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GETTING TO KNOW PALLIATIVE CARE:

Making it easier and more accessible to the public



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Life Discovery Map – Reaffirming senior citizens' value of life

Written by **HFT secretariat**

The loss of power and activity that comes along with aging and the fear of facing the unknown death have stricken many senior citizens with melancholy. As the population rapidly turns into an aging society, assisting and guiding elders to face the aging process and live positively has become a new yet essential assignment to all.

Hospice Foundation of Taiwan has worked together with Kaulin Foundation to jointly launch a board game called *Life Discovery Map*. The purpose behind this board game is to encourage senior citizens to step out of their routine and interact with others. The design of this board game is to offer elders a retro perspective and redefine the key moments of their lives by saying "thank you," "sorry," "I love you," and "farewell" as they wave away the doom and sadness of aging.

The designing concept of *Life Discovery Map* takes Monopoly as a reference. Besides involving movements like tossing dice, removing objects, and flipping cards to allow senior citizens to practice their hand coordination, the game cards are specifically designed by experts according to the *Four Principles of Life*, which guides players to review the events in life, e.g., people they are most grateful for, their greatest regrets, their proudest moments, and their difficult past experiences that are hard to let go. By recalling and reviewing these past events, senior citizens are able to reaffirm their worth.



"By reviewing our past mistakes, we receive a second chance to amend them and let them go; we learn to forgive others and ourselves, bringing life to its completion," said Vanessa Lin, CEO of Hospice Foundation of Taiwan. This fun board game can also serve as a little widget that opens up senior citizens' isolated lives and sets up relationships with others. Kaulin MFG Co., Ltd., the parent company of Kaulin Foundation, has been devoting its resources to social welfare by transforming sewing, textile and design for the good of society. This is the first time the concept of death education has been integrated into its work. In fact, during the designing process, Kaulin Foundation gave thorough consideration to its aesthetics, and tried multiple materials to achieve its durability. Last but not least, it is made out of the leftover materials from the production line, giving it a chance to contribute and finally launch in January 2018.

Yu-chen Lin, CEO of Kaulin Foundation has said, "Textile has a character of being both soft and durable, just like senior citizens who are playing this board game have their own life stories, be it splendid or tragic. We hope to pay respect to their hardships and persistence through the textile's strength."

These first products of the *Life Discovery Map* board game will be introduced to long-term care facilities by Hospice Foundation of Taiwan to promote hospice and palliative care. It is also planned to be used in campus later on...



Medical autonomy: Chimei Medical Center introduces touch screen games and virtual reality

Written by HFT secretariat

The Patient Self Determination Act will be effective on January 6, 2019, and according to this Act, anyone who wishes to sign an Advance Decision (to refuse a treatment) is required to complete ACP consulting process with the ACP team. In light of this, Chimei Medical Center has eliminated its previous communication process



with patients, and decided to use an intelligent education tool by introducing touch screen games and virtual reality. As a result, the general public can experience the journey of life and learn to understand various aspects of medical, emergency and long-term care when one is at the end of the life stage. This will encourage patients to foresee and plan their medical choices when at the end of life, and also help the family to better relate to patients' sentiments and decisions. This device is now functional along with the pilot scheme of Patients Self-Determination Act, and ready for the general public to experience.

The theme of this device is Autonomy and Dignity on the Life Journey, developed by team members of Chimei Medical Center. It offers two modes—one in cartoon and the other in virtual reality ("VR")—to invite people to experience the journey from a newborn baby, to a teenager, to a middle-aged person, and finally, to a senior citizen. At different stages of life, people have different concerns related to their frailty, meaning, and medical care.

Realize, Rethink and Remodel

The first mode will be an interactive cartoon called Into the Time Tunnel, a Review of Life. It invites the viewer to experience life from a baby being blessed, to a teenager ready

to fly high, to a middle-aged adult with great responsibilities, and finally, to a frail old man who requires care from others. This process points out the inevitable nature of being born and aging; and thus, the importance of Advance Directive. At the end of this interactive cartoon, the viewer can print out a personalized choice sheet as a souvenir.

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.

During this mode, we wish to achieve these three goals "RRR":

- Realize one's current stage of life and acknowledge one's current feelings;
- Rethink the adage "Do to others as they do to you," and offer the authenticity of advance medical to encourage people to do ACP so as to avoid the actual suffering;
- 3) Remodel the general public's view and understanding of palliative care and build up the value of life and dying well.

Experiencing medical care in virtual reality mode

The second mode is to experience medical care in different settings in the VR mode. These settings are:

- ER and Intensive Care Unit: Through VR technology, people experience what it is like to receive endotracheal intubation, electric shock, heart massage, under restraint and all relevant life maintaining devices. They are also introduced to palliative care and co-decision in a family meeting;
- 2) Palliative and Hospice Ward: Participants experience the interaction among medical team members (e.g., physician, nurse, social worker, psychologist and so on) and comfort care (e.g., bathing, pedicure and Lymphatic massage).













The design purpose of these two modes is to allow participants to first experience the different stages of life along with its different values and anticipation through cartoons. When participants' age and later need to make such medical choices, they can continue their experience by VR technology to further comprehend the medical situation when they are sick and old. With the introduction of palliative care planning, participants can also learn the differences of having family and the content of palliative care.

Cartoon and VR technology effectively change public's expectations of EOL medical choices

Chimei Medical Center has also shown this device at Taiwan Healthcare Expo. Many participants said the device allows them to experience the warmth of palliative care, in contrast to the coldness of life sustaining treatments which cannot ease suffering but only prolongs the dying process. Participants showed significant willingness to accept palliative care and also sign relevant forms. The palliative and hospice ward director of Chimei Medical Center, Hsieh, said: "The purpose of this device is to assist the general public's understanding more about medical options, and more importantly, to talk about one's options with one's family in advance, thus creating more time and space to make intelligent decisions."

Based on the collected onsite findings, the percentage of people who do not wish to receive life-sustaining treatment at EOL rises after watching the VR video from 69% to 77%. The percentage shows that more than half of the general public is reluctant to receive life-sustaining treatment at EOL stage, but after watching the VR video, they become more willing to prepare in advance. Appropriately, this device will be a helpful consulting tool when people are seeking Advance Care Planning consultation in Chimei Medical Center.





Lead by celebrities, let's talk about death

Written by HFT Secretariat

Promote palliative care in diversified channels

Recently, no matter whether it is the health ministry or hospitals or private sectors, everyone is promoting the concept of Advance Care Planning (ACP), which urges society to talk about one's own desired end-of-life care and decisions as early as possible. This is not only a demonstration of self-autonomy, but can also serve as a checklist for one's family to carry out the final plans. This can ensure one's wish of being fulfilled at the last stage, and also bring peace to the family who is left behind.

Hospice Foundation of Taiwan has launched many events in diversified forms to promote palliative care, including speeches, literature, film, painting, photography and music concert, and etc. Based on the feedback received from the public, these events have gradually become a silent social revolution and break the taboo of talking about death.

Practice saying goodbye by writing it down

In 2013, Hospice Foundation of Taiwan hosted a composition contest, encouraging people to rehearse their final moments in life by writing it down, and also express their thoughts on end-of-life care. Influential celebrities from sectors such as medicine, politics, religion, arts and sports had been invited to participate, as well as the superintendents from six major hospitals. This contest received great response from the society and all the award winning articles were gathered and published to land on the best-selling books chart.



Publish for educational purpose to plant more seeds

Continuing with the public's attention on this subject, Hospice Foundation of Taiwan raised funding to offer this book to thirteen high schools for educational purposes. It also invited celebrities to talk about living and dying with students at these schools in order to plant seeds in their minds.

From the feedback received from these 13 schools, it clearly shown the positive influence brought by book donation. HFT carried on searching possible funds to continue book donation and encouraging teachers to use this book to guide students to think, discuss and write down what they have experienced. This is also an alternative and a more flexible way to root the ACP concept in these young minds. Below are some selected reviews from the students of Chung-Jen Junior College of Nursing, Health Sciences and Management.

2018 👌 Personal Reflection

from students of Chung-Jen Junior College of Nursing, Health Sciences and Management



In my last days of junior college internship, my dear grandpa left us for good. The day before I visited him in the hospital, his eyes seemed dazed, but he still recognized me and gave me a subtle smile. I held his hands and told him gently, "Don't give up; I will be right back after I finish my internship!" He nodded and tried very hard to hold my hand as if he was answering me, "Don't you worry about me, focus on your internship."

The second day after my internship, I phoned my family that I am heading home. My mother on the other side said, "Grandpa is leaving the hospital now too; come home quickly." I was happy because I thought grandpa did it! He had promised me that he would fight and wait for me to return, and he must have done it. I rushed quickly home, excited, but as I drew closer, my mother revealed the truth to me, which was that grandpa had gone the day I last visited him.

This sudden news broke my heart and my sanity. It was very hard to accept. Mom fought back her tears and explained to me how it was really hard and unbearable to see grandpa on and off endo repeatedly, and so finally decided to let him go in peace.

Seeing this article, mom's reluctant look reemerged, and I am starting to realize just how great and difficult a decision it was for us to let grandpa go; it was out of her love to grandpa that she choose to let him go and end his suffering. It was not until now that I finally realized how significant that decision was.

I AM LEAVING MY DREAM LAND FOR YOU TO GROW YOUR DREAM, MY CHILD By YI XUAN ZHU

Being apart from beloved ones always caught me off guard. I am 20 years old and I have experienced three deaths, including that of my dear mom and uncle.

As I recall every goodbye we have said to each other, there are always many regrets. For example, I regret not being able to share my gratitude freely, not hugging them enough, and not letting them know how much I loved them. Now I can only look up to the sky and think of how much I miss them while imagining they are right there looking back at me.

I can still remember them in their last days how they were not worried about their frail bodies, but were still involved in planning for us because they worried about how we might live on after they were gone. We listened quietly as if we did not care too much for fear that these would become their last words.

However we may disagree with death, the course of life still runs its pace to the end. All that remains from them is their love to us. I have never stopped believing that they are up in the sky, smiling back at me to see us living out our dreams.

LETTING GO IS THE HARDEST TREATMENT By QUN TING FU

Every time when we talked about death, the grown-ups would always stop and forbid us because they regarded it as ominous and kids' silly talk. The subject of death has since become the elephant in the room to me. Until I started my internship and saw many advanced patients with tubes all over their bodies, I could vaguely see bones in their bed sores. These patients' daily torture can only end when their final day arrives. How then is the subject of death forbidden when it is the savior of these poor souls? I kept wondering sadly to myself, are these tubes really helping them? Or is it keeping them from dying? Are we forcing them to live and suffer? If one day, this situation happens to my family members, what should I choose?

After reading Dr. Sheng-jean Huang's "Letting go is the hardest treatment", my heart was really touched. Saying goodbye is grievous and tough, but it is certainly a lesson that all of our medical professionals must learn. Just as Dr. Huang says, "Learn to face the limit of medicine bravely, and learn to respect the dignity of life humbly" and also "The lesson of dying well is the hardest and most basic lesson for every medical professional."



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The Healing Power of Therapeutic Dogs

Written by HFT Secretariat



Two special doctors named Harmei and Jason visited hospice wards of Mackay Memorial Hospital on March 8, spending a very pleasant hour with the patients and their families.

Harmei the giant Poodle and Jason the Dachshund are therapeutic dogs specially trained to interact with patients. They are friendlier than normal dogs, highly sociable,

stable, obedient, and can interact with patients under a trainer's guidance. Although patients stroking and combing therapeutic dogs may seem like insignificant gestures, such gentle and relaxed activities can significantly ease patients' tenseness and boost patients' physical energy. Simply by looking at Harmei and Jason's happy faces, patients and their families also reflect happy and rare smiles on their own faces. Even the palliative professionals can be healed by these two furry doctors!

> Animals have been known to make people happy for centuries. In the past three decades, many western countries have started to use animals in supplementary medical roles. According to clinical research, such "companion animals" can distract patients'

attention to pain as patients stroke and talk to the animals, thereby easing their emotions and providing benefits such as: stabilizing triglyceride, decreasing cardiovascular diseases, and minimizing other neurological symptoms, like headache and insomnia.

The American Heart Association has published research showing how dogs bring comfort and sooth heart disease patients. In fact, when patients are visited with therapeutic dogs, their anxiety and adrenaline levels are low and their heart and lung functions are improved as well. Hence, pet therapy is mainly applied to patients with chronic disease, mental illness, developmental delay, and hospice care.



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