



Hospice  
Foundation of  
Taiwan

# HFT Newsletter

Forever Love, Endless Care

January 2018



## *A summary of 2017 World Hospice & Palliative Care day*

PRODUCTION

*Palliative Care day*

Universal  
Health  
Coverage and  
Palliative Care



ROLL 1

2017 Hospice  
Film Festival -  
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Director  
Nien-jen WU's  
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DIRECTOR *Hospice Foundation of Taiwan*



# Universal Health Coverage and Palliative Care: Do not leave those suffering behind

Written by **HFT secretariat**



Since 2005, the World Hospice Palliative Care Alliance (WHPCA) has announced the second Saturday of October to be the World Hospice and Palliative Care Day; which has become the most heart-warming festival in October. On this day (Oct. 14 for 2017), no matter in what area, form or scale, all events echoed hospice purposes and delivered the importance of dying well and End-of-Life care (“EOL care”).

Each year, WHPCA announces a new theme, so as to build up a common goal in developing palliative care and evaluate the current status. By calling more social attention to focus on the rights of terminally-ill patients, these themes are not only slogans, but a call with a heavy heart. This year’s theme – “Universal Health Coverage and Palliative Care: Do not leave those suffering behind” – reaffirms each life has its own dignity and value, and every government should improve the prevalence and accessibility of palliative care in order to avoid the unnecessary suffering due to futile medical care.

## Statistics Reveal the Insufficient Palliative Prevalence

According to WHPCA’s research on the world’s current palliative care status, there are 40 million people who require palliative care each year, and half are at the end of the life stage. However, there are still 42% of the world’s countries and regions that still do not provide any form of palliative care; and only 20 countries have included palliative care under their National Healthcare Insurance (“NHI”) coverage and allow patients to receive palliative care with no economic barriers. This research also shows there are only 14% of



the terminally-ill, who have received palliative care before dying. As for the world's total death population, merely 14% have received palliative care before dying. The current resource and developing progress of palliative care no doubt has a long way to go.



## **Palliative Care - an Inseparable Link when Promoting Citizen Health**

In 2015, 193 UN member states adopted the new sustainable development goals (SDGs), one of which is to achieve Universal Health Coverage (UHC) by 2023. UHC covers disease prevention, cure, rehabilitation, and palliative care. It emphasizes every individual's right to receive quality care, medical treatment and EOL care no matter where they are from or what their economic statuses are. High quality and easily accessible palliative care is the most important EOL care and should be an inseparable part of government health programs.

## **Government Should Stand against Futile Medical Care**

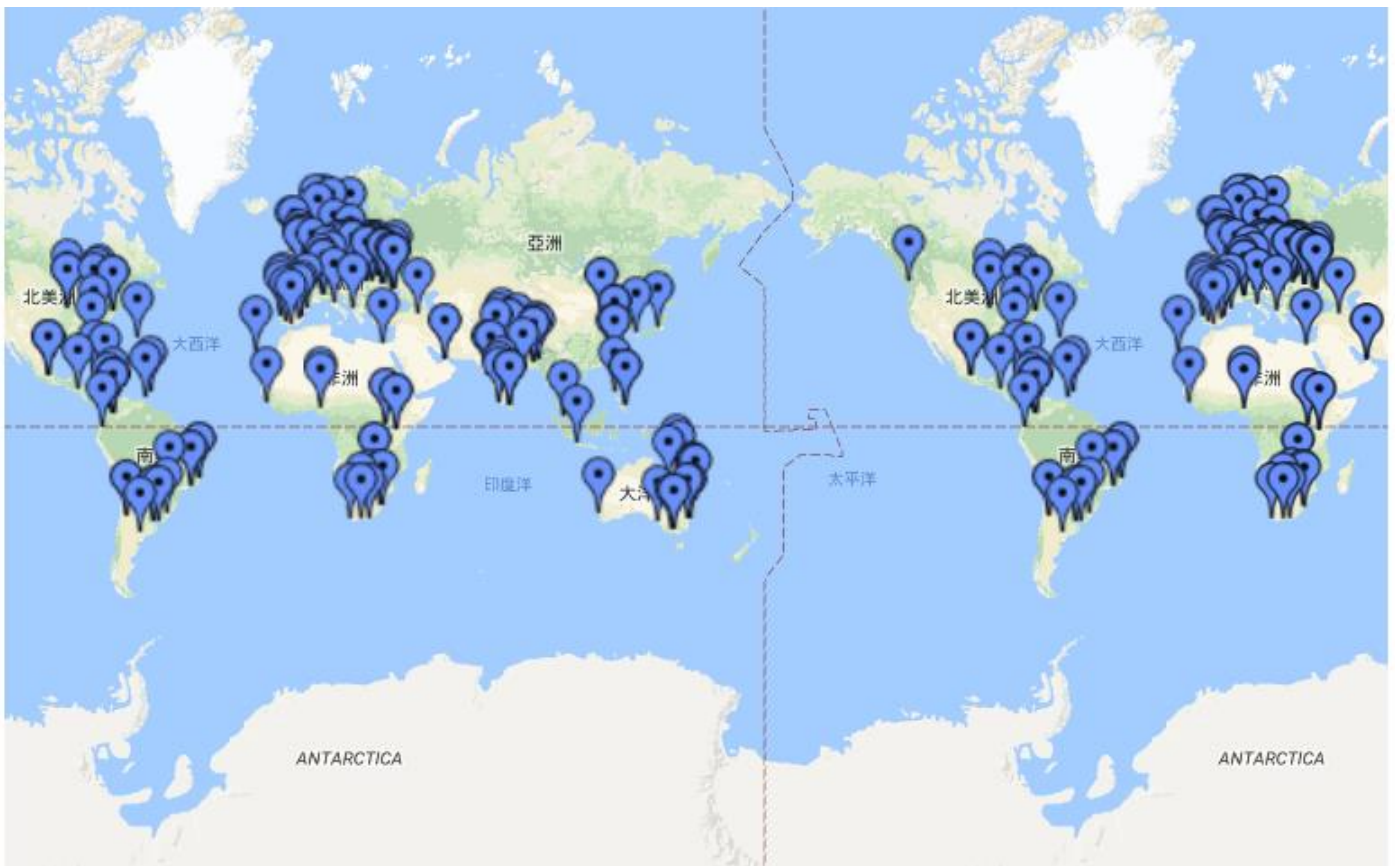
The government has recognized the heavy economic burdens put on families that have a member with a serious chronic illness or is terminally ill. The cost of futile medical care at the end stage often drags down the whole family, and can even cause the collapse of the NHI system. WHPCA reiterates that a well-established medical policy should be able to offer fair protection to all citizens' rights, and palliative care can effectively reduce the cost of futile medical care by reallocating the limited resources and offering the poor with sufficient medical care. This can ensure that no one will face economic crisis due to medical needs, and also fit UHC's long term goal.

## **WHPCA Calls Governments to Action**

Hence, WHPCA chose this year to appeal to leaders and governments to stand up and take action! The medical system in each country has its purposeful duty to protect and ensure its citizens do not suffer unnecessarily the burdens due to illness and financial stress.

## Global Responses!

More than 80 countries around the world have responded to the World Hospice and Palliative Care Day (“Hospice Day”), each in its own scale and style to celebrate this day and be a voice for the rights of terminally-ill patients.



Below are some of the celebrations from around the world in 2017:



### Egypt

Non-profit palliative organization Josaab Foundation showed a documentary of how psychological therapists guide terminally-ill patients to confront disease and death, and provided for a spirited dialog. There were also patients, who shared their true stories and advocated palliative care.



### Czech Republic

St. Stephen’s Hospice opened its gate for the public to have a walk-in and learn more about what a hospice institution stands for and offers. Pianist Gaston Etchegoyen was also invited for a charity concert.





## Australia

The Hummingbird Hospice had an open house on Hospice Day. This hospice stressed the importance that terminally-ill children should still enjoy their childhood while fighting against their diseases; at the same time, their families can find support by connecting with each other. As part of the celebration, there was a jumping castle and also a facial painting stall for entertainment.



## South Africa

St. Francis' Hospice hosted a Super-Business-Hero-Friday and invited people to purchase 100 Superhero Lollipops and superhero outfits to gather donations and show support. By doing so, it hoped to send a message that everyone can be a palliative care super hero.



## China

The 2017 China Universal Health Coverage and Palliative Care-Palliative Care International Summit Forum & Art Auction was held by Beijing's LWPA (Living Well Promotion Association) & China PLA General Hospital. This was the second event held by China in response to Hospice Day.



## Ukraine

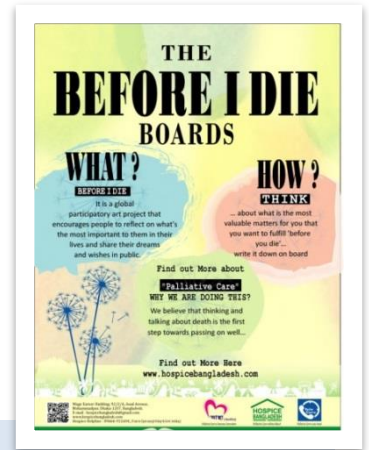
ICPCN encouraged individuals or organizations to promote hashtag #HatsOn4CPC to draw the public's attention to the insufficient resources and uneven distribution of palliative care resources .





## Bangladesh

Hospice Bangladesh hosted an event Before I Die between Sept 14 and Oct 14 to encourage people to overcome the taboo of death and start to talk about it.



## Canada

New West Hospice Society and Camp Kerry Community Choir co-hosted a River Walk for Hospice under the compassionate city banner. Local nurses and doctors set up to educate the community about difficult conversations, advance care planning, hospice at home, and the palliative approach.



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# 2017 Hospice Film Festival - "ACTION!"



Written by **HFT secretariat**

In recent years, the concepts of human right to health and dying well have emerged in mainstream consciousness. All kinds of works from small budget micro-documentaries to tera project blockbusters have chosen medical right, life care or death as their main themes. Through the outstanding screenplays and performances, the audience experiences the agony of saying goodbye to their loved ones and also inspire them to start thinking about the value and meaning of life.



Hospice Foundation of Taiwan ("HFT") has also released videos in multi-languages and forms to promote palliative care, for example, Smiling Face and Forever Love, Endless Care have been shown in the classroom as part of continuing education for professionals. These videos have also been shown at schools, LTC facilities, government agencies, and community colleges.

## **Oct 14 Huashan 1914 - Creative Park**

Having learned of the influential impact of visual communication, we chose October 14 as the day to hold a film festival for celebrating the World Hospice and Palliative Care Day. With the emotional storytelling, audiences had a vivid experience as if they were in the protagonist's shoes and started thinking "What if" questions in their own minds regarding end of life.

After this decision to celebrate World Hospice and Palliative Care Day was made, the board members and counsels of HFT formed a working group and started the selection of the film as they considered the values to be delivered, shooting techniques and screenplay to choose the films that would best represent our beliefs. These heroes behind the curtain were senior welfare film director Nien-tzu WANG, senior media personnel Shu-chuan LEE, former PTS Program Manager/ Assistant Prof. of NCCU Radio and Television Dept., Yae-wei WANG, and Hong Kong University, Head of Nursing School, Chia-chin Lin.



## Post-Screening Discussion Led by Experts

After many discussions regarding film dealerships, broadcast rights, subtitles, manufactured year and box offices, the group finally decided to film Oscar and the Lady in Pink, The Fault in Our Stars, and In His Chart. These three films represented the values of life from three different countries, relationships, and presentation. Through the Post-Screening Discussion, we encouraged audiences to share their life stories with us and hear the experts explain more deeply into the film and their experiences. In order to do so, we invited directors, doctors, and patients to share what they felt and thought through the film screening to share with the audience.

### “Oscar and the Lady in Pink”



When life starts counting down to the last twelve days, what should one do? What should a person do to fulfill one's remaining days with meaning and quality? Oscar and the Lady in Pink sought to answer such a dilemma as it kicked off the day as the first feature film. In the post-screening discussion, we invited pediatric oncologist Dr. Meng-yao LU from National Taiwan University Hospital and Mrs. HUNG (whose own child had been diagnosed with Neuroblastoma at age two and who experienced many aggressive treatments, including once when seriously infected by Mycoplasmas) to share their stories with the audience

from different perspectives. Palliative care is not just for end stage; if it can be introduced to patients earlier, then both patients and families will greatly benefit.





## “The Fault in Our Stars”



The second film talks about how teenagers deal with the shift when their young lives are suddenly brought to the fact of fetal illnesses. For the post-screening discussion, we invited HFT’s chairman Prof. Yuh-cheng YANG, who is known for delivering countless newborns into the world. While he was at the height of his career as the superintendent of Mackay Memorial Hospital a few years ago, he was diagnosed with Lymphoma. His disease had become critical twice, and this

physician-turned-patient experience has turned his seemingly perfect life to fall to rock bottom. Having climbed out of this valley of the shadow of death, Prof. Yang empathized and related even more with his patients than ever before.



## “In His Chart”



“Being sick is a state of extreme loneliness,” as quoted from famous director I-Chen KO. KO was diagnosed with colorectal cancer a decade ago, and has since shifted his focus from filming to social movement. He is often seen at events related to anti-nuclear power movement, sunflower student movement, hug-the-tree movement, and etc. In his passionate involvement in societal issues, KO was no stranger to the Patient’s Self-Determination Act and he also affirmed that he has communicated his medical choice with his family and prearranged for his funeral.

The current Superintendent of Taipei City Hospital, Sheng-Jean HUANG, has led his medical team out of the ivory tower and goes deep into the rural district to practice palliative care at home. This practice reminded all of the nostalgic house call, and brings back the warmth of the doctor-patient relationship.



When a socialist enthusiast meets an ivory tower revolutionist, the sparkle it brings is much expected.

## Nien-jen WU, the Story-teller of Palliative Care

The highlight of the day was the narrative speech delivered by the well-known director Nien-jen WU, who is also the spokesman of HFT. He spoke about his personal experience of a recent accident that made him re-think death. Last year, WU worked with his son and adapted the 1990 Pulitzer Winner W;t as After You Turn Away. In the same year, he encountered the deaths of many friends, which helped him to transform the accumulated feelings and thoughts of loss into words and drama.

## Charity Book Fair: Support Palliative Care

Besides films, the publishers' market has also shown a good variety of palliative and hospice care topics in many sorts of expressions, be it written by local palliative professionals or foreign. Considering this trend, HFT has invited many publishers to host a charity book fair. The general public will be able to see palliative care, bereavement and grief related topics and purchase books at a discounted price while supporting HFT ideals.

Though this year's Hospice Film Festival and Book Fair were held on a small scale, they were carefully designed and planned by HFT in hopes to ignite as much tinder as possible and spread the awareness of palliative care and patients' autonomy rights. HFT continues to believe that one day the concept of dying well will be fulfilled in every person's life.



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# Director Nien-jen WU's Narrative in Palliative Care

Written by **Dong LOU**, translated by **HFT Secretariat**

Whether a coincidence or fate, when WU promised to join HFT's cause and advocate palliative care, he accidentally fell on his bathroom floor and experienced bleeding in his skull. His condition was critical, but he quickly recovered. Soon after his recovery, he worked with his son to present the play *After You Turn Away*, which was adapted from *W;t*, a story about a professor who becomes distant with his physician as the professor eventually dies of cancer. In addition, WU has also suffered a great deal of loss this year, as his friends Liang-jen LI died of diseases, and Reverend George Martinson S.J. and Po-lin CHI's died suddenly in a plane crash.

## Learn from the Impermanence of Life

This series of events helped WU view life in a different perspective and understand more about palliative care. For this year's Hospice Day, he decided to go to the crowd and share about how we should leave this world.

Wu said many people avoid talking about death, which is a mistake because it is only when people are open-minded and gracious to death that they learn to respect life. Thus, learning to accept death is key to leaving this world peacefully.

The experience of slipping on the bathroom floor brought him to the brink of death, which helped him ponder the issue of death more deeply. While growing up in a small mining village where everyone knew everyone else, WU witnessed many neighbors whom



DIRECTOR  
NIEN-JEN WU

DIRECTOR  
DING-QIAN WU



he had greeted in the morning, but only to find them dead in the mines later that same day. With the main source of income for the family ceased, the bereaved families were left with both sadness and debt, and the children were forced to drop out of school in order to find work and support the family. Many moved out of the village to find work. As many of his childhood playmates vanished, WU understood the issues of separation and life and death at a very young age. He learned that being scared of death cannot stop death from coming, and that the only thing to do is to seize every opportunity to live a full life without any regrets.

## **A Zealous Spokesman for Patients' Self-Determination Act**

Under the introduction of HFT board members Ching-ho HSU and Nien-tzu WANG, WU became familiar with HFT's missions and tasks, knowing that HFT is not only about promoting life and death education, but also actively taking part in related legislative affairs and advocating ACP and Patients' Self-Determination Act. He shared HFT's vision and goal that everyone should live naturally, peacefully and with dignity until their last moment, and agreed to shoot a charity advertisement and talk about palliative care as HFT's spokesman. Through these activities, he hoped to promote the social education of palliative care and Patients' Self-Determination Act.

WU said people need to respect life as a natural journey. For example, for the terminally-ill patients, their lives should not be ended prematurely, but every effort should be made to alleviate their pain and enable them to live their last days in grace and peace, including to resolve relational issues. Imagine how wonderful this would be as the family walks through the mourning and grief, and later starts a new life. Isn't this the purpose of palliative care?

WU could still remember his late mother, who had colorectal cancer metastasis in her bones. Bones are supposed to be the strongest part of our body, but his mother's bones were extremely fragile and delicate. WU was afraid once her situation went critical and required CPR, her breastbones would fracture. He couldn't bear to see his mother suffer and asked for DNR. He understood that signing DNR to waive away the emergency aids did not equal sitting still and waiting for death to come.



Although palliative care has now become popular among the general public, there are still dark corners that are not yet reached. Many

people ask doctors to save their incapacitated family members, who mostly depend on machines for life, to the very last minute. This has made many physicians still view emergency aids as the first response, and many terminally-ill patients depend on the life-support machine for a really long time, which wastes medical resources and prolongs suffering.

## The Last Arrangement of Life

“I’ve already told my son that I am going to make the last arrangement of life on my own,” said WU. Though the invasive treatment would prolong his life for six more months, the intubation and machines that come along with being bedridden deprive the quality of life and dignity. “Please, don’t let them perform futile medical treatment. All I need is morphine to help me ease and control the pain, so that I can live my last days in peace and with dignity, and I’ll be content.” This is the so called life autonomy, patient autonomy: make the decision in advance while one still has a clear conscious. Appoint a medical attorney when necessary—this will ensure one’s medical treatment will be done according to one’s will in the future, and not leaving the burden of making this important decision to one’s family.

Last but not least, during this process of contemplating what kind of closure one expects for life, one should also think about how to live before death. For instance, in order to not hold any grudges and regrets, one should seek reconciliation with certain people, events and the past. This is also how people can achieve a climax of self-improvement.

Taiwan is in transition into a hyper-aged society right now. WU, as the latest spokesman of palliative care, would like to stress the importance of completing this “last project,” and make the final and last decision of one’s life. For those who may have doubts or questions, the HFT’s toll free hotline is available for counseling and answers.

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**Hospice Foundation of Taiwan**    [www.hospice.org.tw](http://www.hospice.org.tw)    Line@ ID: @tdt9241n

No. 45 MinSheng Road, Danshui District, New Taipei City 25160, Taiwan  
Tel: +886-2-28081130 Fax: +886-2-28081137 E-mail: [hospice@hospice.org.tw](mailto:hospice@hospice.org.tw)