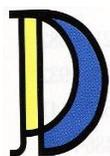


Excerpts from



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

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Dr. Soichiro Iwao reelected as JSDD President for his third consecutive term

JSDD’s new team of leadership announced

JSDD’s council meeting and board of directors’ meeting were held at its headquarters in Hongo, Tokyo on June 29th where new team of leadership began its work.

Dr. Iwao was reelected and remains as the president for his third consecutive term. Dr. Kazuhiro Nagao also remains as the vice president for his third consecutive term, and Dr. Masahiro Nomoto, who is currently The World Federation of Right to Die Societies member, was elected as another vice president.

During this meeting, four-year full term councilors and auditors as well as two-year full term directors were elected. Ten councilor positions were reduced to seven, all of which were filled with reelected councilors from the previous term. Fifteen director positions were reduced to twelve, filled with three newly elected director. Two auditor positions were increased to three, filled with one newly elected auditor. The new council meeting approved the 2018 fiscal year business report as well as the financial report.

The report showed our current membership number to be a slight decrease from the peak year of 2012 with total enrollment drop from 126,000 to 109,155 at the end of March this year. New membership this year was 6,250, similar to the previous year; however, the overall enrollment number deceased by a little over 1,000 after 7,250 members leaving JSDD including death. These numbers show that the recent rapid drop rate in membership has slowed down.

The recurring income for Fiscal Year 2018 was ¥155,000,000 and the recurring expenditure was ¥166,000,000. The deficit was a little over ¥10,000,000, but it shows the recent deficit rate to have slowed down also.

Activity Report

Chugoku Chapter

Number of LW Supporting Physicians increased to 230+

Last year, we sent letters to all medical organizations of Shimane, Yamaguchi, Okayama and Tottori prefectures to recruit more LW supporting physicians. This year, we are focusing on medical organizations located mainly in Hiroshima prefecture. By the end of August, we have received close to 30 new registrations, raising the number of LW supporting physicians in our Chapter to over 230. This means that we now have a ratio of fifteen JSDD members to one LW supporting physician.

We believe that to have a doctor nearby who understands the mental and emotional needs of people who are in the final stage of their lives provides a tremendous sense of security and peace. We are strongly committed to endeavoring this effort.

If you find that your doctor is not a registered LW supporting physician, please let us know. We will be happy to send them our application documents for LW supporting physicians system directly.

Tohoku Chapter

It all started with the Living Will

We often see or hear the terminology ACP (Advance Care Planning) or *Jinsei Kaigi* (translated Life Planning Conference) in mass media nowadays, and not much about the actual concept of the Living Will itself. I believe that having a living will that concisely expresses one's wishes must be the foundation on which the ACP or *Jinsei Kaigi* (Life planning conference) is based.

For over 40 years, JSDD has strived to deepen people's understanding of the living will and propagate its concept. It is a grand historical achievement which nobody can deny. Simply said, JSDD is the founder and fore-runner of the living will movement in Japan. I strongly support the idea of the JSDD sponsored living will. I became a JSDD member, and was just elected as the new chairman of the Tohoku Chapter. "To live fully and to die peacefully..." is what we all pursue. All the activities in which we engage help people understand self-determination and the living will, which is the basis and the starting point.

As the new chairman of the Tohoku chapter, I want to ask all of you reconfirm our basic mission mentioned above. I will continue to repeat it again and again at every opportunity we will have.

Please don't ever hesitate to contact us whenever you have any questions or concerns. It may change the course of your life or bring you a clear sense of security. We have full confidence that you will have a peace of mind because we have come so far to prove that the living will was the start of it all.

-By Takao Ami (Chairman, Tohoku Chapter)

Kanto-Ko-Shin-Etsu Chapter

New Forum Opening up in Nagano City after Three Years Absence



On July 12th, a public forum was held at Hokuto Culture Hall in Nagano City for the first time in three years. The first key note speaker was JSDD vice president, Dr. Kazuhiro Nagano. He talked about the ACP which is a federal policy governed by the Ministry of Health, Labor and Welfare. He strongly emphasized the importance of frequent and intimate communications among patients, families and healthcare providers, but to remember that the core of the matter is the patient's wishes, also known as the Living Will.

Followed by his speech, Dr. Masuo Yi of Yi Clinic who provides in-home terminal care, talked about the importance of spending the last days in the community where the patient considers home. He also discussed the significance of mutual cooperation in the community, introducing his recent activities supporting patients in need and providing emergency consultations through his new non-profit organization called "Shinden no Kaze." He said that one of the most impressionable statement someone made was, "When you can still eat with your own hands and mouth, you won't die so easily."

The question and answer session after the speeches was very hot and lively. It was a very substantial and rich forum.

-By Kenkichi Yoshinari

Tokai-Hokuriku Chapter

End of Life Planning Fair held in a department store to promote “Death with Dignity”*

* Expressions used in this entire newsletter such as “Dying with Dignity”, “Death with Dignity” or “Dignified Death” do not refer to active euthanasia as commonly used in Europe and the US. In Japan, the terms only refer to passive euthanasia, i.e., refusing life prolonging measures.



The third End of Life Planning Fair was held at Meitetsu Department Store, 7th floor, located on the south side of the JR Tokai Nagoya station for five consecutive days in August. The fair is designed to provide support and answers to questions such as “What do I need to do to prepare?” or “What should I do if I don’t want to burden my children or grandchildren?” Chunichi newspaper sponsored this event and requested our participation. We selected our theme to be “Dignified death: Live fully and die peacefully.”

During the fair, seminars were given on four mornings and five afternoons with some popular guests such as Ms. Tokiko Kato (musician), Ms. Ihoko Kurokawa (AI researcher), as well as a

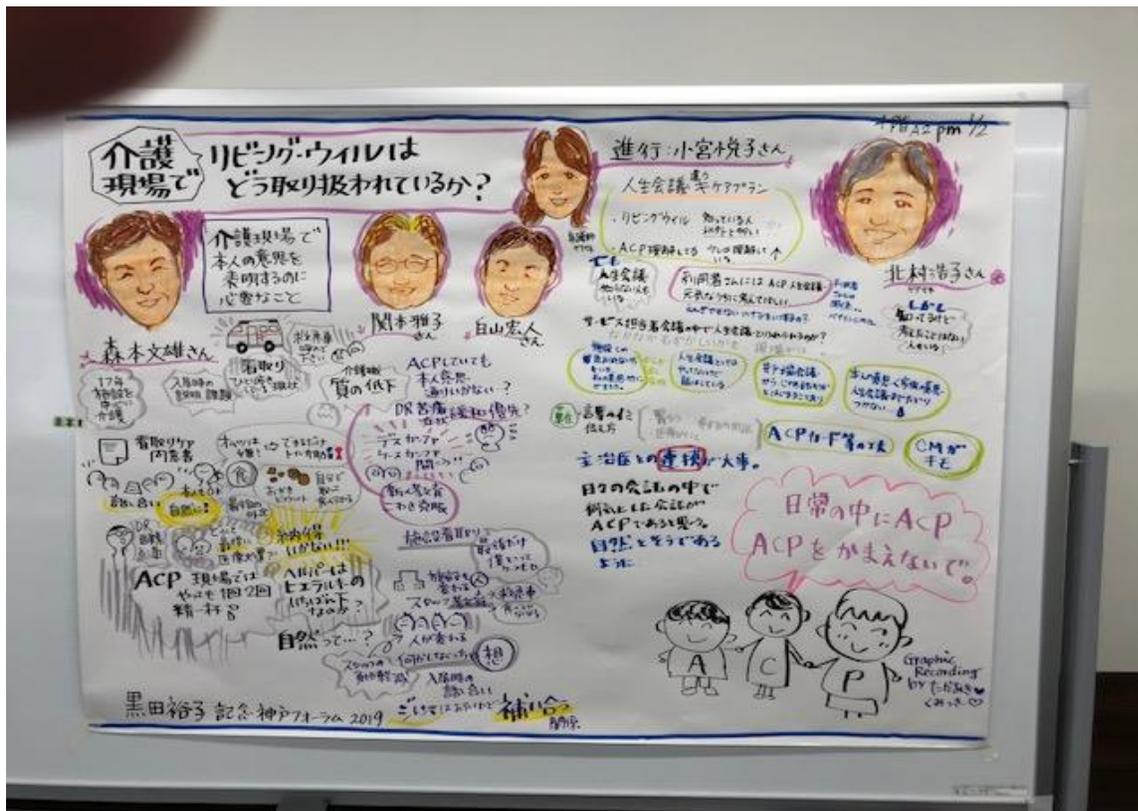
popular local radio host and an inheritance estate consultant, who all made impressive speeches. I, for one, had a one-on-one dialogue with a popular television anchor. A total of about 5,400 people participated, and 3,300 people attended the seminars.

My speech focused on the concept of dignified death, which is the refusal of life prolonging measures which are solely administered for the sake of keeping someone alive. I also explained the global movement of dignified death and clarified the differences between euthanasia practiced in some countries such as the Netherlands, and assisted death which has spread globally from Switzerland. I also emphasized that dignified death starts with having a living will which is an expression of your sincere wishes, upon which the ACP is built, which is the plan of executing your wishes based on intimate communication between the patient, family and healthcare providers. ACP is a document regulated by a federal policy governed by the Ministry of Health, Labor and Welfare. I explained it all. When I asked the audience whether they had heard of the term, ACP, only two hands went up out of 40 people. This was a disappointment, especially after the Japanese government decided to use the term, “Jinsei Kaigi” in Japanese to replace the term ACP, which literally means “Life Planning Conference,” in an attempt to make it more popular.

There were various booths in the venue to include funeral service, estate consultation, financial assistance for retirement, and even the Aichi Prefecture Police Department, who drew attention of participants by presenting cases of money fraud and traffic accidents.

-By Tsukasa Kobayashi (Chapter Advisor)

Kansai Chapter



We participated in the “Kobe Forum 2019 in memory of Hiroko Kuroda” sponsored by Japan Hospice and In-home Care Study Group. Since the main participants were medical professionals and volunteers, we took this opportunity to chime in as our 4th Kansai Living Will Study Workshop with the topic of “What is a Jinsei Kaigi: Life Planning Conference (or ACP)?”

Mr. Kazuo Ozawa (Kansai Chapter Advisor) made his key note speech in the morning with the title “Jinsei Kaigi (ACP) and Dignified Death: in laymen’s term.” The afternoon’s theme was “What the caregivers need to execute your living will.”

After Mr. Fumio Morimoto (Kansai Chapter Director) who has worked in nursing homes for many years made his speech, Ms. Etsuko Komiya (Kansai Chapter Director) and Ms. Hiroko

Kitamura (President of Amagasaki Care Manager Association) reported the results of a survey whose purpose was to determine the extent of living wills and ACPs executed by care managers.

Throughout the day, about 80 people participated. The underlining problem seems that unless the living will, which is the patient's true wishes, is the core of the discussion, the ACP becomes the dominant document used by medical professionals, in which case the patient is placed in a caregiving environment that may not allow or is difficult to execute decisions expressed in his/her living will. This is the real problem we are facing now; therefore, we must try harder to reach out to more people and educate them about self-determination.

Shikoku Chapter



As part of the Living Will Preparation Study, we visited a nursing home in June and a social welfare home in August, a group home, to observe and learn how they are being used. In July, we invited a nurse from another nursing home, Ms. Miyako Kazue, to our office teach us about new methods of closely and intimately attending patients, which is necessary for providing in-home medical care. We also learned how the caregivers can obtain a sense of satisfaction from caring for their patients.

Kyushu Chapter

Two physicians' comic routine was a big hit



The Japan Living Will Kyushu Chapter Study Workshop was held in Nagasaki on June 8th. The first part of the program was a speech called “What is a living will?” by Dr. Satoru Mitsuoka (JSDD Director and Chairman of Saga). He talked about a wide range of topics to include promotional activities provided by JSDD, the current legislative status and the ACP.

The second part of the program was a lecture by two physicians: Dr. Takashi Sakurai of Sakurai Clinic and Dr. Hiroto Shiroyama of Osaka North Home Care Clinic, with the title “Can we suddenly and unexpectedly drop dead? What is terminal care? You’re never too young to think about Advance Care Planning.”

Depending on the illness such as cancer, cardiopulmonary disease, dementia, or stroke, patients’ experiences vary quite a bit. Consequently, how they accept death and how they want to spend the rest of their lives would also be different. Therefore, it is very important to prepare your ACP. They talked about everything in an easily understandable language and in detail.

They showed a video of last three performances by Dr. Sakurai’s drama company as a tool to bring up very specific questions:

“What specific medical care is provided by in-home terminal care doctors?”

“How do we confirm the patient’s wishes?”

“What happens step by step when you call an ambulance?”

“What is a death certificate?”

“Is it possible for cancer patients to spend their last days at home?”

They answered them all in detail. How they explained these serious and complex subjects to the audience was so funny and interesting that it was as if they were two standup comedians making everyone laugh, rather than two physicians. What the participants took away from this lecture will certainly be a tremendous help in their preparation of the living will and ACP.

-Dr. Yutaka Shirahige (Shirahige Internal Medicine Clinic, and chairman of JSDD Nagasaki Office)

New Series: Questions from JSDD members/Answers by Consulting Doctors

No. 1: When is a good time to stop my elderly mother’s parenteral nutrition?



Question from a daughter in her 60s:

This is about my mother who is 92 years old. Last March, she was diagnosed with edema caused a bruise on her left calf. After being hospitalized, she complained about a back and hip pain. She was then diagnosed with kidney cancer. As she is very old, the recommended treatment was palliative care of pain management with medical anesthesia. She had no signs of dementia and had been living all by herself prior to the hospitalization. She had a hard time accepting this arrangement and strongly

expressed her wish to return home. Due to this stress, she had no appetite.

At the end of March, the doctor recommended parenteral nutrition, and I gave my consent. She was normally fed through the mouth at the same time, but the stress caused an acute duodenum ulcer and hematemesis. At that point, they stopped feeding her through the mouth. Two weeks later she was transferred to a nursing care bed, and that is where she is right now.

Although she is bedridden, they have been giving her high calorie infusion for the last several months. She has lost a lot of weight and is sometimes delirious, going back and forth between her dreams. She can have conversations with a smile but inconsistently. This is her condition right now, and one day her consciousness will diminish and eventually go into a deep sleep. At that point, administering of life prolonging measures will come up as the next step. I am now thinking of asking the doctor to stop the infusion.

Is it a problem to stop her infusion? When is a good time to stop? She is very old and has cancer. She is only receiving parenteral nutrition. How much longer will she live at this rate?
(From a daughter in her 60s)

Response from Consulting Doctor A:



I fully understand your close and deep relationship with your mother. I also recognize the fact that you are deeply concerned for her condition and her prognosis. I have to say that it is difficult to project how much longer she will live only from this letter. It is okay to continue with the parenteral nutrition for a year or two years. However, at some point, she may develop an infection from this. I suggest that you ask her doctor directly about her prognosis including her life expectancy.

Response from Consulting Doctor B:



It is very difficult to predict her life expectancy. It seems like she is under a lot of stress considering her mental condition. My impression is that the mental care given by the hospital is seemingly insufficient. Being bedridden with reduced consciousness, her condition sounds terminal. Depending on their cancer progress, sometimes patients live much longer than expected even with parenteral nutrition only. To stop the infusion would be very difficult under the current situation. If fever or any other condition occurs that requires the replacement of the infusion, it may be possible for you to ask them to discontinue the infusion. You will have more definite answers by consulting your mother's doctor in this regard.