

Excerpts
From



**Japan Society for Dying with Dignity Newsletter
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As of June 9, 2014, JSDD has 123,356 members.

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4th Annual JSDD General Meeting of Corporate Members

Annual Financial Report Approved



The 4th Annual JSDD General Meeting with representatives of the corporation was held on June 8, 2014 in Tokyo at the Conference Hall, National Graduate Institute for Policy Studies. 66 out of 67 members attended, of which 28 were by proxy. They endorsed previously submitted FY2013 (April 2013 – March 2014 in Japan) financial report, FY2014 (April 2014 – March 2015)

budget plan and election results of the new director.

In his speech at the General Meeting (see photo), President Iwao stated that his goal was to strengthen and transform JSDD into a powerful and influential organization that can overcome such obstacles as rapid increase in its aging and dying members.

The meeting's first agenda was the review of FY 2013 financial report. All reports on business activities and future budget plan were reviewed and approved. The second agenda was the election of a new director. New president for Hokkaido Chapter, Mr. Koichi Ozaki succeeding Mr. Noboru Kawai was elected as the new director.

The budget plan for FY2014 had already been approved at the board meeting in May 2014; however, it was brought to everyone's attention during this meeting that we are in a deficit situation, and future activities must be managed very carefully.

Movement in Legislation

Delicate timing for passing the bill at the end of the Diet session: Parties continue their internal discussions

The bill honoring patients' will during terminal care, known as the *Dignified Death Act*, is placed in a delicate timing situation at the current Diet session ending on June 22, 2014. Diet Members Coalition for Dying with Dignity (DMCDD), a 169-member team chaired by Teruhiko Mashiko, requested each party to discuss the bill and come up with a unanimous stand; however, this task seemed to be taking more time than expected.



Discussions show no progress, no end in sight

Nearly ten years have passed since the legalization of the living will was brought onto the political stage by the coalition members, sparking various discussions and two drafted bills; one permitting refusal of administering new life prolonging measures, and the other permitting both refusal of administering new life prolonging measures and removal of existing life prolonging measures.

It goes without saying that matters such as this inevitably generate opposing arguments and discussions, and must be approached carefully to heavily consider its political implications, which often leads into a long, drawn out process with no end in sight. It was the project team for the Liberal Democratic Party headed by Shunichi Yamaguchi, which supports the death with dignity movement, who stepped in last December to request all parties to complete their internal discussions by April 2014 so that the Coalition Diet members can bring the bill to legislature during its normal session in June 2014. This plan was confirmed by the Coalition Diet members with the goal of compiling a unanimous view for the Coalition based on each party's unanimous views.

Grand move by the Liberal Democratic Party Project Team

The Project Team has been taking big steps to seek views from JSDD and opposing views from Japan Medical Association and disability groups in eight meetings. The team summarized that legalization of the living will is meaningless unless it includes the removal of existing life prolonging measures, and that the application of the bill should be extended to pharmacists, nurses and dentists as well. Japan Dental Association had pointed out that many dentists are in the same boat as physicians when they perform oral surgery.

The Liberal Democratic Project Team had prepared its majority view to bring to legislature since discussions at every level had already taken place; however, they still had concerns over a couple of opposing arguments. One argument was that the guidelines by the Ministry of Health, Labor and Welfare was sufficient to address this topic. The other was that the legalization would create an environment in which disabled persons feel uneasy or uncomfortable to live. The team still has to overcome some obstacles before they can finalize their unanimous view.

Other major opposition parties had their respective internal discussions during the meeting. The president of JSDD and other members participated in some of their meetings for exchange of opinions. The opposition movement seems to have grown; on May 22, 2014, over ten members of the House of Councilors met to exchange their opposing arguments for the legalization of the living will.

The mass media has been taking up this topic as well. Asahi Shimbun, one of the largest newspapers in Japan, printed a full page article titled, “Is the Dignified Death Act necessary?” on May 9, 2014, in which the vice president of JSDD (Yutaka Suzuki) was interviewed. He was cited that the (legalization) is absolutely necessary to care for terminal patients on their final departures in a quiet and peaceful manner.

JSDD refutes opposition on groundless criticism

Among the various opposing views against the legalization was the criticism of JSDD based on misunderstanding of the organization. For instance, the Liberal Democratic Party received comments that JSDD started as an organization to promote active euthanasia, and that it only changed its name from “Euthanasia Society” to Dignified Death Society” to hide its hidden objective. The opposition side also criticized JSDD’s founder, Tenrei Ohta, over his comment on disability issues. The project team had to remind the group that they were getting off on tangents and needed to focus on the purpose of this meeting, which was to discuss critical issues surrounding the legalization of the living will.

On June 5, 2014, JSDD President Iwao spoke on this same topic during one of the Liberal Democratic Party project team meetings that he regrettably admit that there are some Diet members who do not understand the difference between euthanasia and dignified death. He refuted criticism toward JSDD based on the founder, Tenrei Ohta’s personal opinion regarding disability issues. Dr. Iwao reminded them that JSDD did not make the statement, and that such criticism toward JSDD is pointless and irrelevant.

How to make your Living Will effective?

The 3rd Living Will Workshop of Japan takes on a case study



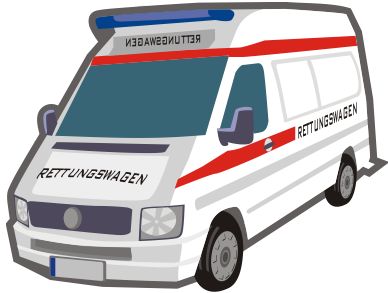
The 3rd Living Will Workshop of Japan was held on June 8, 2014 at the National Graduate Institute for Policy Studies, with the topic of “Living Wills which were not honored.” The entire program was conducted in a discussion forum, which was a new experience for this workshop. Approximately 200 people participated exchanging various opinions, making it a vivid event. Panel discussions were mediated by Mr. Tetsuo Tatsuno, a journalist specializing in medical issues. The six panelists for the workshop were as follows:

- Ms. Akiko Iseda, Adjunct instructor at Graduate School of Tokyo Medical and Denal University
- Ms. Yoko Sakurai, Registered Nurse and in charge of Telephone Consultation at JSDD Headquarters
- Ms. Taeko Maruo, President of NPO Inc.
- Dr. Kazuhiro Nagao, Vice President of JSDD, Director of Nagao Clinic
- Mr. Koichi Nobutomo, Professor Emeritus at Kyushu University
- Dr. Yuichiro Masuda, Director of Minokamo West Clinic

Cases of Living Wills not honored during emergency medical rescue situations

From the survey JSDD had conducted of surviving families of its members, the workshop selected two cases in which the living will were not honored. After detailed explanations of the cases were provided, participants identified and discussed the issues and possible solutions of each case.

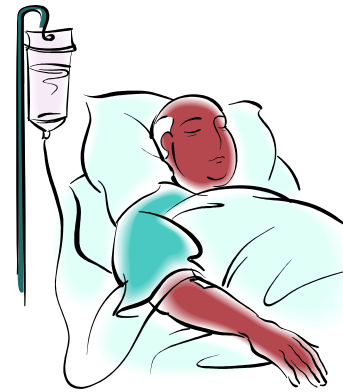
The first case involved a 90 year old woman who fell and suffered cardiopulmonary arrest. Although her family members were aware of her living will, they missed the opportunity to present her living will to the paramedic in the midst of chaos and emotional distress. Consequently, she was resuscitated and hospitalized. When they finally presented her living will to the hospital, they were told that the ventilator could not be removed once they administered it because that would be a criminal offense.



The panel discussion focused on issues surrounding end of life care in emergency situations such as above. According to the Japanese Association of Acute Medicine guidelines, medical professionals can “terminate” the process of life prolonging as long as the patient’s will and family members’ wishes are in agreement. However in actual emergency settings, the emphasis is placed on saving the patient’s life, and to terminate that process and effort: 1) is against the primary mission and obligation of a medical professional; and 2) will possibly bring on criminal charges. For these reasons, the guidelines are not being carried out.

From the audience, a physician stated that if the living will was legalized, they would be much less hesitant to carry it out. One of the panelists suggested that these issues can be avoided if families talk about what each member would want in emergency situations regarding calling for an ambulance and whether or not to be resuscitated.

The second case dealt with an 84 year old man in a nursing home. A feeding tube was recommended, so the man presented the doctor with his living will. The doctor was unsure if the living will included administration of the feeding tube. Pressured by the man’s daughter, who was hoping for her father’s possible recovery with the feeding tube, the doctor administered it. The man began having difficulty breathing. The respirator was declined, but he was administered a blood transfusion. As time went by, more and more tubes were inserted. It was getting difficult to judge what was curable and what was not; whether or not he was in terminal condition; yet, the doctor said nothing to explain the man’s condition.



In this case study, the point of discussion was the definition of terms “incurable” and “terminal condition.” It is difficult to clearly define those terms, as they heavily depend on the patient’s illness and age. One opinion was that the patient is in terminal condition when the doctor and the patient’s family so agree. Another stated that doctors often fail to communicate fully with their patients. For more details about the discussions held during the workshop, please go to the JSDD homepage at <http://www.songenshi-kyokai.com/>.

JSDD plans to update the Living Will Statement

Living will study group invites outside professionals to evaluate and develop an ideal living will

A living will issued by JSDD, known as “Declaration of Dignified Death,” has been highly evaluated by the Japanese society for nearly 40 years as a document respecting the patient’s autonomy. As the living will bill is at the threshold of legislative enactment, JSDD has begun an



evaluation and review of this document to become the standard model nationwide. In March, it established a study group which invited four renowned outside professionals for their input in a broader range of discussions and a report to be compiled by the end of the year.

The two proposed bills prepared by the Diet Members Coalition, *Honoring Terminal Patient's Will Act*, also known as the *Dignified Death Act*, have the following clauses regarding the living will: "The patient's decision at his or her own will must be fully honored (2nd clause)." "The patient's will to refuse the administration of / terminate any existing life prolonging measures must be expressed in a statement in such way as stipulated by the Ordinance of the Ministry of Health, Labor and Welfare (7th clause)."

The two proposed bills prepared by the Diet Members Coalition, *Honoring Terminal Patient's Will Act*, also

The bills do not specify the format of the patient's expression of will or the living will. JSDD plans to propose a model which it hopes to become the national standard. The standard format of the living will must be consistent and compatible, and must meet many legal requirements, which is one of the reasons the study group was formed.

The living will study group consisting of 11 members (seven JSDD members and four outside professionals) was officially established in March 2014, one of the business activities approved in the FY2014 budget plan and will have a meeting bimonthly.

The second meeting's agenda was "the ideal living will," discussing advanced directives used by other organizations in Japan and Taiwan's Palliative Care Act, also known as the Natural Death Act (refer to Newsletter #152). There are many types of living will, but the JSDD version places the most emphasis on the autonomy of the patient; it is comprehensive, but leaves enough room for physician's discretion. What the current JSDD living will does not cover are as follows: 1) a specific format for expressing the patient's will, 2) the issue of determining one's mental capacity, and 3) the document's validity.

Mental capacity of dementia patients and appointment of a medical power of attorney / legal agent

The format for expressing one's will can be the current declaration style or a checklist in which the patient can check off different types of life prolonging measures for different illnesses and conditions. The two main questions are, which format is most effective, and whether family consent is mandatory.

Determining one's mental capacity has become an imminent and important issue as dementia has become a common illness. In Japan, a society with a large elderly population, it is estimated that almost six million people suffer from dementia. The validity of the living will must be stipulated

in terms of frequency and method of reconfirming the patient's will and renewal of the document. A legal agent must be appointed and his or her authority must be explicitly stated.

These points will be thoroughly discussed, reviewed and reported to JSDD by January 2015 so that the modified format of JSDD's living will can be proposed and become standardized once the bill is passed.

Living Will Study Group Members (*Outside Professional)

Hitoko Aoki	Attorney, JSDD Vice President
Kunio Aoyama	Attorney, JSDD Toukai Chapter Legal Studies Society
Akiko Iseda*	Nurse, Adjunct instructor at Graduate School of Tokyo Medical and Dental University
Soichiro Iwao	Doctor, JSDD President
Kiyoshi Kitamura*	Physician, Professor, International Research Center for Medical Education, Graduate School of Medicine, The University of Tokyo
Junko Koga	JSDD Executive Director
Yutaka Suzuki	Physician, JSDD Vice President
Rio Tomono*	Attorney, Nurse
Kazuo Nagao	Physician, JSDD Vice President
Koichi Nobutomo	Physician, JSDD Executive Director
Toshihiko Miyajima*	Visiting Professor, University of Okayama

FY 2013 Total of 886 Medical Consultation Calls

Increase since expanding call hours to 3 days/week



JSDD headquarters compiled its telephonic medical consultation data from FY 2013, one of the services it renders. Results indicated that since it began accepting calls three times a week, the number of consultation calls increased by 470, a 30% increase from the previous year. The total number of cases does not necessarily equal the number of calls since one phone call may consist of more than one topic or case. For example, one phone call consisting of three topics were counted as three cases. The number of actual cases increased from 532 in 2012 to 886 in 2013.

The itemized topics of consultation are shown in the table below:

2013 Medical Consultation Contents	
Topic	#Cases (Percentage)
JSD	43 (5%)
Living will	122 (14%)
Illnesses	123 (14%)
Medical treatments	380 (43%)
Relationship with primary care physician	42 (5%)
Hospital and facility information	77 (9%)
Cost of care	12 (1%)
Other	87 (10%)
Total	886

380 cases dealt with medical treatments (43%), which doubled from last year’s 189 cases. One third of those 380 medical treatments cases were about life prolonging measures, honoring of dignified death, and specific medical treatments. Among them, the topic of life prolonging measures was the highest with 135 cases, of which questions regarding feeding tubes and hydration and nutrition supplement consisted of 95 cases.

The consultants reached the following generalization from the phone calls:

- 1) Many suspect that the current medical care they are receiving may be considered “life prolonging measures” because of how long they have been under that care.
- 2) When an elderly patient has been bed ridden for a long time, where is the decision point to consider natural death honoring the patient’s living will?
- 3) Many are stressed and concerned about insufficient communication between the doctors and family members.

These common points indicate that an increasing number of JSD family members are experiencing pressure and stress regarding terminal medical care.