

Excerpts from

Japan Society for Dying with Dignity Newsletter  
No. 190, July 1, 2023

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## **A new structure is launched.**

**Dr. Yoshihiro Kitamura, Executive Director, becomes President of the Japan Society for Dying with Dignity**

**Dr. Soichiro Iwao (Age 75), who has worked for the last ten years as the President of the Japan Society for Dying with Dignity on the establishment of a public interest corporation and the organization of the Japan Society for Dying with Dignity, retired in June, and Dr. Yoshihiro Kitamura (Age 62) was appointed as the new President of the Society.**

**The new and old Presidents will deliver their greetings.**



**【On assuming office】**

**Aiming for a society where people can choose their end-of-life care**

**Dr. Yoshihiro Kitamura, the New President of the Japan Society for Dying with Dignity (formerly Executive Director)**

My name is Dr. Kitamura, and I have been appointed as President of the Japan Society for Dying with Dignity. After graduating from the University of Tokyo Faculty of Medicine, I devoted myself to virological research for over 30 years. I was fortunate to learn the importance of end-of-life care from Dr. Soichiro Iwao, the former President of the

Japan Society for Dying with Dignity. I am now practicing home healthcare and working for the development of the Japan Society for Dying with Dignity. I hope to continue to improve end-of-life care together for everyone, as our Society has been recognized as a public interest-incorporated foundation thanks to the efforts of Dr. Iwao, the former President of the Japan Society for Dying with Dignity.

### **Spreading the concept of dying with dignity and increasing membership**

After falling into the Covid-19 Vortex, I feel that I have more opportunities to feel death close at hand. However, I think the debate on end-of-life medical care has not yet deepened sufficiently. The right to choose medical treatment at the end of life, according to our circumstances, is a fundamental human right. We will work even harder than before to achieve the reality of a society in which these rights are guaranteed. We will expand the dissemination of information in the public media, including the lectures and gatherings organized by the branches of the Japan Society for Dying with Dignity, as we have done in the past. Through these activities, we aim to increase the number of our members by widely communicating the concept of death with dignity and the creation of Living Wills. We will also continue to offer end-of-life consultations to our members.

We will strive to ensure that when our members reach the end of their lives, they will be able to pass away satisfied that their lives were good. Furthermore, through the "Little Lighthouse" project and other

activities, we hope to provide vital support to those who are dying, those who are seeing them off, and those who have been left behind.

Three years from now, in 2026, the Japan Society for Dying with Dignity will celebrate its 50th anniversary. By then, we would like to work to ensure that the public widely understands the “right to end-of-life care” and that it is clearly stated in the Japanese law by the Diet.



### **【On leaving office】**

**Working on the groundwork to accept the legislation.**

**Dr. Soichiro Iwao: Honorary Chairman (former President)**

On stepping down as President, I would like to say a few words.

I have decided to retire from the position of President after more than ten years of service. I would like to express my deepest gratitude to all members, staff, and stakeholders who have supported me during this period.

The previous President, Dr. Akihiro Igata, had been working energetically on the legislation of dying with dignity. In December 2003, he submitted a petition to the Ministry of Health, Labor, and Welfare (MHLW.) In May 2004, he launched a national signature campaign to petition for legislation, gathering more than 130,000 signatures a year later. As a result, in April 2005, a non-partisan group of parliamentarians formed the Diet Members' Caucus for Dying with Dignity Legislation. In May 2012, the Diet Members' Caucus announced a draft law on respect for the patient's wishes in their end-of-life care. When the Dying with Dignity Act becomes law, the Japan Society for Dying with Dignity is expected to be the legal entity entrusted with the management of the Living Will (LW) register, as stipulated in the law.

### **Overcoming "public interest" disapproval**

In June 2012, I took over as President of the Board under these circumstances. It was necessary to put the association into an organizational structure that would meet the requirements for commissioning after the Act came into force. To this end, I set up a basic issues study group comprising the Board Members and external committee members, which identified the following issues:

1. Obtaining public interest incorporated status
2. Revising the LW (Living Will)
3. Reviewing administrative functions such as membership management
4. Conducting surveys and research activities
5. Strengthening public relations activities.

The Japan Society for Dying with Dignity applied to the Cabinet Office to become a public interest incorporated foundation, but the Cabinet Office had twice rejected the application in 2015 and 2017. The

Society appealed against this in the judiciary, and in November 2019, the High Court of Justice ruled in favor of the Society. As a result, The Japan Society for Dying with Dignity has been transformed into a public-interest-incorporated foundation since 2020. Regarding the LW (Living Will) to be equipped after the legislation, a study group on the revision of the LW (Living Will) was established for four years from 2017, consisting of association directors and external experts, and it was able to present it to you as the new LW (Living Will) last year.

In addition, during the past ten years, the Japan Society for Dying with Dignity has been reviewing its Head Office operations. It has improved its structure and created the groundwork for accepting the legalization of the Society by:

1. abolishing the disparity in membership fees according to the age of members,
2. eliminating the administrative complexity of collecting membership fees,
3. centralizing the bulletins that were issued independently by each branch,
4. holding an annual LW (Living Will) study group.

The Society has been working to improve its structure and create the groundwork for accepting the legalization of the Society. We hope the next generation will build on these foundations to promote our activities further.

I would like to thank you for your long-term support.



## Members' Voices

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

### **Living Will (LW) as a great support**

**Ms. Tamae Nakamura (Age 90), Tokyo**

I have been living alone for about two years after undergoing major surgery at the University of Tokyo Hospital for extra-osseous myxoid **chondrosarcoma**, a malignant tumor of the bone. Presently, I can barely move around my house, even with the help of a walking cart. While I was staying in hospital for one and a half months, I met a member of the Japan Society for Dying with Dignity, with whom I have continued to correspond by letter since leaving hospital. That was the first time I had met a fellow member of the Japan Society for Dying with Dignity.

I must have an MRI scan every three months, but it is challenging to live with sarcoma as I live alone, crippled, and have lost my strength, energy, and appetite. My daughter takes time off from her work every time I have an examination and arranges a wheelchair taxi to take me to hospital, but it is not easy. Because it is a rare cancer, I feel I have to cooperate with the University of Tokyo's research center as

much as possible. Still, I don't know the meaning of life anymore, and it is hard every day as I slowly get weaker and weaker every day.

In such circumstances, I am very pleased to receive the Living Will and read it from cover to cover as a source of comfort. I am living my life to the fullest, cherishing my life after overcoming war, great earthquakes, and poverty. I saw the TV program of Dr. Masako Sekimoto of Kobe, which was introduced in the reportage of Bulletin No. 188. "The role of the doctor is to create a peaceful end-of-life environment. What the patient does is to live life to the fullest". I agree with that. Living with a Living Will is an excellent source of support. This letter is being sent out in the post from Tokyo, Japan, by my daughter.

### **Registered with the Japan Society for Dying with Dignity and Body Donation to Medical Science.**

#### **Mr. Nobuo Seki (Age 73), Kanagawa prefecture**

My wife and I joined the Japan Society for Dying with Dignity when we were in our thirties. At that time, when I told my parents, who lived with us, about joining the JSDD, my father told me, "I don't want to be a murderer like that."

However, when my father read the JSDD manual, he said, "I like this," and invited my mother to join as well. Thanks to this, both of them were able to pass away peacefully without being connected to a tube or in pain.

Sometime later, my wife, my dear partner in life, was found to have uterine cancer. She had no symptoms, and when she found out, she was stage 4B.

She was admitted to hospital at the end of October 2020. She was going to be discharged after about a week, but her symptoms progressed, and they said that she could no longer return home, so I consulted her doctor to fulfill my wife's wish to go home. With the help of social workers, local doctors, and care managers, I hurriedly prepared a nursing bed and an oxygen generator, and she was discharged from hospital on 16 November 2020. My wife said, "I'm glad to be back home, and it feels good to have a bath. I'm so happy ...." and died early in the morning two days later. I thought to myself, "Thank God. If I had been a little late, I would have regretted it for the rest of my life." Everyone I contacted said indirectly, "I have to choose the right words, but I am glad that you brought her home."

My wife's body was donated to medical science. We had been registered with a medical science organization since we were in our 40s. Her remains were returned as bones two years later, also fulfilling a wish to be of service to medical students.

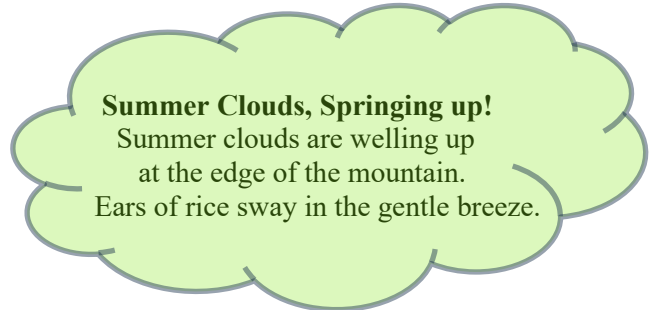
### **A blissful moment looking at the mountain**

#### **Mr. Shinsuke Kishi (Age 83), Tochigi Prefecture**

I am 83 years old, and my strong desire is to live as long as possible. First of all, I want to live to be 88 years old so that I may enjoy the Beiju Celebration (the traditional 88th birthday celebration in Japan.) I have only five more years to go before I can do this. To keep myself healthy, I do exercises to instruction on the radio at 6:30 am, 8:40 am, and 3:00 pm (only 6:30 am on Sundays). I believe that these radio exercises are something that Japan should be proud of in the world, as they exercise the whole body and move parts of the body that are not normally moved.

The next thing I will do is a medical check-up. Once a year, on my birthday, I can have an examination equivalent to a "physical examination" free of charge at a medical institution designated by the city or town in which I live. In addition, the hospital has a restaurant attached to the hospital, where meal

vouchers are available. From a seat on the hospital's restaurant's north side, you can see the majestic Mount Nantai and the Nikko mountain range, and I can spend a blissful moment with my spouse while enjoying a cup of coffee.



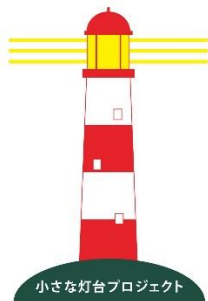
### **I want euthanasia.**

#### **Anonymous (Age 92), Hyogo Prefecture**

As I am over 90 years old, I always carry my membership card of the Japan Society for Dying with Dignity with me, just in case anything happens when I am out and about. The other day, I looked at my membership card and saw again that my husband and I had joined in 2002 when I was 70.

More than ten years ago, my husband had a cerebral hemorrhage and became unconscious, and I refused life-prolonging treatment for him. However, he survived for five months with a gastric bandage operation on the orders of his doctor, who said, "I can't bear to see him starve to death." but those five months seemed so pointless to me. Nowadays, it seems possible to refuse life-prolonging treatment if you or your family do not want it, but this was not the case then. "My statement of wishes" is left at the entrance of my residence.

It may be a long way off in Japan, but I want euthanasia, which is legally recognized in the Netherlands and other countries, to be legally recognized in Japan. I want people to know that some people want to die alone without seeing anyone.



### **Decision support website for healthcare choices during the last phase of life**

#### **The Little Lighthouse Project Guide.**

**A comprehensive community care system to realize dignified end-of-life and end-of-life care at home.**

#### **Do you know about the comprehensive community care system?**

Can you imagine what life will be like when you leave hospital and go home?

Many people are hesitant about end-of-life care at home because they cannot predict what will happen to them and are just frightened. But home healthcare can be more generous and supportive than most people think. It is the "end-of-life episodes" that illustrate this.

Many "end-of-life episodes" from surveys of bereaved families tell us that when people wish to meet their end with dignity, they must meet with receptive cooperating doctors, nurses, or care professionals who understand and supports their wishes. Home healthcare is supported by various professionals working together in a comprehensive community care system.

### **What is a home care nurse?**

As stated in the following episode, "It was reassuring to have a visiting nurse come every day." The visiting nurse is the one who listens closely to the patient's family, understands the patient's condition, and monitors their progress. The coordination skills of the home care nurse are important for the successful collaboration of multiple professions and can be said to hold the key to end-of-life care at home.

[Information Box] update: "What do I need to know and prepare in advance for my end-of-life care?" Please take a look at the following pages. What would visiting nurses like to tell you from their experiences in the field of end-of-life care?

### **Advertisements in the general women's magazine "Fujin Koron."**

A one-year series of advertisements have been running since the May issue of "Fujin Koron." It provides a simple overview of the "Japan Society for Dying with Dignity" and also of the "The Little Lighthouse."

#### **[Episode of end-of-life care]**

At the time of discharge from hospital, a meeting was held with the patient's doctor, nurses, care manager, social worker, home-visiting doctor, visiting nurse, dietician, visiting pharmacist, etc., to confirm the care plan for the patient at home. I mainly provided the care, but the daily home nursing visits reassured me.

#### **[Comments from the Japan Society for Dying with Dignity]**

The person with a clear Living Will (LW), carers who can represent the Living Will clearly, and various professionals who support them: ..... This kind of system results from a "comprehensive community care system." We would like more people to know that such a system exists.



## telephone and email medical consultations



### Results of the 2022 "Telephone Medical Consultation" summarized.

**"I think it has been recognized as a place where people can feel free to ask for advice at any time."**

When I was infected with Covid-19 and treated at home, I strongly felt that I wanted to live the rest of my life at home. I have no relatives and live alone, but is home healthcare possible? (Age 82 Female)

My husband died at the end of March. In the end, I told my doctor that I wanted to die with dignity, but they did not accept it. I would like to die naturally at home, but I would like to know if there is a home doctor in my area. (Age 88 Female)

My father was on a ventilator due to a prolonged loss of consciousness from a stroke. I asked the doctor if I could take him off the ventilator, but he refused. Is it impossible to remove him from the ventilator? (Age 43 Male).

My 98-year-old aunt was injured after she fell down last year and was placed on nasogastric tube feeding. She also has dementia. She is able to eat jelly and chopped food but continues to be on nasogastric tube feeding due to malnutrition. When I presented her Japan Society for Dying with Dignity membership card and asked for the tube to be removed and for the patient to be monitored, they refused to do it, and I was told that it was against the law. (Age 64 Female)

I have been depressed since the age of 48. I look healthy, but my head is confused, and I am suffering. Some foreign countries allow euthanasia, but I would like Japan to allow euthanasia as well.

I want to tell the Japan Society for Dying with Dignity that there are people who wish to commit suicide. (Age 66 Male)



From April 2022 to March 2023, the telephone medical consultations continued from last year in the wake of the Covid-19 disaster. Japan Society for Dying with Dignity (JSDD), the consultant staff (three nurses) have been taking turns to respond, including working from home. Still, in May of this year, Covid-19 was classified as a "Category 5", the same as influenza, so the responses are returning to the pre-Covid-19 level.

Now, the results of its consultations for the year 2022 have been compiled.



The number of consultations was 704, a significant increase compared to the previous two years (502 and 500). The number of consultations by content area (multiple content areas per consultation) was 1868, again a significant increase compared to the previous two years (1159 and 1182.)

### The increasing role of children

Looking at the content of consultations by category, 815 (44%) were related to the medical content of dying with dignity, followed by 598 general medical consultations and 352 mental consultations, for a total of 950 (51%). Consultations on dying with dignity remained unchanged at close to half of all consultations in previous years. In contrast, general medical and mental health consultations together accounted for more than half of all consultations. The reason for this may be that the staff of the consultant staff "have come to recognize the Japan Society for Dying with Dignity's telephone medical consultations as a place where people can easily consult at any time about the details of their illness, guidelines for seeing a doctor, how to lead their daily lives, etc."

72% of the consultations were with the person themselves, 12% were with their children about their parents, and 10% were with their spouses. Consultations about parents from children were 2% higher than consultations about spouses. The consultants believe this may be partly due to an increase in the number of end-of-life medical decisions delegated to children.

