



Excerpts from

Japan Society for Dying with Dignity Newsletter
No. 196, January 1, 2025

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New Year's Message

For the Japan Society for Dying with Dignity's 50th Anniversary, we are working on activities such as the World Convention, Legislation, etc.

Happy New Year!

The Japan Society for Dying with Dignity, as a public interest incorporated Society, marks its 6th year this Spring.

This will be the second New Year since I took over as President from the former Honorary President Soichiro Iwao in June 2023.

All officers and employees will renew their commitment and carry out their duties with a renewed spirit.



(President)
Dr. Yoshihiro Kitamura

The Japan Society for Dying with Dignity is planning various commemorative events to mark its milestone 50th anniversary next year in 2026. One of these events will be the

“Tokyo Conference 2026” of the World Federation of Right to Die Societies, which will be held in Tokyo in November of 2026. Members of 60 right-to-die organizations from 30 countries will participate in the Conference. We will have a bird’s eye view of end-of-life care in the world, and at the same time, we will deepen the discussion on the concept of death peculiar to Asia.

The advance directive (Living Will = LW) issued by the The Japan Society for Dying with Dignity is highly regarded in society as a statement of intent for end-of-life care based on the person's autonomy. We want to promote this LW to Government Diet members more actively and have it legally secured and incorporated as an advance directive respecting the “end of life” method of expressing one’s will as soon as possible.



Now, the number of members registered with our Society (JSDD) is less than 80,000, a significant decrease from about 120,000 10 years ago. Since the Japan Society for Dying with Dignity is operated by an annual membership fee of 2,000 yen, a decrease in income due to a decline in membership will greatly limit the Society's activities. In order to maintain and expand the activities of the Society, we must strengthen our efforts to secure operating funds through donations and bequests in addition to annual membership fees. Tax benefits are available for donations to the JSDD. If you would like your valuable assets to be utilized for the benefit of Society in the future, the Japan Society for Dying with Dignity would be happy to discuss this with you.

We want to enhance our awareness-raising activities further.

The prolonged Corona disaster made holding lectures and other events difficult, and we could not conduct sufficient Living Will awareness-raising activities. To supplement these activities, a radio program called “My LIFE! My CHOICE!” is a radio program to raise awareness of dying with dignity. Many listeners received the radio broadcasts well, but

now that a certain point has been reached, we will continue to conduct awareness-raising activities with even more power as a unique communication by Dying with Dignity.

The Japan Society for Dying with Dignity is also compiling a database of information from bereaved families on how our members' last days were and how the Living Will has helped them, and it is making it available to the public as the "Small Lighthouse Project." To make this information available to as many people as possible, we have published a series of articles, "Living Better: A Guidepost - Michi Shirube -" in the Fujin Koron, a monthly magazine published by Chuokoron Shinsha. In this series, we share our valuable experiences of end-of-life care with our readers.

The JSDD website (<https://songenshi-kyokai.or.jp/>) contains many columns, including the latest information on dying with dignity in Japan and abroad, information on JSDD's receptive doctors, and the "Small Lighthouse Project." I intend to continue to disseminate information more actively.

I want to ask for your further support for JSDD and wish all our members good health at the beginning of the year!

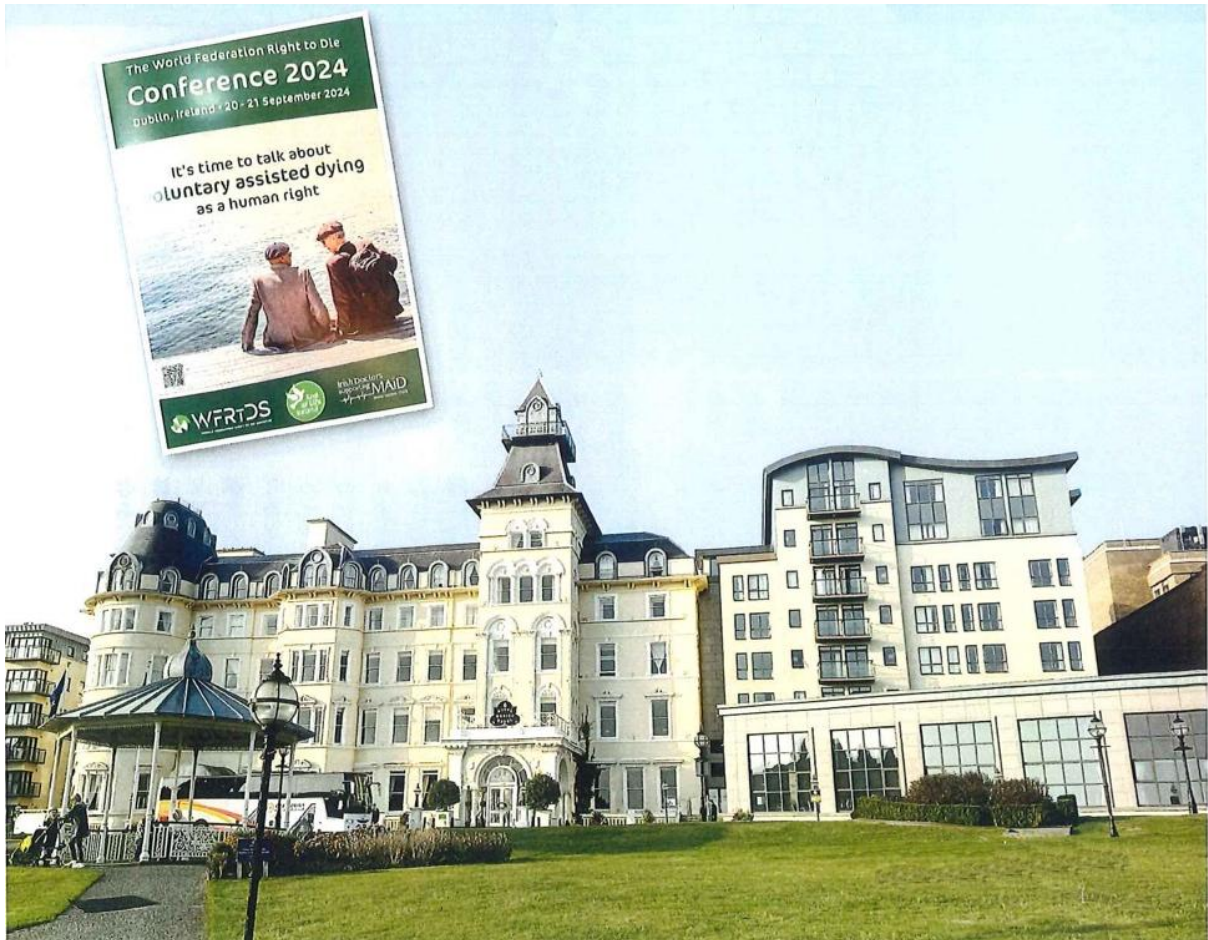
The report on the World Federation of Right to Die Societies (WFRtDS) Conference in Dublin, Ireland.

The 2026 WFRtDS Conference will be held in Tokyo, Japan!

Including the first time, it will be the fourth time that the Conference is held in Japan.

The previous biennial, "World Federation of Right to Die Societies Conference," was held in Dublin, Ireland, September 19-21, 2024. Dr. Kitamura, President, Dr. Satoru Mitsuoka, Ms. Kiyoko Kamibeppu, and Mr. Koichi Jimba, Directors of the Japan Society for Dying with Dignity attended the meeting, which will be held next in 2026. The 26th WFRtDS Conference was unanimously decided to be held in Tokyo. The first WFRtDS Conference was held in Tokyo in 1976, followed by Kyoto in 1992 (the 9th Conference) and Tokyo in 2004 (the 15th Conference), and the next Conference will be the 4th Conference to be held in Japan.

The following is a report on WFRtDS Dublin Conference including the future Conference in Japan.



The venue was the Royal Marine Hotel, a classic-looking hotel located in the suburbs of Dublin, about 20 minutes by car from Dublin, in a villa-like setting. On the eve of the convention, a meeting of the seven Directors (Board) of the World Federation of Right to Die Societies was held for two hours in the evening, and was attended by Dr. Kitamura, President of the Board of Directors. After the meeting, a dinner was held with members of the Federation and the JSDD Board members.

The General Assembly on the first day of the Convention, the 19th, was positioned as “the biennial World Convention of the Federation.”

In the morning, for about two hours, about 70 participants from 11:00 AM prepared round tables and attended the main proceedings, budget, and settlement of accounts, as well as the election of board members and the next host city. Dr. Kitamura, JSDD’s President of the Board of Directors, made a speech for the Japan bid, while Dr. Mitsuoka and Ms. Kamibepu distributed Japanese postcards and brochures about Tokyo. The audience was drawn in by Dr. Kitamura’s speech and the video introducing Tokyo, and it seemed as if they were already looking forward to the event in Japan. “I talked to about ten people while distributing the materials, and they all said they would go to Tokyo.” said Mr. Mitsuoka. “I was given an orange and a green voting flags, (green = Yes and orange= No.) I voted “Yes” for having the next Conference in Japan.” said Mr. Jimba. “I would like to report that the decision to host the next Conference in Japan was unanimous,” recalled Mr. Jimba.

The Preparatory Committee for the event was formed, and correspondence was made.

In the afternoon, the meeting proceeded in the form of reports from each country, but in reality, it ended up with various opinions and problems pointed out and raised by each country regarding “Dementia and Euthanasia.” Although no specific solutions or directions were presented due to the difficult theme, the sincere efforts of each country were conveyed.

The first day of the Conference was hosted by the WFRtDS, and the second and third days were hosted by the Irish Society. The second and third days of the Conference were held in a slightly larger room than the first day, with about 100 participants seated at about 20 round tables. “The program structure was not very academic, and I had the impression that most of the participants were from the general public.” said Dr. Mitsuoka. Six people gave presentations on euthanasia, death with dignity, etc., on both the second and third days within their allotted time of eight minutes. As an overall impression, Dr. Kitaura said, “In Tokyo, I hope that the audience and participants will be not only the general public, but also doctors, medical professionals, and scientists, as I would like the Tokyo meeting to be a place of learning for them. Dr. Mitsuoka, Mr. Jimba, and Ms. Kamibeppu, all Board members, look back on the Conference, saying, “It was not like a systematic compilation like a Japanese Conference, but rather a free presentation of opinions from each country.”

Building on the valuable experience gained from participating in the Dublin Conference, concrete initiatives have already begun to shape the approach for the "2026 Tokyo Conference.



Dr. Kitamura, President of the WFRtDS Tokyo Invitation Speech



Meeting with participants from various countries

50th
Anniversary of
the Society

World Federation of Right to Die Societies – Tokyo

Strengthening activities to gain the backing of the “Death with Dignity Law”



(Honorary Chairman: Dr. Iwao Soichiro)

“Tokyo in 2026” (Two years from now) was decided
at the Autumn 2024 Dublin Conference.

Dr. Soichiro Iwao, who has been deeply involved in “Death with Dignity” since his days at the Ministry of Health and Welfare (now the Ministry of Health, Labor and Welfare) in Japan, spoke about his past involvement with the World Federation for the Right to Die Societies, the global situation regarding the “Living Will”, the response to “euthanasia” in various countries and the current situation in Japan, and the basic stance of the Society. Dr. Soichiro Iwao, Honorary President of the Japan Society for Dying with Dignity, has been deeply involved in “Dying with Dignity” since his days at the Ministry of Health and Welfare (now the Ministry of Health, Labor and Welfare.) “There is a line between euthanasia and death with dignity,” he says, “and we must further deepen our efforts to make death with dignity a law.”

Q. -The first international Conference of the “World Federation of Right to Die Societies” was held in Japan. Wasn’t it?

Dr. Iwao: Yes, it was.

In August 1976, soon after the establishment of the Japan Euthanasia Society, the predecessor of the present Japan Society for Dying with Dignity, an international Conference was held in Tokyo with 19 national representatives and invitees from the United States, the United Kingdom, the Netherlands, and other countries. Therefore, two years after the bidding campaign was held in Dublin, Ireland, the 2026 Tokyo Conference will mark the 50th anniversary of that event.

The landmark trial of Ms. Karen Cullen

Q. -What was discussed at that first Conference?

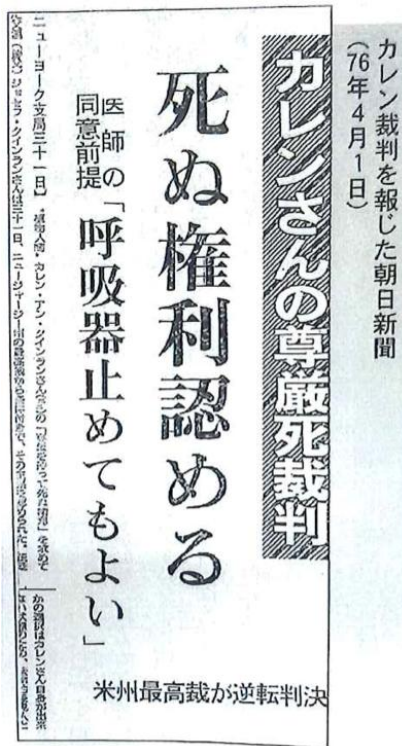
Dr. Iwao: The U.S. delegates talked about the “Karen’s Death with Dignity Trial” that took place in March of that year, including the decision that recognized her right to die for the first time.

Q. -The decision to allow Ms. Cullen to be taken off life support.
Was it widely reported in Japan?

Dr. Iwao: Yes, it was. This ruling that “patients have the right to die concerning their right to self-determination” became a milestone that brought momentum for “right to die” legislation in many states across the U.S. The term “death with dignity” was also used for the first time. -And seven years later, in 1983, our Society also changed its name from the “Japanese Society for Euthanasia” to the “Japan Society for Dying with Dignity.”



From left, Dr. Mitsuoka, Board Member, Dr. Kitamura, President, and Ms. Kamibeppu, Board Member, who participated in the Dublin Convention



Asahi Shimbun newspaper reporting on the Cullen trial

(April 1, 1976)

Karen's Death with Dignity Trial

The right to die is recognized.

Assumption of doctor's consent.

Respirator may be turned off.

Q. -That was the trend. What did other countries talk about at the first Conference?

Dr. Iwao: The representative from the United Kingdom said that “public opinion and support are necessary to legislate euthanasia,” and the representative from the Netherlands pointed out that “passive euthanasia” is considered an individual right, but “active euthanasia” has problems.

Q. -At the convention, the “Tokyo Declaration” was also issued?

Dr. Iwao: Yes, it was. The “Tokyo Declaration” announced that “the choice of death at the end of life should be left to self-determination,” “a Living Will, an advance directive, is an individual’s right,” “efforts should be made for legislation,” and “a liaison center for information exchange should be established.” It was also decided at the same time to “hold an International Conference” every two years on a rotating basis. The name of the Conference was changed to the “World Federation of Right to Die Societies International Conference” and the number of participating countries has been increasing since then. The Conference has been held three times already in Japan: in Tokyo in 1976, Kyoto in 1992, and again in Tokyo in 2004.

Q. -The core, so to speak, of this Conference, is the advanced directives, or Living Wills?

Dr. Iwao: Living Wills around the world are called “Patient’s Rights Act,” “Patient’s Decision-Making Act,” “Patient’s Right to Self-Determination Act,” “End-of-Life Care Directive Act,” etc. The legal framework has been established in over 20 European countries, North and South American countries, and many Asian countries such as Korea, Taiwan, Hong Kong, Singapore, Philippines, Malaysia, Thailand, etc. In Asia, countries such

as South Korea, Taiwan, Hong Kong, Singapore, the Philippines, Malaysia, Thailand, etc., have established legal frameworks.

Q. -It is quite extensive?

Dr. Iwao: Yes, it is.

Q. -What is the situation in Japan?

Dr. Iwao: This legal framework for advance directives/Living Wills is still under discussion in Japan.

Euthanasia laws need a different framework

Q. -When you say “right to die,” many people inevitably think of euthanasia?

Dr. Iwao: I think many people do, but I would like to emphasize that the legal framework for euthanasia needs to be different from an advance directive (Living Will.) The Netherlands, Belgium, Switzerland, Canada, and some states in the U.S. have legalized “euthanasia” and “physician-assisted death” under certain conditions, but many countries, including Japan, do not recognize these.



All meetings at the Dublin Conference were conducted in English, with no simultaneous interpretation.



A packed audience listening through headphones with simultaneous interpretation. In a scene from the 9th Kyoto Conference, about 900 people, including representatives of 19 organizations from 15 countries, filled the venue, and simultaneous interpreters played an active role (from "30 Years of JSDD.")

Q. -So, you are saying that the Japanese Society for Dying with Dignity is distinct from "euthanasia?"

Dr. Iwao: That is correct. Since its establishment, one of the Society's goals has been to legislate "dying with dignity." Its basic stance is a "legal guarantee of non-initiation and discontinuation of life-prolonging measures" and "immunity of doctors" based on the right to self-determination against the Society at that time when life extension was the first and foremost priority. We have promised that Japan will legislate the "Death with Dignity Law (Living Will Law)" like other countries, and our members have agreed with our philosophy, joined our Society, and have continued to support us.

Q. -To ensure that the wishes of all people at the end of life are fulfilled?

In recent years in Japan, there has been a major trend toward respecting the wishes of terminally ill patients, regardless of whether there is a law or not. Isn't that right?

Dr. Iwao: That is the trend. Compared to the past, excessive life-prolonging measures are now discouraged. However, it is only decided on site according to the guidelines by the medical care team called ACP (Advance Care Planning.) It does not mean that the wishes and intentions of all people entering the "last stage of life" will be fulfilled. The Japan Society for Dying with Dignity will continue its activities so that all people can have the backing of the law. We will return to the Tokyo Declaration, the starting point of the first International Conference, and continue to appeal for the legalization of Living Wills in Japan through this international conference. We hope that you, our members, will

understand the purpose of holding this International Conference, and we ask for your support an endorsement.

(Interviewer and bulletin editor: Mr. Takeshi Gunji)

From the telephone and email medical consultations

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Let's Discuss, "What If?"

This is a page where we introduce specific consultation cases and answers given over the phone or by email. A nurse will answer the questions, but sometimes, we will ask for the help of an advisor doctor.

Anyone can suffer a serious and life-threatening illness or injury at any time. When a person's life is in imminent danger, it is said that about 70% of people find it challenging to make their own decisions or communicate with others about their future medical and nursing care. To live as one's own person until the end of one's life, this issue focuses on ACP (Advance = Future, Care = Medical, Nursing, and Care, P = Planning).

Q. My 84-year-old husband was diagnosed with Malignant Lymphoma. He did not receive any anticancer drug treatment as he did not have any symptoms, but he had a persistent fever for a week. He was admitted to the hospital yesterday for emergency care.

At admission, I submitted a Living Will and my statement of wishes to the medical facility. My husband is currently in and out of consciousness. The hospital told me that they are going to do ACP at the end of this month and that my family and son should participate. What does ACP do? I would like to participate with prior knowledge.

A. With ACP, the C part is about the person, family, doctors and nurses, and health care professionals working together to discuss the issue. It is better to do this before the person's decision-making capacity deteriorates. It is a process of discussing the treatment and medical care policy, respecting the wishes of both the patient and the family, and discussing what is important to them when receiving medical treatment and care and what they want to do.

Q. What do you mainly talk about?

A. There are several. • Discuss the outlook for the disease and condition, the treatment and palliative care the patient wishes to receive, and the policies regarding the treatment and care the patient does not want. • What is important for the patient, such as desired medical treatment and care? • What kind of medical treatment and care does the patient want to receive at the end of life? • What situations do they want to avoid? • Where

would you prefer to receive medical treatment and care? • If you were to lose consciousness, who would you trust to discuss your medical and care your doctors?
• If you were in a critical condition with little hope of recovery, what kind of treatment and care would you want?

Q. Once I have decided, can I change it?

A. Yes, you can. It is okay to be unsure, unable to decide, or change later. The process of discussing and thinking together is what is important. ACP is not a one-time event. Feelings change according to one's mental and physical condition, so they can be changed through repeated discussions.

Q. What happens if the person loses consciousness?

A. Based on the person's Living Will (statement of wishes), the family and the medical care team will share and respect their wishes.

Having the ACP is less burdensome for the family and healthcare professionals. Unwilling life-prolonging measures (ventilator measures, artificial nutrition, cardiopulmonary resuscitation such as cardiac massage, artificial respiration, and electric shock) are avoided for the patient.



It is recommended to discuss how you want to spend your terminal days at family gatherings such as New Year's, when you are diagnosed with a serious illness, or when you are hospitalized.

ACP has the advantages that the patient's wishes are respected, Quality of Life (QOL) is well maintained, as is emotional stability achieved, the family members of the deceased are comforted, and medical professionals can provide better medical treatment and care. ACP will also be important for the future, when you are in a condition where you have to decide on a treatment plan on your behalf, in order to live your life as you wish while receiving the medical care you want.

(Ms. Keiko Furuta, Medical Consultant)