



Excerpts from

Japan Society for Dying with Dignity Newsletter
No. 191, October 1, 2023

Main Contents:

- Change of Presidents - Photo Report
- Living Will Square
- Report on the Facilitator Training Workshop
- From telephone and email medical consultations

Change of Presidents - Photo Report 1

Press Conference on the Change of JSDD's President & also a Concert by Yumiko Samejima in the Foreign Correspondents' Club of Japan – Aug. 3rd

Secretary General of the "Diet" also attended the press conference. Yumiko Samejima, a new advisor, enthusiastically sang ten songs.



On August 3, three days prior to the commemorative lecture by the new President, a press conference, "Dying with Dignity ---- World and Japan," by the former and new Presidents of the JSDD and a concert by Ms. Yumiko Samejima, a soprano singer who was appointed as a JSDD advisor in June, were held.

The 140 seats at the Foreign Correspondents' Club of Japan were filled to capacity.

Mr. Hiromi Mitsubayashi, the chairman of the House of Representatives Health, Labor, and Welfare Committee and the secretary-general of the Diet Members Caucus for "Thinking of Respecting the Will of the Individual at the End of Life," also attended the press conference.



Former President of the Japan Society for Dying with Dignity (JSDD)
Dr. Soichiro Iwao

In his presentation entitled "The History of JSDD in the International Community," Dr. Iwao explained about the Japan Society for Dying with Dignity's activities over the past 47 years in detail and in an easy-to-understand manner, making full use of slides during his talk.

Chairman, Health, Labor and Welfare Committee, House of Representatives

Dr. Hiromi Mitsubayashi

I have worked as a doctor at a university hospital for many years. I would like to work in a bipartisan manner toward the legislation of death with dignity based on the confirmation of the patient's will in a "life meeting" by utilizing the knowledge of terminal care I have experienced there.



New President of the Japan Society for Dying with Dignity (JSDD)
Dr. Yoshihiro Kitamura

I would like to work toward the legislation. Now, every week on the radio, a celebrity speaks passionately about his/her "departure". You can also watch it on our website. Please take a look.

Yumiko Samejima's concert held following the press conference.



She sang about ten songs, including "Omoigo," a lullaby composed by Empress Michiko, and "Hymn of Love", "Lily Marlene", "My Way", "Like a Stream of Rivers," and others. Finally, with copies of the "Songs of the Four Seasons" from the bulletin in hand, everyone sang the lyrics from the song "Furusato" in unison, "Usagi oishi kano yama ♪ ~" ("The mountain where I chased rabbits ♪ ~")

Change of Presidents - Photo Report 2

Commemorative Lecture concerning the change Presidents in Ito Hall in the University of Tokyo Aug. 6th

Along with the change of Presidents, the 47-year history of the Japan Society for Dying with Dignity was discussed, and the various issues and challenges surrounding end-of-life care in Japan. Also, future prospects of the JSDD were explored.

After a short break, we welcomed Ms. Akiko Nishina, an actress, who was interviewed by Mr. Hiroki Ando, a freelance announcer.

Ms. Akiko Nishina talked about her repeated battles with cancer, how her feelings changed over time, and what she thinks about now in retrospect. Dr. Yoshihiro Kitamura joined her in answering simple questions about dying with dignity.



Dr. Yoshihiro Kitamura
JSDD President

**"The basic principle is "You decide your departure."
(Dr. Kitamura)**

With the advent of the multi-lethal society, there is a growing interest in end-of-life care. The basic principle of end-of-life care is not to "leave it to the medical group" but to "decide on your departure by yourself." It is not a "set course," like a restaurant, but an a la carte order. To do this, we must write the Living Will. We will support everyone at the end of life and work to make it legal.



Ms. Akiko Nishina
Actress

**"It was a repetition of being aware of death and forgetting it."
(Ms. Nishina)**

I am now 70 years old and have had four cancer surgeries, including cervical cancer at 38 and colon cancer at 60. Each time, I was aware of death, forgot about it, and became aware of it all over again. Now, I would like you to see me off with a round of applause at the end of my life.



From left to right:
**Dr. Kitamura, Ms. Nishina, and the
MC, Mr. Ando.**



Dr. Soichiro Iwao,
Former President of JSDD
Currently: Honorary Chairman

Dr. Iwao: "What remains is the legalization of death with dignity."

Over the past decade or so, as the President of JSDD, I have been actively involved in the organization as a public interest incorporated Society, revising the Living Will, reviewing secretariat functions such as membership management, and strengthening research, surveys, and public relations activities.

What remains is the legalization of death with dignity. It is a step-by-step process, but I hope we will progress toward its realization.



Members' Voices

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

Until my husband is coming to pick me up

Ms. Tokuko Shintani, Age 91, Tokyo

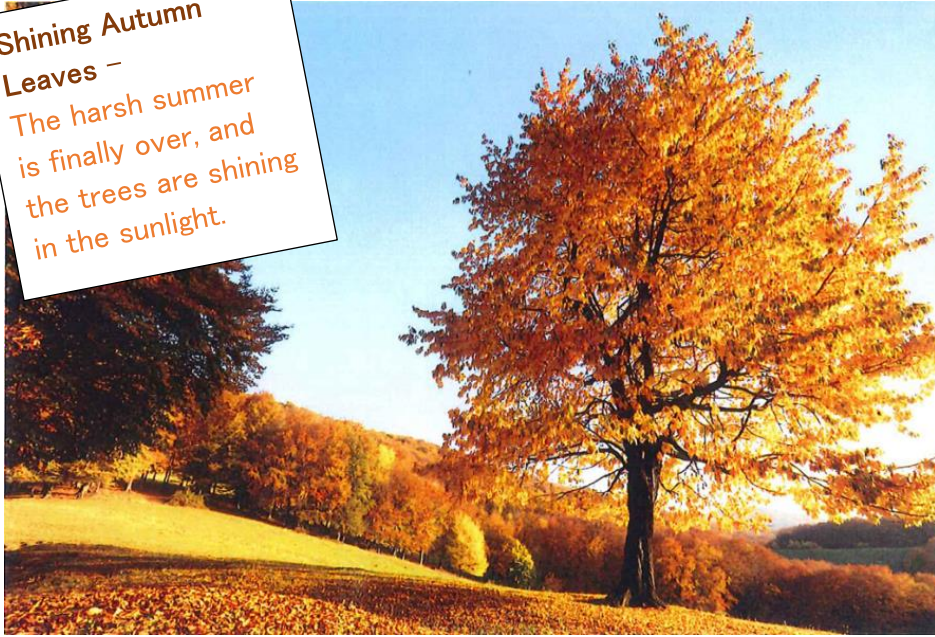
It has been eight years since I lost my husband, who was one year older than me. Five years earlier, my husband was diagnosed with prostate cancer, but after surgery, he made a full recovery. After that, he went to the hospital for chronic heart failure, back pain, etc., but there were no major problems in his daily life, and the two of us enjoyed occasional overnight trips together. However, his appetite gradually decreased, so we went to the hospital and listened to his doctor's diagnosis of his present medical condition.

At the suggestion by the doctor that he should be admitted to the hospital for tests for a while to see how he was doing. My husband, who had been sitting with his head down, suddenly looked up and crossed his hands to make a cross with a loud voice said, "No gastrostomy, no life-prolonging measures," and then he said "No." I was just stunned. After a moment, the attending doctor nodded his head and said, "I understand.

My husband was then hospitalized. I visited him daily, and my husband accepted me calmly as I talked one-sidedly to him. On a night, about ten days after he was hospitalized, someone heard a noise in his room, and the person on duty rushed over to see if he had dropped his cell phone. When the person on duty picked it up, handed it to him, and asked him who he was calling, he replied, "My wife," and fell asleep with the phone still in his hand. I was unaware that he was trying to call me even though I always had my phone by my side. What was my husband trying to tell me...? My husband departed peacefully two days later, with my sister and I watching over him. Against my husband's wishes, I blamed myself for not asking for life-prolonging measures. My husband was a teacher, and we were not blessed with children.

After my husband passed away, I was sorting through his belongings and found a notarized will. Looking through his notarized will, I found a section where he expressed his gratitude to me. I cried, thinking that he had never shown even the slightest sign of such appreciation. I have been hospitalized and operated on repeatedly since then, and I am now living in a facility with the support of others, learning from my husband and thinking about how my life should end. About four years ago, I joined the Japan Society for Dying with Dignity after learning of its existence, and I am now waiting for my husband to come for me with peace of mind.

**Shining Autumn
Leaves –**
The harsh summer
is finally over, and
the trees are shining
in the sunlight.



Building a Rainbow-Colored Bridge!

Ms. Junko Ito, Age76, Shizuoka Prefecture

From what place does my husband, who passed away five years ago, watch over me? A meadow with a fresh breeze, a hill overlooking the sea, or a star shining secretly.... I put my hands together with my thoughts on the image of the deceased. But I cannot draw a map to the place where my husband rests.

It seems to me that there is a difference between climbing the stairs to heaven and crossing the River of Sanzu. I have to ensure that I don't get stuck in a maze in which I might get stuck. My husband, after all, is the only one who can help me with my lack of sense of direction. So, I decided to make one last request to him. "Please build me a bridge across the dawn sky, a rainbow-colored arch bridge!"

As a civil engineer who has worked on many large bridges and roads, I am sure you will make my wish come true. I will find my husband waiting for me on the other side of the bridge, and I can amble along slowly to be with him. Like my husband, who met a peaceful end with the quintessence of the JSDD as his foundation, I want to retreat from the fear and anxiety of death. It is not wrong to draw such a childish fantasy.

Until I hear my husband's voice saying, "A bridge has been built!" I will cherish each day and welcome the end of my life.

To my wife, who died with dignity

Mr. Akira Sugino, Age 89, Kanagawa Prefecture

My wife, who had been suffering from malignant lymphoma since last year, died with dignity in June. The doctor at the hospital where she was staying had told her that "there is a possibility of remission if chemotherapy and radiotherapy are exhausted, but it is difficult to cure the disease completely." Without a word of advice, she came home from the hospital saying, "There is no need for life-prolonging treatment, only palliative care. Less than a year later...."

My wife's local family doctor refused to see her because he said "Doctors are supposed to treat patients, and there is no medical insurance to care for patients who refuse treatment and say they want to die well." She started using potent narcotic drugs in April, and I had to bring my wife to the hospital every week.

As her disease progressed, she developed dementia, and I could not take care of her at all, so the community care manager arranged for her to receive home nursing care and home medical care. Incidentally, even though it was their job, I learned a lot from the strict but gentle care provided by the visiting nurses.

I took care of her until the end of her life, as she chose to die with dignity, saying, "This is my aesthetics of life." and in accordance with her dying wish, I completed her burial in a tree. I am consoled that I have finally fulfilled my responsibility. In closing, I would like to add a few words of farewell from my wife.

“After all this time, I realized the beauty of a cherry blossom on the Earth.” By Eiko

Living Will Facilitator Training Workshop in Saga **Deepen exchanges with people from other professions in a camp format.** **74 people participated in the first event held in three years.**



Lecture by Dr. Haruhiko Miura. The attendees were in an atmosphere where they did not want to miss a single word.

The Living Will Facilitator Training Seminar was held in Tosu City, Saga Prefecture, from July 22nd (Sat.) to 23rd (Sun.) It had been three years since the outbreak of the Corona Disaster, but the workshop was a great success with 74 participants, including the instructors, and was filled with enthusiasm.

What is the purpose of this training

- ① To learn the latest information on decision support and deepen your thinking and facilitator learning about the relationship between The Living Will and ACP (Advance Care Planning and Life Conference.)
- ② To definition of the Japanese ACP and explanation of the action guidelines.
- ③ To experience ACP group work with "The Living Will" and "My Statement of Preferences Form," as revised in November 2022.
- ④

To learn the principles of clinical ethics that are essential for performing ACP.

⑤ To learn about clinical ethics and how to proceed with ACP regarding discussions concerning the discontinuation of dialysis and non-initiation and withdrawal of ventilators for amyotrophic lateral sclerosis (ALS.)

⑥ To experience consensus-building through dialogue with a wide variety of people from various professions.

⑦ It was a wide-ranging project to build trust and networks between associations and professionals through exchanges between medical, nursing, and welfare professionals working in home health care, primary care, and palliative care settings, and a diverse group of people, including religious leaders and intellectuals.

Group work with a variety of instructors

Lecturers are:

Mr. Masayoshi Egoshi (Egoshi Law Office),

Dr. Makoto Eriguchi (Head of Neurology, Saga-Ken Medical Center Koseikan),

Dr. Sumiko Kanegae (Hiramatsu Hospital Hiramatsu Clinic Home Healthcare Department),

Dr. Kazuhiro Nagao (Vice President of the Japan Society for Dying with Dignity),

Ms. Keiko Narisada RN (Director of Nursing and Community Relations, Yukenkai Kimura Hospital),

Dr. Yasuyoshi Ninosaka (Ninosaka Clinic),

Dr. Haruhiko Miura (Professor, Iwate University of Health and Medical Sciences), and

Dr. Satoru Mitsuoka (Director of Japan Society for Dying with Dignity, President of Kyushu Chapter, President of Saga)

The first day was a classroom lecture, and the second was a group work session with seven people in a group, for ten groups. It was a valuable experience for the participants to deepen their meaningful learning over the two days. The camp-style training program helped us to strengthen our bonds as colleagues who share the same interests, and we all look forward to our reunion next year.

(Ms. Masako Eto, writing)

✳ A facilitator is a person who takes a neutral position and is responsible for bringing together the participants' opinions in a meeting and guiding them to a better conclusion.



The attendees listen attentively to the lecture.



Dr. Masahiro Deguchi of Nagasaki Prefecture presented a group work session. He concludes his presentation with the words, "Is there any love there?" and ends with a stunning performance.



telephone and email medical consultations



**“I want to spend my last days at home.
I need home medical care....”**

I want to face my final days at the home where I used to live, but what should I do? What are the procedures and costs? We receive many such questions from the elderly. In this issue, we focus on consultation about home medical care.

[Case Study]

I have lived alone since my husband passed away several years ago. I have been doing my best until now at the age of 86, but recently, I get tired easily, and my legs and back have become weak, making it difficult for me to go out. Depending on the day, I am in and out of bed. I have been visiting the hospital for high blood pressure and abnormal fat metabolism, but even these visits are becoming difficult for me to manage on my own.

Q. I would like to spend my final days at home, where I have fond memories of my husband.

A. If it becomes difficult for you to go to the hospital alone, you can receive home medical care.

Q. Please tell me what home medical care is.

A. Home medical (home visiting) care is for people who need continuous medical care. Doctors and nurses visit the patient's home regularly based on a predetermined schedule and provide treatment, prescriptions for medicines, and tests, just as if the patient were going to the hospital. Visits are not limited to your home but can also be made to your group home or senior citizens' home. When care is needed, doctors, nurses, lawyers, rehabilitation specialists, pharmacists, nutritionists, and other professionals will each work together to provide support and help you live your life as you would while recuperating at home.

Q. How can I find a hospital that can provide home medical care?

A. Consult with your current doctor, nurse, medical welfare (social worker) at the hospital's consultation office, care manager, or the comprehensive support center or welfare department for the elderly in your municipality. Alternatively, you can consult directly with a nearby medical institution that you are considering using.

Q. How do I go about the procedure?

A. First of all, you need to be convinced.

① Before you begin, you should meet with the home health care agency to confirm your wishes and medical policy and verify costs and emergency response.

② If you are satisfied with the service, you can apply for an application. Required documents include: a "medical information form from your family doctor," "medical insurance card," and "nursing-care insurance card."

③ Finally, you will inform the doctor or nurse of the date you wish to receive medical care, and the date and the time will be adjusted. A doctor or nurse will visit your home regularly on the fixed date and time to provide medical care.

Q. What should I do if I suddenly have a fever, for example?

A. Many home healthcare facilities also provide house calls. House calls are irregular medical services provided at the patient's or family's request. It is advisable to consult with the doctor beforehand about handling sudden fevers, sudden changes in medical conditions, and emergencies.

Q. How much does it cost for home medical care?

A. Medical insurance is available. The coinsurance payment is about 10-30%, depending on the individual's income and age. The cost of medications when they are provided and the cost of nursing care insurance when used are extra. If the monthly coinsurance payment exceeds a

certain amount, you can apply for a "high-cost medical care reimbursement" to return the co-payment.

Q. Is palliative care also available?

A. Palliative care is designed to relieve pain associated with the progression of cancer and a variety of other conditions, such as back pain. Listening and consultations are also part of palliative care. Since home care is provided in the usual setting, consulting with a doctor or other health care provider is easier. You should let your doctor and others know your thoughts and wishes in advance.

Q. Can I receive end-of-life care at home?

A. Many places now offer Advance Care Planning (ACP) based on your living will.

The ACP is to discuss and share your wishes for medical treatment and care with your family and medical care providers in advance in case you can no longer communicate your wishes.

Home healthcare provides a team of support to fulfill your wish to spend your final days in the comfort of your own home where you used to live as you wish.

If you can live at home as you usually do, you will feel stable and maintain your QOL (quality of life.) Consultation for home medical care is available from the time you think about recuperating at home, not after you become bedridden. An increasing number of places offer various services to those who wish to receive home medical care. Why not start using a consultation service such as a local comprehensive support center to gather information rather than struggling alone?