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Forever Love, Endless Care

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Amongst the Scent of Books and Tea, Life Is "Just Fine"

After completing her medical studies, Dr. Wan-Ting Hsieh fulfilled her ambition by entering the medical field. At the onset of her professional journey, she ventured into the realm of hospice care. Presently, she holds a prestigious position as the Director of the Palliative Medicine Department at Chi Mei Medical Center. Yet, deep within herself, she realizes that there is still missing a crucial piece in her perception of hospice care.

Today, with the hospice unit running smoothly and a cohesive team in place, Dr. Hsieh has finally found the time to seek out that missing puzzle piece. More precisely, she's rediscovering it and fitting it back into place. This vital piece takes the form of the *SüRüM Bookstore*, set to launch in October 2023 as a community space fostering discussions about literature and life.

Bypassing the Hospital to *Live Well* in the Community

"Live well, live meaningfully. Within books lie many versions of life, and the life obstacles ahead represent the crucial steps into a new dance." This message is the invitation by Dr. Hsieh forthcoming *SüRüM Bookstore's* opening; it reflects her heartfelt desire for everyone—a gentle aspiration cultivated through years dedicated to hospice care.

The origin of the bookstore stemmed from a sense of dissatisfaction with the present state. It was about four or five years ago when the Patient Right to Autonomy Act (PRAA) was just passed, and while everyone was energized by another stride in hospice care, Dr. Hsieh remained composed and carefully examined the inadequacies and implementation dilemmas within this development.

"At that time, I had a sense that according to the regulations, we could only conduct



Advance Care Planning at hospital outpatient clinics. However, these consultations were often geared toward individuals who weren't yet ill," Dr. Hsieh says. She has been a constant presence at the forefront and has witnessed the most authentic front-line scenarios. She continues, "Many individuals felt the need to sign these documents for themselves, but found it uncomfortable that they had to visit the hospital in order to schedule an appointment."

Immersed in hospice care, Dr. Hsieh is undeniably committed. She frequently engages in community outreach to advocate for hospice care and PRAA, conducting workshops and health education. However, she finds herself repeatedly questioning whether this inadvertently confines hospice and PRAA further within medical institutions: "Aren't hospice and PRAA fundamentally community-oriented and universally applicable concepts?"



As a doctor and writer, who is self-deprecatingly embracing the multifaceted life, Dr. Hsieh pondered how to liberate the concepts of hospice and self-planning within the PRAA from the confines of hospitals and introduce them to a broader audience. After all, whether one is planning for their health, life, or estate, decisions aren't made with a single lecture or consultation; there's a wealth of intricate details to delve into, including one's own emotions.

"When advocating for hospice or the PRAA, our goal was always to strive for the best. However, this isn't something that people can grasp quickly. It's not just about



understanding what the regulations state, but more importantly, comprehending one's inner thoughts," she explains. Dr. Hsieh firmly believes that this understanding is crucial to returning to the core values of hospice—embracing the entirety of the individual, the family, and the entire journey.

Opening Up the Sky to Create a Community Hub

When Dr. Hsieh found herself unsure how to find the missing piece and materialize her longing, a colleague from her long-standing hospice team, after hearing her thoughts, cleared the fog, saying, "'Director, I know what you're aiming for! What you're after is a hub for activities.'

That simple phrase struck her like an epiphany, and Dr. Hsieh couldn't contain her excitement, exclaiming, "Yes! That's the idea. I want to initiate a 'social movement' for compassionate living, mindful existence, and dignified passing."

Expanding on her thoughts, Dr. Hsieh emphasized how, especially in cases like the Patient Right to Autonomy Act (PRAA), people need time for self-awareness, self-acceptance, and understanding how to safeguard their rights under the law before they can plan ahead. These processes require nurturing and support, but within the healthcare system, time is often the most limited and pressing resource.

"Not only time and pace, but also space and environment are essential," expresses Dr. Hsieh, who anticipates a place where people could feel at ease that is much different from the formality of a medical consultation, and perhaps could even internalize through small, engaging activities.

"In essence, it's about having the time and space to assist everyone in planning for a fulfilling life, a peaceful passing, and a meaningful existence," summarizes Dr. Hsieh. Besides being a physician, she's an author and an avid reader. In the realm of hospice care, books often become a medium of connection with patients. With thoughtful arrangements, simple words on a page or even an illustrated book with straightforward sentences can wield unexpected power in providing companionship.



In an instant, her world expanded. She no longer confined herself solely as a hospice physician, but instead, Dr. Hsieh embraced her background and expertise, stepping into the community to establish a bookstore. Here, within this realm, she engages with people to contemplate how to live each day to the fullest, saying: "We all desire comfort in our bodies, joy in our hearts, harmony in our relationships, and peace in our spirits. Hospice shouldn't just be associated with death."

Originating from Marketplace Stalls, *Book of Final Wishes* Leads to Life Planning

From feeling inadequate within to clearing the fog and forming the idea for the bookstore, Director Hsieh spent a full two years on this journey. Even so, this was just the beginning.

Returning to the practical aspect, she couldn't help but worry that her inner thoughts might ultimately be nothing more than a romantic notion that wouldn't truly resonate with people. Hence, before establishing the bookstore, she needed validation, and her method was to participate in various marketplace stalls.

"Even if people don't buy the book or I find it too challenging, I can always step back," Hsieh reflects. Yet, beneath her smiling demeanor, there remained a bundle of tension that held her captive.

When she set up her stall, she designed the *Book of Final Wishes* and conducted a series of workshops titled *A Good End Is Just Fine*. She elaborated that the Chinese character [終, i.e., sounds like *zhong*] – meaning *end, finish* – represents the concept of peace and tranquility; yet this character has many homophones. As one example, she substituted it with [鍾] – meaning *to concentrate on one's affections* – in hopes for individuals to better appreciate themselves. And another example, she used [忠] – meaning *loyal, faithful, devoted* – to encourage people to be honest and loyal to their inner feelings. The *Book of Final Wishes* is really more about whether one is living well or not, and less about thoughts related to death.





The *Book of Final Wishes* comes with four postcards: A Fine Body, A Fine Mind, A Fine Relationship, and A Fine Finance. Each postcard offers distinct cues to guide the writing process, which Director Hsieh suggests: "This is essentially a translation of medical language. By following the postcards' guidance and jotting down details about your closest relatives or designated healthcare proxies, along with plans regarding your spiritual, relational, and financial aspects, these can be taken to an Advance Care Planning clinic in the future, serving as an invaluable reference."

Initially, the booth didn't attract much attention and faced skepticism, with few people showing up. Despite these doubts and challenges, Director Hsieh found her confidence. One participant excitedly remarked after attending an event, "I've been searching for this kind of activity!"

She explained that she frequently engages in similar gatherings, spurred by her grandmother's passing, which made her ponder about life and death. "We didn't even know her clothing preferences because no one had ever asked her, and we were unsure how to approach the topic."

Transforming the Bookstore into a Public Haven and a Launching Pad for Hospice Care

Throughout her involvement in hospice, Director Hsieh had encountered similar sentiments before, but these discussions were primarily conducted within clinical



settings and hospital wards, facilitated by professional guidance. Hence, when individuals expressed: “Participating in related activities only guides me on how to live and die well, but they don’t provide specific guidance for when I need to sign an advance decision. I never imagined having a professional doctor sit down with me here to discuss these matters!” Her confidence surged as she realized that SüRüM Bookstore would undoubtedly serve as a community haven and another pivotal starting point for hospice care.

Lectures might help individuals develop the right mindset, but they don’t provide the practical steps needed to reach that mindset. SüRüM Bookstore will serve as that pathway.

"That person's affirmation was significant, indicating that the role of physicians remains crucial in life and health planning. It's meaningful for doctors to step out of their traditional roles and engage with the community," Director Hsieh expresses with delight, announcing SüRüM Bookstore's opening in October, and promising an ambiance amongst the scent of books, tea, desserts, and occasional events.

She anticipates and understands that SüRüM Bookstore isn't about evoking or capitalizing on emotional sentiments; instead, it's about engaging in romantic and intriguing activities together. Her hope is that “in the future, when individuals embark on life planning, the time spent at SüRüM Bookstore will offer them the most substantial support.”



In Life's Final Stretch, Can We Still Retain the Desire to Eat by Mouth?

Chewing, swallowing, and enjoying food constitute a significant joy in life. However, when factors like aging, stroke, dementia, or terminal illness impede a person's ability to swallow, balancing life-sustaining nutrition while preserving the joy of eating by mouth becomes the wish of many patients and a deeply distressing challenge for their families.

"Grandma is willing to open her mouth to eat!" The daughter was overjoyed seeing her 95-year-old Grandma Zhang successfully have her nasogastric tube removed, reclaiming the ability to eat by mouth and even speak. She had not anticipated that, through the collaborative efforts of a speech therapist, a dietitian, a home doctor, and a nurse practitioner, the nasogastric tube could be removed within just two months. Moreover, her mother could now join the family for meals outside the home.

Grandma Zhang, who suffered from severe dementia, was hospitalized due to shock during the Chinese New Year. She subsequently developed aspiration pneumonia and required a nasogastric tube. Uncomfortable by the presence of the tube, she frequently removed it on her own. Witnessing her distressing actions, her family felt deeply saddened and anxious, fearing she might be confined to a bedridden life dependent on tubes. Hoping to restore her ability to eat by mouth, they sought the assistance of Ms. Hsueh-Pei Wang, a therapist and the director of Enjoy Swallowing and Speech Clinic.

"Due to her prolonged struggle with dementia, Grandma Zhang seldom speaks and, being hospitalized for an extended duration, she's developed a strong sense of defensiveness. When encountering unfamiliar faces, she becomes highly anxious, keeping her mouth tightly shut. Despite her silence, she emits throaty purring



sounds." After Director Wang's assessment, tailored strategies were devised and gradually implemented. Eventually, Grandma Zhang transitioned from consuming only thickened or frozen liquids to eating shaped meals. Remarkably, within a month and a half, she progressed to the point where the nasogastric tube could be removed.

Following that, Grandma Zhang's swallowing training progressed to the extent that she could consume *home-cooked soft meals*. "With her family's assistance and meticulous meal preparations, she was able to revert to her former lifestyle," Director Wang mentions. What's truly remarkable is the improvement in Grandma's cognitive abilities—her speech capabilities have surpassed her pre-hospitalization state. Not only does she engage more actively with others, but she also initiates conversations and inquiries. As a result, her family can now take her out for meals together.

Eating Comfortably Is of Greater Importance than Deciding Whether to Remove the Nasogastric Tube

Numerous terminally ill patients encountering swallowing difficulties may eventually confront the need for a nasogastric tube due to inadequate nutritional intake or the risk of aspiration pneumonia. During this period, their families often grapple with a challenging dilemma. They yearn for their elders to enjoy beloved foods in the twilight of their lives while simultaneously worrying about the heightened risk of aspiration pneumonia if the nasogastric tube isn't inserted. This dual concern renders the decision of whether or not to proceed with the NGT insertion exceedingly challenging.

Drawing from over a decade of experience as a nurse and speech therapist, Director Wang reassured Grandma Zhang's family that even if an elderly individual opts for home care with a nasogastric tube, they can still engage a speech therapist to facilitate oral feeding if the desire to eat persists. This doesn't mean the complete cessation of mouth feeding once the tube is inserted. "Our aim in assisting terminally



ill patients with oral feeding is to ensure that elderly individuals receiving home hospice care can eat comfortably, preserving their dignity," she emphasizes.

The concept of comfortable eating aims to provide dementia or terminally ill patients with swallowing difficulties the choice to eat orally when they desire, and the option to abstain or use alternative methods (like gastrostomy or IVs, etc.) when they don't wish to eat. This approach transforms eating into a form of *enjoyment*. There exists a wide array of methods and tools, and as a speech therapist, Director Wang begins the intervention by asking the patient, "What do you most want to eat?" Once the patient's favorite food is identified, she determines a safe texture that aligns with the patient's swallowing ability. For instance, steak can be transformed into a *soft steak* that gently dissolves when chewed by the gums, or a *frozen steak* that dissolves when pressed against the palate (see picture). If the patient desires beer but faces difficulties with water due to choking, she prepares thickened beer that maintains its delightful bubbly texture!



Once the patient's favorite foods are established, the next step involves aligning these preferences with their swallowing abilities to identify a texture that not only caters to their tastes but also ensures safety in consumption. This might involve options like *frozen shaped steak* or *thickened beer* that retains its effervescence.

Eating or feeding techniques are personalized, with speech therapists instructing caregivers on safe feeding methods. For promising patients, therapists gradually



train and improve their swallowing functions.

"Speech Therapists" Helping Patients Rediscover the Pleasure of Eating

The role of a speech therapist, in essence, involves assessing and discussing the needs of the patient and their family, offering assistance in swallowing training, speech rehabilitation, dietary guidance, and caregiver education. “Simultaneously, evaluations are tailored based on the family's caregiving capabilities, and the training goals sometimes focus on reducing the risk of aspiration pneumonia,” Director Wang describes the support speech therapists provide for terminally ill patients in home care under Long-Term Care 2.0.

In the past, families seeking the assistance of a speech therapist through medical units often required a referral from one department to another, typically from the original department to the rehabilitation unit. However, under the current Long-Term Care 2.0 program, when terminally ill patients transition to home hospice care and require feeding and swallowing support, speech therapists have been included within the scope of Long-Term Care subsidies. As long as patients face swallowing difficulties or use a nasogastric tube at home, they can undergo evaluation and confirmation by professional physicians and speech therapists at medical institutions. Subsequently, they can apply for *long-term care professional services* to aid caregivers in patient care. Additionally, families can seek out *speech therapy clinics* within medical institutions, where speech therapists can visit patients at home to practice eating by mouth and safe swallowing, aiming to enhance their quality of life.

Director Wang highlighted that the core of rehabilitating swallowing disorders typically involves training the ability to swallow. It's akin to a fitness regimen tailored for the muscles involved in swallowing. Through various strategies and techniques, speech therapists train and fortify these muscles to improve the swallowing functions.



If someone is in the late stages of a serious illness and requires home hospice care, given the various physiological challenges they may face, the approach advances to a collaborative effort. This involves assembling a team comprising a speech therapist, an otolaryngologist, a dietitian, and a nurse practitioner. They work collectively, entering the patient's home to address issues related to eating and swallowing.

Enjoy the Dignity and Right to Eat by Mouth

In practice, when speech therapists enter the home of a terminally ill patient, they typically initiate discussions with the patient or their family about things like “What is your greatest desire?” “Is there something specific you crave?” “What were your favorite foods in the past?” Using a guided approach, they gradually work towards fulfilling the patient's wish to eat by mouth. Director Wang refers to the renowned Japanese concept of *Joy-in-Swallowing Support* in home healthcare to illustrate this. “Their belief is that the patient should choose what to eat, while the responsibility of the medical staff is to determine how to eat and ensure safety. Therefore, upon returning to home hospice care, the team assists patients in consuming their desired foods in the safest manner possible.”

What many families aren't aware of is that speech therapists can instruct patients on how to use the muscles in their mouth and throat, aiding in the removal of the nasogastric tube and facilitating the intake of food and liquids by mouth. “At times, physicians may educate family members that it's safer to have a nasogastric tube inserted to prevent the risk of aspiration pneumonia.” Consequently, this leads to depriving the patient of their right and opportunity to eat.

Sometimes, family members feel substantial guilt if the patient chokes on food, resulting in a life-threatening situation, and “they blame themselves for that particular spoonful,” Director Wang mentions. Even with a nasogastric tube inserted, there remains the risk of aspiration pneumonia. The speech therapist's responsibility is to remedy such regrets and provide the patient with another opportunity to eat.



She once accompanied a grandmother with Parkinson's disease into home hospice care. The grandmother experienced discomfort due to excessive saliva that felt sticky and lodged in her throat. It was mistaken for phlegm, unextractable despite efforts. "Upon understanding her condition, our focus was solely on training her swallowing function. During our sessions, we fed her small amounts of jelly water to facilitate swallowing. The aim was to teach her how to swallow, naturally reducing the need for phlegm extraction," Director Wang explains. This approach aligns with the emphasis on comforting care in home hospice, ensuring the patient's comfort and dignity.

Embracing Beauty Even at Life's End

The beauty of life lies in the ability to engage with the world. When illness strips away the joy of existence, does prolonging life simply mean extending suffering? Finding happiness in savoring food by mouth is profound, but compelling someone in their final days to be fed intravenously is similar to depriving them of the right to a natural passing. It's a delicate balance and requires utmost respect for the wishes of the patient and their family.

"After all, fasting is not necessarily a good way to die," shares Director Wang. Drawing from her extensive experience aiding numerous terminal cases, she profoundly believes that "having loved ones by your side and enjoying meals until life's very end" bring the greatest happiness.

Dr. Kanji Nohara from Japan suggests that what brings vibrancy to the final stages of life, where death is imminent, is *food*. At this stage, *food* ceases to be merely a source of nutrition; rather, it becomes a form of communication. For the remaining family members, it might also serve as a ceremonial way of bidding farewell.

Director Wang says that there's now a wide range of Dysphagia Diets available, which includes liquids, mousses, purees, solid textures, and even dishes with flavors resembling homemade meals. These can be tailored into various *delicious* care



meals, considering the patient's chewing and swallowing abilities. "There's really no need to worry about inadequate nutrition. Some of these meals are highly nutritious, with a high nutritional density, where even a small portion can fulfill the nutritional requirements of an entire meal," she emphasizes. She stresses that in life's final stretch, being able to eat with our mouths and share the delightful taste of food with our loved ones may enrich people's lives, fostering a sense of completeness and leaving no room for regrets.



Thoughtful Discernment about the True Meaning of a Good Death

In the past, I've encountered occasional misconceptions where some people mistakenly view the cessation of antibiotics, IVs, and blood transfusions for terminally ill patients in hospice wards as a negative act of passive abandonment, dubbing it as *cutting off water and electricity*. However, it's crucial to understand that as terminal patients enter the final stage, these life-sustaining medical interventions cease to offer benefits and may even increase the patient's physical strain. Continuing them only prolongs the patient's needless suffering.

In instances where antibiotics lose their effectiveness in managing infections, they might additionally strain the liver and kidneys. Moreover, with debilitated patients whose blood vessels are as delicate as silk, administering injections often requires numerous attempts before successfully inserting the needle.

Similarly, when nutrient fluids are administered with good intentions, the terminally ill patient, due to organ failure, cannot tolerate these fluids. Consequently, excess fluid retention occurs, leading to pleural effusion and ascites, further complicating breathing! In such cases, physicians conduct a thorough evaluation of the patient's condition, provide professional guidance, and, through comprehensive explanation, discussion, and communication with both the patient and family, reach a consensus to either *withhold* or *withdraw* these life-sustaining medical interventions. They also emphasize holistic care—physical, psychological, social, and spiritual—to enhance the patient and family's well-being. This approach aims to improve their quality of life and facilitate a peaceful passing for the patient. It's indeed a highly positive and proactive medical process! It's disheartening when individuals who don't grasp the process label it as *cutting off water and electricity*.



Ethical Medical Decision-making

In the face of extreme suffering experienced by certain patients, I believe we all resonate deeply and earnestly consider ways to relieve the distress for these patients and their families. This is why the concept of *fasting to death* has sparked such widespread attention! However, it appears to have led to misunderstandings among the public, causing considerable confusion. In reality, clear explanations exist regarding the appropriate care for these patients.

If a terminal patient's condition reaches an irreversibly severe stage, even nearing death where the patient is unable to orally intake or digest food, reducing or ceasing food intake becomes a necessary intervention. As previously mentioned, the objective is to ease the patient's needless suffering, not to expedite their passing. Hence, this constitutes a *natural death*, not a deliberate *fasting-induced death*.

Even in the advanced stages of a terminal illness, if a patient can still orally consume food, efforts should be made to support their natural eating and allow for a comfortable life. If the patient wishes to cease eating as a means to expedite the end of their life, caregivers should engage with empathy and acceptance. Their focus should be on addressing the patient's physical, mental, and spiritual anguish, nurturing their inner resilience to bolster their will to continue living. It's crucial not to simplify this situation as merely assisting in a *fasting-induced death* to reduce their suffering.

In cases where individuals have lost the capacity for self-expression, are bedridden, and cannot orally take in food, the medical team should conduct a thorough assessment of the severity of their condition. Considering their prior intentions, empathizing with the perspectives and distress of their family members, and engaging in an ethical deliberation process, the focus should revolve around prioritizing the patient's welfare while maintaining harmony in the family. Moreover, it's crucial to adhere to existing legal frameworks to ensure the provision of suitable medical care for the patient. If discontinuing artificial feeding aligns with the



patient's best interests, it constitutes a natural progression within the disease's course toward death, and not a deliberate *fasting-induced death*.

Physical, Mental and Spiritual Health Care

Careful evaluation of a patient's condition, adherence to medical ethics, compliance with legal norms, and the ongoing adjustment of healthcare to prioritize patient-centered care at every stage represent the core professionalism and responsibility within the realm of medicine. A dignified passing is an integral part of our valued culture, a shared aspiration for us all. Yet, achieving a peaceful end isn't effortless; it's a challenging learning journey that requires personal commitment, the backing of family, and the support of the medical team. It's hoped that through the compassionate presence of both family members and healthcare professionals, patients can find physical, mental, and spiritual solace, embracing life positively until the end, thereby finding peace in both life and death.

Hence, careful and thoughtful consideration is crucial. It's imperative not to let the public misconstrue fasting as a means to achieve a peaceful passing. To prevent any misunderstandings that could adversely impact society, it's essential to foster discussions that include diverse perspectives. Through these discussions, we aim to elucidate the true meaning of a dignified passing, ensuring clarity for all and fostering a more harmonious and fulfilled society.

