



Excerpts from



**Japan Society for Dying with Dignity Newsletter  
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**DR. SOICHIRO IWAO WAS REELECTED AS THE JSDD PRESIDENT**

**JSDD welcomes new Board Directors**

Japan Society for Dying with Dignity (JSDD), now a general incorporated foundation, held its Board of Directors/Councilors meeting on June 24 at the Tokyo University Hall in Hongo, Tokyo. The newly elected directors and councilors will serve for the next two years.

Dr. Soichiro Iwao was reelected as the President (Representative of the board), and both Dr. Yutaka Suzuki and Dr. Kazuhiro Nagao were reelected as Vice Presidents. Mr. Kunio Aoyama (former High Court Judge) was elected as the third Vice President.

Of the 15 director positions with a two-year term, ten were reelected, and five new members were elected. There was no election for the executive positions of councilors and auditors since their terms had not been completed yet. The FY 2016 Business Report and the FY 2017 Business Plan were introduced at both board of directors and councilors meetings.

**Membership numbers declined but budget improved**

JSDD membership reached its peak in 2012 at 126,000 members, but since it has been in gradual decline to present at 113,000 members. 2016 showed a bit of an increase compared to the previous year, attributed by the media’s viral spread of sensational comments on “Dignified Death and Euthanized Death” and “the Living Will” by famous writers; however, outnumbered by the rapid death rate of JSDD members.

JSDD mainly operates on the income of membership fees, thus a decrease of membership has a direct impact on its financial balance. A strategic measure of effective campaign leading to an increase of membership fees is an imminent agenda.

The FY 2016 financial statements showed an ordinary income of ¥157,000,000, which was ¥13,000,000 less than the previous year. On the other hand, by cutting down on inefficient activity cost by ¥26,000,000 from the previous year, we were able to reduce its expenditure to ¥169,000,000. Although our total deficit was ¥12,000,000, this was an improvement of ¥13,000,000 compared to the previous year.

## **FACILITATOR TRAINING WORKSHOP DEBUT**

### **New program “Living Will Facilitator” develops**

This summer a new event called “LW Facilitator Training Workshop” was held in Saga Prefecture, something JSDD has never conducted before. A facilitator, in this case, is like a helper or an assistant for the LW.



The workshop was held on July 22-23 for two days at the conference room of National Ureshino Medical Center in Ureshino City, with approximately 50 attendees. Other than the local JSDD Chapter officers, most of the participants were people interested in LW, but not necessarily JSDD members, and they were from Saga and Nagasaki Prefectures. The project organizers were Dr. Satoru Mitsuoka, Director of JSDD Headquarters and President of Saga Chapter and Mr. Yutaka Shirahige, President of Nagasaki Chapter.

The first day started with an introduction by Dr. Iwao, followed by speeches by Dr. Koichiro Itai, a professor at Miyazaki University Medical School, and three others. Afterwards, a question and answer session was held. The second day began with a group discussion on “Transforming to an ideal advance healthcare directive,” then Dr. Takehiro Matsumoto, an Associate Professor at Nagasaki University Medical School, spoke on the topic of “New LW promotion proposal with adaptation of ICT (Information Communication Technology).” Unique features were presented as this was quite a new venture, and many attendees were from various professional sectors. The two day session during which time all attendees stayed overnight in the same building brought an intimate and friendly dormitory type of atmosphere.

(Photo: Lecturers walked around the group tables. The standing lecturer in center is Mr. Yutaka Shirahige, President of Nagasaki Chapter. National Ureshino Medical Center)

## **Much interest in LW by non-JSDD members: Diverse professional backgrounds from Saga and Nagasaki Prefectures**

Participants included roughly half male, half female, majority in their 40-50s, mostly physicians, nurses, pharmacists and caregivers associated with medical facilities and the local medical network. Some were medical school and nursing school professors of Nagasaki and Saga Universities, as well as administrators from the municipalities and the National Ureshino Medical Center.

The second day's group discussion was on the topic of "An ideal advanced directive," which was meant to serve as suggestions to improve JSDD's LW format, and appeared to be the focus of many people's attention. Participants were broken into seven groups with six to seven in each group, and had discussions for about an hour while the guest speakers walked around and joined in their discussions. At the end, each group presented its own key points and summary.

## **Difficult writing style; many ideas and proposals from the younger participants**

The current living will is very difficult and "text book-like" in its writing style, which does not appeal to the general public. The writing should be easy and simple in its style, as they pointed out. Currently, JSDD only sends an information pamphlet to those who request to become a member. JSDD should prepare more visual resources such as DVDs, and develop a training program for professional advisors for people interested in joining.

Two days were not enough time to cover all the topics on the agenda, and all participants requested to come back again for the next session. It was only a two day session, but what they shared during those two days (including a hotel room per 4 persons) led to a much more meaningful contribution and mutual understanding.

The "Living Will Facilitator" program, which just started, has not seen any clear advantages or roles in future JSDD activities yet; however, everyone saw its potential to grow into a special network of people who share the same concerns and interests in the Living Will.

President Iwao concluded that the facilitators will become an eminent presence in the works of the new LW format with support from other chapters of JSDD.

Speech Titles and guest speakers were as follows:

- Global trends in supporting self-determination  
By Dr. Soichiro Iwao, JSDD President
- Workshop for self-determination to honor patients' wishes  
By Mr. Yutaka Shirahige, President of Nagasaki Chapter
- Issues of adult guardianship and medical agent  
By Mr. Masayoshi Egoshi, Attorney / Director of Saga Chapter

- Issues and examples of supporting self-determination and “Last wishes in an end note” published by Miyazaki City  
By Mr. Koichiro Itai, Professor at Miyazaki University
- JSDD Living Will workshop report  
By Dr. Satoru Mitsuoka, Chairman of Saga Chapter

### **Sharing LW content on local medical network: proposed by Professor Takehiro Matsumoto**



During the workshop, Dr. Takehiro Matsumoto, an Associate Professor at Nagasaki University School of Medicine, proposed sharing of LW content on the local medical network. In Nagasaki Prefecture, Ajisai Network is now under operation, which is the largest network of its type around the nation, giving service to 340 medical facilities and around 67,000 registered patients allowing medical coordination.

The shared information contains all patients’ medical records including diagnosis, surgery, visual information such as CT scan and prescription medicine. For example, a primary physician can access all the medical data on the patient treated by other physicians in participating hospitals on the network.

### **A breakthrough in disseminating patients’ LWs despite many issues**

If the LW was included in the patients’ online medical charts, terminal ill patients’ wishes would be easily accessible to any healthcare personnel from anywhere.

Professor Matsumoto proposed a comprehensive data based system to store not only the LW, but also donor cards and orange notes (dementia information).

As the LW is a very personal and private information, each person must personally amend it. As with all medical information, the appropriate security level of protecting individual privacy must be resolved.

As JSDD is the largest organization in Japan to store LW information, some voiced their opinions that JSDD should be the pioneer of this system.

## JSDD ACTIVITIES UPDATE COLUMN

### Hot discussions among domestic and international professionals The 6<sup>th</sup> session of LW Study Workshop cordially visited by Dr. Takaku, Former Chairman of Japanese Association of Medical Sciences

The 6<sup>th</sup> Japan Living Will Study Workshop was held on June 24 at Tokyo University Ito International Research Center with an audience of around 300 people. The main topic of the workshop was how to support people with declining mental capacity. Voices from various medical backgrounds and reports from overseas were among the vivid discussions.

Dr. Satoru Mitsuoka, who operates an internal medicine clinic in Saga City (also JSDD director) was the coordinator. Seven panelists (photo below), of which five were female, included two panelists from overseas and some activists from their local communities, quite a unique combination of panelists.



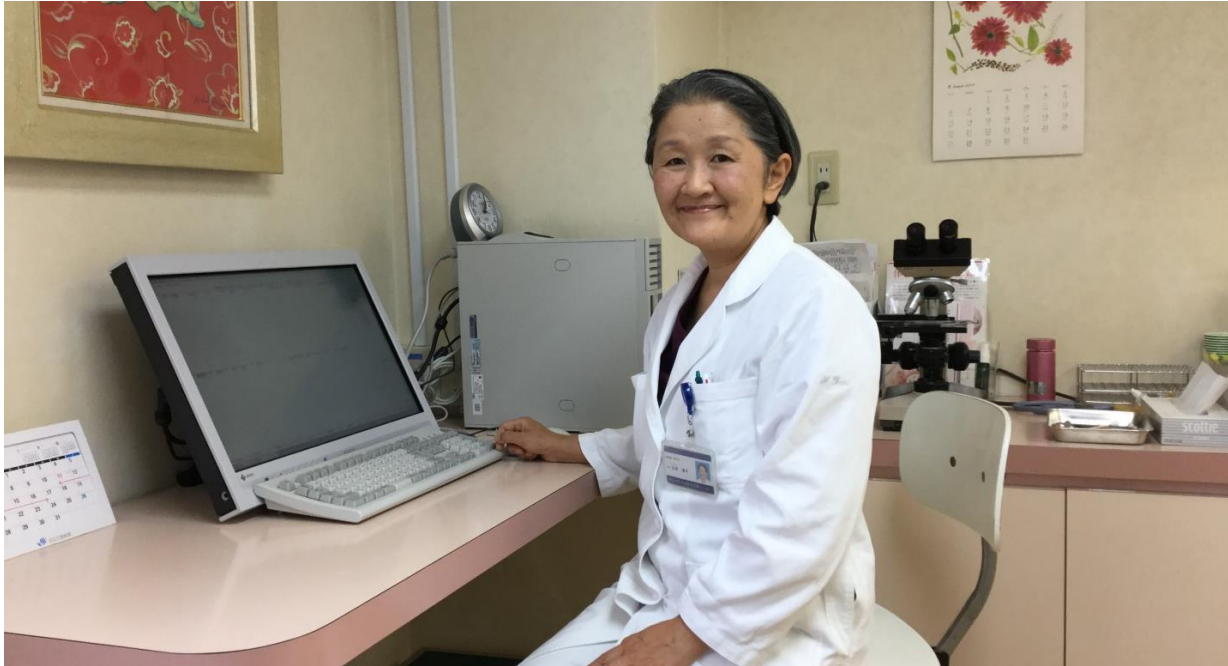
Dr. Fumimaro Takaku, the Former Chairman of Japanese Association of Medical Sciences, made a pleasant surprise appearance and told the audience that when he found out about this LW study workshop, he decided to invite himself for the first time to such a highly valuable event.

Medical professionals from various settings gave their live reports on their observations: Ms. Yukiko Ueno (nurse) and Dr. Sumiko Kanegae (physician) from Saga Prefecture, and Dr. Suzuki (in-home medical care taker) from Tokyo. Ms. Chieko Matsukuma (attorney) from Aichi Prefecture spoke about the legal issues of medical consent and agent. Reporting from overseas were Dr. Mutsuko Onishi (USA) and Professor Chabot Akane (the Netherlands), who talked about the supporting facts regarding patients' self-determination in their respective countries and joined the discussions.



## **THE PROSPECT OF DEVELOPING A SYSTEM FOR LW SUPPORTING PHYSICIANS**

### **Spot report: Dr. Hiroko Gomi of Ichihara City took care of over 3,000 in-home terminally ill patients**



**“I don’t need to sleep at all,” says Dr. Gomi of Anegasaki, Chiba Prefecture, who takes care of in-home terminally ill patients 24/7, 365 days a year on duty. What is it like to live like her, and what is her obsession?**

“I drive an emergency vehicle (hospice car) when patients are in horrible pain and suffering. I serve 24/7, 365 days/year on call to support those who want to live at home until their last moment and who want to be discharged from hospital as soon as possible.”

That is what is stated on her website. Dr. Hiroko Gomi (59) has operated this clinic located near Anegasaki Station (JR) in Ichihara City, Chiba Prefecture for 25 years. The number of her in-home terminally ill patients to date is 3,000. For the last several years, she has taken care of roughly 200 patients annually, which amounts to over one patient every two days.

“This area is a rural country, and many elderly people who feel that they are in the dying process would prefer to be home. Families also respond willingly by moving the patient’s bed at the center of the house so that the patient can live his or her last days in a casual and natural atmosphere, which has been a traditional way to die for many centuries. I get calls from homes, and I go do my duty.”

## **“I don’t wear pajamas to bed.”**

When asked, “isn’t it awful to have to work 24/7, 365 days a year?” she responds that she leaves her cell phone number to all of her patients and tell them, “whenever you need me, do not hesitate to call me. I am always ready to come to you. It does not matter when it is: Sunday, holiday, midnight, any time. I don’t wear pajamas to bed.” Further, she continues “I really don’t have to sleep. If I sleep like ordinary people, I wouldn’t be able to do this type of work!” Her devotion is clear and without any reservation.



Her clinic has a staff of 24 professionals altogether including full time and visiting nurses. Dr. Gomi’s emergency vehicle (the hospice car) is equipped with a red flashing light, the same one used by masked police patrol cars. “There are very few vehicles like this one nationwide. I have a permit from the police department,” she says.

## **Dying with dignity deeply struck a chord with me**

There was a case in which a terminally ill patient told everyone, “Please leave me alone when I die.” The patient’s family and primary doctor all agreed to provide in-home care and let him die naturally. He suddenly had an acute change in his medical condition, and his family had to call for an ambulance and rush him to the hospital. She was warned that when a patient is taken to the hospital against his or her will, the patient ends up in a coil of spaghetti tubes around his or her entire body. All the arrangements and efforts we make to that point is flushed down the drain. When something like that happens, she and the patient’s family would request the hospital to release the patient and take him or her home.

Four years ago, she applied to be in the LW supporting physicians’ registry because the concept of dying with dignity truly struck her chord. She was particularly impressed by the writing at the end of JSDD’s LW which states “my deep appreciation goes to those who fulfilled my wishes ..... it is solely my responsibility for all actions taken in full accordance with my wishes.....” This description is rooted from the inherent, intrinsic nature of our Japanese culture which we have embraced for centuries; expressing our true consideration and compassion towards other people and our sense of noble purity toward death.

She made no reservation to say that JSDD is absolutely in need of advertising and PR efforts, and that a lot more people must know about the concept of dying with dignity and the registry of LW supporting physicians.