

Excerpts from



Japan Society for Dying with Dignity Newsletter No. 175, October 1, 2019

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New Year's Greetings

Let's begin the New Year with discussions on what the Living Will should be

By Dr. Soichiro Iwao



This is the first year of the Era of Reiwa.*

**Prince Naruhito officially ascended to the throne on May 1st 2019 as the 126th Emperor of Japan, and his reigning era was named REIWA which means "beautiful harmony."*

Happy New Year to all JSDD members. I would like to take this opportunity to say a few words. JSDD, Japan Society of Dying with Dignity, started in 1976 as a volunteer corporate organization. In 2015, we changed its corporate status to a general incorporated foundation which remains to date. We have been continuing our efforts to emerge our society which allows the exercise of end of life self-determination as a medical decision.

Final decision made after winning the trial and the appeals trial with no further appeals

We filed an application to the Prime Minister of Japan to obtain a public interest accreditation twice in 2013 and once in 2015. Unfortunately, our requests were rejected on the grounds that permitting JSDD to become a public interest corporation may inadvertently send a negative message by misguiding physicians in making decisions regarding terminal medical treatments.

Since we were not satisfied with the outcome, we brought the case to Tokyo District Court in June 2017 in order to annul this disposition. The court decided that our activities do, in fact, meet the public interest; however, the government was not satisfied with this decision and consequently appealed to the Tokyo High Court. On October 30, 2019, the High Court decided in favor of the decision made in the first trial, supporting our status as a public interest corporation. Since the government did not appeal this case to the Supreme Court, we finally won the case, which highly recognizes the value of our mission and effectiveness of this “Living Will” publication.



Addressing matters pointed out by the court

There were some matters the court pointed out that we must look into, such as the need to confirm the authenticity of the signatures on the Living Wills and that the contents regarding medical treatments fully reflect the patient’s own decisions and wishes.

In September, JSDD formed an advisory assembly called “Living Will Study Conference,” consisting of newly elected directors and other subject matter experts to discuss the future vision of JSDD and how to blend the JSDD issued living will and the ACP (*Jinsei Kaigi* or Life Planning Conference), a concept introduced by the Ministry of Health, Labor and Welfare. We are anxiously awaiting the group’s proposal that addresses all the court’s matters.

As our elderly population increases and there are more advancements in life support medical technology, I feel that our natural life and death cycle that we have observed traditionally have now been distorted artificially. “We die at home surrounded by the family.” This traditional trend is now coming back with the movement of in-home medical care, but the quality of life at

the end has not improved. Unless we all have the capacity to fully embrace the wishes of a dying person, we are not satisfying anyone or achieving anything in terms of terminal medical care.

My resolution is to continue our strong efforts to promote the concept of the living will along with the concept of the ACP (*Jinsei Kaigi* or *Life Planning Conference*).

8th session of Japan Living Will Study Workshop
Think of the ACP (*Jinsei Kaigi* or *Life Planning Conference*) as a life memoir
with the living will as is its prologue



On November 30th, the 8th session of Japan Living Will Study Workshop was held in Ito Hall of Tokyo University, Ito International Academic Study Center. Extra folding chairs were needed as the audience was approximately 450, much more than anticipated.

The audience listened enthusiastically to the speaker's striking talk that combined a heartfelt story with witty humor. Dr. Soichiro Iwao made an introductory speech, stating that the day's agenda was the Life Planning Conference. "How is the Living Will different from the ACP (*Jinsei Kaigi* or *life planning conference*)? How do we maximize both of their uses? That's what we are going to figure out today."

Dr. Satoru Mitsuoka (JSDD Director), who owns a clinic in Saga City, was the conference coordinator as he was in the previous years. The conference started with the keynote speakers followed by a panel discussion.



The first keynote speaker was Mr. Kunio Yanagida, one of the top ranking non-fiction writers in Japan. The title of his speech was “Our life as a memoir.” He said that our life is like a book. Unless you talk about it, no one will know about it. Your life so far has been a written story. You are now going to write the last chapter of your book. It is something that you have to create. No one will write it

for you. Only you can write your own last chapter. It was as if he was talking to everyone individually. Everyone was deeply touched, and many were taking notes with teary eyes.

Bursts of Laughter from the audience

The next speaker was Dr. Hisayuki Miura, manager of Home Health Care and Community Health Collaboration Promotion Department at the National Center for Longevity Medicine. He explained the concept of the ACP in the simplest way for anyone to understand. He emphasized that it is important that the whole community participates in the process and not limiting it to terminal care.

“ACP / Jinsei Kaigi - life planning conference from an ethical point of view” was the speech title for Dr. Kouichiro Sakai, professor at Miyazaki University Medical School and manager of the Biomedical Ethics Department. He talked about bioethics and the difference between terms, “lifesaving” and “life prolonging.” He spoke in Miyazaki dialect and with a heavy accent that was almost comical, which brought a lot of laughter to the audience. The last speaker was Dr. Kazuhiro Nagao, JSDD Vice President. The title of his speech was “Living Will is the introduction of the ACP - Jinsei Kaigi - life planning conference.” He used a power point presentation, and his talk was light and witty as usual.



The second part of the workshop was a panel discussion with the four speakers. The contents of this discussion as well as the whole workshop will be uploaded on the JSDD website with videos, and Mr. Kunio Yanagida's speech will be covered in the next newsletter.

Activity Report

Tohoku Chapter

Tohoku Chapter's first meeting in Hirosaki a huge success

We quickly ran out of chairs. The 23rd session of Tohoku chapter Hirosaki open forum was held with an overflowing audience. A total of 182 people came together on November 3rd at Hirosaki City Communication Plaza.

The topic of the meeting was "In-home palliative care that is amenable and serene." The keynote speaker was a local physician, Dr. Shoichi Sakamoto, who spoke about "In-home medical care for peaceful death: the secret of attaining peaceful death." He explained the gloom of the current local situation rather humorously. The average life expectancy in Aomori prefecture is ranked 47th, very last in Japan. Cancer has been the number one cause of death in Japan for the last twelve consecutive years. He emphasized preventive care. Go in for a health check up every year and never miss preventive shots. Only when the average life span and healthy years are extended, in-home palliative care is worth having, and the possibility of achieving a peaceful death will increase. Finally, he asked the audience, "What dying with dignity pursues is a peaceful death, isn't it?" It was a truly a convincing speech.

The panel discussion was about sensible in-home palliative care. Dr. Shoko Baba, director of Aomori Prefecture Chapter who is a pioneer of palliative care, said that hospitalization and care for out-patients as well as medical care visits are all available. Ms. Toshiko Sugo of Visiting Nurse Center explained the challenges of in-home terminal care. Dr. Makoto Ishizawa, chapter director who is also the director of Hirosaki City Medical Association, presented various innovative cases of in-home palliative care.

Until this session, all local chapter forums were held in Aomori City. This session in Hirosaki City for the first time received an overwhelming welcome. After the closing, the chapter directors opened up the floor for personal consultation time. Many people were able to receive advice and resources in a casual environment, which really showed how successful this event was.

Reported by Takao Ami, Tohoku Chapter President

Kanto-Ko-Shin-Etsu Chapter

Students shaking their heads at difficult terminology

On November 9th, I observed a class called, “End of Life Medical Care and Living Will,” part of the Saturday program at Den-en-Chofu Gakuen, a women’s school in Setagaya Ku, Tokyo. This Saturday program is one of the school’s special features in which the invited lecturers teach classes on a variety of topics.

This day’s lecturer was Mr. Yoshiro Ohara (75), a former engineer and director of Kanto-Ko-Shin-Etsu Chapter of JSDD. This was an elective class for the students, and there were altogether 43 students from first year of middle school to seniors in high school. This program has been operating for ten years now, first starting in 2010. The first year only had three students, and the class was taught quietly in a corner of the library. This year, there are nine core and elective classes with a total of 360 students attending.

“The progress of modern medical technologies has brought our society a longer life span, which is unprecedented by anything our mankind has ever experienced; however, this has also brought negative consequences for many bedridden and vegetative patients,” the class started, presenting updated statistics and problems. The instructor continued, “The baseline fact is that when discovering that they have an illness in its terminal stage that is untreatable, most people want to die without pain and suffering even if dying comes a little earlier. We now see that more people are open about it. What do you think?” I saw many reactions from the students, some whispering to their neighbors, “What? I never thought of that,” and shaking their heads.

The class moved on to the topic of “ultimate pro-life principle vs. dignified death*” and then “the difference between active euthanasia and dignified death.*” Other topics included discussions on “prolonged consciousness disorder,” differences between “incurable vs. terminal illness,” “non-commencement of life prolonging measures vs. termination.”

**expressions used in this entire newsletter such as “dignified death” or “dying with dignity” do not refer to active euthanasia commonly used in Europe and the United States. In Japan, it only refers to passive euthanasia such as refusing life prolonging measures.*

When the hour and five minute class was over, I asked the younger students, second year of middle school, what they thought of the class. One of their comments was, “It wasn’t something real to us, besides, I could not understand some of the difficult words and terminology.” “May be knowing this stuff will help us in the future,” another student said. As an observer of this class, my input to the instructor was, “We may need to simplify it a little to get down to the younger students’ level so that they can understand the concepts better.”

Reported by Takeshi Gunji, Editorial Department

Tokai-Hokuriku Chapter

Fully packed Grand Hall in the Medical Association building

The Grand Hall at Aichi Prefecture Medical Association building has the capacity to seat 300 people, and we had 343 attended. Consequently, additional folding chairs were carried in to accommodate the overflow.

The keynote speaker was Dr. Yohei Ohashi (56), a palliative care doctor from Kainan Hospital (Yotomi City) who was struggling with cancer himself. His speech was called “How to care for your patient with empathy.” Some people came to the hall one hour before the opening time, and when it was opened, there was an overflow of audience as mentioned earlier. His book entitled “Palliative care doctor who is suffering from cancer” was already drawing public attention. Three days prior, Chunichi Newspaper which sponsored the forum printed a front page article headlined “Terminal cancer doctor speaking at his alma mater, Mie University,” which helped advertise for the success of this event. Comments were provided by Yohei Nojima, the new Chapter President.

Written by Tsukasa Kobayashi, Chapter Advisor

Chugoku Chapter

Two inspirational speeches

This is a report on an open public forum held on October 6th in the San-in district of Matsue. The first speech was called “Natural death is not painful” by Dr. Yuji Matsumoto.

This is my summary: I learned about death from experiences near me; the sudden death of my friend and roommate, the death of my grandfather, my grandmother and my father. I was becoming very familiar with death, though it was rather vague. Let’s look at the top causes of death among Japanese people in the past. In the 1920s and 30s (during the “Showa Era”), most people died of gastroenteritis; in 1945 after WW II, tuberculosis was the top cause of death; during the 1980s, brain diseases; and between years 1990 and 2000 (the “Heisei Era”), cancer was on top. The average life span extended from 58 to now 81. As it will extend more to 100 in the future, and the perspective on life and death will become even more important.

Traditionally, people died in their own homes in Japan. Today, 90% of people die in the hospital. This phenomenon is rather unique from a global perspective. Anybody can die without a doctor. To die from withering is natural and shouldn’t be painful, but adding medical technology to prolong life is causing more pain. Rather than wrapping up a patient’s body with complex medical tubes, letting him go naturally might be happiness for the patient. If that is the way you want to pursue your end of life, what is important is to communicate with your family how you want to die while still in good health. Let me repeat, dying is not painful. Make sure your last wishes are passed on to your family.



The second speaker was Daiko Iizuka, the president of Ichibatayakushi Temple, and his theme was “Living a life is a being lived life.” Here is the summary:

I am not a member of JSDD, so today I’d like to talk to you as a man of religion. I have learned about death from seeing how my old master and seniors died. They all died in temples naturally without any attachment to life. The speech made by one of the widows was inspiring. “As I was not able to do

enough for him while he was around, I want to do the best I can for him today. It is such a great pleasure that I can do this for him. I thank you so much. I now realize there are two kinds of pleasures in life, one is giving pleasure and the other one is receiving pleasure.” This was a wonderful speech.

Once I asked a temple parishioner to let me know when he was dying so that I could chant a sutra for him. Sutras are meant for the living. In 500-600AD, Prince Shotoku* of Japan had established a pharmaceutical clinic in Shitenou temple to help others. Life is like one encounter in a long journey. We should live life to its fullest by enjoying the beauty of nature like the changing of the four seasons and embracing each day.

**Prince Shotoku/Shotoku Taishi (573-621AD): the Prince of Holy Virtue, was a Japanese regent, statesman, and scholar. He prepared the Seventeen-article Constitution in 604AD and contributed significantly to the political-cultural development that led to the Taika Reform of 645-649AD.*

By Susumu Sakai, Chapter Vice President

Shikoku Chapter Activities in Kagawa, Matsuyama and Tokushima

(From Kagawa) The sixth session of Japan Living Will Study Workshop Shikoku Region was held in Takamatsu city on September 22nd. The topic was “To be yourself till the end.” The speeches and the panel discussion were conducted by various professionals, each representing a different perspective. The speakers included JSDD Shikoku Chapter president, grieving family of members, a social worker from Takamatsu City Social Welfare Association, and Buddhist monks who support end of life movements. One grieving family member talked about the reality of in-home care and medical treatment from his own experiences, based on which he developed his own ideas of what a life’s end should be.

(From Matsuyama) An open public lecture meeting was held in Matsuyama City on November 2nd. Dr. Yasunori Nagai’s speech, “Your way of living and your way of dying” was about what in-home care and terminal care should be by presenting actual cases he has encountered. He also

explained the “Jinsei kaigi / life planning conference” and how important it is that you have intimate conversations in advance with your family and medical providers regarding the medical treatments you wish to be given when the time comes. The audience overfilled the auditorium, and additional folding chairs had to be provided.

(From Tokushima) A social meeting and tea party was held on November 24th in Tokushima City. “Jinsei Kaigi / life planning conference” was the main topic discussed. The first question raised was “how do you want to pass on your wishes to be executed?” Some suggestions were made such as (1) do not hide your wishes; (2) do not make one decision as the final one; and (3) ultimately, you must decide and make it happen. The next question was “to whom do you want to pass on your wishes (or have you already)?” Is (was) it your partner, children, siblings, friends, primary doctor or care manager?” Working in small groups, many shared their wishes, and some had already passed them onto multiple people in their lives.

Kyushu Chapter

The objective of a local lecture meeting

In Kyushu Chapter, each prefecture functions as an independent entity and conducts their own various activities. In Ohita Prefecture, an open public lecture meeting is held annually and a visiting lecture is conducted several times a year upon request. On November 10th, a public open forum was held in Usukine City.

In the past, all the forums were held in the highly populated Ohita City and Beppu City, and concept such as dying with dignity and living will are now widely recognized in those areas. Therefore, we started to target other local areas. Such as Nakatsu City two years ago and Usukine City last year.

The program typically starts with a general explanation about the concept of dignified death and the mission of JSDD by our staff, followed by keynote speeches by invitation. Last year, we invited Mr. Katsunori Kawano, the vice president of Ohita Chapter who spoke about “Welcoming a peaceful ending” and Dr. Hiroshi Inoue of Eiko Hospital whose speech title was “The kind of hospice palliative care we pursue.” Fifty four people in attendance actively participated in the Q&A session. Naturally, small local events do not draw large audiences; however, a recent poll shows that many of the participants are first time attendants of public events such as this. Concepts such as dignified death and living will are new information for them, which implies that this type of event is greatly meaningful.

By Osamu Aso, President of Ohita Chapter

Questions from JSDD members/Answers by Consulting Doctors



Question:

I am in my 80's. Since I am in good health, I rarely go to the hospital. I heard that when an ambulance is sent, it is assumed that the patient being picked up requested life prolonging measures, thus it is automatically administered. This can mean that you lose quality of life and living becomes meaningless. My cousin who was one year older than me fell when he suffered from a subarachnoid hemorrhage (SAH). Even though it wasn't requested, they performed a brain surgery, and he died five years

later. I decided to write my living will to avoid such cases against my will.

Answer:

When it is an emergency case, and no one knows of the outcome, it is okay to assume the best possible medical treatment from the ambulance crew and subsequently in the emergency room in the hopes of a cure. For example, if it is an early stage of a stroke, you may possibly be discharged from the hospital after several days or several weeks of hospitalization. Half of your body can be paralyzed unless appropriate medical treatment is administered early on.

Question:

I am determined to not receive any life prolonging treatments whatsoever, and have consent from my family not to call the ambulance.

Answer:

Suppose your family is in shock and forgets about your agreement and calls for an ambulance. You can still present your living will to the ambulance crew to pass it on to someone at the hospital. The living will issued by JSDD is the most recognized documentation in the Japanese healthcare system, so this will become the basis for withdrawing any life prolonging measures administered in case you're diagnosed with an incurable and terminal illness.

Question:

If my family had already called for an ambulance and then realized that LW was available, is it possible to cancel the ambulance?

Answer:

It depends on where you live, but it is possible that they can just contact your doctor and confirm your DNR status. Currently, the Ministry of Internal Affairs and Communications is looking into developing a standardized nationwide system.

Question:

When it is apparent that the dying process is near, is it possible to provide end of life care at home rather than calling for an ambulance after talking with the doctor?

Answer:

If the patient is in terminal stage and lifesaving treatment is not available, you may have an advance talk with your doctor and exchange information about how to proceed. This is highly suggested.

Question:

How do we find doctors who can support the patient's last wishes?

Answer:

You can refer to our JSDD website. We provide a list of living will supporting physicians. You can also find a list of recommended in-home terminal care doctors in the weekly magazine called ASAHI MOOK. The first step you should take is to consult with your own doctor. Your local administration offices and total support centers also have a consulting window with someone who can guide you in the right direction.