

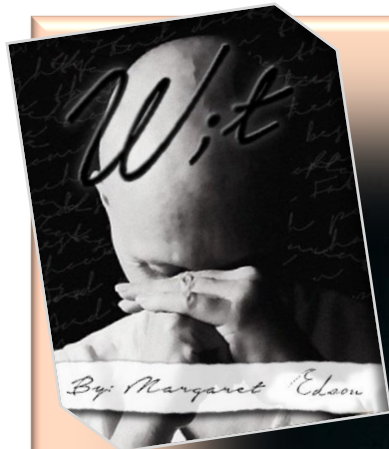


Hospice
Foundation of
Taiwan

HFT Newsletter

Forever Love, Endless Care

October 2016



2016 WORLD HOSPICE & PALLIATIVE CARE DAY



AFTER YOU TURN AWAY



After You Turn Away

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Hearing People's Needs

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Hospice Foundation of Taiwan hopes HFT newsletter will serve as a platform for us to share more palliative news in Taiwan with you.



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After You Turn Away

by *HFT secretariat*



With this year's World Hospice and Palliative Care Day (WHPCD), Hospice Foundation of Taiwan would like to turn the public's attention upon palliative care issues with the latest theater play *After You Turn Away* (當你轉身之後), adapted by Wu Nien-jen and directed by Wu Ding-qian.

After You Turn Away is an adaptation based on American playwright Margaret Edison's play called *Wit*. *Wit* is a Pulitzer award winning play, and has been used for educational purposes for many medical schools around the world. The action of the play takes place during the final hours of Dr. Vivian Bearing, a university English professor, who discovers her ovarian cancer is in metastatic state and, after a series of painful treatments, finally dies. The play portrays the lack of humanity during her treatment, the communication gap between her and the physician, and the physical and spiritual suffering she endured.

Wu Nien-jen is one of the most famous middle-aged men in Taiwan. As long as you have your television on, you will see him vigorously participating in playwriting, directing, marketing and contributing to charitable causes. Now he has one more role to play, which is the spokesman for palliative care.

Growing up in a mining village, Wu thinks being a miner equates to bearing the highest risk of life. During his childhood, mining accidents were common and the whole village was under a vile of death. He says, "We were laughing and telling each other jokes in the morning, and you saw them lying flat being carried out of the mine in the afternoon." He could never understand why a

living man can disappear in just an instant. Furthermore, his most dreadful experience was not only the dead relatives disappearing, but their deaths also affected the living. For example, those whom he played with after school may one day have to leave the village, take over adults' responsibilities, and start earning money for their families.

"I have seen life and death come and go since I was small, and I don't feel strange about it. I know that death is waiting somewhere in the corners and will show up at any minute." He has come to realize that fear does not slow the process of death, but that it is better to cherish and value the time we still have together while alive.

Wu says he holds steadfastly to his faith to live every day as if it is his last day, leaving no regrets in his life. "This seems like a very reasonable idea, but it is very hard to put into practice. My latest accident has helped me to comprehend this even more thoroughly. I started working since I was 16 years old, and I should really take some time for to relax and enjoy my life. It's a good idea to get things done as soon as possible, as tomorrow might not come for you."

Especially when Wu learned that the Hospice Foundation of Taiwan (HFT) is dedicated to ensure that everyone can leave this world with dignity and peace, he generously invited HFT to be the co-sponsor of this year's play *After You Turn Away* to introduce and promote palliative care to the public. Additionally, he has volunteered to make charity advertisements for HFT.

Wu says to respect the natural course of life is not necessarily to end life in advance, but rather, it is to do everything possible to relieve the pain in order that the patient can say love, thank you, sorry and goodbye to their family with dignity and leave in peace. How wonderful it is to help the bereaved reorder their lives with courage!

Wu has already expressed his will to his son that he wishes to make his own decision when it comes to the end of life. He says, "If I am diagnosed with severe cancer, though my life can be extended for six months with the aid of intrusive treatment, all those bedding and tubing leaves me with no dignity and life quality. So, please, in my last remaining months, I don't want any unfruitful treatment. I would rather take morphine to control my pain and live my last days with dignity and pleasure. That will be all."

In the press conference of *After You Turn Away*, Wu tells his son that he doesn't want his urn to be stored in some pagod



Wu Nien-jen



a, where his family and friends never have the time to visit. He would rather occupy a place in their hearts, which is enough.

Taiwanese society is now an aging society, and will soon enter the super-aging society. Palliative care and Advance Care Planning should both be promoted to every family, as people contemplate the decision they will make at the end of their lives. “When half of your life has already passed, you need to start thinking about end-of-life decisions. If you are worried or don’t know where to begin, you can consult Hospice Foundation of Taiwan, or call the toll free hotline 0800-008-520” says Wu.

Compared to the adapted play, Wu said the original play is rather cold, as Westerners are used to handling patient-physician relations with reason, but this is not the case for Taiwanese society. He made great effort on adapting the play to suit the Taiwanese audience, and has bestowed it with openness, warmth, and positivity. The result is that the patient can find love and warmth from the nurse and friend, and head toward the end of life with ease.

Wu hopes this play can encourage people to think more about life, and like the leading actress in the play, to view life with a sense of humor. He says, “When it comes to the end, pain is not the only thing there.” In Wu’s view, death is like an airport transit, a necessary journey to the other place. Only when people embrace death with an open heart can people learn how to respect life, accept death, and leave the world in peace.

After You Turn Away is presented by Greenray Theatre Company and has scheduled 15 performances all around Taiwan. Hospice Foundation of Taiwan will also be present to provide assistance and information. We sincerely invite you to see the show with a tender, open heart and think about your end-of-life decisions with an informed and clear mind.





World hospice &
palliative care day

Hearing People's Needs

By **Prof. Chantal Co-Shi Chao**



The minimum need for a terminally-ill patient is to be comfortable, and to achieve this, the first step is to reduce the patient's pain to its minimum. In a research done in 1999, I came to the conclusion about the ten most important criteria to assist in a patient's dying well, and the top priority is reducing pain and discomfort. If the pain cannot be relieved, the patient often feels melancholy and helplessness,

and thus remains in a constant state of depression, sadness and loneliness. Having experienced pain already, the patient becomes anxious and fears any recurring pains. This anxiety lowers the patient's tolerance for pain and weakens the will to live.

In the past, it is said that patients so desperately ask for anesthesia that they even beg physicians and nurses. At times, they may even wander from hospital to hospital in their desperate search to obtain it. This is not fiction, but true, tragic stories that happen everywhere.

Today, the medical circles have made enormous improvements with effective pain management, and also corrected many misconceptions. World Health Organization published the 3B and 3R principles. 3B refers to the WHO Ladder which includes By the Ladder, By the Mouth, and By the Clock. By the Ladder means to provide medicine in three steps, from non-opioid, to mild-opioid, and finally to strong-opioid. With each step is the combined use of an adjuvant. In addition to eradicating the misconception that patients should endure as much pain as possible, patients should take medicine as the last resort so as to avoid addiction. If patients with chronic diseases need to endure pain until it is unbearable, by the time the medicine intervenes, it often requires heavier doses, and the constant pain will also wear out the patients' tolerance and faith. They might end up relying on pain killer medicine even more.

As for 3R, it means Right Drug, Right Dose, and Right Interval. The modern pain management for chronic diseases has changed from previously providing medicine when patient feels pain to nowadays taking medicine regularly. The medicine will be given through less intrusive ways, starting with oral dosage, then to subcutaneous injection,





then to skin patches, and finally to anal suppository. The specific use of any drug and its dosage will also need to be evaluated based on the individual patient's condition.

When it comes to relieving pain, medicine is not always the only option. There are some supplementary treatments that can also effectively ease and relieve pain. Some examples include relaxation techniques, acupuncture, Transcutaneous

Electronic Nerve Stimulation(TENS), shiatsu, physical therapy, rehabilitation, music and art therapy, even humor, aroma, spiritual and religious care can all offer the same merit that has been proven scientifically and with documented support.

I always ask my audience why it is terrifying to have an incurable disease. Are we afraid of dying, pain, losing our dignity and quality of life? Or are we afraid that we might be a burden to our loved ones? Actually, most people are afraid of pain more than death, and as such, enduring unnecessary pain is an inhumane and meaningless suffering to the terminally-ill patients. Only when we assist patients to manage their pain effectively, can we help them to reclaim the quality of their lives.

Even though pain management has greatly improved, the general public is more informed of palliative care knowledge, and honor has been bestowed by the Lien Foundation's Quality of Death, problems remain. The current Taiwanese hospitals that provide palliative care are now serving around 170,000 end of lives per year, but with rather scarce human resources as well as lack of training and facilities. Additional problems include the significant reduction of professional training hours, low nurse-to-patient ratios even when health coverage has been increased, and the decline of overall palliative care standards.

If we lower the standards of palliative care in order to provide palliative care to more regions and patients, I would ask this question: "Is lower standard palliative care what patients expect to receive?" The answer is based on the fact that high-quality palliative care hospitals have no beds to spare while lesser-quality palliative care hospitals remain at below 30% in ward occupancy. It is clear what patients want as they have made their decisions toward higher quality palliative care, and we must respond by providing high-quality palliative care.

Prof. Chantal Co-shi Chao Shares Her Experience with Palliative Volunteers

by **HFT Secretariat**



Prof. Chantal Co-Shi Chao

Hospice Foundation of Taiwan has unprecedentedly hosted the “2016 Palliative Volunteers Training Lectures” in the entire nation of Taiwan.

These lectures were given by “the mother of palliative care of Taiwan” Prof. Chantal Co-shi Chao.

Her first lecture invited all volunteers and people who were interested in palliative care in northern Taiwan to gather at the Taipei Veterans General Hospital. Prof. Chao spoke of a reporter, who had previously asked her if palliative care means no treatment at all and if patients only take excessive amounts of morphine only to move into and remain in the palliative care ward. Prof. Chao then asked the reporter further about her resource, and the

reporter replied that she learned it from a senior palliative volunteer.

Even volunteers with years of service don't really understand palliative care

Such remarks as from the reporter have shocked Prof. Chao, who has been dedicating herself to palliative care development in Taiwan for more than thirty years. Prof. Chao realizes that not only non-palliative professionals lack palliative knowledge, but also the volunteers who have been providing services for many years. These misconceptions of palliative care have hindered the general public from knowing their rights of a good end of life. Hence, Prof. Chao has decided to hold these lectures in Taiwan and personally speak and explain palliative care.

The first lectures attracted more than 800 volunteers. There are very few speakers in Taiwan who possess such charisma as she does. Prof. Chao started her lecture with an actual clinical experience of a terminally-ill patient with multiple organs failure; this patient was sent to ICU with many tubes inserted into her body and she noticeably suffered a lot. Prof. Chao couldn't help but to ask the attending physician if the patient can survive after all the suffering, to which the attending physician replied with an astonishing, "Of course not!"

Prof. Chao then questioned, “If that is the case, why make the patient suffer?”

The attending physician replied confidently, “The responsibility of being a doctor is not to give up on our patients!”

However, Prof. Chao pointed out that this is definitely not a special and unique case. It is enough to notice that even the clinical professionals' lack of palliative knowledge is led by misconception through this simple conversation.

Break the common myth about palliative care

During her 3.5-hour lecture, Prof. Chao broke the common myth of how the general public usually sees palliative care, and through her decades of experience with terminally-ill patients, she instructed the volunteers how to offer their assistance that fits the patients' physical, psychological, social and spiritual needs.

Prof. Chao suggests people to provide themselves to the patients and to their family members during this difficult time. She notes that besides having a zealous heart, there are also clinical norms and requirements that need to be followed.

Prof. Chao stressed that volunteering service is a “sincere activity” that requires sensitivity and empathy for terminally-ill patients and their family members as they walk through this valley of the shadow of death. Patients and volunteers must provide their naked selves to each other without any disguises and build up relationships with mutual trust, interdependence, and understanding. Besides physical, psychological, and spiritual care, terminally-ill patients often require religious support as well. Many volunteers who devoted themselves to palliative care are often motivated by their own firm and strong faith. But while providing their time and service, volunteers need to get rid of their own religious convictions in making condescending judgments or comments.

Avoidable clinical mistakes

Prof. Chao also reminded the audience how many volunteers come with an eager heart, but forget the utmost prerequisite, which is to consult the attending nurse if there are any precautions to be aware of as they assist the patients. There have been some irreversible mistakes that should not have

happened during clinical care. For instance, a volunteer was caring for a terminally-ill patient with costal metastatic and beating suction, yet was unaware of the patient's condition and ended up causing broken ribs to the patient. Other patients even suffered from aspiration pneumonia just because the volunteers were trying to be helpful by feeding patients food. What may have started with good intentions could actually end up paving the road to an earlier death than is necessary.



Prof. Chantal Co-Shi Chao



Palliative volunteers

