



Excerpts from

#### Japan Society for Dying with Dignity Newsletter No. 192, January 1, 2024

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## **New Year's Message**

#### Promoting Awareness-Raising Activities, including in the Media, and Aiming for "Dying with Dignity Legislation"



Dr. Yoshihiro Kitamura, President of the Japan Society for Dying with Dignity, a public interest incorporated foundation

Happy New Year.

The Japan Society for Dying with Dignity enters its fourth year this spring as a public service corporation.

I took over the position of President from Dr. Soichiro Iwao, (Current Honorary Chairman) in June of last year. The Board Members and I will continue our duties with a fresh mindset.

The Society's Living Will (LW) is highly regarded in society as an advanced directive for endof-life care based on individual autonomy. Two years ago, we published the "LW Revised Edition" in line with the current era.

We believe this revised version is highly effective in confirming the individual's intent, as envisioned by the law. Therefore, we aim to incorporate it into dignified death legislation as soon as possible and advance parliamentary measures.

## Urgently Indicating the Direction of Awareness Activities

The main activity of our Society is the "Promotion and Enlightenment of the LW (Living Will)." However, due to the prolonged impact of the COVID-19 pandemic spanning over three years, it is truly regrettable that sufficient activities could not be carried out, as organizing events such as lectures and roundtable discussions for members became challenging.

Amidst these challenges, we have undertaken initiatives such as starting a radio program called "My LIFE! My CHOICE!" (TBS Radio, Radio Osaka) two years ago to promote awareness of dignified death.

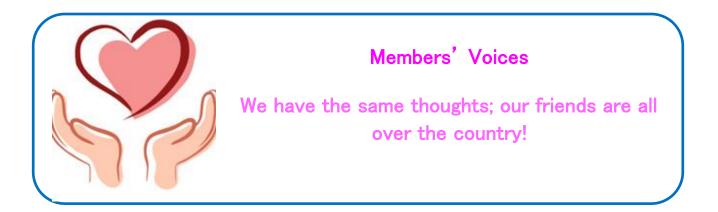
Furthermore, last year, in the monthly magazine "Fujin Koron," we introduced episodes received from the "Bereaved Family Survey" on a particular website called the "Little Lighthouse Project." Through this, we shared valuable experiences of bidding farewell to parents and spouses with readers on a broader scale.

Regarding the dissemination and promotion activities utilizing such media, including their continuation, we are eager to indicate the specific direction of future activities promptly. On the Society's website (<u>https://songenshi-kyokai.or.jp/</u>), you can find archives of the radio broadcasts above, as well as a wealth of columns covering the latest domestic and international information on dignified death, information on the Society -accepting cooperating physicians, and the "Little Lighthouse Project."

We will continue to utilize social media platforms such as SNS, blogs, YouTube, etc., to disseminate useful information.

Finally, as the number of members continues to decline, support such as donations and bequests from all of you is crucial for sustaining and expanding our activities.

We sincerely ask for your increased support to the Society, and we extend our best wishes for the excellent health of all our members. This concludes our New Year's greetings.



## **Healthy Lifespan and Natural Death**

#### Ms. Junko Konno (Age 77) Hokkaido Prefecture

Having moved from Niigata to the admired Hokkaido, I have lived here for over sixty years. I had worked as an educator until the age fifty-five, raised a son, and am now I am enjoy living alone. My husband had passed away early in life.

What I think about now, while participating in events in the city, is healthy life expectancy by even one year and have a natural death.

I have heard that in the Netherlands and Canada, at the age of 10, children are asked to think about "how they want to die." Only those "who do not wish" to have an organ donation after death sign the petition.

In Japan, the opposite is true: "people who want a to donate an organ" sign a petition. I agree with the idea that transplantation can keep many people alive, as in Europe and the U.S., and I also hope for organ transplantation and cooperate in organ donation.

Last year, I informed my aunt, in my hometown of Niigata, about a dignified death. I also told my son. Although my aunt lives in a region bound by old customs, she said, "I'll think about it." By expressing the desire for a dignified death, I believe both the individual and those bidding farewell can be liberated from various struggles. Currently, I have joined my town's Astronomy Club and learned much about the universe from experts. I want to live valuing my life, the universe, and the Earth.

## Struggling with Sleep

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

My mind is restless, and I have no appetite. Thinking it was psychological, I went to the psychiatric hospital I had visited before and received medication. I took it for a while, but then I spoke about my symptoms to the regular internal medical doctor since it didn't show any effect. With a gentle face, the doctor said, "Well, it might be good for diabetes but...." Hearing that, my mind was relieved. The doctor said, "I'll prescribe medication, so please don't take the psychiatric hospital's medicine." I am currently taking that medicine, but some symptoms remain.

Currently, my biggest worry is "sleep." Not feeling sleepy, waking up before dawn, and not being able to sleep afterwards difficult. The "waiting time" in the dark, waiting for the night to open, is not calming. It is quite painful.

I thought that if I tire my body, I might be able to sleep, so I went by bicycle to a venerable shrine a bit far away. I rode up and down the shrine's approach, and faced the main hall, I prayed, "Please heal me." Those are what my days are like, but my wife's bright attitude is my salvation.



Snowy bamboo forest scenery in Kyoto's Sagano, "Bamboo Grove Path," is quietly being covered in white.

## Scattering Ashes in the Vast Ocean! Ms. Masako Matubara (Age 77) Tokyo

Having undergone six surgeries, including two for cancer, since my 50s, I have survived each time with the help of my younger sister. As I am living alone in my house while visiting hospitals, I wonder what will happen to me. Before becoming unconscious and bedridden, I am considering "suicide." If cancer recurs, I won't undergo surgeries anymore. I believe that the last thing I want to do for my children is to help them avoid emotional and financial burdens. I don't want to enter a nursing home, and honestly, I don't need a funeral.

Every year during my childhood, I spent delightful summers being stung by jellyfish near our house in Hayama, Kanagawa. I hope for a sea burial in the vast ocean. I will also dispose of all my personal belongings. If you come to the Morito Coast with a few photos, we might be able to communicate in our hearts. That would be enough. In my heart, there is neither Heaven nor Hell. I don't want to leave even a single bone fragment. If humans have souls, then they really want to return to the Universe. People "come from space and return to space" and so on. These are the words that resonate with me the most right now. There is nothing left to do. I am only thankful for my family.

## Taught by my husband's final moments Ms.Eiko Maekawa (Age 82) Osaka Prefecture.

It has been 18 years since my husband passed away at the age of 70 when I was 63. We learned about the Japan Society for Dying with Dignity 10 years before he died. My husband saw it on TV and said, "I want to join." "I was not interested in joining because we are both healthy and I don't know how to join...." But my husband said, "I saw it in the newspaper." And he joined immediately after inquiring about it. He recommended it to me, and we both joined.

About a year later, despite not drinking alcohol, my husband was diagnosed with liver cancer. The doctor who had been examining him changed workplaces, and my husband, who was devoted to the doctor, continued to travel far to see him. He was in and out of the hospital repeatedly, and even after he was discharged, he drove to the hospital and told his doctor about the Japan Society for Dying with Dignity and also showed the doctor his membership card.

Just before his passing, the doctor called my son and me into a room, and he informed us of everything. The doctor, understanding thoroughly, provided treatment in line with my husband's wishes, alleviated his suffering, and he passed away while the doctor was on duty. The way my husband passed away is considered his "will," and I am in the process of suggesting to our son to consider joining the Society soon. Thanks to being a member of the Japan Society for Dying with Dignity, we were able to avoid prolonged nursing, and my husband was able to depart without much suffering. Now I wonder if that was the best thing that could have happened.

Since my younger days, calligraphy has been my hobby, giving me purpose in my solo life. Some classmates are no longer around, and it gets lonely with each passing day, but being a member gives me a sense of security, and I live energetically.



## "How should I interact with doctors who don't understand the concept "Dying with Dignity?"

When they tell their doctor that they are members of the Japan Society for Dying with Dignity, they receive a consultation in which they are concerned that their wishes will not be respected because they see that there are medical professionals who do not know about the Society or do not have a deep thought about dying with dignity.

This time, along with such cases, we will discuss the checklist for trustworthy healthcare providers.

#### [Case Studies]

Currently undergoing treatment at a large hospital after cancer was found. Informed the primary doctor of being a Japan Society for Dying with Dignity, member during one of the check-ups. When showing the membership card and explaining with the addition of "My Statement of Preferences Form," the response was, "I'm surprised your son has agreed to this." Although the primary doctor seems to be against dying with dignity, the person is troubled about how to deal with such a doctor in the future.

# Q. Are doctors or healthcare providers unaware of the Japan Society for Dying with Dignity?

**A.** While the term "dying with dignity" is well known, but there are still many doctors and healthcare providers who are unaware of the existence of the Japan Society for Dying with Dignity.

## Q. Even if the Living Will (LW) is shown, is there a possibility that life-prolonging treatment will still be carried out, and is it impossible to stop it if one wishes to do so?

**A.** It is currently challenging to achieve dying with dignity based solely on the person's wishes. When a patient is brought to the hospital by ambulance due to sudden illness, life-prolonging measures may be initiated without a firm confirmation of the patient's intention. Once life-

prolonging measures commence, it is difficult to interrupt them, even if the person or their family wishes to do so.

#### Q. How can one make the primary doctor understand their wishes?

**A.** Having repeated discussions and building a trusting relationship can deepen mutual understanding. It might be helpful to consider the following checklist while discerning a doctor who can fulfill the desired medical care:

1 Provides compassionate examinations.

- 2 Explains things understandably.
- (3) Listens to the patient's concerns.
- 4 Examines the patient while looking into their eyes.
- **(5)** Doesn't show displeasure when asked questions.
- 6 Supports the treatment that the patient wants.
- 7 Never burden patients and refer them to specialized medical institutions when necessary.

So, how many of these points did you find relevant?

If you find it difficult to trust your doctor or healthcare provider and are troubled, consider seeking a second opinion or consulting a cooperating physician.

Some healthcare providers may not correctly understand dying with dignity.

Similar to the case mentioned, presenting your membership card to the primary doctor may be the first time they become aware of the existence of the Japan Society for Dying with Dignity. However, you are doing something significant by creating opportunities for doctors unaware of learning about it and actively presenting your choice in medical care.

It is up to each and every one of us, the "protagonists of life," to change the current situation in which it is up to our luck to meet a doctor who "accepts dying with dignity" so that we can live healthy lives and protect our own peaceful endings.