



# 20

## Things You Should Know about

### the Patient Self-Determination Act

The Legislative Yuan passed the third reading of Patient Self-Determination Act on Dec. 18th 2015. This is the first Act specifically dedicated to Patient's autonomy right, and also the first national act that is centered on patient's rights of knowing, choosing and deciding, which literally hands the medical decision right back on patient's hand.

Here we have gathered the 20 most common Q&As for you at a glance.

Q1. Why do I need PSDA?

Q2. Why does it take 3 years for PSDA to be effective?

Q3. What is the difference between PSDA and the current Hospice Palliative Care Act (HPCA)?

Q4. Why not just amend the existing HPCA to protect the right of a good death rather than create a new act (PSDA)?

Q5. Why is there a need to protect the right to know?

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**Creating a Customized Environment for Palliative Care in Long-term Care Facilities**

**Sharing Taiwan's Experience in Palliative Care At the 2nd Hospice Summit in Asia-Pacific, Beijing 2016 (Mandarin)**

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# 20 Things You Should Know about the Patient Self-Determination Act (PSDA)

by **HFT secretariat**

The Legislative Yuan passed the third reading of Patient Self-Determination Act on Dec. 18<sup>th</sup> 2015. This is the first Act specifically dedicated to Patient's autonomy right, and also the first national act that is centered on patient's rights of knowing, choosing and deciding, which literally hands the medical decision right back on patient's hand.

As long as you are above 20 with full competence, you are ready to make your own advance medical decision. In the future, when you found yourself in situation like advance illness or persistent vegetative state..., you can choose whether you wish to prolong life via medical interference or not. In view of public's unfamiliarity with this Act and tends to confuse with the current Hospice Palliative Care Act, here we have gathered the 20 most common Q&As for you at a glance.

Q1

## Why do I need PSDA?

Every life is uniquely valuable, and every decision made regarding your life should be respected and protected. This is the reason why PSDA came into being.

PSDA is the first patient-centered act. It is clearly stated in the act that every patient has the right to know, to choose and to decide personal medical decisions. For those who have made their decisions and later fall into a coma or become too ill to make decisions, their autonomous wills will be protected by the law and carried out.

You can also make your medical decisions through an Advance Directive (AD) when your health condition deteriorates and meets the five clinical statuses (e.g., end of life stage, persistent vegetative state, and etc.). You can decide if you wish to prolong your life through medical interference or if you choose to receive palliative care to ensure a quality death.

Through this expression of patients' medical choice, autonomy and dignity are being respected while the right of a good death is being protected. Patients, family members and the medical team can all learn to understand the patients' true desires via the Advance Care Planning (ACP). This will help achieve the harmony between doctor-patient relationships, and also alleviate the grief and loss. By returning the right of decision-making back to the patients, this also eases the guilt for the bereaved and helps them to realize they are helping their loved ones by supporting their decisions.

In addition, PSDA provides medical professionals a clear legal basis to follow when the five clinical status mentioned in the act are encountered.

**Q2**

## Why does it take 3 years for PSDA to be effective?

Even though PSDA has already passed, it will still need a three-year buffer before it becomes fully effective. On the one hand, the three-year time frame is to help the public learn more about this act, so that people can be equipped with more knowledge to protect their own rights. On the other hand, the time gives the public and private sectors appropriate time to discuss how execution should be regulated.

**Q3**

## What is the difference between PSDA and the current Hospice Palliative Care Act (HPCA)?

Hospice Palliative Care Act only protects the right of medical decisions of the terminally ill patients; however, PSDA has added four new targets. Additionally, when signing the current Letter of Intent, HPCA requires only the patient and two witnesses; whereas the Advance Directive mentioned in PSDA will require an Advance Care Planning consultation process provided by the medical institute and registered in the National Health Insurance system. (See Table 1)

Table 1

Aspects	Hospice Palliative Care Act (HPCA)	Patient Self-Determination Act (PSDA)
<b>Concept</b>	<ol style="list-style-type: none"> <li>1. Protect patient's right of a good death</li> <li>2. Patient signs Intention Letter personally, or the closest relatives can sign the consent form</li> </ol>	<ol style="list-style-type: none"> <li>1. Protect one's dignity, autonomy and right to a good death. People with a sane and sound mind can make their own decisions</li> <li>2. Patient-centered. Protects patient's right to know, to choose and to decide</li> <li>3. Combined with other</li> </ol>

		reinsurance mechanism: Advance Care Planning consultation (ACP), Advance Directive (AD), and medical surrogate agents
<b>Criteria</b>	Terminally ill only (advanced cancer and eight non-cancer diseases)	Five types of clinical status: 1. Terminally-ill 2. Irreversible coma 3. Persistent vegetative state 4. Advanced dementia 5. Incurable diseases that include unbearable pain
<b>Scope</b>	1. Resuscitation 2. Life-sustaining treatment that will prolong the dying process	1. All medical treatments that may possibly prolong patients' lives, including: resuscitation, life-sustaining devices, blood, antibiotics, and etc. 2. Feeding tube (nutrition or fluid)



**Q4 Why not just amend the existing HPCA to protect the right of a good death rather than create a new act (PSDA)?**

HPCA focuses on terminally ill patients only, and PSDA focuses on the medical right of every citizen in all medical circumstances.

Currently, HPCA does not provide a sound protection to the patient's right to know, to choose, and to decide. Furthermore, both the Medical Care Act and HPCA state "If a terminally ill patient, who has become unconscious or failed to express his/her will clearly, has not signed the letter of intent ... his/her close relative may replace the patient's will by signing a consent form". Thus, the signed consent form is not necessarily the patient's will.

In contrast, PSDA legislation will protect the patient's right to know, to choose and to decide, even if the patient falls into a coma and is unable to clearly express his/her will; thus, the patient's will is still being carried out.

**Q5**

## **Why is there a need to protect the right to know?**

The current Medical Care Act states: “Medical care institutions shall explain ... to the patient or his/her legal agent, spouse, kin, or interested party, and must obtain his/her consent...”

This seemingly appropriate statement actually hinders the medical team from explaining the patient’s condition to himself/herself, and often does not reveal the whole truth. Both having a patient who does not know his own health condition and family members who are not able to have a meaningful conversation with the patients are not only a waste of extremely valuable and short remaining time, but also a failure to provide for the patient to fulfill his last wishes. Although this Medical Care Act arose out of the love to patients, it has often ended up wasting precious time and causing regrets to both the living and the dead.

PSDA, on the other hand, has a clear patient-centered position to protect patients’ right to know by stating that patients have the right to know the diagnosis, medical options, and the consequences and risks that follow. Only when patients do not strongly express objection can the medical team inform the patients’ personal medical information with other related parties.

**Q6**

## **What do medical options mean?**

Medical options mean when patients are well informed with their own diagnosis, and understand the therapeutic guidelines, treatments, medications, prognoses and possible adverse reactions. It means the patients are ready to communicate with their medical team on how they want the treatment to be and in “dying well”.





## What is the importance of legally protecting a patient's right of decision-making?

It is a common clinical scenario that medical professionals, family members, and patients will fight for the medical decision-making. The expressed will of patients is often seen as an act of weakness or desperation, leaving the patients underprivileged and vulnerable as people who are ill and unheard at the same time. PSDA stresses the importance of respecting patients' right to decision-making, and reaching the consensus by having the medical professionals, family members, and patients sit down and discuss under the Advance Care Planning Consultation process. This will ensure the family members understand the patients' will and help achieve the ideal final stages of life based on the patients' view.



## What do other advanced countries regulate in PSDA?

World Medical Association has repeatedly stated “Refusing medical treatment is the patient's basic right and conforms to medical ethics”. Patient autonomy is not just an international trend, but also a universal value recognized by the international society. Here we will see the examples of the United States and Germany:

In the Cruzan case in 1990, the United States Supreme Court ruled in favor for the refusal of medical treatment, including feeding tubes that prolong life. In the same year, the Patient Self-Determination Act was passed by the United States Congress. This Act ensures the patient's right to refuse medical treatment, provides Advance Directive as a legal status, assigns a medical surrogate agent for those who are not able to express themselves clearly.

In 1990, the Federal Court of Justice of Germany (BGH) ruled that as long as there is a written will (*der mutmassliche Wille*), the patient—even those who are incompetent—can still have the right to refuse artificial sustaining treatments such as feeding tubes. In 2003, BGH announced the legal enforcement of *Patientenverfügung*; and in 2009 amended Article 1901 in the German Civil Code (*Bürgerliches Gesetzbuch*) stating:

- (1) A person of full age can give his/her consent in written form to determine whether he/she would consent or refuse to any specific tests, treatments or medical interventions not yet directly immanent at the time of determination in advance (§ 1901a.1 BGB).

- (2) The patient's living will is effective regardless of the nature and stage of any illness of the person under custodianship (§ 1901a.3 BGB).
- (3) The patient can refuse any kind of medical treatment, including those physicians deem valuable.
- (4) The first priority of the appointed medical surrogate agent or court assigned custodian is to protect and fulfill the patient's will.
- (5) The patient's expressed will and the medical surrogate agent's decision should both be made under the premise that a proper and comprehensive medical professional advice is given (which makes ACP consultation important).
- (6) The will expressed by the patient will be the most crucial and effective; the second most effective is the paper in Advance Directive-like form; and the third most effective is the presumed will on the basis of previous given oral or written statements, ethical or religious convictions and other personal values. Finally, the patient's close relatives and other significant persons can make the decision based on the patient's best interest. (§ 1901a.2 BGB) (§ 1901b.2 BGB)



## Is PSDA a form of legalized euthanasia?

In 1987, the World Medical Association (WMA) distinguished the differences between patient autonomy and euthanasia. Be it euthanasia or physician assisted suicide; both are acts of deliberately ending the life of a patient via medication. Even though it is at the patient's own request or at the request of close relatives, euthanasia is deemed unethical.

In 1992, WMA reaffirmed physician-assisted suicide, like euthanasia, to be unethical; however, the right to decline medical treatment is considered a basic right for the patient. A physician will not be deemed to act unethically for respecting a patient's right to decline medication, even if this results in death. Allowing natural death to occur is not considered unethical. (See Table 2)

Table 2

Category	Description	Countries Allowed
Euthanasia	Provide patient a lethal dosage that ends the patient's life in order to ease patient from	Netherlands, Belgium, Luxemburg, Columbia

	insufferable pain and incurable diseases.	
<b>Physician-assisted suicide</b>	Patient take the dosage prescribed, prepared and offered by physician.	United States (Oregon, Washington, Montana, Vermont and California), Switzerland and Canada
<b>The right to decline medical treatment</b>	Physician respects patient's will by not prolonging life, allowing the natural course to take place.	Universally recognized value



## Q10 Does declining medical treatment mean suicide?

Declining medical treatment doesn't necessarily bring immediate death, and thus, is not considered suicide. Take the well-known Quinlan case for instance. Karen Ann Quinlan, 21, attended a friend's birthday party at a local bar, where she collapsed and stayed in a coma after consuming alcohol and diazepam because she had eaten almost nothing for two days. Her parents requested that she be disconnected from her ventilator to prevent her from further suffering, and their appeal was granted by the New Jersey Supreme Court in 1976. When Quinlan's ventilator was removed, she surprised many by continuing to breathe unaided, and was fed by artificial nutrition for nine more years until her death from respiratory failure in 1985. Her case highlighted the subject of "dying well", and promoted the legislation of protecting the patient's autonomy to refuse unwanted medical treatments and to die with dignity.

Quinlan is not a unique case. There are many other patients who refuse or remove life-sustaining treatments (LST) and do not pass away immediately clinically; or even if they pass away, it is not caused by the lack of LST, but often is the natural progression of the patients' disease. Thus, declining medical treatment does not mean suicide.



**Q11**

**When choosing not to receive any medical interference to maintain life, what else can be done instead?**

Physicians and medical institutes, who respect patients' decision to terminate, remove or refuse LST or tube feeding when under the five kinds of clinical statuses mentioned in PSDA, will still need to provide hospice and palliative care. Comfort care, pain management, psycho-social and spiritual care, and guidance will be provided to help patients express their gratitude, sorrow, affection and farewells to their loved ones, thereby ensuring their remaining days are filled with dignity and without regrets.

**Q12**

**When is it appropriate to start Advance Care Planning consultation?**

**A. When in a healthy state or with no life-threatening diseases:**

Patients can have the general Advance Care Planning consultation to help obtain enough medical advice and PSDA information so as to make one's own Advance Directive.

**B. When in a serious illness:**

Patients with full capacity can plan ahead by having Advance Care Planning consultation at appointed medical institutes to learn more about the future progress of one's disease, and later decide or revise personal Advance Directive.

# Q13

## How does one register an Advance Directive?

Anyone over 20 years old with full capacity can create an Advance Directive with the following provisions:

- A.* Advance Care Planning consultation certification from an authorized medical institute;
- B.* Notarized by a notary public regarding the full capacity status in the presence of at least two witnesses;
- C.* Registered in the National Health Insurance.

### Advance Care Planning Consultation

- Signee (over 20 years old with full capacity) + at least one second degree kinship + medical surrogate agent + authorized and recognized medical team

### Advance Directive

- Made and signed all medical options in written form
- Appointed a medical surrogate agent

### Effectiveness

- Certified by an authorized and recognized medical team
- Notarized with at least two witnesses
- Registered in the National Health Insurance

### Clinical Status

- **Five types of clinical status:**
  - Terminally-ill
  - Irreversible coma
  - Permanent vegetative state
  - Advanced dementia
  - Incurable diseases that include unbearable pain

### Execution

- Reconfirming procedure
- Physicians perform palliative and hospice care

## Why must mandatory Advance Care Planning consultation be received in order to create an effective advance medical directive?

Q14

In order to avoid any decisions made out of misinformed or improper medical resources when making an advance medical directive, a complete disease analysis along with the pros and cons and prognosis all need to be provided in order for the professional medical consultation to help patients make their best informed decision.

## What is the difference between Advance Directive and the current Intention Letter (DNR)?

Q15

	Advance Directive	Intention Letter (DNR)
Target	Includes non-terminally ill patients	Terminally ill patients only
Content	Patient can refuse any required medical treatment or care that may possibly prolong patient's life, including a feeding tube (nutrient or fluid)	Patient can only refuse resuscitation or life-sustaining devices
Professional Medical Consultation	Advance Care Planning consultation provided by appointed medical institutes is required and certification must be provided	No relevant regulation; free to write as one sees fit

Notes in the National Health Insurance System	Valid until complete	Depends on one's choice
Legal Status	Competent to represent patient's will when in a coma or when unable to express clearly	Rather limited and unable to function properly and clinically
Commonalities	Clearly stated when patient refuses life-sustaining treatment, adequate palliative care should be provided to assist patient's "dying well"	Terminally ill patient can choose the palliative care that is required

**Q16 Does every hospital provide Advance Care Planning consultation?**

For eligibility and requirements of the medical institutes that provide Advance Care Planning consultation and how its consultation team is made up, all the details will be discussed and announced with its execution regulations at a later time.

**Q17 How do I assign a medical surrogate agent?**

Anyone over 20 years old with full capacity can be assigned as a medical surrogate agent when both agreed to and signed in written form. However, when you are the beneficiary for the patient's organ, it is not legal for you to be patient's medical surrogate agent.

The medical surrogate agent you appoint will represent you to make every medical decision, and it is very important that you appoint a person who both understands your thoughts and

values of life and is physically close to you so as to stay by your side when needed. Your relationship with your medical surrogate agent will need to be managed as well. For instance, you can review whether your medical surrogate agent still has your trust and share the same values with you or not, or you can always terminate your proxy at any time.

**Q18**

**How many medical surrogate agents can I appoint?**

You can appoint more than one medical surrogate agent, and each agent can represent the patient's will independently. But while expressing the patient's will, they will need to show their identity to the medical institute or physician.

**Q19**

**How do I let medical professionals know the medical treatments I have chosen?**

The Advance Directive achieved through the process of Advance Care Planning Consultation will be registered in the National Health Insurance system to allow the medical institute to access and follow your selected medical treatments.

**Q20**

**After I have made my Advance Directive, is it possible that if I still have a chance to be cured, an accident occurs that causes the doctor to give up on me?**

No. PSDA clearly states that besides advance cancer patients, four categories of patients are entitled to decide whether they would terminate, remove or decline resuscitation treatment or feeding tubes. However, before enforcing this right, patients will need to be diagnosed by two specialist physicians, and consulted by the palliative team twice to make sure the patients' clinical status applies to the Act, so as to make up the patient's Advance Directive. The process is discreet and strict, so it is impossible for patients who still have a chance to be cured be given up on because of the Advance Directive.

PSDA has also regulated that medical institutes and physicians can only perform palliative and hospice care to patients who conform with Art.14 (1) the five clinical statuses and Art.14 (2) which has been diagnosed by two specialist physicians and consulted with the palliative team twice; otherwise, there should be no delay in providing proper emergency care or relevant required measures to patients.



## **Special thanks to:**

- *Mrs. Yang, Yu-shing*

Former legislator/Drafter of the Patient Self-Determination Act

- *Prof. Sun, Hsiao-chih,*

National University Taiwan, Department of Philosophy



# Creating a Customized Environment for Palliative Care in Long-term Care Facilities



by **HFT secretariat**

The theme of the 11th APHC (2015) hosted by the Hospice Foundation of Taiwan (“HFT”) was Transforming Palliative Care, which anticipated that the palliative care network might be truly implemented. Furthermore, the conference emphasized that a good death should be ensured in local communities in a way that the palliative ward, home care, and community care can all work together very efficiently.

The Taiwanese government is currently promoting Long-term Service Care Program 2.0, and encouraging long-term care facilities to join and promote the so-called palliative care in long-term care settings. However, long-term care and palliative care have always been categorized under two different systems, and therefore, lack interaction and coordination. For example, the current long-term care training course supervised by the Ministry of Health and Welfare does not provide any palliative training. The same lack of palliative training applies also to long-term care training courses from other organizations.

HFT proposes the following four steps to help bridge the gap between palliative care and long-term care:

## **I. Expand the Palliative Service to Long-term Care Facilities**

Since last year (2015), HFT has organized palliative courses targeted at long-term care facilities’ staff, and made palliative care in long-term care settings as top priority. As a result, HFT has developed mid and long-term plans intended to expand palliative services to long-term care facilities. Furthermore, HFT has connected with related palliative societies, organizations, and associations, hoping to echo the government’s current policies and promote palliative care in long-term care settings.

So far, HFT has held four lectures throughout Taiwan to discuss the palliative needs for long-term care facilities, and understands first-hand the current predicaments they are facing as well as acknowledging future requirements. With these lectures, the hope is for HFT to deliver a diversified palliative care proposal that fits various long-term care facilities.



## II. Integrate the Four Palliative Care Needs in Long-term Care Services

From the feedback received, HFT has concluded the following four as the most crucial:



1. Improve the administrator's palliative care knowledge and practical experience;
2. Continue educational training for professionals (i.e., nurses and social workers);
3. Initiate educational training for local and foreign nurse aides;
4. Assist remote areas that have no or scarce palliative resources with their own local palliative teams.

Amongst these four, attention has been focused mainly on the knowledge of hospital administrators and managers and on the educational training of nurse aides (#1 and #3 above).

Although the public and private sectors both provide palliative on-the-job training courses, most facilities still lack executive power and incentive to promote palliative care in the institutions. By offering custom-made courses that can satisfy the requirements and demands for palliative care, HFT hopes to encourage more long-term care facilities to initiate palliative care. These courses include topics such as: palliative care for cancer and non-cancer patients, how to ready staff for palliative care service, clinical training, grief counseling, death education, spiritual care, how to cope with unexpected death, how to talk about DNR, and etc. The essence of these courses is to encourage the elderly to openly discuss their Advance Care Planning and help the facilities to fulfill the needs of the elderly.

## III. Train the Trainer Strategy – a Practical Workshop

In response to the needs of the long-term care facilities, HFT held three-day practical workshops around Taiwan in November and December 2016. The workshops included a keynote speech and four panel speeches in the mornings, as well as in-depth discussions in the afternoons. The topic of the keynote speech was “How to create palliative care in long-term care settings”, and focused on the facilities' concerns about establishment and resources for setting up palliative care service.

The four panel speeches presented different professional viewpoints from administrators, nurses, social workers, and nurse aides, who all provided knowledge and skills required to promote palliative care in long-term care settings.



The afternoon discussions encouraged workshop participants

to share ideas and experiences on how they overcame common difficulties through means of communication and education. Their valuable experiences might help others to locate the practical resources and new methods needed to promote palliative care.

Furthermore, a case study was discussed to demonstrate how professionals from different areas mutually support each other and work as a team. It also brought the theories associated with palliative care into practice.

#### **IV. Provide Trainers with Resources to Prepare Teaching Materials**

Besides recommending experienced palliative care speakers and teachers and besides holding courses and speeches, HFT has also made efforts to publish palliative care teaching materials. In these teaching materials, professionals in long-term palliative care focus on three main topics:

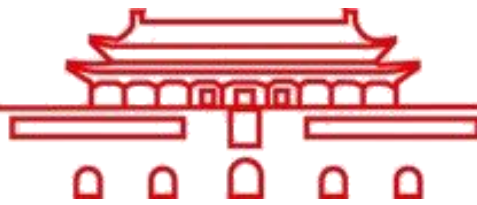
- Palliative Care, including symptom control, comfort care, and;
- Education, including the continuing palliative care education to different professionals;
- Case Study, including real clinical cases to share experiences and serve as references to long-term care facilities.

#### **Concluding Remarks**

According to the Ministry of Health and Welfare, Taiwan is entering into a hyper-aged society in which the elderly consist of more than 20% of the total population, that is, every one out of five people will be an elderly person over the age of 65. As such, the elderly who stay in long-term care facilities will surely increase drastically. For them, the facilities will be like their own home as palliative care is now expanded to Eight-non-cancer patients, whether chronic diseases or critical illnesses. Hence, the development of palliative care in long-term care facilities is a crucial need in response to the change of times.

Hospice Foundation of Taiwan intends to become a major supporter of the development in palliative care for long-term care settings. Additionally, we believe the palliative care should not be standardized, but rather, the highest quality must be provided. This is why we reiterate the importance to build up a custom-made palliative care in long-term care settings based on each facility's unique demands and conditions in order to ensure the elderly's ideal dying well.





# Sharing Taiwan's Experience in Palliative Care At the 2<sup>nd</sup> Hospice Summit in Asia-Pacific, Beijing 2016 (Mandarin)

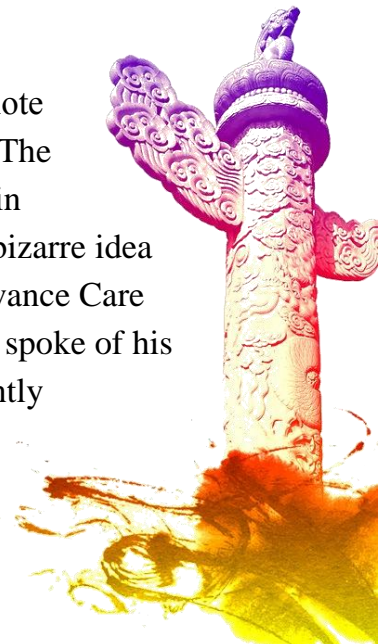
*by Vanessa Lin, CEO of Hospice Foundation of Taiwan ("HFT")*

According to a China Cancer Statistics survey published in 2015 by CA Cancer, J Clin shows almost 4.3 million Chinese were diagnosed with cancer, and 2.8 million died as a result of cancer. In the same year, the 2015 Quality of Death report published by Economist Intelligence Unit ranked China as 71 out of 80 countries in terms of overall quality. From these statistics, it would seem most cancer patients did not receive good end-of-life care, and possibly suffered a great deal while dying. Meanwhile, it is beyond imagination what and how the non-cancer patients may have felt regarding the quality of death. These research studies have attracted significant attention from the Chinese authorities and medical communities; nevertheless, high-quality end-of-life care is not something that can be achieved at once, but requires significant time and experience.

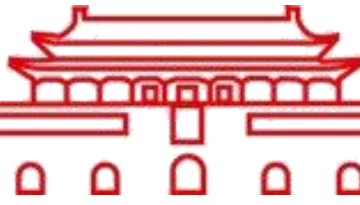
In response, Beijing Cancer Hospital--the leading cancer research and healing institute in China--and Hospice Foundation of Taiwan co-hosted the 2nd Hospice Summit in Asia-Pacific ("Summit"), which convened in the Mandarin language. The Summit was held at China National Convention Center on October 29, 2016 with more than 800 participants gathered to learn about end-of-life care and quality of death. Among the participants were many physicians, allied nurses, and volunteers.

The Summit began with HFT board member Dr. Yuen-liang Lai's keynote address on The Dialogue between the Medical Humanity and Technology – The Story of Taiwan Palliative Care. Regarding the promotion of palliative care in Taiwan, Dr. Lai mentioned how palliative care transitioned from a rare and bizarre idea to a common and important practice today. From Do-Not-Resuscitate to Advance Care Planning to further progress in the Patient's Self-Determination Act, Dr. Lai spoke of his hope to share with others about Taiwan's palliative experience, which currently ranks first in Asia and sixth in the world.

Attending the Summit from China were Professor Jiejun Wang from Shanghai Changzheng Hospital and Professors Tang Liang, Pingping Li and Lili Tang from Beijing Cancer Hospital. They spoke on various topics







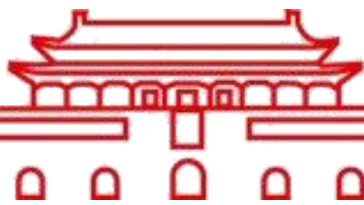
including: the main reasons for low quality of death in China from cancer medication, pain management, system and psycho oncology.

Prof. Wang pointed out that pain control with palliative care could significantly improve patients' quality of life by 15%. However, pain control remained an obstacle due to the restriction of laws and rules related to payments and procurement. As a result, there were still more than 40% of hospitals with patients who needed constant narcotic analgesics and were applying for the Narcotic Drug Purchasing Card, which could be a very complicated process. Furthermore, only inpatients might receive narcotic drugs; for this reason, the access of narcotic drugs for patients in China remained very difficult and rare. Many cancer patients lived in pain and died in pain. Prof. Wang further announced that the Chinese government was currently setting the benchmarks to cease intensive care, in hopes that palliative care would not be only for end-of-life care, but also a supportive care lasting throughout the entire caring process.

Prof. Liang advocated that the governmental authority must set up the standard procedure for pain management. He also stressed that the outpatient service should be the crucial link for both inpatient and home care, and especially that 95% of pain assessment should be done for outpatients. Furthermore, pain management should be benchmarked by patients' sleep quality, followed by comprehensive medication, education, and follow-up procedures to provide patients the proper pain control medication. Doing so would improve patients' quality of life significantly.

Prof. Li reminded the medical professionals at the Summit of the 4A Pain Management Principles, and that pain is a subjective perception. He suggested the two reasons for the gap in proper pain control as the following: the concern for both side effects and patients' risk for addiction, and also the misjudgment of the patient's pain. Speaking from an educator's point of view, Prof. Li reiterated the importance of communication between doctors and patients. Only through the channel of language could doctors achieve the best balance between a professional's knowledge and skill and a patient's anticipation.





Prof. Tang, the key person who introduced psycho-oncology to China, expressed her point of view from another angle, that is, from the patients' psychological state of mind. She emphasized how distress can shorten patients' survival period, let alone their quality of life. Therefore, she urged that the Distress Thermometer should be fully implemented, so that psycho-oncology could provide an all-around supervision on patients' psychological and spiritual states, as well as grief and bereavement support. Additionally, psycho-oncology might also be used to identify any palliative team members who experience burnout or fatigue in order to ensure they could provide proper end-of-life care to patients.

HFT also invited Dr. Chun-kai Fang (Director of Mackay Memorial Hospital's Hospice and Palliative Care Center), Dr. Cheng-hsu Wang (Chairman of Hope Foundation for Cancer Care), Dr. Shih-che Chiu (Director of Taiwan Hospice Organization), Dr. Sheau-feng Hwang (Director of Taichung Veteran General Hospital's Palliative Care Center), Dr. Chien-cheng Huang (Chi-me Hospital, Emergency Medicine), Ms. Pei-yi Li (Supervisor of Mackay Memorial Hospital's Nursing Dept.), Ms. Shih-yin Chang (Chief Nurse of Mackay Memorial Hospital's Palliative Ward), Mrs. Pao-fang Chang (the honorary team leader of Taichung Veteran General Hospital Volunteers) and myself, Vanessa Lin (CEO of HFT). Other Taiwanese speakers were arranged for the afternoon sessions, and with their diverse background and experiences, every session received positive feedback from the attendees. Indeed, Taiwan's palliative experience has provided Chinese palliative professionals a valuable reference through this Summit.

In summary, both China's great development gap between rural and urban areas, and the uneven distribution of medical resources have made the advancement of palliative care difficult. However, with this second large-scale Hospice Summit in Asia-Pacific, palliative professionals have exchanged experiences as they continue to advocate the importance of the right to die well, raise government and public awareness, and improve the quality of death for everyone.



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