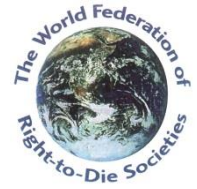


Excerpts  
From



**Japan Society for Dying with Dignity Newsletter**  
**No. 155, October 1, 2014**

As of September 8, 2014, JSDD has 122,198 members.

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**JSDD organization will be converted from a General Incorporated Association to a General Incorporated Foundation**

**Priority is promotion of the living will that is practical and realistic:**  
**No changes for its members**



On September 11, 2014, JSDD held a special meeting with all corporate members, who voted unanimously to change its organizational type from a General Incorporated Association to a General Incorporated Foundation. Initiated by this approval, the General Incorporated Foundation, initially funded by JSDD in October, will be absorbing the current General Incorporated Association and start as a new organization in April 2015. The

new foundation will focus on promoting the living will and pushing the legislation to pass the bill, all in an effort to meet the needs of people today. We are also considering changing our name to one more suited for its new status and goals.

**To Our Members: from President Soichiro Iwao**  
**An organization that meets today's needs and promotes the living will**  
**---- About the change of the organization -----**

Nearly 40 years have passed since JSDD was founded, now with its members growing to more than 120,000 in recent years. The special meeting of the corporate members was recently held, unanimously voting to change our organization from a General Incorporated Association to a General Incorporated Foundation. As a new type of organization starting in April 2015, we would like to focus our efforts and activities that are in line with today's needs.



Some of you may wonder why we are changing the type of our organization after having changed into a General Incorporated Association just recently. When we became a General Incorporated Association in April 2010, an “association” would have best served its purpose.

**Entering a new phase of promoting the living will and a new path for legislation**

As we moved forward, however, we ran into a variety of unexpected hindrances. For instance, as a General Incorporated Association, all members are considered corporate members and are expected to be directly involved in its daily operations. However, we found out that most of our members are only interested in having the organization to carry out their living wills and are not necessarily enthusiastic about devoting their time and participating in the operational aspect of the organization.

Besides, we elect representatives to send to the general meeting of the corporate members in which important decisions are made for the organization. We elect one representative for every 2,000 corporate members, currently with a total of 68 representatives. The difficulty in establishing a fair and open election is determining the right criteria for candidates, where there is a big gap between ideology and reality. With the new organization, we are able to operate in a streamlined manner, more in line with members' expectations.

Recent trends indicate that the average age of JSDD members is 77 years old, and the rate of dying members is much faster than incoming new members. This decrease in the number of membership means decrease in revenue. We are unable to ignore this phenomenon.

Regarding legislative activities, the Diet Member Coalition prepared two draft bills called Honoring Terminal Stage Patient's Self-determination. We are at a point where each political

party will bring its respective unanimous conclusion to the table. Unfortunately, these bills were not submitted to the legislature in the last session.

The ultimate goal of the law is to honor terminal stage patients' self-determination by legalizing the living will, but it is known by the general public, including the mass media, as the "Dignified Death Act." Diet Member Coalition believes that the term, "dignified death" may be causing unnecessary misunderstanding and portraying a negative perception, and is searching for a new name for itself.

The term, "dignified death," has a historical significance and is a well-established phenomenon in our country. However, its concept is slightly different from most other countries where euthanasia is a part of it. We are also considering renaming our new organization that reflects more on promoting and supporting the living will.

### **Obstacles ahead must be overcome with all of our efforts**

We see some changes in today's society where the majority of people do not wish to receive any life prolonging treatments. It is our job to let them know that the living will is the passport they must present to the medical professionals which allows them to carry out those wishes. Our new organization must take the lead in eliminating any obstacles keeping us from accomplishing that goal.

Changing the type of our organization from a General Incorporated Association to a General Incorporated Foundation has no disadvantage whatsoever on the status of its current members. The member's benefits and relationship with the organization remain completely unchanged. Under the new type of organization, we will focus on promoting the concept of dignified death and its recording document called the living will. Thank you all for your understanding and support for this change.

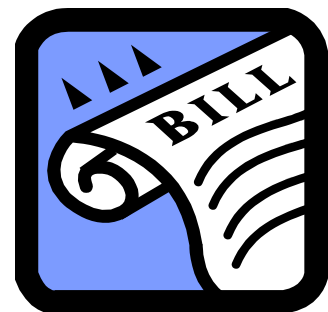
## **Chronological Events of Legislative Efforts** (by JSDD and Diet Member Coalition)

**December 2003:** JSDD drafts Terminal Care Outline Bill and petitions to former Minister of Health, Chikara Sakaguchi. Disseminated it to all Diet members.

**March 2004:** JSDD begins collecting signatures of legislators in support of the bill to form the Diet Member Coalition.

**April 2005:** "the Diet Member Coalition for legalization of Dignified Death (DMCLDD)" is formed with 60 members, headed by Taro Nakayama (Liberal Democratic Party=LDP).

**June 2005:** A collection of signatures (140,000) submitted to the chairs of both Houses of Councilors and Representatives.



**November 2005:** DMCLDD holds hearings until spring of 2006 (Japan Medical Association=JMA, Japan Bar Association=JBA, Religious Groups, Hospital Groups, Government Authorities, etc.)

**November 2005:** Legal Bureau of the House of Representatives drafts a legislative outline for open discussions of the bill, requested by the DMCLDD.

**April 2007:** The Ministry of Health, Labor and Welfare submits guidelines for “Decision Making Process for Terminal Medical Care.”

**May 2007:** DMCLDD announces the legislative outlines for Dying Process. JMA and JBA announce their official opposition.

**June 2007:** DMCLDD holds a hearing for JMA and other related agencies.

**November 2009:** Ruling political party changed by general election. The chair of DMCLDD changed to Makoto Sakurai (Democratic Party=DP) who proposes his own legislative policy.

**March 2011:** DMCLDD changes its leaders: Chairman Teruhiko Mashiko (DP), Secretary General Shunichi Yamaguchi, and Executive Administrator Toshiko Abe (LDP).

**March 2011:** JSDD presents a petition to DMCLDD which includes five items, one of which deals with the placing of priority on honoring the patient’s self-determination rather than family’s decision.

**September 2011:** DMCLDD announces basic points of the bill, which honors the patient’s self-determination expressed in writing. Emphasis on refusal of “initiating” life prolonging measures only.

**November 2011:** JSDD requests the Coalition to include withdrawing of existing life prolonging measures and deleting the requirement of family approval from the bill. JMA still holds a cautious attitude.

**March 2012:** DMCLDD announces a draft bill for honoring terminal stage patient’s self-determination with emphasis on refusal of life prolonging measures and deleting the requirement for family approval.

**June 2012:** DMCLDD proposes the second draft bill including the removal of existing life-prolonging measures.

**February 2013:** Prime Minister Abe makes a comment at the budget committee of the House of Councilors, “I want a system in which Dignified Death is reality.”

**March 2013:** JBA and incurable/fatal disease patients group express their opposition at a DMCLDD general hearing.

**December 2013:** Dignified Death Project Team is formed by LDP, headed by Shunichi Yamaguchi. He requests every political party to have its own internal discussion and reach a unanimous conclusion to pass into legislation at the 2014 session of general legislature.

**February 2014:** The Project Team stood up by the ruling LDP holds hearings (JSDD, JMA, disability groups, etc.). Chairman Yamaguchi repeatedly announces at the press release that the bill will be submitted to legislature during the 2014 session.

**June 2014:** The Project Team successfully gains unanimous support of the second draft bill including withdrawal of existing life prolonging measurements as a result of nine meetings. However, they were unable to submit it to legislature before the end of the session.

**Number of DMCLDD members by Political Party (as of September 2014)**



Liberal Democratic Party	123
Democratic Party	27
Komei Party	5
Yui and Ishin Party	13
Next Generation Party	7
Minna	2
No party	2
<b>Total</b>	<b>179</b>

**Spread the word about the Living Will**  
**Promotional Leaflets – Testament of Life**

**Over 10,000 copies circulated**  
**Available at hospitals and clinics nationwide with physicians' support**

Let's spread the word that there is something called the living will. JSDD printed new promotional leaflets in June and started campaigning through physicians who are in support of the living will. By the beginning of September, nearly 300 hospitals and clinics agreed to place these leaflets, 10,000 in total, for patients and their families to freely take.

This new leaflet (see photo) is printed on a standard letter size paper, designed with a picture of a puzzle with one piece labeled "Living Will" needing to complete the puzzle. JSDD's message is to fit this "Living Will" piece to your life to make it complete. Above the title, Testament of Life, there is a print that states "Not many people know about it" in red ink, which is a message



that reflects our honest assessment of ourselves for not having made enough effort to publicize the living will.

Many research polls show that the living will topic draws a lot of attention and interest among people, but they do not necessarily have a full understanding of it, nor are they convinced that they need to take action. A research conducted by a study group of medical policies for the elderly at Chiba University Hospital shows that out of 10,000 Chiba residents questioned, only 5% of them had a written living will. About half of them had organ transplant donor cards, and only 14% had a declaration of dignified death – a document issued by JSDD. On the other hand, 41% of the respondents wished to have a written advance healthcare directive. It is our obligation to inform these people what the living will can do for them, and that it can be easily registered with us.

## **Terminating Artificial Dialysis for Renal Failure ...**

### **The Japanese Society for Dialysis Therapy proposes Advance Healthcare Directive**

Many patients work normal hours while receiving a four-hour dialysis three times a week for 5-10 years. On the other hand, many elderly patients with complications associated with dialysis, and are forced to end the treatment in a timely manner.

The Japanese Society for Dialysis Therapy made an announcement in June proposing withdrawal of the treatment as one of the patient's options. Medical providers must explain to their patients about the necessity of having a written advance healthcare directive in order for his/her wishes to be honored.

Artificial dialysis is used to cleanse the blood of patients with a kidney dysfunction. According to a 2013 research, about 310,000 patients are undergoing dialysis, 53% of whom have been receiving the treatment for over 5 years.

In the past year, 38,024 more patients started receiving artificial dialysis, of which more than half are over 70 years of age with the average age of new patients being 68.7 years old. In 1983, the average age of patients going through this treatment was 51.9 years old. In the last 30 years, the average age of dialysis patients increased by 17 years.

Based on these figures, we can suspect that artificial dialysis was once a useful treatment for middle aged patients eager to get back into the work force. However with the aging society, we are faced with a growing number of issues associated with dialysis as a treatment.



### **Question of treatment length as average age of dialysis patients increases**

Many new patients are diagnosed with long term illnesses such as diabetic nephropathy (Kimmelstiel-Wilson syndrome) and cardiovascular disease. There is a noticeably increasing number of cases in which dementia patients are unable to withstand the gruesome hours of treatment and pull out their own tubes in the middle of a treatment. As it becomes more and more difficult to determine whether these patients'



quality of life is improved by this type of treatment, dialysis may be considered a life prolonging measure at some point.

Typically, patients die within 10 days of terminating dialysis from uremia. The decision is a serious one for not only the patient, but also for the medical professionals. Many doctors began voicing their concerns regarding what is considered an appropriate length of this treatment. They are seeking standard criteria and guidance.

### **Seeking options rather than termination**

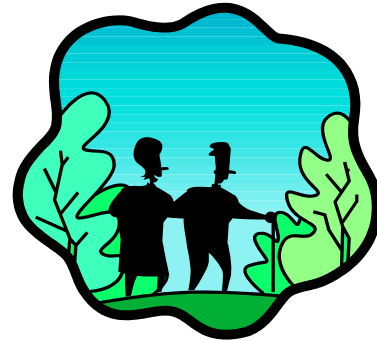
In 2009, the Japanese Society for Dialysis Therapy initiated a working group to establish guidelines for providing dialysis as a treatment to elderly patients. After thirteen meetings with open discussions, it finally reached a proposal in 2013, followed by public hearings seeking public opinion. During the course of discussions, the organization went through many changes in its awareness on this matter. For instance, the word “termination” was perceived as too aggressive. Instead the word “withholding” was used to replace “non-commencement” or “termination” of a treatment, which left room for interpretation. The proposal contained five main points: 1) Supporting the patient’s self-determination; 2) Honoring the patient’s self-determination, etc. Here, the work group required an action from the medical providers, such as explaining in detail of possible outcomes resulting from continuing the treatment to their patients and their right to an advance healthcare directive.

Termination of dialysis treatment is directly linked to death. When the proposal was first introduced, a slippery slope argument emerged; however, after several years of open discussions and hearings, the association is certain that giving patients a choice of “withholding” this treatment is the best medical care provided for the patients.

Sadly the Japanese people have not expressed much interest or concern regarding patient’s self-determination and advance healthcare directive. It will be an enormous step forward for medical providers to take the lead in promoting patient advance healthcare directive as proposed by Japan Dialysis Association.

## **Striking News: In Search of 10,000 missing dementia patients** **Many living in nursing homes still unidentified**

I was watching a special program on NHK called “10,000 Missing Dementia Patients” aired on May 11<sup>th</sup> with a patient wearing a flowery top and slacks with silver decorations. I wondered, “How is it possible that we still can’t find this nice looking woman’s identity?” The program followed this unidentified woman who was protected in a care home located in Tatebayashi City, Gunma Prefecture for seven years. It was shocking to see the difference in her appearance between the picture taken while she was in protected custody and now, a bed ridden old woman.



After the program, NHK received numerous calls from its viewers, which led to identifying her as a former radio announcer (67 years old) from Asakusa, Tokyo. She was picked up near Tatebayashi Station of Tobu Railroad line and brought under protective custody. She was dressed neatly, but was clearly suffering from dementia. Her undergarments were labeled with her name, but when she was asked for her name, she answered “Kumiko.” It was not her name.

### **The seven-year story that shook our society**

Several hours before she was brought under protective care, she had been wandering around Asakusa, next to Tatebayashi station of Tobu Railroad line. About two years prior, she had been diagnosed with Alzheimer Disease. A picture of her was posted on bulletin boards all over Tokyo, adjacent prefectures, local municipalities and even welfare institutions; however, her identity was never found. She became bed ridden about four years ago.

This TV program had a huge impact on all of us. The National Police Agency announced last June that 10,322 missing dementia patients were requested to be searched just in the year 2013. Most of them were found and identified, but 388 were dead, and 151 are still missing. Including the previous year, there are currently 258 total missing dementia patients. Thirteen people who are under protective care are still unidentified.

Naturally, identification of dementia patients is quite a challenge. The following data shows the percentage of missing dementia patients found based on the amount of time to identify them (collected from 2013 National Police Agency data):

Same day-----	6443 people
2-7 days-----	3506 people
8-14 days-----	71 people
15 days – 1 month-----	45 people
1-3 months-----	48 people
3-6 months-----	14 people
6 months – 1 year-----	10 people
1-2 years-----	11 people

Based on the data, 63% of reported cases were found within the same day. Including the same-day cases, 98% were found within one week. However, there were as many as 48 people who were not found for 1-3 months and 67 people not found for more than 3 months.



Local governments started to take more assertive actions. Saitama Prefecture publicly announced that a man was under protective custody of a nursing home for 18 years, which led to his positive identification as a man from Tokyo. Chiba Prefecture publicly announced in June that six people were in protective custody at five different institutions, five of whom were suffering from dementia, in some cases for over 13 years. It also posted on its website the missing persons' photos, physical descriptions and conditions, and other pertinent information which may help identify them. Shizuoka Prefecture followed suit and posted similar information about their unidentified dementia patients.

One may question why it takes so long to find these patients' identities once their pictures and information are disclosed. Certainly, the privacy act regarding safeguarding of personal information contributes to the difficulty of finding their identities, but as it turns out, the police and local administrations do not freely share information among one another with each agency working in a vacuum.

What we need is a combined effort of "S.O.S. Network" to find missing dementia patients. Some local agencies have already shown their efforts in this regard. The National Police Agency directed each prefectural police department to strengthen their workforce and make full use of all the databases pertaining to the missing persons.

There are 4 million people diagnosed with dementia today. Tomorrow, it can be you or someone you know well.