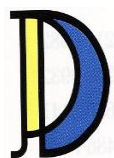


Excerpts from



**Japan Society for Dying with Dignity Newsletter
No. 188, January 1, 2023**

Main Contents:

- New Year's greetings and 2023 prospects by Dr. Soichiro Iwao
- 11th session of Japan Living Will Study Workshop (in person and virtual)
- Telephonic and email medical consultations (#12)



New Year's Greetings and 2023 prospects

Accelerating the dissemination of our revised Living Will through mass and social media such as the radio and Social Networking Services (SNS)

Dr. Soichiro Iwao, President of JSDD, Public Interest Corporation

Happy New Year!

As we begin a new year, all our board directors and staff will strive to conduct our mission with a fresh mindset.



The Living will (also known as Advance Directive for Terminal Medical Care) issued by JSDD has been highly regarded as the official document of patient's will and intent for terminal medical care that is based on self-determination. In our previous newsletter #187, we officially introduced the revised version of the Living Will, in which we emphasized the importance of integration and conformity in confirming the patient's will and intent. The new model also incorporates modern social trends to maximize effectiveness and to posture for the legalization of dying with dignity. As it was explained comprehensively in the previous newsletter #187, our board members also provided a comprehensive explanation of the new model in person during the 11th session of Japan Living Will Study Workshop held

in November under the title, "New Living Will: Planning my own end-of-life and terminal care."

Adding more columns to our homepage

The baby boomer generation now make up the majority of the elderly population. The average age of registered JSDD members is 79. The number of registered members as of November 2022 was approximately 90,000, compared to 120,000 ten years ago. This declining trend is continuing. We gain over 5,000 new memberships every year, but the attrition rate due to death and resignation has been a lot higher than the recruitment rate. This is likely attributed to the high number of elderly members dying and other organizations such as medical facilities and local municipalities impacted by our activities starting to issue their own Advance Directive for Terminal Medical Care. According to the JSDD database, the average age of initial member registration is 71.7 years of age, and the average age of death or resignation is 85.8 years of age. This means that the average length of membership is only about 14 years.

It is unfortunate that we were unable to conduct enough educational and promotional activities through lectures and discussion meetings due to the prolonged COVID-19 pandemic.

What we did instead last year was broadcasting a lot of radio programs on the topic of dying with dignity, such as "Let's think together with your family about the Living Will", or "My life, My Choice". We believe that the use of the radio network is an effective tool considering that the target age group spends more time listening to the radio. We plan to continue and expand this line of effort in the future.

Our homepage (<https://songenshi-kyokai.or.jp/>) has been presenting many columns such as archived radio programs mentioned above, domestic and global updates on the topic of dying with dignity, and a list of LW supporting physician from the registry, and a more recent program, "The little lighthouse program." Moving forward, we plan to explore our communication through SNS, Blog and YouTube, and continue to dispatch more messages and information to the public.

A decrease in our funding due to the declined membership numbers restricts our activity level a great deal. Any amount of donation to JSDD will be tax deductible since we are now a public interest corporation.

I sincerely ask for your continued support of JSDD and wish you a healthy new year.

The 11th session of Japan Living Will Study Workshop

Revised Living Will Template: End of Life and Terminal Care that designed for you.

The 11th session of Japan Living Will Study Workshop was held on November 19, 2022 in person and virtually. Having the workshop in person was the first time since the outbreak of the COVID-19 pandemic three years ago. The topics covered include the revised living will template and its origin, its process, status of terminal care in Japan, and local and global updates, as well as the status of legalization for dignity in dying. These topics were explained by the six JSDD directors responsible for different fields. The following is a summary of the workshop.

Opening Speech

Dr. Soichiro Iwao, JSDD president

“Prepare your Living Will first.”



It has been three years since we held a conference in person while battling COVID-19 pandemic. We were reminded that what was considered normal such as having close contact with other people, visiting other places and having access to a reliable medical service nearby, were not given, but a privilege. There have been a lot of changes in the way we approach end of life

between before and after the outbreak of COVID-19. What we found out after having two virtual conferences during the pandemic was that one's dignity is deeply linked to self-determination, and it must be shared and understood by people close to you in order to materialize. Advance Care Planning (ACP) is an effective process for sharing your values and thoughts. However, end of life decisions are not something you make with other people. It is something you decide by putting yourself through a calm and tranquil atmosphere and think deeply how you want it to be. Then, you need to write it down in the form of a Living Will.

Two main components of maintaining dignity are self-determination and shared understanding by the people around you. The new living will template is much more suitable for the current generation. We will be sending out messages from different angles by the six representing board members on the reasons for this revision and its effectiveness.

The new Living Will: its origin and the process
Dr. Satoru Mitsuoka, JSDD Director, Mitsuoka Clinic CEO

“Influenced by social changes.”



Ever since the foundation of JSDD 46 years ago, we have seen some major changes in our society's posture towards dying with dignity and terminal medical care. The emerging elderly population making up a large percentage of our society is the most evident. At the time JSDD was founded, the elderly population was 7.9 %. By 2022, it increased by almost four times to 30%. Other factors such as a rapid increase of dementia patients, an increase of smaller family size (either solitary or only two per household), more countries legalizing active euthanasia, and the most recent COVID-19 pandemic, which nearly collapsed our healthcare system by exhausting limited resources such as life prolonging measures and even emergency rescue medical services.

The social perception of the living will concept has also changed quite a bit due to a change in values. Quality of life is not about life extension. Refusal of resuscitation (DNR) is now more of

a standard. The whole palliative care culture has changed from the traditional policy of secrecy for cancer patients to transparency and aggressive treatment. Furthermore, there has been a change in the decision making process for treatments. Until recently, the common response from the patients has been, “I’ll leave those decisions to you, doctor.” This process now requires an informed consent from the patient and is executed in accordance with advance care planning (ACP).

Along with this flow of changes, it has become even more crucial for patients to have discussions about their wishes and intent in advance, such as ACP or Life Planning Conference. In response to these changes in society and consequent criticism as well, JSDD launched a thorough study group to examine the living will, and has come up with this new revision as a result.

JSDD has been able to positively deal with various criticisms so far, but lately has not been able to quickly react to the rapid social changes. JSDD President Iwao proposed a staff camp to discuss the next 10 years for JSDD. This discussion camp was held in 2016 and 2017 in Saga and Nagasaki, where we identified the current problems and brainstormed solutions to develop the organization’s future strategy. Upon request, we reflected on the living will and “My Wish List” accordingly. Participants included doctors, nurses, pharmacists, social workers, care managers, lawyers, TV and radio announcers, and priests. Many people from a wide range of sectors had opportunities to speak up.

In March 2018, the Ministry of Health, Labor and Welfare released guidelines for the medical decision process regarding end of life. This started the ACP culture and revived JSDD’s living will. In July 2018 and January 2020, JSDD conducted ACP facilitator training, during which time many questions arose such as “When, how and who should initiate the ACP process?” “When and who should formulate the patient’s will, intent, choice, expression and support network?” During the facilitator training, we came to a conclusion that ACP is a process during which the living will is developed as a tool. Therefore, we expect them to coexist.

Along with these activities, we also continued to develop our future strategy. We established the living will committee in order to revalidate the mission of JSDD, adjust our conformity with ACP, and manage our responses to criticism. We invited philosophers and ethicists to add depth to our discussions. In March 2021, the committee submitted recommendations to change articles in the corporation contract, the living will text and format. Finally in November 2022, the new revised template of the living will was published, and the whole presentation was introduced in the October issue of the JSDD Newsletter.

Status of end-of-life medical care in Japan
Dr. Kazuhiro Nagao, JSDD Vice President, Nagao Clinic CEO

“Unless you write it down, nothing will happen!”



I am a town doctor in Amagasaki. I personally provide end-of-life medical care to about one patient every couple of days. They are all in-home patients who are dying with dignity. For me and other doctors who provide end-of-life medical care, in-home terminal medical care is nothing unique: it is a natural and normal process of dying. However, in Japan as a whole, it is unfortunately not the norm. I would like to emphasize that as long as you write down your own living will, your wish can come true. What is really important is that you spend a sufficient amount of time in ACP or End-of-Life Planning Conference to come up with a viable medical plan with your doctor and those who are close to you.

What will happen in the future of Japan? Close to 30% of our current population is elderly, and we are seeing a rapid increase in the death rate for those who are over 85 years of age; the rate will peak in 2040. The next 20 years are going to be horrific. Currently, we have 1.3 million deaths per year, but it will increase to 1.65 million deaths in 2040. This rapid increase is a very rare case in the history of mankind. How do we overcome this rapid increase? What kind of medical care should be provided for people over 85 years of age? How do we deal with the differences in value? Please understand that we are plunging into an era that we have never experienced before. What is important is that we maintain strong will and intentions. Document your wishes in your living will, and it will be helping your healthcare professionals. If you don't do this, they will be forced to automatically connect tubes and administer "life prolonging measures" to their patients.

You may find some hospitals that support dying with dignity. Sometime ago we sent a questionnaire to all university hospitals, and only one hospital replied YES to supporting dying with dignity. Now we are gradually seeing more geriatric hospitals that are current on this topic. Please note the number of hospitals that provide service to support dying with dignity is increasing. Though it varies among regions, some research shows that 80% are dying in hospitals and 10% are dying at home. The other 10% are dying at nursing homes.

Over 80% of all deaths occurring in hospitals are only in Japan, not in any other country. The numbers are 58% in France, and about 40% in Sweden and The Netherlands. Research says that 60% of Japanese people want to have in-home terminal care. Only 10% had what they had wished for; 60% were unable to die the way they wanted. This is reality. Here, I repeat again: Write down your own living will, and the probability of you getting what you want will be a lot

higher. It is okay to just write it all down first, and then think deeper. Without the document, nothing will happen.

About the Little Lighthouse Project
Kazuko Kondo, JSDD Director, Registered Nurse,
Chairman, Mothering and Life Management Research Center

“Someone’s experience can help another.”



This is an exclusive project for JSDD that started in December 2021 from an idea that we want to serve like a lighthouse that gives light to small boats struggling in big waves in the dark ocean waters. The website was created to support people exercising self-determination in choosing their own end-of-life medical care. Data collection from many end-of-life medical care cases is the basis of this project. Just by reading what is posted on our website, one can gain the scope of their thoughts to start their ideal end-of-life planning. This is the purpose of this project. It is also a reliable source of information obtained from a variety of experiences by JSDD members with added comments from the JSDD staff. A special feature of this site is the series of end-of-life medical care planning that started a year ago, consisting of over 190 episodes. The idea that someone’s experience can be a tremendous help to someone else is our foundation. In November, we had over 22,000 views. These episodes reflect all kinds of complications and heart breaking struggles to include the decision to end your own life, fear of facing death, the difficulty of making the right decision or good decision. JSDD staff compliments their decisions and gives positive words to each case of the episode. There is no right or wrong answer.

Unique capabilities of a local municipal office: Yokosuka City Office
Rieko Kawana, JSDD Director, Former Senior Official of Yokosuka City

“Creating a safe and comfortable talking space and atmosphere”



For 38 long years, I have worked at the Yokosuka City Office and led various projects. For the last eight years, I have been involved in the promotion of an in-home medical care system and creating a safe, comfortable municipality in terms of space and atmosphere. I would like to talk about the promotion of the living will from this career background.

Right now, all local municipal offices are attempting to create a community in which people can comfortably live until the end, and Yokosuka City is one of the pioneers. How can we comfortably live the last part of our lives receiving proper medical care and other services? The first thing you must do is to look at yourself in the mirror and see the whole picture. Yokosuka City is no different than other cities with an increasing number of elderly population and death rate. Currently, the number of people dying in hospitals is overwhelmingly high. The questionnaire indicated that 60% preferred to receive in-home terminal care and farewell if at all possible. In 2011, we started to implement a system for in-home care and in-home terminal care. We first found a deeper connection and linkage between medical providers and healthcare service providers, and established a professional network among all healthcare personnel. We then stood up an in-home medical care committee. The key element in its success was to create a safe and comfortable space and atmosphere so that they could all talk at an equal level.

The committee's agenda was as follows:

1. The need for local residents to understand the concept of in-home terminal care.
2. No existing professional network among all medical care organizations
3. Shortage of family medicine doctors and nurse practitioners in the near future
4. The need to upgrade existing training and education to increase their skill levels
5. Renovation of patients' homes before they are discharged from the hospital

Today, I would like to talk about how we addressed agenda #1 above in our promotional efforts to educate the local residents.

In Yokosuka City, we have been issuing in-home care guidebooks and hosting in-home care symposiums and lectures on end-of-life medical care, for which participants had the opportunity to have personal discussions. The guidebook is called "Let's live at home until the end," which includes anecdotes that people can relate to and easily read. Another guidebook is called "Send your own message in a living will," which explains the importance of the living will and JSDD information and a link for its website. We also issued a small guidebook entitled "Living Will: Yokosuka version," which helps the readers to start thinking about their end-of-life and the

importance of talking with their families about it. As a result of all these efforts, more people have been dying at home, and less people have been dying in hospitals. Yokosuka City ranked top in the number of in-home deaths in the 200,000+ population category a few years ago.

Participating WFRtD Meeting in Canada and future prospect
By Dr. Yoshihiro Kitamura (online participation), Director of JSDD,
Professor, Japan Medical University, Center for Medical Education

“The right to receive medical care in dying.”



I participated the World Federation of Right to Die Societies Conference in Canada recently where I was able to exchange so many ideas with other participants. We know that there are not many countries that legally offer medical aid in dying, and Canada is one of the few. There are many legal rights and services available in Canada during the terminal stage. First of all, the right to an ACP and living will is legally protected. Everyone has the right to express their wish regarding end-of-life medical care and to document it.

Second of all, you have the right to receive, refuse, or cease medical treatment, and to change your mind. All those rights are protected by law. Here is another right you have that is protected by law, which may be unexpected: the right to stop eating and drinking. This includes artificial nutrition and hydration such as tube feeding. This is probably not an illegal act in Japan either.

Now, I am going to talk about the right to receive medical assistance in dying (MAID), in other words giving medical treatment to help a patient die. There is history behind this. In June 2016, a new law was enacted which made MAID legalized. However, this was only legal when imminent death was reasonably foreseeable. In most cases, this meant about a month to live with cancer patients. In March 2021, this law was amended and the safeguard condition of “imminent death is reasonably foreseeable” was abolished. A patient suffering from mental diseases wishing to receive MAID can now legally receive assistance, but more detailed legislation and a supporting medical system are to be reinforced within the next two years.

There are two ways to provide MAID:

1. A doctor or a certified nurse gives the patient lethal medicine.
2. A doctor prescribes a lethal medicine, and the patient takes it unassisted.

The difference is who actually pushes the button, the doctor, or the patient. The following patient conditions must be met: (1) Canadian citizens over 18 years of age; (2) mentally capable to make medical decisions; (3) signs informed consent; and (4) diagnosed with an incurable disease.

The 2021 report in Canada says that 10,064 people died with MAID, which is 3.3% of total deaths in Canada. 47.7% of them were women, 52.3% were men, and the average age was 76.3 years old. The number of deaths w

From the perspective of a new diet member of Japan
Rio Tomono, (online participation), JSDD Director, Diet member, Attorney,
Registered Nurse, Public Health Nurse

“I want to tackle the enactment of end-of-life medical care legislation.”



I became a member of the National Diet in the election of last summer. My first target is legislation for end-of-life medical care. In the medical setting, you may be forced to make a life or death decision in the most crucial situation. Very often when the patient is unable to make decisions regarding life prolonging measures or tube feeding, that decision falls on the family or the doctor. Most of the time, family members or the doctor will be left with the stress and agony of making the right choice for the patient. Advance care planning and preparing a living will while still in good health is very important. In Japan, there is no legislation to protect the right of self-determination for end-of-life medical care.

Based on the premise of the living will, I would like to talk about legislation regarding end-of-life medical care. In some instances, the doctor must cease or withdraw a medical treatment that the patient is already receiving in order to honor the patient’s will. Even if the doctor has the patient’s consent, this action may be considered homicide with consent from a legal perspective. The patient’s right to self-determination is protected by the Constitution; however, it is unclear whether this applies to end-of-life decisions? How do we ensure that this right is protected by law? We have guidelines for this, but no legislation. These issues have been recently brought up in the legal community. Such debates over the need for legislation regarding dying with dignity have been around for a while, and there is even a formal committee called the Diet Members Coalition for Dying with Dignity which supports protecting patient’s right to self-determination for end-of-life medical care. I would like to have a deep discussion with you as to why a law to protect this right is absolutely necessary.

Telephonic and Email Medical Consultations (#12)



I am in so much pain that I would rather die!

Pain is something that is difficult for other people to understand and recognize. Chronic pain can not only diminish your quality of life, but it can cause mental illnesses, loss of vitality and eventually desire to die. We selected a case in which communication was through emails. A patient was suffering from neuropathic pain caused by diabetes and requested to die with dignity. The patient followed the advice from our JSDD consulting doctor who specialized in palliative care and received treatment from the pain clinic. She is now recovering with less pain and is ready to receive a new treatment. We wanted to share this case openly because someone else may be in the same situation, giving up on palliative care and treatment.

Patient:

I am a female in my sixty's, diagnosed with Type II diabetes 20 years ago when I was 48. I've been injecting three different types of insulin five times every day. Six years ago, I started to develop neuropathic pain in my legs that lingers all day and all night, and the medicine does not work. I went to an endocrinologist and orthopedic surgeon, but they did not understand this pain. I have difficulty walking, so I stay in bed or sit down all day. It is torturous. I am seriously considering discontinuing the insulin injections, and then just die naturally. I am unable to cook and feel sorry for my husband.

Doctor:

When did the pain start? What kind of pain is it, and when does it hurt the most? What activities did you have to give up because of the pain?

Patient:

The pain started six years ago. At first, it was heavy and dull, and then it gradually changed to neuropathic pain. The tip of my toes feels numb, but I can feel pain. The pain feels like I'm stuck by needles. The sole of my foot is unstable and I can't balance myself. I am unable to do any housekeeping work or walk around without someone's help or a cane. I may look normal from the eyes of others, so they do not understand the kind of pain I am in. My doctor prescribed some kind of pain medication that doesn't work. I requested an opioid, but he seems reluctant because the pain is not from cancer.

Doctor:

If the pain in your legs comes from diabetes, the best way to manage it is to control your blood glucose level. You can consult with a pain control center for outpatients. The level of pain is hard to quantify, unlike blood glucose levels. Only the patient is able to measure the level of pain. It is hard for someone else to understand it. We recommend that you get support not only from your family, but also from care managers and the welfare service. The care service can make your everyday life more comfortable and help you to rehabilitate. By changing your daily habits and incorporating a more active social life with people other than your family, the pain will decrease.

Patient:

I know there is a pain control center, but I never had a referral. I thought only cancer patients could use it. At my upcoming endocrinology appointment, I will inquire about it. I have care

management insurance in addition to national health insurance, but I do not know when and how I can use it. I may go to the municipal office to ask about it.

Doctor:

When your doctor diagnosed you, you did not ask the doctor to give you a referral to the pain control center. That is a very hesitant attitude. You have to be more aggressive and tell him that you need a referral. If your doctor does not give you a referral you have to ask him for a reason and display a demanding attitude. You need to ask your doctor for a clear explanation of why the prescription is needed and its side effects. To alleviate your pain, you need to change your daily lifestyle and your attitude to a positive outlook.

Patient:

When I am in a face-to-face meeting with the doctor, I am afraid of saying something to upset him, and I become hesitant. I did go see my doctor as you advised. I was given a referral without any problems, and was able to see the specialist on the same day for diagnosis. After taking a medical questionnaire, I stopped insulin injections and had an epidural injection in my back. I was a little nervous, but the pain was reduced immediately. At night, the pain comes back, but I take LOXONIN, and I feel fine. The fluffy feeling in the sole of my foot is from diabetes, so I still need a cane to walk, but the pain is reduced and I feel good. I am so glad that I had this consultation. Today, I had my third epidural injection. I had pain afterwards, so they kept me in the hospital overnight for testing. They wanted to give me a block injection on my leg to see if it was effective. I want the pain to be reduced but am a little scared about the procedure.

Doctor:

When they recommend a new treatment, you must ask for a full explanation of the purpose, side effects and possible complications directly from the doctor who proposed it. Make sure you understand and consent to everything fully prior to the treatment. It is not just a matter of you hospitalized or not. You are now able to express yourself instead of going through a third party, and take matters into your own hands.