Taiwan more accessible in all kinds of settings, especially in LTC facilities with enormous demand.



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