



Excerpts from

Japan Society for Dying with Dignity Newsletter  
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- Abstracts from the 12th Japan Living Will Study Group Palliative Care Today  
= The end of life without pain and suffering =
- Results of the 2023 “Bereaved Questionnaire”
- Living Will Square
- From telephone and e-mail medical consultations

## The 12th Japan Living Will Study Group (on-site and on-line) Palliative Care Today

### How far can we go in dealing with pain and suffering? ~ Hoping that no one will ever wish to die from pain and suffering~

The 12th Japan Living Will Study Group Meeting was held on December 9th last year at the University of Tokyo campus and online. The theme of the meeting was “Palliative Care Today”. The most common consultation received from the Japan Society for Dying with Dignity members was about “pain relief”. They were voices of longing for “a peaceful end without pain and suffering”. As a coordinator, Dr. Satoru Mitsuoka / Director of Japan Society for Dying with Dignity introduced palliative care, its current status, efforts in various fields, and looked at “palliative care today”.

This is a summary of that request.

#### ■ Coordinator:

**Dr. Satoru Mitsuoka: (Director of Mitsuoka Internal Medicine Clinic & Director of Japan Society for Dying with Dignity)**

#### ■ Lecturers (in alphabetical order):

**Mr. Toshifumi Kosugi: (Director of the Palliative Care Department, Saga-Ken Medical Centre Koseikan)**

**Dr. Dai Yumino: (Chairman of Yumino Heart Clinic)**  
**Dr. Haruhiko Miura: (Professor, Iwate University of Health & Medical Sciences)**  
**Ms. Masako Akiyama: (Visiting nurse/Head of Living for Health Care)**  
**Dr. Kazuhiro Nagao: (Vice President of Japan Society for Dying with Dignity)**

## How to deal with intractable cancer pain.



**Dr. Toshifumi Kosugi**

### **First and foremost, remove pain from the body.**

“Does cancer hurt?” “The World Standard for Cancer Pain Relief/WHO Method of Cancer Pain Treatment” and “Continuous Subcutaneous Injections and Nerve Blocks for Intractable Cancer

Pain.” I will focus on and talk about cancer pain.

Cancer patients experience physical, social, mental, and spiritual pain. Spiritual pain is the pain of wondering why one has to live with such pain and suffering. There are painkillers and nerve blocks for pain, but these only work for “physical pain” and not for mental, spiritual, or social distress.

So, how often, percentage-wise, does cancer cause physical pain? According to a 2018 WHO (World Health Organization) survey, 55% of those undergoing treatment worldwide and 66% of those with metastatic or terminal disease experience pain. 1986 WHO issued the “Five Principles of Pain Therapy” as a global standard.

The Five Principles of Pain Therapy are:

- ① Orally (as easy as possible, anywhere in the world)
- ② At set times (regularly take before the pain starts)
- ③ In stages (from non-narcotic painkillers to more potent narcotics)
- ④ In doses appropriate to the individual patient (doses adapted to the age, size, and physical condition of the patient)
- ⑤ Consideration of details appropriate to the individual patient (countermeasures against side effects of narcotics such as nausea and constipation) of the five principles of the drug use were revised into the four principles in 2018. “③ In stages” has been eliminated and replaced with “Use strong narcotics from the beginning,” etc.

Next, “Is the WHO method of cancer pain treatment effective?” Studies show that 71% of cancer patients with controllable pain were reduced by 1/3 or that 76% of cancer pain was well controlled for about 2,100 cancer pain patients. In other words, the WHO method of cancer pain treatment provides 70-80% pain relief. The 70% to 80% rate is an excellent figure; however, it was also reported that 8% required nerve blocks, 3% nerve destruction,

and another 3% spinal analgesia (epidural and subarachnoid.)


In Japan, 380,000 people die of cancer each year, and if 50% of them suffer from pain, that means that about 15,200 people out of 190,000 will be treated with nerve blocks and about 5,700 with nerve destruction and spinal cord analgesia and that pain will not be relieved without these treatments. So, even if pain relief is possible for 70-80% of the patients, the remaining 20-30% (38,000-57,000 patients) are either wind up writhing in pain until they passed away or else they are sedated and asleep.

What then, is the “purpose of cancer pain treatment?” The goal should not only be to take away or lower the pain, but to do anticancer treatment without drowsiness or nausea, and to return to daily life and work. Since QOL (Quality of Life) is low, only oral medication, nerve blocks, radiotherapy, etc. are necessary. Cancer patients complain of various kinds of pain, so doctors must listen to where and what the patient's pain is and respond to it.

WHO says, “Take medicine, take medicine,” but it takes time to take a pill alone, and in case of pain that cannot be taken away, injections are also used. The Society for Palliative Care and other organizations have also issued guidelines. One of them is called “continuous subcutaneous injection.”

## CSI: Continuous subcutaneous injection

- 27G winged needles or 24G indwelling vein needles puncture by pinching subcutaneous tissue
- Trunk, thigh, upper arm
- Easy, safe, and reliable
- No need to secure vein
- Minimal pain during puncture
- Not restrained by IV lines in the extremities
- Dosage is about 1 ml/h or less



It is easy to pinch the skin and push it in. When the pain starts, for example, you press a button and the pain medication is added. When is continuous subcutaneous injection necessary because of severe pain? You use rapid induction when you want to stop the pain as soon as possible, and then switch to oral medication as soon as the pain calms down. It is also used when you can't take your medicine. Other medications are also available but take days to take effect. In addition, anesthesiologists also perform nerve blocks. Think of it as many nerve blocks as there are many nerves. The nerves transmit the pain stimulus from the disease, so the idea is to sever the pain. While looking at the X-rays, we block the pain by inserting a needle into the nerve and injecting 100% medical grade alcohol into the nerve pathway. Anyway, to get rid of the pain in the body, this is most important. Then, mental, social, and spiritual pain will be removed.

**To be close to the LIFE of heart failure patients**



**Dr. Dai Yumino**

**“Sharing is the most important value between doctors and patients.”**

We are discussing how to help the growing number of cardiac patients who stay in the comfort and security of their homes. The most essential issue for the future will be how to enable patients with heart disease and cancer to live peacefully at home without being readmitted to the hospital. We, “Yumino Clinic,” currently have four locations in Tokyo, two in Osaka, and one in Fukuoka. With 103 doctors and 443 staff members, we provide home medical care, focusing on cardiac disease.

Here is a case study.

①A 63-year-old male cancer patient. Stage IV lung cancer, multiple metastases. He wanted to stay at home until the end of his life, was introduced to home medical care in 2019, and received home medical care for two months. He reached the end of his life under the watchful eye of his family.

②A 64-year-old male patient with heart failure. Repeatedly hospitalized and discharge five times a year due to exacerbation of heart failure. Introduction of home care in 2019 to strengthen heart failure treatment care in the place of daily life, and continuation of home care without rehospitalization. What I would like to say by comparing ① and ② is that cancer patients are dying, but patients with heart disease can live a long and peaceful life by providing appropriate medical care in their daily lives. We provide medical care in the place in which they live because we believe that “the patient’s LIFE is not in the hospital but in the place of life.” And because we believe that illnesses should worsen in their home, not in the hospital. We have listed five points for the home management of heart failure, and we always reflect on these five points in our practice.

They are:

- ①Appropriate heart failure treatment
- ②Team medicine
- ③Family care
- ④Palliative care
- ⑤Decision-making support

Regarding symptom relief ④ palliative care in the cardiovascular field is difficult. Heart failure may be a sudden death rather than a gradual worsening of the disease. This makes prognosis difficult to predict. Also, prognostic predictions vary because of the diversity of the base patients that cause heart failure. There are many treatment options. It is difficult to relieve symptoms. These and other factors make palliative care for heart failure and other conditions difficult.

Next, I will discuss ⑤ Decision-making support. There are several times to do so, including the first time you interact with a physician, when you are readmitted to the hospital, and when you are discharged from the hospital. Still, you should make your intentions known not only to the physician but also the medical staff. In the case of cancer, we think about “what we are going to do,” but in the case of heart failure, we have to talk about it at the last minute. Writing a Living Will does not improve the prognosis, but many things can expand from there by writing it down. Your social worker will give you a Living Will or a survey form when we start home health care.

The content of the survey form is essential, but most importantly, it is an opportunity to talk. When determining the “now,” the past, the future, and the surrounding factors will affect the “now,” so it is essential to have a variety of dialogues. This is where the original “importance of the LIFE perspective” comes in. LIFE has the meaning of life, living, and vitality. LIFE (I want to spend the end of my life at home.) LIVING (I want to spend my life surrounded by memories. I want to use services within the money I can afford.), and VITALITY (I don't want a cure, but I want relief from pain.) It is essential to have this patient's LIFE perspective, not the physician's side. It is necessary to take the viewpoint of what the patient wants to have done.

So, what does “better decision-making” mean? It is about making a well-informed decision consistent with personal values and that those who participate in the decision express satisfaction with the decision. This joint decision-making will be based on the latest evidence and a proposal like, “If I were you, I would do this....” Medical professionals are professionals regarding diseases, but they are amateurs when it comes to patients. On the other hand, the patient's family may be amateurs regarding the disease, but they are professionals when it comes to themselves. At first glance, it may seem challenging to mingle, but building trust there and communicating with each other to make decisions is essential. “I'll leave it to the doctor.” Although it is good to have a doctor-patient relationship such as “I'll leave it to the doctor,” it is difficult to establish a trusting relationship between doctor and patient. Shared values are of the utmost importance in a relationship of trust. Sharing the same perspective and feelings.

In summary, the first step is proper treatment of heart failure. That will lead to symptomatic relief. Healthcare choices are made through shared decision-making. A trusting relationship between patient and physician is essential for shared decision-making. The relationship of trust requires how to build shared values ----- These are necessary to “help people live a LIFE that is unique to them.”

## **Palliation of symptoms of chronic kidney disease (palliative care) and ACP (Advance Care Planning)**





**Dr. Yasuhiko Miura**

**Thinking about death is not ACP.**

I will start talking about dialysis. Dialysis is the removal of waste products from the blood using the semipermeable principle of dialysis membranes. It is performed three times a week for three to five hours at a time. This requires going to a dialysis facility. Dialysis is also a life-sustaining treatment since patients die within about ten days of discontinuation of dialysis. The number of dialysis patients is currently 350,000 in Japan and continues to increase. Among them, the number of patients in their 70s and over is increasing. About 30,000 of these dialysis patients are hospitalized. One out of every ten patients is hospitalized.

In 2018, the Japan Medical Association introduced the concept of ACP (Advance Care Planning.) In ACP, it is important to talk about the person's view of life, values, and life and death before care is needed. It can be said that we live in a "life story." It is called a "Narrative" and I believe that ACP should be an extension of this view of life and values and that it determines the medical practice of the final stage of life. In this light, I think it makes sense to think in terms of "I have lived this way, so this is the kind of care I want" based on ALP (Advanced Life Planning), which I have been thinking about for myself since before I needed care.

Prior to the advent of this ACP, advance directives (advance directives) began to appear around 1990. "To express your wishes regarding the medical treatment you want or do not want to receive while you are still conscious in case later you are in a coma, vegetative state, or have severe dementia and are no longer able to make your own decisions regarding the medical treatment you will receive." This is documented in the Living Will.

Regarding the "discontinuation or suspension of dialysis," it is ethically considered that the patient's right to self-determination should be guaranteed, and it is said that it is essential to weigh the benefits of dialysis against the disincentives. The Japan Dialysis Society revised its "Recommendations on the Decision-Making Process Regarding the Initiation and Continuation of Dialysis" in 2020 after the Fussa Hospital incident.

With this recommendation, the concept of not starting or discontinuing ongoing dialysis and providing palliative care (conservative renal therapy) was proposed. This may raise the question, "Is it really a good idea not to start dialysis or to stop it?"

In Japan, “suicide/refusal” to discontinue dialysis is an infrequent cause of death among dialysis patients, accounting for only 0.5% of all deaths. On the other hand, in the U.S., deaths due to “dialysis discontinuation” account for 18% of deaths, making it the leading cause of suicide among dialysis patients. You intend to end your life as it is because a life where you are tied to the bed three times a week for five hours at a time that doesn’t fit your lifestyle.

Under these circumstances, I have compiled my own list of “things to keep in mind when a request to stop or suspend dialysis is made.”

- ① What are the reasons for the request to discontinue or suspend dialysis?  
Are the reasons understandable from the point of view of all concerned?
- ② Does the patient have decision-making capacity?
- ③ Is the patient affected by depression, brain damage or other disorders?
- ④ Is there a firm desire to discontinue dialysis? Are there advance directives, ACP, etc.?
- ⑤ Are there any measures that can improve the main factors of the patient’s desire to discontinue dialysis? Or have these measures been exhausted?
- ⑥ Are the patient’s family and surrounding parties supportive of the patient’s wishes?

Finally, obtaining information on the conditions of compliance and discussing them in a multidisciplinary conference (e.g., clinical ethics consultation) is desirable.

Finally, look at the “return of the concept of palliative and grief care.” Previously, when chemotherapy and other aggressive treatments proved ineffective, the patient would go to palliative care. There, they would die. And grief care is provided after death. Now, it is different. The idea is that palliative care begins when the patient is suspected of having cancer and is then seen. Basic palliative care is also provided during the stable period.

So, we need to write and rewrite the ACP. Thinking about dying is not ACP. ACP is to consider and decide what kind of life you want to live with this disease in the future, and to do so firmly will lead to grief care. The same is true for patients with kidney disease. Basic palliative care is also provided during the stable outpatient dialysis phase. This is basically the kind of care that dialysis staff should provide, but if specialized palliative care is needed afterwards, a specialized palliative care team can help.

First, they must become proficient in primary palliative care for their respective illnesses, and then their staff will perform ACP.

## **Report from The Living Health Center**



**Ms. Masako Akiyama**

**Please feel free to consult with us as soon as possible.**

In 2010, our activities were introduced on NHK's "Professional Work Style." At that time, we focused on home nursing, especially hospice, and provided many end-of-life-cares at home. I often received requests from people who were about to die. Still, I thought it was too late for that, or rather, I needed a contact point where I could easily consult with them long before but luckily, I came across the International Seminar on Cancer Nursing in 2008. That's when I learned about the "Maggie's Center" that was started in the UK. It is a new consultation support facility specializing in cancer. Based on my 20 years of experience in home nursing, I decided to create such a style of consultation in Japan. This is the beginning of "Maggie's Tokyo."

We have been organizing the "Symposium on Promoting Home Care for Residents" since the year 2007. Not only Shinjuku residents but also care managers and hospital personnel working in the ward attended as audience members, and a former bookstore owner who came to listen there in November 2000 offered to provide an empty store. We renovated the inside to create a slightly stylish and cozy place. The bookstore's location has a very high aging rate of 55% compared to about 19% in Shinjuku City.

Since there were many medical institutions in the area, we thought it necessary to establish a system to support the area between medical care and daily life, so we opened the "The Living Health Center." The idea of "having a place where people can feel free to ask for advice" matched the valuable voices of local residents who said, "I want to be useful to the community," and also met the needs of professionals who said, "We need a place where professionals can meet with each other to provide constant support. We hold various events there also. Some of the events are the training for in-home caregivers, classes to prevent heat stroke, a drop-in place for people with mild dementia, radio exercises, etc. I would like to know if the know-how I have cultivated in-home nursing is helpful as I am involved in such community activities.



## The Living Health Center opened on 1 July 2011



We also have a cancer survivor in our group, so we provide counseling for them as well. In this context, we also hold a “The Living Health Center Study Session” once a month. Our 142nd study session was just held the other day. Participants ranged from care managers to ward officials, home nursing, dietitians, administrative scriveners, and journalists.

Here are some examples of the many people involved. This is an example of someone who used the “The Living Health Center” while still in good health. His wife first said, “My back hurts, so I wonder if I can do something about it?”

Sometimes, she came to see us and complained that food got stuck in her throat, and esophageal cancer was found. Due to her advanced age, surgery was complicated, and she was treated with radiotherapy. The team handled the situation, and she was discharged from the hospital and returned home to meet her final days. This person rewrote her desires every year while she was well. It is truly a “Living Will.” When she was discharged from the hospital, she was asked, “Do you want to do IVH (known as TPN internationally) (home central venous nutrition) or gastrostomy?” When it came down to it, she chose gastrostomy because she wanted to be outside. Many people have said, “I don’t want to have a gastrostomy,” but it was a decision based on her lifestyle. This is an example of decision-making support in which various information is provided, and the patient makes their own decision. As the patient stated at the end of her life, “I was allowed to do what I wanted to do,” and I believe that this is precisely what will lead to my “death with dignity.”

Finally, “The Living Health Center” has six functions.

They are:

- ① Consultation service
- ② A place to learn with citizens
- ③ A safe place to stay
- ④ A Place for exchange
- ⑤ A Place for cooperation
- ⑥ A place for nurturing

People who came to see our "The Living Health Center" are now creating similar “Living

Health Centers” in various parts of the country and taking advantage of local characteristics. We are about to become a 60-70-person facility. The numbers in our group continue to increase. Please feel free to come to the “The Living Health Center” as soon as possible.

## **We can go this far, Palliative care at home**



**Dr. Kazuhiro Nagao**

**The current situation is that people do not pay attention to palliative care.**

I have been a town doctor for twenty-eight years, and although I have recently stopped for a while, I have taken care of about 1,500 people at their homes and provided palliative care until the end of their lives. I would like to share my experience.

Now, as for the target patients of in-home palliative care, my Nagao Clinic (now Sanwa Clinic) has provided palliative care to a wide range of patients, but the most common were those with terminal cancer. Then there are neurological incurable diseases (e.g., ALS,) and organ failures such as chronic heart failure, chronic renal failure, respiratory failure, etc. Also, there is dementia and senility.

Forty years ago, when I became a physician, there were few drugs related to this type of palliative care, and morphine was rarely used, but now there are a variety of drugs that can be used at home. The painkillers are Loxonin and Koronal, Lyrica, an analgesic aid, and opioids (medical narcotics.) Painkillers can now be used at home with some restrictions, so it is not so different from the hospital setting. The dosage forms have been enhanced over the years and include various medications, such as oral, paste, and rescue (liquid.) They can be kept at the bedside of the patient’s home. As Mr. Kosugi mentioned at the beginning, continuous subcutaneous injection, can also be done at home. Though collaboration with pharmacists and visiting nurses will be necessary. Of course, painkillers can also be injected by intravenous drip.

And let us not forget morphine, which remains the primary drug of choice. I know that there are still many doctors who have the misconception that it is too early to administer morphine. Still, the guideline has changed so that pain should not be tolerated, and as Mr. Kosugi said, “morphine should be administered from the beginning” for cancer pain. Still at

university hospitals and home, however, the current situation seems to be that the focus is on anticancer drugs and not on palliative care. In fact, there is an academic society for palliative medicine in Japan, but there is no academic society for palliative care, which may be an indication of this.

Here is a summary of the direction of palliative care:

- ① Regardless of whether it is cancer or non-cancer
  - ② Expansion of the indication of opioids to non-cancer patients
  - ③ Introduction of palliative care from an early stage
  - ④ Provide seamless palliative care
  - ⑤ Palliative care in the form of food and nutrition
  - ⑥ Palliative care in the context of comprehensive community care.
- Food support “to enable patients to eat until the end of their lives” ⑤ is essential, and “palliative care within the context of comprehensive community care” ⑥, such as the activities of Ms. Akiyama and her colleagues, will become increasingly important.



## Results of the 2023 survey of bereaved families.

**86% of the respondents told their healthcare providers about the Living Will (LW), and 95% of them found it effective.**

**“Having their organizational support is a big help.”**

“My husband avoided life-prolonging measures and departed peacefully. I am glad we were prepared.” On the other hand, “Even though my aunt herself chose to die with dignity, I wished she would have lived a little longer by prolonging her life.” A survey of bereaved families reveals the realities of what it was like to face the “final days.” We will listen to these voices and use them in future activities to promote and educate the public.

**I realized that longevity is a risk.  
That is why I wholeheartedly support the efforts of the Society. (Chiba Prefecture)**

● When my mother had a subarachnoid hemorrhage 13 years ago, I told the doctors and staff at the hospital, but no one knew anything about the LW. I was so shocked at how useless it was that I asked them to learn more about it, but it was different this time with my father (93 years old.) Everyone showed understanding, and I was relieved that the LW (Living Will) had finally spread. (Miyagi Prefecture)

● My sister-in-law was 88 years old when she was hospitalized without knowing that she had terminal cancer. Shortly after, her condition became critical. The doctor then asked us, "What kind of treatment do you want in the future?" I had known for some time that my sister-in-law was a member of the Japan Society for Dying with Dignity, "to be free from pain and suffering," and I informed the doctor of this fact. My late sister-in-law had a very gentle and beautiful face. My husband and I are also members of the JSDD. (Tokyo)

● When my husband (87 years old) was taken to the emergency room, I was accompanied by a care manager because I was in the hospital and had no children or relatives. I had been talking from time immemorial to the care manager about the LW (Living Will,) so I asked her to inform my husband's doctor. As a result, my husband avoided life-prolonging measures and departed peacefully. I am glad that we were prepared for this. I always carry my JSDD membership card with me. (Saitama Prefecture)

● My mother (87 years old) has denied life-prolonging measures since she was in her 60s and has repeatedly reminded us, her two children, of this, so there was no hesitation in this regard. The LW (Living Will) accepting cooperating doctor, who cared for her at home, listened to us very carefully and responded to our family's requests, and we had no complaints. However, in the last days of her life, it was painful to see her lamenting the fact that she was no longer of any use because of her dementia. (Chiba Prefecture)

● My husband had told me that his mother could no longer eat using her mouth, and the doctor recommended that she have a gastrostomy, but he refused. However, he was told, "You could be responsible for her death," and an agreement was made. After that, he cried many times because of the heartbreaking situation with his mother and her chest pains. Because of this experience, we decided to become members of the JSDD. When my husband was taken to the emergency room at age 78, I presented my membership card to the paramedics and the doctor. My husband's wishes were respected, and I appreciated it. (Osaka)

● When my mother (89 years old) could no longer eat using her mouth, the facility where she was staying suggested that she be placed on artificial nutrition with the possibility that she would be able to eat by mouth again. She had created an LW (Living Will) before she developed dementia and was persuaded that "the family should make the choice" due to the fact that they could not confirm how she felt about it now. I believe that this facility tried hard not to give up on my mother's future, and I still regret that I followed their advice. In the end, they accepted my mother's LW (Living Will) and moved her to a place that gave her generous nursing care, and she left peacefully. (Osaka)

**The family members, who were divided over life-prolonging measures, finally agreed that the person had a Living Will. (Tokyo)**

**The fact that we were supported by an organization was a big help. (Hyogo Prefecture)**

● My wife (73 years old) was able to go home because she clearly expressed her “Living Will” and her wish to “pass away at home.” It was a great strength that we were supported not only by our desires but also by the Society as a whole. I was relieved because all I had to say was, “I am a member of the Japan Society for Dying with Dignity.” (Hyogo Prefecture)

● When my husband (73 years old) was getting weaker and weaker and still wanted to drink water through his mouth, I did not know what to do and turned to a telephone-based medical consultation service. They were kind enough to listen to me and give me good advice. I put a few drops of water between his lips and gums, and then I tried it with my husband’s favorite cola, he seemed very satisfied, and his last breath came peacefully. I had nonchalantly joined the Society but had no idea they could help me so much. (Aichi Prefecture)

● We had talked about the LW (Living Will) beforehand, and he (my father) had signed a refusal to prolong his life when he entered the facility. But later when the time came, a person from the facility called and said, “Your father (94 years old) is not breathing. Please decide whether to call an ambulance or wait for the commissioned doctor to come and write a death certificate.” We were very distraught. My husband said, “I will call you back. He hung up, thought for a moment, and then informed them that he accepted his father-in-law’s death.” It would be a good idea for everyone to be prepared to receive another emergency confirmation call in case of an emergency, even if it had been decided in advance. (Tokyo)

● I first learned about the LW in 2006 when my 87-year-old mother-in-law firmly refused to see if she had to undergo dialysis. Then my mother-in-law’s family doctor asked me, “Do you know about the Living Will?” My mother-in-law, husband, parents and I joined the JSDD following my mother-in-law and have remained members to this day. How the presence of LW-accepting cooperating doctors is emotional support for patients. I sincerely hope that the number of doctors who understand an LW will increase in the future. (Mie Prefecture)

**I realized that the significance of joining the Japan Society for Dying with Dignity is to think about living. (Tokyo)**

**How the existence of receptive cooperating doctors is an emotional support for patients**

**I sincerely hope that the number of doctors who understand me will increase. (Mie Prefecture)**



● When my mother, a member of our Society, was rushed to a medical center in Tokyo 15 years ago due to an intracerebral hemorrhage, a young surgeon connected many tubes to her almost-deceased body and said triumphantly, “This person is still alive.” She was then moved to a private hospital that we had known for a long time, and after a few days, she left peacefully while still on oxygen. We believe that when the “time” comes, we will die. We would like to make these ideas, which can be a bit philosophical, known to students who want to study medicine and teachers who are still vaguely familiar with the old ideas of medicine. We believe that how we die is the absolute right of each person who is facing death to exercise it at the end of their life. (Tokyo, Japan)

● My mother (90 years old) had dementia, but we made sure that everyone around her knew that she was a member of the Japan Society for Dying with Dignity, so she was able to meet her end peacefully with the help of everyone. My family doctor, home visiting doctor, facility, and facility doctor all understood me well. (Kanagawa Prefecture)

● My grandmother was like a mother, raising me from a baby in a father-son household. Two years ago, she had to enter an institution because she could not walk due to a cerebral hemorrhage caused by a fall. We decided to find a facility where we could see each other every week, even with the COVID-19 disaster, so we could go for walks and talk in her wheelchair and spend some precious time together. There were many times when she was in danger. Still, thanks to the LW (Living Will,) I was able to make memories of my grandmother peacefully until the end of her life without causing her unnecessary suffering. I am grateful that I could respect my grandmother's wishes, whom I loved so much that I wanted to share her life span. (Kanagawa Prefecture)

● When I finally transitioned to end-of-life care, I experienced suffering from conflicts that far exceeded my imagination. I used the LW (Living Will) as an excuse for myself rather than for my 79-year-old husband...that was certainly one aspect of it. (Tokyo)

● When my mother (97 years old) was cared for at home, I presented her the Japan Society for Dying with Dignity membership card to the doctor before discussing how we should proceed toward the end of her life. Still, whether this was the reason or not, I felt that the subsequent nursing care was cut short. (Gunma Prefecture)

● When my husband (83 years old) presented his LW (Living Will) while residing in a facility, he was told, “We don’t have to do anything, even if you have COVID-19.” which was very hurtful. They did not understand the purpose of the LW (Living Will) and used it as an instrument to save themselves trouble, which was an infringement. In fact, when my husband had COVID-19, they would not call an ambulance nor admit him to the hospital.

However, the hospital where he was last hospitalized for another condition listened carefully to our wishes and allowed us to meet our final days as we had wished. (Hyogo Prefecture)

● My aunt died without any treatment because of her choice of death with dignity. I feel resentful of the Society because I wish she could have lived a little longer by prolonging her life. (Aichi Prefecture)



● In the last days of my mother's life (93 years old,) I felt very bad and it was hard for me to hear the nurses rather than the doctors say repeatedly, “Don't you want her to receive treatment?” Even though I told them it was her wish, they kept repeating it. (Fukuoka, Japan)

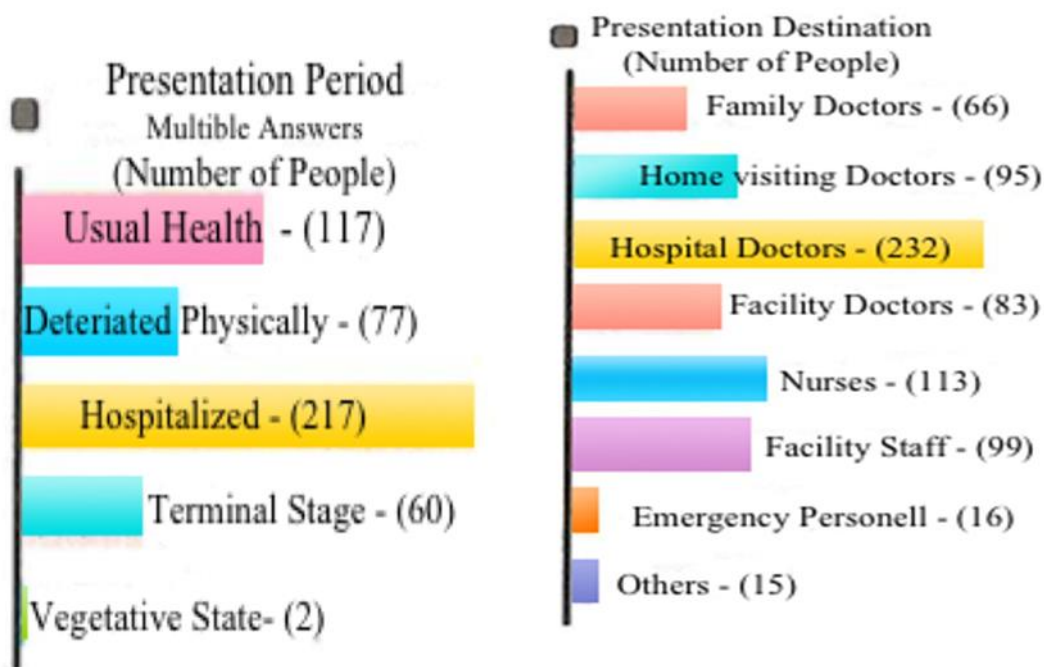
**“Presented to the doctor-in-charge” was the most common response “at the time of admission to hospital.”**

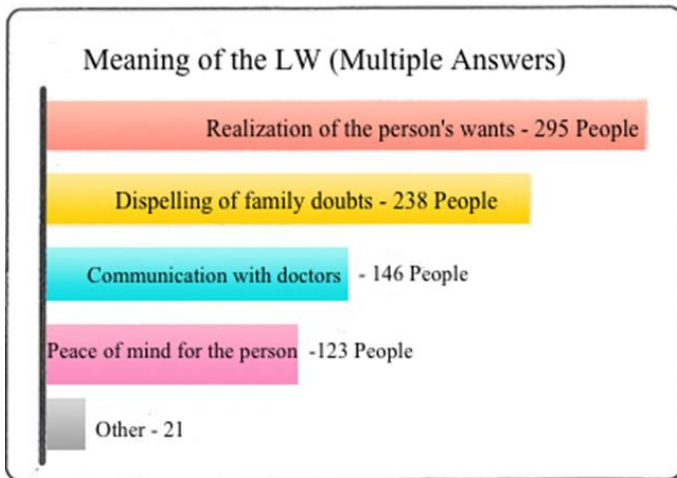
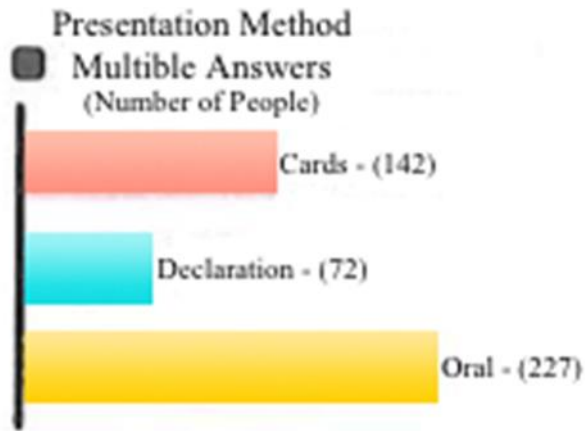
In 2023, the restrictions on visitation bans to prevent the spread of COVID-19 infection have been eased; the number of places to say goodbye is gradually increasing.

Nevertheless, parting with a loved one caused a great deal of conflict and bitterness, and everyone seemed distressed. In the questionnaire, you stated that “only those who cannot see an ill loved one can understand this feeling”, please take a look at the Society's “The Little Lighthouse Project.” You can find information about people who have actually experience dealing with “end of life care,” advice from the Society and information to support your life and your mind at the end of life.

In 2023, we received responses from 433 people. 372 people (86%) of the bereaved relatives had informed their health care providers of their Living Will (LW), and when asked, “Was the LW accepted?” 74% answered “Well accepted,” and 21% answered “Somewhat accepted.” In total, 95% of the bereaved relatives acknowledged the effectiveness of the LW.

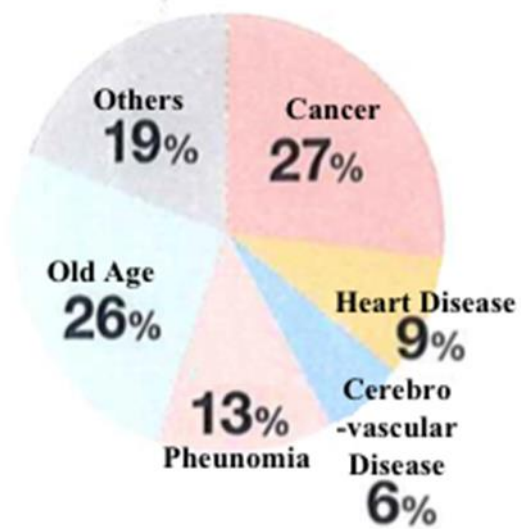
We would like to express our deepest gratitude to all those who took the time to fill out the survey during this time of profound sadness.





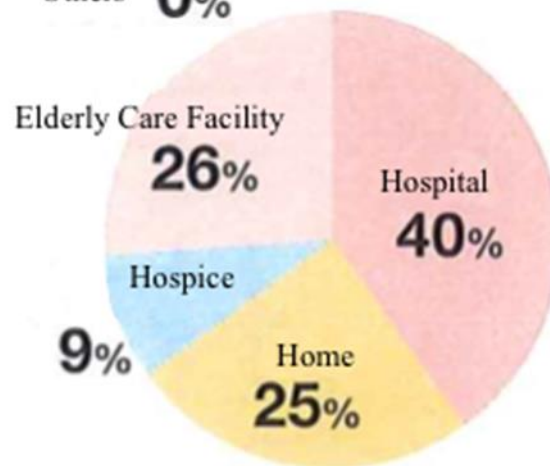
■ Cause of Death

Accident - 0%

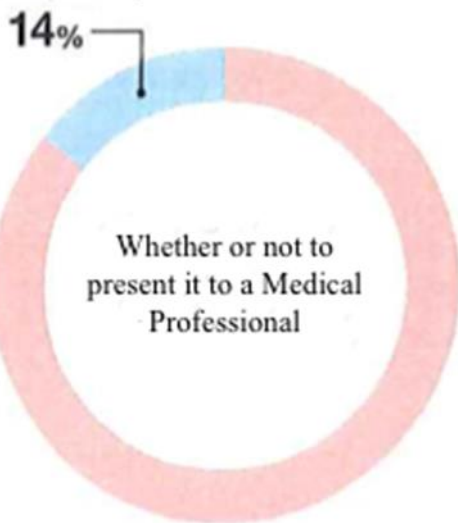


■ Place of Death

Others 0%



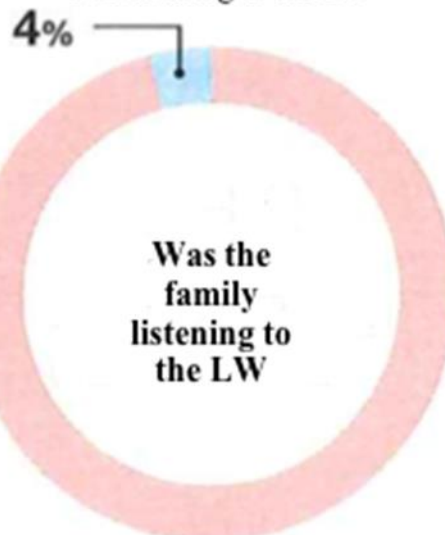
Not presented



Presented

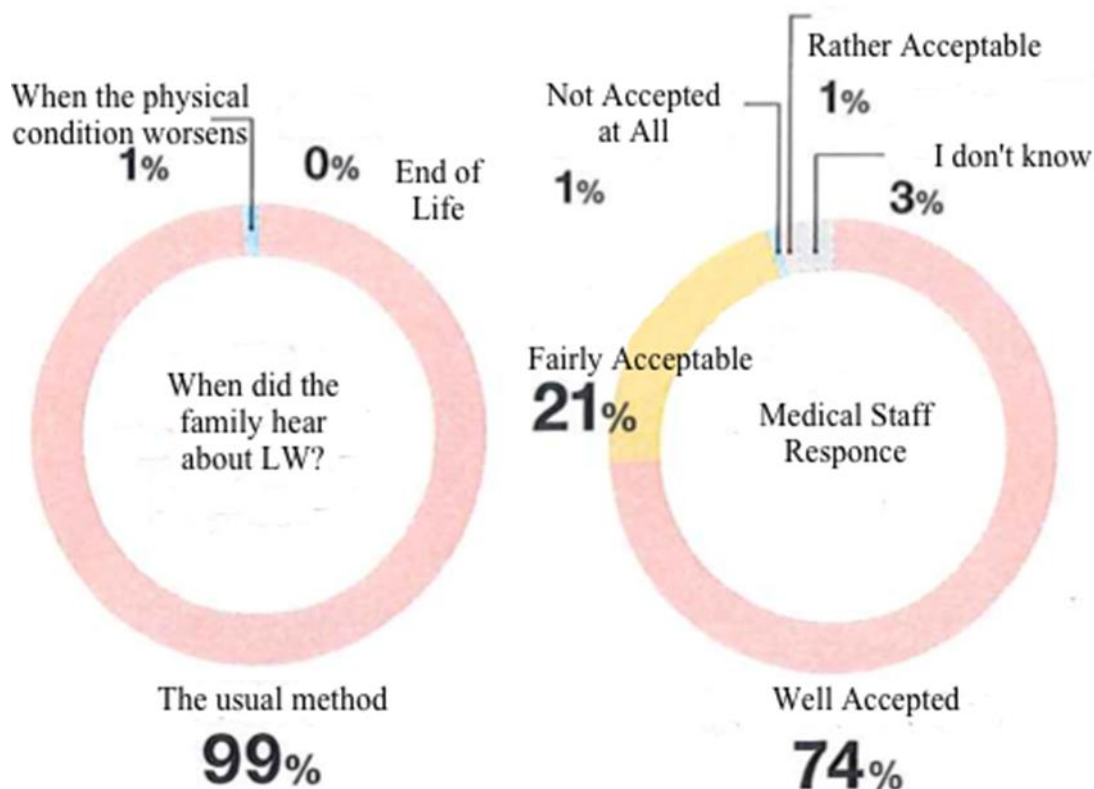

86%

Not listening to the LW



They were listening to the LW

96%

**Members' Voices**

We have the same thoughts; our friends are all over the country!

To convey the Japanese view of life and death.

Ms. Rui-Yun Wang (Age 83) Canada

I lived in Kunitachi, Tokyo, for 51 years as a general practitioner and closed my practice three years ago. I am setting up an institute in Canada to summarize what I have learned in Japan. I have cared for and treated my parents, husband, and eldest sister for 31 years (including end-of-life care) in Japan. I believe it is thanks to the LW (Living Will) and the doctors who accepted it that all four of us could live our entire lives without suffering.

I became a doctor to keep myself alive and have studied only how to live. I kept thinking about “what it means to live” and “what is true medicine,” I found that the secret was hidden in Japanese culture. In Japan, there is an ancient “ikikata” (way of life) in which a person lives naturally without the intervention of a physician. In Japan, the importance of living in harmony with nature has been handed down from ancient times.

Japan is a microcosm of the world and a gathering place of knowledge and wisdom from all over. The conclusion of my life’s research is that Japan is the Kaburaya of the world and a country of learning. Dr. Donald Keene said, “If you want to know the world, study Japan.” I think that is exactly right. I am now living in Canada and want to tell the world about Japan.

I have come back to Japan for a short period of time to organize, clean up, and take over my research, and what I would like to say to the people of Japan is to enjoy life in the wonderful culture of “living in harmony with nature” that has been handed down in Japan for centuries.

## I have been singing the “Songs of the Four Seasons.” Ms. Sumiko Hasegawa (Age 98) Kanagawa

Thank you for sending me a new membership card the other day. The card has given me emotional stability for over ten years. The card fits my body better than the medicine the doctor gives me, and I have grown older than I thought possible. I also look forward to the LW (Living Will) newsletter that is sent to me four times a year, and the “Songs of the Four Seasons” in it reminds me of my childhood, and I sing them. I also have fond memories of being taught by Shigeru Kuzuhara, a children’s song poet, when I was in a girl’s school. I hope that today’s children will sing many good Japanese children’s songs.

Please take good care of yourselves in these times of disaster.

### From telephone and email medical consultations

16

#### “Tell me how to get to a receptive cooperative doctor?”

More than 2,000 registered receptive cooperative doctors agree with the purpose of the Japan Society for Dying with Dignity and respect dignified life and death. The expectation and trust of the members in the receptive cooperative doctor is great and should be increased. This time’s article focuses on the cases of consultation received at the medical consultation service and how to consult with receptive cooperative doctors.

[Case study]

● I have been told that the prospects for recovery from my illness are difficult. I do not want any further treatment and would like to go home. Is there a receptive doctor willing to undertake home-visit medical care?

● My mother is on follow-up for kidney disease at a general hospital, but refuses to undergo dialysis. I hear that she will have respiratory distress if she doesn't choose it. Can she receive palliative care such as anesthesia through home health care?

● I have been diagnosed with breast cancer and told that it is progressing rapidly. I live alone. Can I be cared for at home?

● Are there any differences between a receptive physicians and general hospital physicians? What kind of assistance is available?

● I have been treated at a pain clinic for scoliosis for many years but stopped after unsuccessful treatment. I am elderly and am looking for a receptive doctor nearby who can help me ease my pain with pain medications.

● I was referred to a clinic by the JSDD because there was no receptive doctor nearby. Please tell me the name of the book.

● Living on a remote island, few medical facilities understand the LW (Living Will.) I would like more receptive physicians to accept the LW.

The desire for a receptive cooperative doctor varies. It seems that the older the patient gets, the more he/she expects to meet a doctor who respects his/her Living Will (LW) and wants to entrust the final stage of his/her peaceful life to them. The receptive cooperative doctors provide medical care in various settings, such as university hospitals, general hospitals, clinics, and long-term care facilities.

Please refer to the JSDD website "Living Will receptive cooperative doctors." If you have difficulty using and searching the internet, please get in touch with us by telephone or by regular postal mail for information.

On the occasion of a medical examination:

- ① Call in advance to confirm clinic hours, etc.
- ② When you request an appointment with a resident physician at a university or general hospital, please call to make the appointment's date and time.
- ③ When you visit a doctor, you can display your membership card and Statement of Preferences Form to communicate the medical care you desire so that they can better understand.
- ④ If you cannot see the doctor in person, family members or other concerned parties can also consult with us, so please get in touch with us.

The number of receptive cooperative doctors who respect the LW (Living Will) has recently increased. Nothing is better than to meet with a doctor who is supportive and attentive to your values and your daily health condition. I recommend that you have a



“family doctor” who will be attentive to your thoughts and feelings from an early stage.  
(Medical Consultation/Ms. Chihoko Hirabayashi)