

HFT Newsletter

Forever Love, Endless Care

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In the blink of an eye, six years of commitment



Palliative Care Is a Form of Software, not Hardware.

After a day's hard work, the first thought that pops into our head is usually to lie down on ...

If you have any palliative news you would like to share, please write. in to Hospice Foundation of Taiwan at hospice@hospice.org.tw!

Hospice Foundation of Taiwan 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

Patient Self-Determination Act Passes Third Reading

by **HFT secretariat**

The Legislature Yuan of Taiwan has passed the Patient Self-Determination Act (PSDA) on December 18, 2015. This act allows patients to have a say in their medical care at the end of life. The Ministry of Health and Welfare indicates that the act is the first patient self-determination act published in statutory form and will begin to take effect three years later.



The purpose of PSDA is to re-emphasize the importance of patients' rights when it comes to medical decision making, especially when it is a matter of life or death. Patients can make their own Advance Directive via Advance Care Planning by stating whether they wish to accept or refuse any kind of medical treatments when diagnosed with the following conditions: being terminally-ill, in a coma or persistent vegetative state, or with advanced dementia or incurable diseases that include unbearable pain.

The highlight of PSDA is it gives Advance Directive a legally binding nature, which occurs when patients receive Advance Care Planning consultation provided by approved medical institutions. The result is the patients' own Advance Directive, which then needs to be notarized or witnessed by two fully capable adults, stamped by the institution, and be registered in the National Health



Patient Self-Determination Act passed Third reading in Legislature Yuan, main advocate Legislators Tan(left), Yang (middle) and Chiu(right) celebrated this huge step forward together with joy.

Insurance system. Additionally, two specialist physicians are required to confirm if patients meet the five definitions stated in the act.

In order to minimize the skepticism of the medical staff, immunity is introduced to this act. That means medical institutions and physicians are freed from criminal liability when they do not completely fulfill the patients' Advance Directive based on the staff's own judgment or willingness; or when they perform according to the patients' Advance Directive to suspend, remove or refuse life sustaining treatments. When it comes to the all-too-familiar scenario where patients and family members are inconsistent, this act allows the medical institution and staff to focus on the patients' will and prevents family members from interfering.

For now, the passing of this act is considered a major step forward and a milestone for holding high values on patients' self-awareness and autonomy in Taiwan. As criminal liability is excluded from PSDA, it is intended to encourage medical staff to respect the patients' own decisions when it fits certain circumstances as stated in the act. As Advance Directives will be made by different individual with various religious, moral backgrounds and values, the Ministry of Health and Welfare has invited representatives from all interest groups, especially from the medical association, to discuss openly about the enforcement of this act. Once the enforcement rules are finalized and published by the authorities, a series of public awareness campaign will soon followed.



The draft of Patient Self-Determination Act passed Third reading in Legislature Yuan, main advocator Legislator Yang (middle) celebrated this huge step forward with bipartisan comrades.

Promoting Spiritual Care in Community-based Palliative Care

Written by Tsung-Tueng Bhikkhuni; translated by HFT Secretariat

Who do you turn to when you face sudden loss and great agony in your life? Wouldn't it be great if there is a place in your community that is able to provide spiritual care counseling? A place to assist in the communication between end-of-life patients and their families, so that everyone can have peace of mind knowing things are well taken care of? This is the vision of the Great Compassion Academy ("GCA", also known as Dabei Xue Yuan) since it was first established to promote community-based palliative care.

After 20 years of serving in palliative care, I have observed the physical, psychological, social, and spiritual needs of patients and their families. I know that terminally ill patients are often troubled by things and wishes that remain undone; and I know that family members are also anxious for not knowing what to do to help.

In *The Tibetan Book of Living and Dying*, it says, "There is no greater gift of charity you can give than helping a person to die well."

In response to the desperate needs of spiritual guidance, we at GCA wish to provide the support and companionship needed by end-of-life patients and their families as they return home from the hospitals. As this is a need that we see too often in many end-of-life patients, we would like to approach them as someone who has actually been in their shoes before and understand what they need. This is the purpose we have established GCA.

GCA is run by a group of clinical experts, Buddhist masters and disciples, who started this place together from scratch. They desired to provide community-based spiritual care and therefore set up an excellent spiritual care team formed by volunteers. GCA is not just a mere Bodhimaṇḍa with

大悲學苑啓用安座典禮

Great Compassion Academy (Dabei Xue Yuan) Opening Ceremony.

Righteous Belief, but has been authorized by the Public Health Department of New Taipei City to provide Palliative Care Education and Training since 2015.

The education and training is provided mainly through the community's palliative professional continuous education courses. Among the total 80 hours of clinical certification courses this year, GCA is responsible for lecturing Communication skills with end-of-life patients, assessing their spiritual care needs, and implementing

case studies. All of these are supported by exchanges of clinical experience.

Additionally, GCA provides spiritual care courses for volunteers and clinical staff. This includes basic, advanced, on-the-job, and internship courses. More than 200 people have already completed this course, and we continue to provide regular monthly classes for clinical staff.

For community-based palliative care, we offer counseling services of medical resources to Taipei City and New Taipei City citizens, and we also offer palliative related counseling to the general public as well as referrals—both residence and nursing home—under governmental supervision.

Furthermore, GCA has set up Dabei Homeland for all end-of-life patients and their families to visit and relax. It offers various classes from Monday to Friday, and everyone can participate. This offers a small paradise and getaway for patients and families to take a breath and rest during their intense daily routine.

GCA has been putting increased focus on communities rather than on hospitals. With support from experts, we are focusing on the education of palliative care, hoping to assist and ease patients and their families through this difficult time.

Hopefully, GCA will be a significant starting point for Taiwan's palliative spiritual care development, and ensure that all patients and families in need will find comfort for their souls through palliative care.



Uncle Jean, Sheng-jean Huang, currently superintendent of Taipei City Hospital (man in black T-shirt) has volunteered to serve as life-long speaker for GCA. Hoping to enroll more volunteers to help promote community-based palliative care.

Springtime in the Hospice Ward

The application of horticultural therapy in the hospice ward

Written by **Sheng-lin Huang** (First Taiwanese horticultural therapist acquired US certification) translated by **HFT Secretariat**

In the blink of an eye, six years of commitment has flown by as I have led the horticultural therapy group in the hospice ward at Chang-Geng Memorial Hospital. This all began with a question on a phon call I received from a social worker in 2009 asking: "How can we bring horticultural therapy into the hospice ward?"

This got me thinking: "How can horticultural therapy help patients in the final stages of their lives?" This therapy encourages patients to participate in gardening work for the wellness of their bodies, minds, and souls. With palliative patients who might not have enough strength to leave their beds, I wonder how I can impress them with horticultural therapy, so that they might be inspired and comforted.



Playful plants to cheer the spirit.

It is not just about company

My doubts were answered by reading Florence Nightingale's Letters from the Crimea. Nightingale's words have enlightened me, that is, isn't the whole point of horticultural therapy to bring nature to those who can't leave hospitals? That way, they can still enjoy the comfort and joy of flowers and plants even though they are unable to reach nature by themselves.



The plants we send to patients are returned to the corridor garden.

With the support of social workers and the head nurse, I started exploring and observing what horticultural therapy can do for the palliative care unit. In these past six years, I have started to understand why the head nurse once told me: "The hospice ward is not a place for patients to await their death; these patients don't just need company, but a true and heartfelt companionship."

What they have taught me

One day when we were about to show patients how to tie a moss ball that carried our wishes for their loved ones, a feeble patient with a nasogastric tube was wheeled into the room by his attendant. We invited the patient to join us, but he shook his head and hid behind the curtains in order to observe us. We didn't want to force him to join, so we invited his attendant instead by chatting together.

I said to them: "We are going to tie a moss ball today. It is very easy to care



Grieving parents expressed their sorrows through moss balls and cards.

for and you can send it as a gift. Have you thought of anyone you would like to give it to?"

"Oh, how about sending this to your sister?" the attendant asked the patient.

This suggestion seemed to arouse the patient's interest, and he leaned over despite still having doubts if he could finish the task. With the volunteers' help, he was not only able to tie a moss ball, but also wrote "I love you, sis" on a blessing card to express his love and gratitude.

Later, a married couple walked in with worried faces. They said little to each other, but did tie a moss ball with blessings for their daughter. On their cards, they wrote: "To baby: lots and lots of love for you. Dad" and "Baby, no matter where you are, mom wishes you the best. Mom". It turns out this couple had lost their daughter and were having a difficult time dealing with the loss.

The healing power of plants

One time when we were doing ikebana—a Japanese style flower arrangement—a wary, old lady curiously walked in, and started doing her own ikebana with the volunteers' encouragement. During the process, she shared with us that she came here to visit a sick relative of hers. When the old lady finished her work, she looked at it and started to smile. I was instantly touched by her smile.

There were also little children who came here to visit their parents or elders in the families. When I see these children, I can't help but feel sorry for them because they are about to lose a family member. I showed them how to decorate cards with plants and flowers, and send the cards to the people they cared about to express their blessings.

Time and again, whether with children or adults, I have witnessed the comfort and healing power of horticultural therapy, and I am assured of its value and importance to hospice and palliative care.

With the support of the hospital administration, we have placed many indoor plants at the corridor of the hospice ward next to the French windows to make it an indoor garden. As the indoor plants are mostly evergreen plants, every Spring and Autumn season we will bring in some floral plants that are in season to enhance colors. These seasonal flowers can also suggest the change of seasons in the hospice ward.

Since the corridor garden has been set up, we've noticed people are starting to walk around more. More patients and family members are willing to step out of their wards to enjoy the plants, or at least sit by the plants to relax and enjoy the scenery. As the elevator doors open, visitors will be greeted by the greens in the corridor garden. We hope with the different layout of the corridor garden, people can be refreshed and cheered up.

Implication of life and blessings

Plants need attentive care, and they will return to you just as much as you have devoted to them. The corridor garden is not big, but all the plants are thriving and in full bloom. Simply by looking at it, people feel its dynamic and vibrant life, and are therefore encouraged and inspired.

In every horticultural therapy class of mine, I insist on everyone writing a blessing card. It could be for yourself, your family, your friends or even for your care attendant. Whomever it may be for, it is a good idea to practice sending your blessings to others.

During the process of creating your work, it requires concentration. Through that, patients can escape from reality and temporarily focus on their work in their own little world. When they finish the work, oftentimes a sense of accomplishment and self-affirmation will result, which surely cheers the low spirits.

Features of hospice horticultural therapy

With multiple attempts and trials, I have concluded the following to be important features of an effective hospice horticultural therapy class (A-I):

A. Hold an individual class, not a series of classes

As every patient's condition is different and unpredictable, a consecutive course design with seeding and cottage is not appropriate. For example, patients who attend class this week might not be able to participate again next week; the same is true for family members. Thus, it is better to design each class independently in order to allow participants to join spontaneously and to

complete their work.

B. Fit for bedside decoration

Every time we are about to start a class, volunteers always go knocking on doors to invite patients to join us; and almost always, there are patients who don't want to leave their beds. As a result, the volunteers and I will start by ourselves, and later send the plants we've completed with our blessings to those patients. Due to the limitations in the ward, we believe the bedside cabinet is the most ideal place for these plants, and thus, the size of the finished work must be small and be able to fit the bedside cabinet. Sometimes when we see these plants end up in the corridor garden, we are reminded that another patient has left this world peacefully.

C. Improve indoor air quality

Wards are mostly closed spaces. Besides relying on air conditioning for indoor air ventilation, having plants like Sensevieria, Yellow Palm, and Devil's Ivy helps improve indoor air quality.

D. Deliver blessings

Every plant is sent with a blessing card that delivers a message full of mindfulness and encouragement to the patient who receives it.

E. Feel the nature

By staying indoors at a constant temperature, patients tend to forget the seasons. However, by sending patients Spring flowers and Autumn leaves, they are reminded of the changing of seasons.

F. Recall pleasant memories

With different festivals during the year, we also hold many different activities like Chinese New Year's greetings, Mother's Day carnation flowers, Dragonboat Festival (Duanwu Festival) fragrant sachets,



Horticultural therapy encourages patients participation, no matter big or small.

and Christmas tree decorations. Through these holiday events, patients can recall pleasant memories.

G. Interact in groups

Since every patient has different health conditions and it is challenging to ask everyone to sit through the entire class, we have adapted from a classroom setting to a vendor setting. After setting up the tables and materials, we then invite as many patients as possible to join us. Regardless of how long they will be with us, it is like a miniature version of group therapy in which people share their stories, their troubles or their emotions with us. Whatever they feel like sharing, we are happy to listen.

H. Inspired by botanical vitality

Most of the plants we choose are easy to take care of. Even in small spaces like the corridor or the wards, they grow with vitality, which can certainly influence patients and others.

I. Silent comfort

No matter where you care for your plants, be it at home or in the ward, through the process of caring for the greenery, your heart will be comforted, too.



A view of the corridor garden

All of the above features not only remind us to devote more heart into the course design, but we have also discovered that patients along with family members, companions, care attendants, and even doctors, social workers and nurses need to be included. After a year's horticultural therapy classes, the hospital administration has taken notice of the therapy's healing power, and has decided to increase the number of classes from once to twice a month. More hospital units have also

begun participating, which started with the palliative care unit, but later with the cancer unit and the rehabilitation unit.

What's worth noticing is that many patients have in fact previously farmed as their occupation or have had a small piece of land to grow vegetables for their retirement. By doing some horticultural activities, it allows them to recall their good memories of working with the soil. For some people, they place value in what they have achieved with farming. Interestingly, people have started to share their stories through farming as they interact with others and get in touch with nature again. This has encouraged the interactions between patients and their families as well as among the patients

themselves; it can also count as a Life Review Method.

The complete horticultural works not only brighten the ward with colors, but it also gives the medical team an opportunity to praise patients' works, and to help them feel a sense of achievement and competency.

As the bond is created between patients and plants, medical team members can invite patients to care for plants by encouraging them to leave their beds. This will serve as wonderful opportunities for them to make friends and to exercise.

All these changes made by the interactions and emotions with plants have made us believe once again, that the palliative care ward is not a place for patients to sit quietly and await their death; but rather, it is a place for them to carry on a meaningful life and see life as worth waiting for and pursuing.



A view of the corridor garden

Palliative Care Is a Form of Software, not Hardware: An Interview with Dr. Enoch Lai

Written by Ching-sui Hsu, translated by HFT Secretariat



After a day's hard work, the first thought that pops into our head is usually to lie down on the sofa, watch TV, take a shower, or simply do nothing at all – anything to feel relaxed at home. However, what if your entire lifetime is compressed into such a day of hard work? How then would you like to take a rest? Would you prefer to stay at your familiar home surrounded by family as you say your goodbyes? Or would you prefer to rely on a machine to prolong your life?

Home Is the Best Destination

According to a survey, more than 80% of end-of-life patients wish to die in peace at home. Home not only makes us feel safe, but also provides a shelter for everyone. When it comes to the last phase of our lives, our homes provide us with more autonomy, privacy, and dignity.

Taiwan has been actively promoting community-based palliative care in recent years, as palliative teams pay regular visits to patients so patients do not have to make frequent trips to and from the hospitals. Thus, by avoiding unnecessary medical visits and treatments, more quality time is made available for the families, which in turn allows the concept of "dying well" to be realized.

Dr. Enoch Lai from Mackay Memorial Hospital stresses, "Most people think you can only receive palliative care when you are staying in the palliative ward. This isn't true. Palliative care does not refer to the tangible hospital facilities, devices, or equipment, but rather, to a form of 'software', an attitude to life, and a way of caring for the terminally ill patients".

When a terminally ill patient is given a notice that they have fewer than six months of life remaining, the aim of palliative care is neither to cure the disease nor accelerate or slow down the death process;

but rather, the aim is to ease the symptoms and to support patients and their families by providing spiritual care to improve the quality of life. This is why Dr. Lai calls palliative care a kind of software. It doesn't require physical wards or doctors, but all it takes is a certain mindset, which can then be applied to every specialty and routine care of terminally ill patients.

A Quality Life Free of Pain

Palliative care has developed from within the hospitals wards to the patients' residences, and now it even expands to shared care and community care; as such, it has transformed into a "software" format. That is, no matter where the patients are seeking assistance from, as long as palliative care is needed, the palliative team will bring and ensure a good and pain-free quality of life. This team includes doctors, nurses, social workers, nutritionists, and volunteers.

Dr. Lai points out that since 1990 when Mackay Memorial Hospital first set up the palliative care ward in Taiwan to promote this new concept, palliative care has evolved extensively in order to meet the patients' needs.

Palliative Care Fit for Local Culture

Mackay Hospice and Palliative Care Center was established in hope of providing palliative care for terminally ill patients. The professional training courses for palliative care staff started the same year, and they have developed an unique style that best suits the Taiwanese culture. An open and candid discussion with patient proves beneficial.

"Newborn births are welcomed by family

members, and so it should be when it comes to the departures of people we love," explains Dr. Lai. The Taiwanese Department of Health started promoting palliative care at home in 1996, and it was thought that this home care version of palliative care would meet the expectations of Taiwanese families, but it proved not to be the case. Due to urbanization, patients normally stay at home while their family members are out and preoccupied with work. Besides, as influenced by the period of Japanese rule, people still believe patients should only return home when they have recovered from illnesses. Therefore, dying at home was not a common or acceptable idea for people at that time.

According to the statistics in 2000, only 7.5% patients died at home or in a hospice ward; this number grew to 14% three years later, but the result is obviously limited.

With more effort being put into the promotion of palliative care at home, especially through personal experiences and stories in the media, more people are feeling curious about palliative care and are opening their hearts to this concept.

In 2004, the Taiwan Ministry of Health and Welfare and the Taiwan Hospice Organization started promoting Hospice Shared Care Service, which has allowed terminally ill patients to receive

palliative care even when they are no longer staying in the hospice ward. Thus, the palliative care team works with your current medical team to ensure a proper and complete end-of-life care.

With the backing of governmental policy, patients who have received palliative care have risen to 40% in 2011 and to 51% in 2012.



Dr. Enoch Lai, Senior Physician of Mackay Memorial Hospital working closely with palliative team.

The development of palliative care has now become diversified, from hospital wards to homes, to shared care, and even to communities and nursing homes, which are working with appointed hospitals to have regular palliative care team visits.

Dr. Lai suggests that palliative care can be adapted easily to fit various needs. He says, "As long as we can bring peace to terminally ill patients' minds, then it is the ideal place for receiving palliative care. It doesn't have to be a specific location."

In the "Age of Great Harmony," it describes that the ultimate goal for achieving this Great Harmony is to "provide for the old until their death". "With our lives approaching the terminus, not everyone is choosing the same terminus; palliative care is just one of them", Dr. Lai concludes. As respect for an individual's autonomy is rising, future legislation is expected to ensure terminally ill patients with the right to have a say with their own lives.

Back