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Forever Love, Endless Care

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A Peaceful Farewell –

An Essential Life Topic to Initiate Early

The Beginning and Future of Pediatric Hospice Care –

Enabling and Perpetuating Love



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A Peaceful Farewell— An Essential Life Topic to Initiate Early

With over 30 years of hospice care advocacy in Taiwan, most people are now embracing the concept of a dignified end of life, and are increasingly clear in their views and accepting in their attitudes. However, the *path* to a peaceful farewell still seems somewhat unclear to some. Only through fully enhancing the psychological, legal, caregiving, ethical, and other considerations of hospice care is it possible to find fulfillment for the last mile of the life journey.

When asked how they would prefer to approach the end of their lives, most people hope to bid the world farewell in a serene and fulfilling manner. A *good ending* is the pinnacle of end-of-life care, serving as the ideal objective of hospice care and embodying the pursuit of peaceful and dignified transitions.

Hospice care has been promoted in Taiwan for over three decades, with Professor. C. S. Chantal Chao being recognized as the pioneering *mother of hospice care*. According to Professor Chao, hospice care emphasizes a holistic approach encompassing the body, mind, spirit and society. It does not hasten nor prolong inevitable death. Its sole purpose is to assist patients and their families and friends to navigate the last mile of life's journey safely and peacefully.

Nowadays, the Taiwan public has formed a clearer attitude and understanding towards a dignified end. Hospice teams no longer have to spend extra time and effort communicating with families of patients when it comes to futile life-prolonging efforts. The discussion has been elevated to one regarding what can be done to increase the comfort of the patient after withdrawing futile medical interventions.

The Hospice Palliative Care Act and the Patient Right to Autonomy Act are two critical pieces of legislation regarding the final stages of life. The former focuses on palliative care for terminally ill patients, while the latter confers the right to refuse meaningless and futile life-prolonging treatments. These two pieces of legislation not only improve the quality of life for terminally ill patients by preventing ineffective medical interventions, but more importantly, they represent how society as a whole has taken on a different perspective. The strive for *autonomy* has now extended to medicine and the contemplation of what constitutes life.

In 2022, the Ministry of Health and Welfare expanded the scope of health insurance coverage for palliative care, so that elderly individuals in the terminal stage of frailty are now also eligible. This move holds significant positive implications for promoting a dignified and peaceful end to life, reflecting a society that is progressively more compassionate and considerate.

However, a dignified death isn't always a simple or romantic affair, and it definitely cannot be achieved with a vague request such as: *Do not resuscitate me*. Sometimes, it is more difficult to stand by and do nothing than do everything in one's power to save someone's life. Every dignified death is the culmination of many difficult considerations and choices.

Ethical Aspect –

Appropriate Medical Intervention Prevents Regret

The most common misconception from the public about death with dignity is the distinct barrier between medical treatment and hospice palliative care. It's often thought that the issue of dignified death is confronted only when the illness has progressed passed the point of no return. However, according to the World Health Organization (WHO), patients with life-threatening conditions or illnesses may begin hospice care at any time. This allows for the



gradual understanding of the patient's own outlook on life, so the most appropriate medical interventions can be adequately discussed.

Another common misconception is equating *Do Not Resuscitate* (DNR), that is, the refusal of medical treatments, with a dignified death. Dr. Sheau-Feng Hwang pointed out that in countries where medical costs are high, patients are often forced to stop treatment due to financial constraints, despite wanting to continue. In such cases, although patients do not suffer from excess and futile medical interventions, the question is then whether they consider this a dignified end to their lives. Taiwan's National Healthcare System has greatly reduced the financial burden of medical services, so that what is needed is for patients and family members to work together and figure out what their *bottom line* is.

Dr. Hwang once met an old nurse who was battling cancer. In her work, the nurse had seen for herself many patients who suffered the side effects of chemotherapy, and therefore, she refused treatment thinking it would only prolong suffering. Despite being a proponent of dignified death, Dr. Hwang took a different approach and encouraged the nurse to give chemotherapy a try. He explained to the nurse that chemotherapy can be stopped at any time, and that if the therapy is effective to reduce the size of the tumor, she would gain some comfort and valuable time. One week later, the nurse conquered her fears and was able to control the pain; eventually, she became well enough to leave the hospital to fulfill her life's dreams. Before she left though, she made a special visit to express her gratitude to Dr. Hwang.

"Doctors have an obligation to inform patients on when the treatment can be stopped, and when other choices are available," Dr. Hwang emphasizes. There exists a significant chasm between the decision of whether to continue or to cease medical treatments, and that's where the conversation often begins. A genuine dignified end of life should be one where patients are informed of and fully understand all of their available options, so that they make the most

appropriate decision. While there may be no easy or perfect decision regarding end of life, it is crucial to strive for a situation where patients and their families are spared from lingering regrets.

Legal Aspect –

Death with Dignity May be Different for You and Me

Dr. Wan-Ting Hsieh is one of the few doctors who also hold a law degree. She explains that ideally, most medical personnel are willing to honor the patients' desires, but in practice, this is very challenging to implement. This is primarily because in most cases, patients are no longer capable of communicating their wishes, and it is often left to family members to make decisions on their behalf.

Both the Hospice Palliative Care Act and the Patient Right to Autonomy Act have stipulations on the types of diseases and stages of illnesses for which hospice care is eligible. As a result, some patients may be unable to achieve their desired dignified end of life as they do not fit the criteria (e.g., not having eligible conditions or not being in an advanced state of illness). Dr. Hsieh explains that the Hospice Palliative Care Act is limited to terminal patients only so it's easier to reach a consensus between patients and their families.

On the other hand, the Patient Right to Autonomy Act covers a broader scope of decisions (e.g., Should antibiotics be used for severe infections? Should a nasogastric tube be inserted?), and each decision has the potential to prolong the patient's life considerably. To prevent disagreements between patients and their families, the law faces challenges if the patient has not already made a request.

“The law must take a clear stance, but clinical medicine tends to be more flexible,” says Dr. Hsieh. Some medical professionals find it difficult to see



patients suffer and are willing to respect both patients' and families' choices, often by adopting a more relaxed interpretation or allow for greater flexibility in medical interventions. However, other medical professionals will adhere to the strictest interpretation of the law, driving families to seek a second opinion, where conflicting answers can be encountered. These scenarios create the most common disputes regarding a dignified end of life care in the medical field.

An elderly man with terminal lung cancer was admitted to the ICU because of a heart attack. They managed to save his life, but afterwards, he was unable to undergo his normal course of treatment. Wanting a dignified end of life, he requested to be transferred to the hospice ward, where he authorized his youngest son to act as his Health Care Agent (HCA) and make medical decisions on the father's behalf. This decision was partly motivated by the elderly man's desire to make amends for having given up his youngest son for adoption as an infant; the gesture greatly moved the son. As the old man's condition deteriorated, Dr. Hsieh was afraid that he would not survive a second surgery. She conferred with the son, but that was when they reached an impasse. The son thought that a dignified death meant refusing treatment for only acute symptoms, but he wanted to give his father "another chance to fight it" if his father came down with another heart attack.

If the doctors followed through with the son's wishes and proceeded with the surgery—even though it was in complete compliance with legal regulations—the father would likely have pass away in the midst of his suffering. Under extreme stress, Dr. Hsieh continued to communicate with the son and hinted that his father should consider the potential risks and true meaning of having a HCA. The medical team also continued to discuss the father's condition every day, hoping to give him a dignified death that abides by not only the son's wishes, but also legal and ethical conditions.



“This underscores the fact that each person has different expectations of a dignified death,” says Dr. Hsieh. In the end, the father passed away in his sleep before everyone had to make a difficult choice; however, Dr. Hsieh reminds us that the discussion of a dignified end of life should be held as early on as possible, and with as much detail as possible.

For example, many people want to spend the last moments of their lives in a familiar setting like their own home, yet there may be differences in *when* it is the right time to go. Further questions may include: *Should I go home with a ventilator to take my last breath, or should I spend quality time with friends and family at home without one?* If it’s the latter, *Who will be responsible for end-of-life care?* Or even, *Which home should I return to, my hometown or where I currently live or the home of one of my adult children?* These are all questions that require detailed discussions before reaching a consensus.

Caring Aspect –

Fulfilling Patient Wishes & Providing Care Until the Final Moments

Having dedicated 23 years of her life to hospice care, nurse Ms. Hsiao-Ching Liu reflects that when she initially entered the hospice ward, most patients were terminal and there was little she could do for them. She often joked that at times, she was more an undertaker than a nurse. However, as public awareness is on the rise, many more patients with severe illnesses are requesting hospice care earlier than before. Therefore, the road to a dignified end of life is also becoming more personalized and customized.

“Everybody has a different idea about what constitutes a *dignified end of life*. Some believe that it’s at home surrounded by their children and grandchildren, while others believe that it’s a body free of any medical insertions and devices, and passing away quietly without disturbing others,” says Ms. Liu. However,



this might not always imply an irreversible choice. She shares an example of a patient whose acute symptoms stabilized in the hospice ward, leading to an increase in appetite and energy. This then prompted the patient to view life differently and eventually return for continued treatment.

Ms. Liu notes that no matter how one chooses to approach the end of life, hospice requires extensive care to alleviate the pain of different discomforts. An example is the removal of the nasogastric tube. Although terminal patients no longer require extensive nutrition, they still need some intervention to minimize their suffering in the difficult last stretch. In such cases, comfort feeding can be initiated. Through professional assessment, suitable food textures can be provided, or even a little olive oil to alleviate problems caused by stomach acid. Similarly, for terminal patients with constipation, appropriate care and treatment can be administered as well. The overly simple approach to *stop eating and drinking* is certainly not the only way to a dignified end.

Ms. Liu remembers that she once had a patient who was a very experienced and successful chef, who had cancer of the digestive system. The tumor made it difficult for a food lover like her to eat, so she would only take a few bites and refuse to eat more. Nevertheless, she still enjoyed trying different foods. Towards the end, she decided to remove the nasogastric tube and reclaim her chef's robes to make her famous braised pork balls (also known as *lion's head* in Mandarin) for everyone. Despite her fatigue and the cancer-induced swelling that nearly prevented her from wearing the chef's robes, she still took Ms. Liu's hand in hers at the end and said with deep emotion, "I'm so happy, so very, very happy."

"Beyond the body, the spirit is another important consideration on the path of hospice care," acknowledges Ms. Liu. When the patient experiences suffering towards the end, there are many techniques to alleviate a patient's discomfort. Families can also find other methods to show love and care, such as talking,

singing, listening to music, or even helping the patient fulfill a final wish. The last phase of life does not have to only be marked by tears, but can also be a time of serenity and gratitude.

Emotional Aspect – A Dignified End of Life Involves Taking Care of Those Left Behind

“Having a death that can be anticipated and adequately prepared for is—for both the patient and their companions—a dignified death,” says Ms. Wei-Chun Lin, a clinical psychologist at the Cancer Center of Chimei Hospital at Liouying. Everyone desires a sense of control in life, and if patients and their families are fully prepared psychologically for the journey ahead, then it can prevent unnecessary medical interventions early on and bring about a sense of peace in the later stages.

Psychologists play an important role in family meetings within the hospice ward. They are responsible for assisting patients and their families in the organization and exploration of their thoughts and feelings, and helping them reconstruct a picture of what family life was for the patient. Additionally, psychologists must carefully determine whether family members are genuinely honoring the patients’ wishes when making medical decisions on their behalf.

“Some family members will tell me that the patient has a pessimistic demeanor and often talks about wanting to die,” Ms. Lin says. However, behind these hopeless, negative comments may be the patient’s attempts to seek attention from their family members, without really intending to give up on life yet. In some cases, the patient’s condition might not be as dire as it seems, but the family’s reaction might be unexpectedly hesitant to continue the battle. This could be due to the caretakers’ finding themselves at a financial or emotional breaking point on the long and arduous medical battle.



The family members or caretakers will then require resources from mental health professionals or social welfare for assistance.

One Friday afternoon just before the end of her shift, an elderly man in a coma was wheeled to the hospice ward accompanied by two devastated daughters. His condition was very dire, so Ms. Lin hastily encouraged the daughters to express their thanks, apologies, affections, and goodbyes. In the presence of their father, they reminisced about the past together.

Ms. Lin had expected that when she returned to work on Monday, the elderly man would have already passed away. To her surprise, he had temporarily stabilized and improved, and was even able to enjoy some time outdoors in a wheelchair. She asked him, “Did you hear what your daughters had said?” He nodded slightly. Then Ms. Lin continued, “Did it feel good to hear what they said? Would you like to hear it again?” And the elderly man, whom the daughters had described as a stern and busy man, broke into a smile and chortled, “Yes! It felt *great!*”

“Once a person has passed away, there is no opportunity for closure,” Ms. Lin points out that a dignified end to life is not limited to the person who is passing away, but should include consideration for the friends and family, too. For patients with unresolved family issues, Ms. Lin encourages them to seek closure. She says this not only ensures that the patient has no regrets, but it is also about minimizing potential emotional turmoil for family members who are left behind.

Regardless of the length of one’s journey, the best possible outcome to hope for is one that is fully prepared for the final mile as the last goodbyes are expressed. Therefore, initiating discussions about a dignified end of life early on allows both the patients and their families to find peace in this transition, ensuring that the path towards the end is one of peace and contentment.



The Beginning and Future of Pediatric Hospice Care— Enabling and Perpetuating Love

Hospice care is not limited to adults. Although the number of people needing children's hospice is currently in the minority, the unique physical, mental, and spiritual needs between children and adults require a comprehensive approach to children's end-of-life care. This includes tailored planning for pediatric patients as well as extended support for their families. Over the years, Dr. Frank Leigh Lu has persistently advocated for Taiwan's medical field to acknowledge the importance of pediatric hospice care. He has even drawn inspiration from international practices, in the hope that one day the gaps in pediatric hospice care can be bridged and fulfilled.

According to statistics, approximately one percent of all deaths, or about 1500 cases, in Taiwan each year are among children under the age of 18; this is the impact of the low birth rate. Even though the proportion of child fatalities is low, the impact on families and even the siblings may be significantly greater than can be imagined.

Dr. Frank Leigh Lu, Director of the Department of Pediatric Pulmonary and Critical Care Medicine at National Taiwan University Children's Hospital, recognizes the need for pediatric hospice care from the forefront. As early as 2012, he not only set up the Children's Hospice and Palliative Care Integration Team at NTU Children's Hospital, which demonstrated his commitment to addressing this need; but he further dedicated himself to organizing relevant seminars and exchanging information with the international community, with the aim of enhancing the recognition and importance of children's hospice care in both Taiwan and on a global scale.



A Divide between Worlds Unveils the Gateway to Exploring Pediatric Hospice Care

"Why are you not God?!" Even after all these years, these words occasionally ring in Dr. Frank Leigh Lu's ears, reminding him of a tragedy that tore a patient's family apart.

He was in his third year as an attending physician in the pediatric intensive care unit, and despite his enthusiasm, he repeatedly encountered and came to terms with the arrival of death. Some children, even with aggressive treatment, could not escape the grasp of death, like the child who, in the prime of his youth, succumbed to a sepsis so severe that even the ECMO failed to be effective. He watched over that child, yearning for a miracle, but this time God chose to remain silent.

"In the end, we switched off the ECMO, and he was pronounced dead shortly afterward," Dr. Lu recalls. This incident is not an uncommon occurrence in pediatric intensive care units, yet the grief it caused was too overwhelming for the family to bear. To Dr. Lu's surprise, a year later, he received a notice from the hospital that the father had chosen to file a lawsuit against him.

Before the lawsuit could be filed, a mediation session had to be held at the local health department, and it became a scene that Dr. Lu would never forget.

The grieving father, accompanied by his lawyer, sat down opposite Dr. Lu. When the chairman asked the father to present his thoughts and opinions, the father pounded the table with his fist in anger and frustration, and stood up with his accusing finger pointing dangerously close to Dr. Lu's nose. He yelled in a near-hysterical manner, "Why are you not God?!"

This meeting ultimately ended with the chairman's dismissal of the lawsuit, but in Dr. Lu's heart there was a heavy weight like a huge stone. Three years later, when he crossed paths with this father on the street, the young man had a sad face and empty eyes, walking along the road as if he were a wandering spirit. Dr. Lu



mustered up the courage to initiate a conversation with him, only to learn that the father, because of the child's death, had never been able to let go of his pain and guilt in losing his child. He struggled to concentrate on his work, his family life grew strained, and tragically, in some cases, the issue of hospice care may lead to the dissolution of marriages, which is very saddening.

In the face of these devastating events for the patient's family, Dr. Lu could only tell him what kind of psychological support services were available at the hospital, but he could do nothing more. He never saw the father again, however, the incident did not end there. Instead, it stirred something in Dr. Lu's heart.

"Despite hospice development in Taiwan spanning many years, there's relatively limited care for children. Even though the child mortality rate in Taiwan is only one percent of all annual deaths, the impact on the whole family is profound," he reflects. Being at the forefront, the daily reminders prompt Dr. Lu to contemplate: "What can we do besides lament? We should take action!"

Establishing a Care Team for the Official Implementation of Pediatric Hospice

According to Dr. Lu, "The loss of a child is a devastating blow to the entire family, and hospice care cannot stop at the hospitalization alone; it must continue to provide support and counseling to them even after the patient's death." In a bid to gain a deeper understanding of pediatric hospice care, Dr. Lu pursued further studies in Boston from 2003 to 2005. He explains, "When I returned to Taiwan, I wanted to create a child-friendly health care team that would include not only the child's care, but also provision of support for the child and the family."

This aspiration was finally realized in early 2012. With the active support of NTU's hospital administration, the hospital's medical and nursing staff, social workers, and psychologists within the institution, the *Children's Hospice and Palliative Care Integration Team* was established at the NTU Children's Hospital.

The endeavor also involved art therapists, music therapists, and many others in the effort.

Even though the team's efforts are not reimbursed by health insurance, it has not quenched the enthusiasm of NTU's medical staff, which raises funds and even holds regular seminars and case discussions, all for the sake of providing a better medical environment for pediatric patients.

Someone once asked me, "Do you prefer to save lives in the ICU or facilitate the passing of children?" Dr. Lu responds, "To me, ICU should be about giving the most appropriate care to the children, and it is meaningful work as it aligns to the best interest of the child." Along with his team, Dr. Lu initiated their efforts in the ICU, and gradually extended into the pediatric cancer unit, where they have hired many personal care workers to participate in children's hospice care and treatment.

In the process, they have come to realize that early intervention of children's hospice not only provides more timely support for various issues, decisions, fears and concerns, but also allows this support to persist and develop even in the case where the child's life tragically comes to an end.

Similarly, there was a child who, after being admitted to the hospital, struggled to accept his own condition. He went from cursing and throwing things to becoming completely silent, with a look of horror and hatred in his eyes for not only the doctors and nurses, but especially to his own parents. His resentment was understandable, yet the team could not find a way to reach into his heart.

It was not until the team learned by chance of his love for Harry Potter that it gave the team a little hope. Dr. Lu explains that at first the art therapist had to self-direct the play, and the child remained silent until one day he saw the art therapist paint one of the character's clothes in the wrong color; that's when things took a different turn.



"That's not the right color!" the child shouted and pulled the drawing towards himself; he then filled it in with the correct color for the character. This marked a turning point, and he began engaging in the art therapist's sessions. In his drawings, he progressed from using only black ink to his appearing behind a barred window, and later, he sketched a door. Over time, his drawings became increasingly vibrant, depicting images of himself playing with other children. Consequently, his demeanor improved, too, and he eventually resumed conversations with his parents. They even embraced each other and discussed the future together.

"If we hadn't taken these steps, he would have remained angry until the day of his departure, which would have been even more traumatizing for the whole family," Dr. Lu says empathetically. He emphasizes that the child's ability to make peace with himself, his illness and his family at the final moments of his life is exactly the essence of what children's hospice aims to achieve.

Program Support Inspires Nationwide Hospitals Involvement

"Hospice and palliative care aim to transform the most challenging memories into positive experiences. It's not just about avoiding suffering, but also about fostering deeper connections and building legacies of love, whether in the present life or beyond, and even continuing the growth and learning of life," says Dr. Lu. To him, the passing of a child does not mean a complete end, but rather, it leaves behind sentiments of gratitude, appreciation, and blessings.

Hence, after NTU Children's Hospital established the Children's Hospice and Palliative Care Integration Team, it not only provides compassionate care during a child's hospitalization, but also follows up with the family for a minimum of two years after the child's death. Dr. Lu highlights that they are willing to be with the family for longer if they are willing, being prepared to accompany the family until normalcy is restored in both physical and psychological well-being.



According to Dr. Lu, Taiwan's initiative in forming children's hospice teams for supportive care began with Taipei Veterans General Hospital, followed by NTU Children's Hospital. Other hospitals also have varying degrees of involvement in children's hospice care, but their numbers are limited. When Dr. Ying-wei Wang assumed the role of Director of Health Promotion Administration in 2016, he urgently instilled a program implemented to address the gap in hospice care, specifically focusing on the frail elderly individuals and children.

With a deep commitment to pediatric hospice care, Dr. Lu dedicated himself to obtaining qualifications as a hospice specialist. Presently, there are fewer than 10 pediatricians in Taiwan's field of pediatrics who also have a hospice specialist license, and he is one of them. As a result, Taiwan Academy of Hospice Palliative Care entrusted Dr. Lu with the work of children's hospice-related efforts. He has been instrumental in contacting major hospitals to form pediatric hospice-related teams. Additionally, he gathered pediatricians, nurse practitioners, social workers, psychologists, children's medical counselors, art therapists, music therapists, and others to publish the *Taiwan Children's Hospice and Palliative Care Reference Manual*, and have even organized many seminars and training courses.

"This initiative has also led to the establishment of children's hospice teams at Changhua Christian Hospital and National Cheng Kung University Hospital," Dr. Lu says. He mentions that the program has been a major step forward for children's hospice in Taiwan.

Drawing on Overseas Experiences to Establish Children's Hospice Homes

However, the three-year program came to a halt with the change of leadership at the Health Promotion Administration. Despite the absence of ongoing government support and a reduction in resources, Dr. Lu continues to organize monthly seminars, and has even incorporated children's hospice into the curriculum of NTU's Department of Medicine and residency programs. He explains, "Currently,

pediatric hospice care in Taiwan has not yet reached the stage of widespread development, but we have seen progress. Hopefully, more resources and strength can be gathered in the future.”

Dr. Lu is not alone in his efforts, as there are many countries around the world that are committed to children's hospice care, and all of them have something to teach Taiwan.

The neighboring Japan, for example, is where he most longs to go.

He shares, "I once had the opportunity to visit Maple Leaf House at National Center for Child Health and Development, a children's hospital in Tokyo, Japan. It was founded with the support and sponsorship of Helen House in London, England." Maple Leaf House is a two-story house, and its model of care originates from Helen House. He continues, "Helen House's concept of children's hospice is not quite the same as a hospice ward, in that the whole family can stay there, and its focus is not primarily on medical care."

Dr. Lu points out that in addition to Maple Leaf Home in Tokyo, Japan, there are also children's hospice homes in Osaka and Yokohama. Furthermore, Japan has a comprehensive system of care for seriously ill and disabled children at home, encompassing care all the way through hospice. These are areas where Taiwan lags behind and needs improvement.

There is growing interest worldwide in children's hospice. For example, in 2023, Malaysia established a Children's Hospice House. Hong Kong has the Society of Children's Palliative Care, which is dedicated to promoting issues related to children's hospice. In China, hospice-related care units are located in Shanghai, Beijing, Nanjing, and Sichuan. Professionals from Taiwan's hospice community have also selflessly offered assistance and guidance to these regions.

"We hope that one day Taiwan can also establish a children's hospice home," Dr. Lu further says. Having worked with children for a long time, he further explains



that children don't think the same way as adults: "Some want to go home, while others want to be with friends they know."

Dr. Lu explains that the location for children's hospice does not necessarily have to be at home. The most important thing is to create an environment where the child feels happy, comfortable, and at ease. Therefore, in addition to hospice wards and home-based care, Taiwan's approach to pediatric hospice should be diverse, and establishing children's hospice homes are the next logical step. "What path should Taiwan's hospice care take in the future? What resources are available to help in this endeavor? These are the elements of progress and development moving forward," he emphasizes.

"Living Well" Hospice Creates Fond Memories

While children's hospice in Taiwan is currently in its early stages of development, Dr. Lu affirms that the development of children's hospice brings a different kind of motivation than adult hospice, which has significantly more resources. He says, "For example, unlike adult hospice that often intervenes only in the last 3 to 6 months of life, children's hospice requires support over many years. Therefore, when facing the end of life, even though it remains impactful and influential, the resources, interactions, and support accumulated during this time can significantly enhance subsequent care, making it more comprehensive."

Traditional hospice care often focuses on *a good death*, but Dr. Lu frequently poses the question to his audience: "What about when you're alive?"

"Often the children don't know what to do, or how to live a meaningful life, or how to fulfill their wishes in their limited lives and physical capabilities." Dr. Lu reflects, "*Living well* is also very important, which is why we need a team to enrich the children's limited lives with vibrant and meaningful experiences. It is equally important to create lasting memories, recollections, and bonds of love for their families."



Dr. Lu candidly acknowledges that Taiwan still has a long way to go in children's hospice, especially since NTU Children's Hospital often receives referrals from other hospitals, which do not have relevant resources. On the other hand, he also anticipates addressing the needs of children lost through stillbirths and miscarriages in the future, "which is an unmet aspect and a missing piece of the puzzle in Taiwan's overall hospice."

While the path ahead for children's hospice may be lengthy, it is not without promise. Dr. Lu is filled with confidence especially with all the opportunities for learning and adaption from abroad; along with the increasing number of domestic medical professionals who are devoting themselves to this cause. He says, "Even though child mortality accounts for only one percent of annual deaths in Taiwan, the profound impact and far-reaching ripple effect it creates on the family cannot be underestimated. My hope is that every child can receive the most suitable care, as hospice and palliative care are fundamental rights for everyone."

