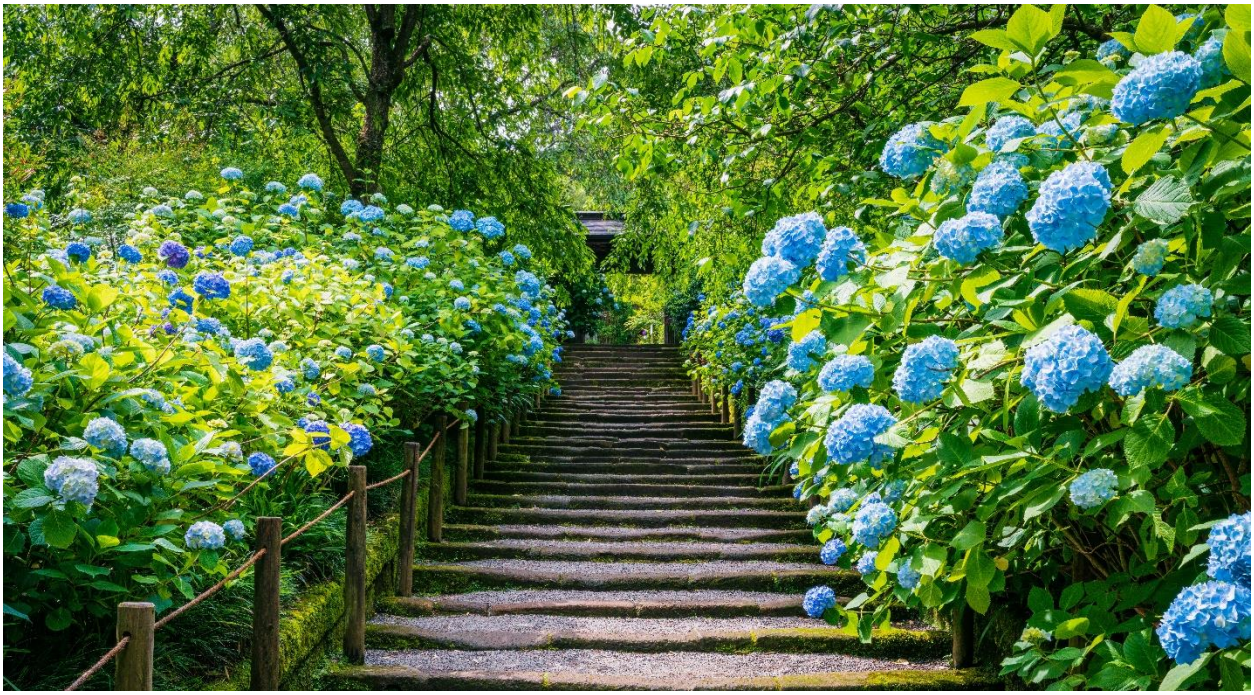
**Excerpts from**

# Japan Society for Dying with Dignity Newsletter
**No. 186, July 1, 2022**

**Main Contents:**

- FY2022 Business and budget plans finalized
- The living will stipulation revision
- A guide to “The little lighthouse project”
- FY 2021 Telephonic and Email Consultation Summary



## FY 2022 Business and budget plans finalized

**Commencement of the Living Will revision and academic research in preparation for the new era**
**-Introducing more enlightening activities through the media**

FY 2022 Business and budget plan for Japan Society for Dying with Dignity, Public Interest Corporation, was finalized by the board directors' virtual meeting on March 12th. FY 2021 financial statements were reviewed and approved by the virtual council meeting on June 11th. Dr. Soichiro Iwao, JSDD President, stated that this fiscal year we will start to establish a new structural system that matches the current needs in preparation for the celebration of JSDD's 50th anniversary in four years. Specifically, we will review and modify the current living will to make it more in alignment with what we need. We will establish a counterplan for further enlightenment and educational promotion based on the recommendations made by four sectional meetings. They were conducted for the purpose of pursuing a more aggressive execution, especially in the areas of mass media to further expand our activities, and academic research to further develop and fulfill membership benefits.

**Membership Status**

There were 94,401 members at the end of FY 2021, 6,244 members fewer than the previous year. We lost around 5,600 members last year and 3,000 the year before, so the downhill trend still continues. The new enrollment was 2,159, which was 505 less than the previous year. The number of cancellations due to death or failure of payment for three consecutive years was 8,403 compared to previous year's number of 8,227. We had an increase of cancellations and a decrease of enrollment, therefore our total membership number has been dwindling. As to the new enrollment, around 35% of the new members were in the 70s age group, which remained unchanged for over a decade, followed by the 80s and 60s age groups. The average age of new enrollment was 57 years old between 1976 and 1980, which jumped to 72 years old between 2021 and 2022. By the way, online enrollment which we started in 2017 has recently reached 1,000. The majority of them were in the 40s to 70s age groups. We are gradually starting to see indications of increase in younger members.

**Business Report and Plan**

We have three Business objectives:
1. To expand and educate the population about the concept of the living will
2. To manage the living will national registry
3. To research and propose new projects

In support of objective #1, we had planned 30 lecture forums, 150 seminars and 100 visiting lectures, but due to the emergency declaration and stay – home order during the pandemic, we were only able to conduct 12 lecture forums, 39 seminars and 24 visiting lectures. Instead, we conducted more virtual lectures and video dispatches. Both our head office and regional chapters introduced educational activities using mass media. For example, we were aired in a TBS radio program called "Let's discuss your living will with your whole family" ten times in a series.

The number of physicians who comply with a living will in the national registry was 2,057, only 45 increase from the previous year and not quite reaching our goal of 3,000. As to the telephonic and email medical consultations, we had 502 calls and 1,159 consulted cases compared to last year's 557 calls and 1,313 cases. With regards to new projects, we set up a new website in December called "The little lighthouse project," a group platform that help people who take care of dying patients share their experiences and obtain information about self-determination during the final days and physicians who comply with a living will.

As to objective #2, please refer to the above current membership status which reflects our current national registry of the living will. To support objective #3, we conducted a questionnaire regarding symptoms during the last stage of life and through the dying process in order to determine proper clinical protocols in conjunction with the little lighthouse project.

## Revision of the current living will stipulation

### Updated version of the living will stipulation to be published this fall

As published in JSDD newsletter #183 (October 2021 issue), JSDD has held multiple committee meetings with professionals in the fields of ethics, philosophy, medicine, nursing, welfare, and law to discuss the content of the living will for over four years since 2017. Using their reports as the reflection of JSDD members and their families' voices and opinions and advance directives issued by other organizations as a reference, we were finally able to compile our final draft.

The three clauses of the current living will stipulation are below:

- If modern medicine concludes that my disease is an irreversible or incurable one, and I am diagnosed to be in terminal stage, I refuse any medical technology used to artificially prolong my life.
- However, I request an effective pain management by any method, including the use of narcotics.
- I request that all life sustaining procedures to be withdrawn if I fall into an irreversible condition known as protracted consciousness disorder (persistent vegetable state).

The newly revised three clauses of the living will are as follows:

- If my death is imminent or my unconsciousness remains for an extended period of time, I do not wish to receive any life prolonging measure.
- However, I would like to receive the best palliative care available to alleviate pain and suffering of both my mind and physical body, including the use of medical narcotics.
- I request the above two clauses to be discussed repeatedly among my agent and medical care providers so that my request will be satisfactorily achieved.

This new context reflects the full concept of the living will that JSDD has appealed for almost half a century. It also aligns with the current trends and values that are cherished by JSDD members and acceptable to the healthcare providers. In this issue of JSDD newsletter, we would like to highlight the key points of the revision and leave the details for the next issue of the newsletter.

**Response to the criticism that the living will only honors the refusal of life prolonging measures and not the termination of already administered procedures**

Only recently, phrases such as "dying with dignity" and "natural death" are widely accepted by the general public. From the beginning of its foundation, JSDD has received severe criticism from other organizations that support patients to receive the best life prolonging medical treatments. They argued that especially the severely disabled patients would be forced to live uncomfortably and eventually not able to live.

For three years since 2017, JSDD went through an administrative litigation against the Japanese Government to become a public interest corporation. The defense's argument was that the only ones who benefit from JSDD are its members since the vast majority of the population who desire the best life prolonging medical treatments are unable to write their own living wills; therefore, JSDD does not meet the criteria to become a public interest corporation. In response, we decided to make the living will a more comprehensive concept expanding its coverage to all sorts of wishes and ambivalent emotions to include life prolonging measures as a part of a wish list.

However after further in-depth discussions, we decided to keep the same concept which we had cherished from its foundation and not expanding the scope of the concept. Basically, we concluded that we restrict the scope to the refusal of life prolonging measures only, maintaining the first clause. JSDD respects and honors patient's self-determination, a human fundamental right stipulated in the thirteenth clause of the Constitution that stipulates that all citizens to be respected as individuals. We are pursuing to promote a society in which everybody can fully live their lives and end their lives comfortably as they wish that is legally acceptable. We have no intentions of hampering those who wish to receive the best life prolonging medical measures as possible and or denying those who rely on artificial life support from living with dignity. We intend to make an official statement to that effect separately.

**Regarding the elimination of protracted consciousness disorder (persistent vegetable state)**
The third clause of the current living will states that if I suddenly develops an irreversible condition known as protracted consciousness disorder (persistent vegetable condition), I request that all life sustaining procedures to be withdrawn. When JSDD was initially founded, it was quite common for patients who were unconscious to be automatically administered artificial respirator and nutrition tubes. Once administered, there was absolutely no way to remove them. In recent years, the Ministry of Health, Labor and Welfare as well as many various medical associations have established guidelines which permits institutions to terminate life sustaining procedures such as artificial respirators and dialysis. The new clauses do not specify the condition as protracted consciousness disorders and covers all other conditions of extended unconscious state and when death is imminent.

**Regarding dementia and self-determination**
The fundamental basis for the living will is self-determination; however, the rising number of dementia has become a major issue in this matter. Many cases of patients claiming a different wish from what was documented in their living wills or not remembering that they had prepared their living wills have been reported to JSDD. Under these circumstances, more and more support is needed by those close enough to the patient to know how he or she wants to live and die.

The Ministry of Health, Labor and Welfare announced the ACP (Advance Care Planning) guidelines in 2007 on how to provide terminal medical care while sharing information and reaching agreements among the patient and healthcare providers. In modern days, it is almost impossible to ignore the opinions of the patients' family members. Patient's self-determination is the foundation of all this, but in the case of dementia, opinions of the patients' close friends and family are also very important and should be considered. This is why the new clause was added to make it more pragmatic and realistic.

We will continue the explanation of the new context of the living will in the next newsletter. We sincerely ask all the members for your understanding and cooperation.

## In support of self-determination for medical choices during the final stage of life


### A guide to “The little lighthouse project”
### Learning what dying with dignity means from experience

**“The little lighthouse project” was created last year.**
**It is updated every month, so please check out the site periodically.**
**Terminal patient care is a great burden**

It goes without saying that family members who care for their terminally ill patients for the first time naturally would feel a great burden, but even professional healthcare providers such as doctors, nurses and care givers in care facilities who have to face someone’s dying situation on a daily basis feel the same mental burden.

In 2021, a healthcare monetary reward system was revised which included terminal care both in-home and clinical. “The little lighthouse project” was created as a support system for both family and caregivers to lessen their burden through mental preparation and encouragement to build confidence.

**Opening / Disclosing a List of LW supporting Physicians Registry**
Emotional analysis from the Surviving Family Questionnaire indicated that the respondents highly rated the LW supporting physicians’ understanding and acceptance of the living will and their sense of satisfaction with terminal medical care. We hope to meet more LW supporting physicians through this project. Through this site, we would like to share many stories from the members on this topic from their experiences.

### Terminal care episode

We think it is a good idea to refuse any life prolonging measures while in good health, but when end of life becomes a reality, it is a tremendously hard thing to say you want them to stop and let your loved one go. Especially if the patient had a clear mind, you fear that the patient might have heard you say that you wanted to end his or her life. Is this feeling inevitable?

### JSDD comment

You have experienced a terrible situation having to make a hard decision to refuse a life prolonging measure for your loved one. You must have felt so much pain, but you were not wrong at all. That is what a medical agent is supposed to do. You have accomplished what your loved one wanted you to do. We salute with high respect for your courage.

# Compilation of Telephonic and Email Medical Consultations for Fiscal Year 2021

**Many JSDD members are now aware that this service is not only for matters regarding dying with dignity, but includes consultation on all medical issues**

"My 91 year old father seems to really like the special nursing home that he was placed in five years ago. After receiving his first Covid booster, he started having a lingering fever. He was diagnosed with aspiration pneumonia and was told he needed to be hospitalized due to low oxygen level. He refused because he wanted to go back to his favorite nursing home. He had special permission to see his family for a short period. He responded when we called him, but his mind was not all clear. We are concerned about his future." (65 year old female)

I want to rewrite "My Wish List" to prepare myself in the future. Can I add the comment, "I wish to receive the best medical treatment available?" (61 year old male)

My husband (87) is administered a nasal feeding tube due to repeated cases of aspiration pneumonia. As his weight is going down, he was recommended stomach tube feeding but he refused. I am also very old and not sure if I can take care of him physically at home. What should we do? (85 year old female)

I lost my parents and am now all alone. I am very much an introvert and have lived my whole life without linkage to other people. I feel so lonely and insecure, just need someone to listen. (60 year old female)

Our local hospital added a palliative care ward, but I was told that they only admit terminal cancer patients. I want to ask JSDD to take an action so that they would admit other terminally ill patients other than cancer. (85 year old male)

*****

For the period of April 2021 to March 2022, Telephonic Medical Consultations continued after the pandemic started the previous year. Three consulting nurses took turns to be on call while teleworking.

We have compiled all the results from the Telephonic and Email Medical Consultations for FY 2021. The number of the calls was 502 compared to the last two years of 500 and 557, around the same level. The number of itemized topics was 1,159 (one call covering multiple topics), slightly lower than the last two years of 1182 and 1313 topics.

**Reported at the Japan LW Study Workshop**

Let's look at the itemized topics. "Medical treatment in connection with dying with dignity" was close to half of the total calls with 518 cases (45%), and the next was "General medical care and mental concerns" with 214 and 213 cases, a total 427 cases (37%). "Medical treatment in connection with dying with dignity" remained unchanged, but "General medical care and mental concerns" gradually increased with more than 37% increase over the past several years. The consulting staff said that people are starting to realize that this consultation is not only for dignified death related issues but any other topic is welcomed.

Our consulting staff was invited to speak at the 10th session of the Japan Living Will Study Workshop, and they expressed their gratitude for this great opportunity to let people know that our role is to help all JSDD members and in exchange find out the real current issues surrounding elderly patients and their families.