



Excerpts from



**Japan Society for Dying with Dignity Newsletter
No. 160, January 1, 2016**

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«40th Anniversary of JSDD Foundation»

**Reexamining the contents of the Living Will in preparation for the
upcoming ultra-elderly society of Japan**

By JSDD President, Dr. Soichiro Iwao



I sincerely wish all of our members a happy new year. This year, we will be celebrating our 40th anniversary.

I would hereby like to look back on our past efforts to promote the living will, and bring up some issues we will be facing in the upcoming 10 years.

1976 was not only the year JSDD was established, but also when the ratio of people dying at home versus people dying in hospitals reversed.

Life turning events such as birth, aging, illness and death have been occurring as part of normal life cycle in our homes in the past. Only one third of those wishing to die at home actually consider it a possibility, according to a national survey conducted by the Ministry of Health, Labor and Welfare.

A recent demographical data showed that the number of death in Japan exceeded the number of birth in 2005, and at this rate, the number of death in 2015 was estimated to be around 1.3 million. As for place of death, statistical data in 2014 showed hospital to be at the top with 77.3%, followed by 12.8% of death occurred at home, and lastly, nursing home at 7.8%. While

hospital deaths peaked in 2012 and has been declining, nursing home deaths of 2.8% in 2005 has been on the rise.

This trend may be contributed by a special program broadcasted by NHK (Japan's National Television Corporation) last fall in which terminal stage patients dying in nursing homes were portrayed positively. There has been a better public understanding and acceptance about elderly patients simply classified as old age and not being rushed to emergency rooms.

Our society faces a large number of elderly deaths in 10 years

How do you imagine our society (in Japan) 10 years from now? Many statistical surveys show the following prospect:

- There will be about 35 million elderly people, one fifth of whom will be diagnosed with dementia
 - One third of those elderly people will be living in solitude (about 6.8 million!)
 - Annual total number of deaths will be approximately 1.6 million, of which 90% will be elderly
- Thus, by 2025, we will be living in a society with a large number of elderly deaths

If death is unavoidable, we should receive the proper medical and palliative care while avoiding unnecessary life prolonging measures and end our lives with self-assurance and a peace of mind. That is what the Living Will is all about.

Professionals discuss issues in a meeting



The Living Will issued by JSDD has been highly evaluated and well accepted by our society as a document and a tool which allows patients to dictate their end of life medical treatments based solely on their will. Unfortunately, its propagation rate has been much lower than that of most other civilized countries. Along with recent changes in our public awareness of the topic, coupled with uprising popularity of “life ending notes,” various forms of expression have been

issued and utilized. In light of this situation, JSDD formed a study group to meet and discuss this matter for the past year in an attempt to make the living will a more feasible and flexible document and reach out to all elderly and terminally ill people.

We placed the report from these discussions on our JSDD homepage. The report concluded that the current living will template issued by JSDD is all inclusive and based on autonomy and self-determination of the patient. However, it pointed out the need for a strategy to generate more practical and effective results to meet the needs of today's complex society.

What are the new requirements for a living will?

We are transforming into a society in which an increasingly large number of elderly people live in solitude and/or are diagnosed with dementia. The new living will must meet these changes in our society. More specifically, the following conditions will be required:

- 1) A third party's signature (witness) certifying that the living will was prepared solely based on the individual's self-determination under no duress or coercion, and the individual was competent in doing so.
- 2) Renewal of the living will only upon confirmation that the individual's will remains the same.
- 3) Agreement or acknowledgement by the individual's family or close relative to gain full cooperation from the individual's health care providers.
- 4) Appointment of an agent who can make decisions in the best interest of the individual in time of declining mental competence or changes in medical conditions after the living will was issued.

In pursuit of self-determination by all members

In our society, the voices of family and relatives weigh more than the patient's, therefore the individual is not able to receive the kind of medical care he/she wishes for. The movement by the Diet Coalition Members is now at a recess, but we hear strong support from the health care providers who face these issues every day to legalize the living will.

When we consider what our end of life medical care will be like in 10 years with so many expected elderly deaths, self-determination must be every citizen's responsibility. As we enter the New Year, we will look into the living wills used in Europe and the United States to deepen and refine our own living will which accurately reflects and guarantees self-determination of every individual. I ask all of you to have intimate conversations with your family members about how you want to die and make efforts to spread the word and recruit more members so that as a society, we all recognize and understand our movement. Thank you in advance for your continued support and cooperation.

«40th Anniversary of JSDD Foundation»

Photos tell the story of JSDD

We celebrated our 40th anniversary on January 20, 2016. 40 years ago when there was very little concern over end of life medical care we raised the torch high and screamed, "Honor the patients' will!" We have traveled a long, winding road which reflects precisely the history of the living will movement in Japan. The photos will talk you through the events throughout the last 40 long years.

January 20, 1976 - Our boat sailed from Kanda, Tokyo



On this day, the first meeting to establish our organization called “Euthanasia Society” was held at the YMCA building in Kanda, Tokyo. With our slogan was “Any life prolonging medical treatment against one’s will damages human dignity,” about 60 professionals including physicians and lawyers gathered. Only one or two newspapers printed small articles about this event, and public reaction was almost nonexistent. However, the meeting was intense and the level of participation by the attendants was very high, as seen in the photo.

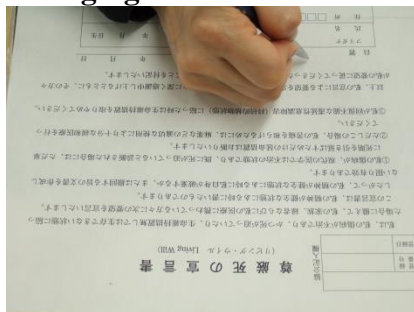
Merely three months after the society was founded, the case of Karen Ann Quinlan became one of the most sensational news even in Japan. New terms such as “dignified death” and “self-determination” were tossed around, but only 200+ people truly supported the concept of the living will and were enrolled as members.

First several years: fighting opposition groups

No increase in membership was seen for the first several years. The organization was perceived by most as an active euthanasia support group, which brought a lot of opposing views. One of the board members was scheduled to make a speech during a symposium held at Kyoto University, but was canceled at the last minute due to adverse pressure. These incidents did not discourage our members. Instead they held study groups in small packed rooms (photo from 1979) and continued to support the campaign undauntedly and patiently.



Changing its name from *Euthanasia Society* to *Japan Society for Dying with Dignity*



In 1981, the World Medical Association held its 34th World Medical Assembly in Lisbon, Portugal, where the *World Medical Association Declaration of Lisbon* was adopted. The declaration states that a physician must act in the best interest of the patients to guarantee their autonomy and justice. The concept of dying with dignity was widely propagated throughout the world and the Japanese public gradually became familiar with the concept. In order to avoid any more unnecessary misunderstanding, our society decided to change

its corporate name from Euthanasia Society to Japan Society for Dying with Dignity in 1983.

The content of the living will became close to what we have today, which became the cornerstone of our future development.

Shocking news of Tokai University euthanasia case and our rapid membership increase to 20,000

An incident occurred at Tokai University Hospital in 1991 in which a terminal cancer patient was given a lethal dose of potassium chloride. The hospital's poor standards of terminal medical care was exposed to the public, and the mass media focused on disclosing details of this case every day. This made our society so popular that our membership increased to 18,000 in 1991 and 20,000 in 1992. Our board members testified in the Yokohama District Court and explained the difference between passive and active euthanasia.

With over 200 study group symposiums, our society is viewed as the hub of information

During our social turbulence, our members never ceased to host study group symposiums with the range of topics including palliative care, advance medical care, overseas legalization of the living will, and dementia. Over 200 symposiums were held since the society was founded until 1995. The 76th study symposium held in 1990 at the Tokyo University Alumni Assembly Hall especially was an immense success.



Stage production: a unique idea by our regional chapter members



In 1999, in an attempt to facilitate public understanding of difficult issues surrounding terminations of life prolonging measures, Tokai Chapter members produced and staged a play called *Whose Life is it anyway?* Doctors, lawyers, and other members of Tokai Chapter went on the stage to play their respective characters in this play.

We divided the country into nine regional branches and placed a chapter office in each to support the campaign to increase JSDD membership using many creative ideas. Activities with the Pinkoro Drama Company by Hokkaido Chapter was one of the many unique events executed by our chapter members.

Adding living will courses to medical school curriculum

In 2000, only 16% of the 80 medical schools nationwide offered courses which included the topic of living will. After conducting an in-depth research about our medical education, we submitted a proposal regarding end of life medical care to the Ministry of Education, the Ministry of Health and Welfare, and all medical schools in Japan. We emphasized the need for a class covering end of life medical care to be part of the core curriculum of our medical program, and demanded more budget and faculty support from the government.

The World Federation of Right to Die Societies Conference held in Tokyo

In October 2004, the 15th World Federation Conference was held in Tokyo which attracted 500 participants representing 11 countries and 17 independent groups. Eight subcommittee meetings were held, each with different topics such as “Dignified Death and Dementia” and “Decision to Hasten Death.” Lively and sometimes heated discussions were seen throughout the conference.



A Zen priest seen as a powerful female figure

Ms. Jakuchō Seto-uchi, a prominent novelist who became a Zen priest, was invited to speak at the annual society meeting in Tokyo. The audience was limited to 800 occupants, but there were three times as many people who tried to attend this event. Some people were able to observe the speech through a monitor set up in the overflow room. Wearing her black Buddhist robe, her speech full of humor captivated the whole audience. She is a long time member of JSDD, and her tireless activities through writing and lecturing in support of the dying with dignity movement sets her aside as a powerful female



figure invaluable to our cause.

140,000 Signatures started our movement to legalize the living will



In 2004, another grand campaign began to collect as many signatures as we could nationwide in support of the legalization. Regional chapters and headquarters held forums and lectures to collect signatures from audiences, and eventually 140,000 signatures were collected. Diet Members supporting the legalization of the living will organized the Diet Coalition in legislature, and the petition was submitted to both Upper and Lower Houses.

Prime Minister Abe’s supportive comment in a Budget Committee Session



In the February 2013 Budget Committee session, a large poster board of JSDD’s living will template was placed at the main table. When asked for his opinion about the topic, Prime Minister Abe replied, “Ending one’s life with dignity is a fundamental human right. It is the responsibility of our government to provide a system which protects that human right.

A new start for our society as a General Incorporated Foundation

We began our society as a voluntary organization,

but in order to gain social status and public trust, a corporate status was needed. Applications to the authorities were denied four times in the past, but finally in 2010, we were granted legitimate corporate status based on the National Non-Profit Organization Reform. In April 2015, we started a new chapter in our history as a General Incorporated Foundation.

JSDD member profile update

Male vs. Female (1:2)

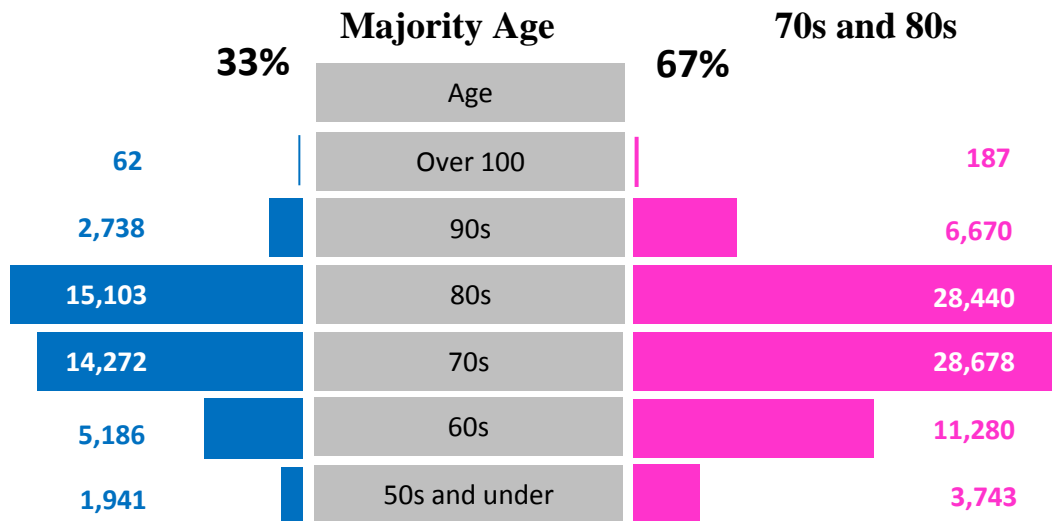
Total: 118,300 members

Male: 39,302 members

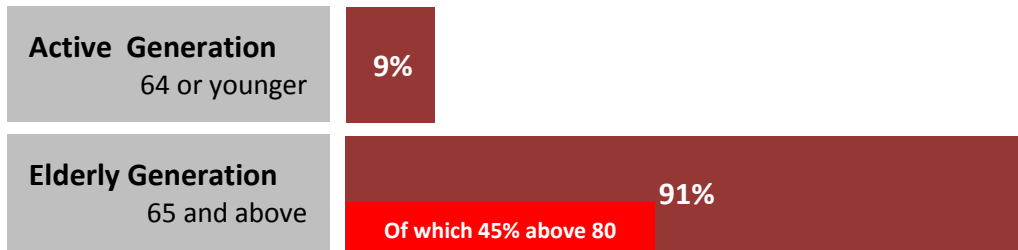
Female: 78,998 members



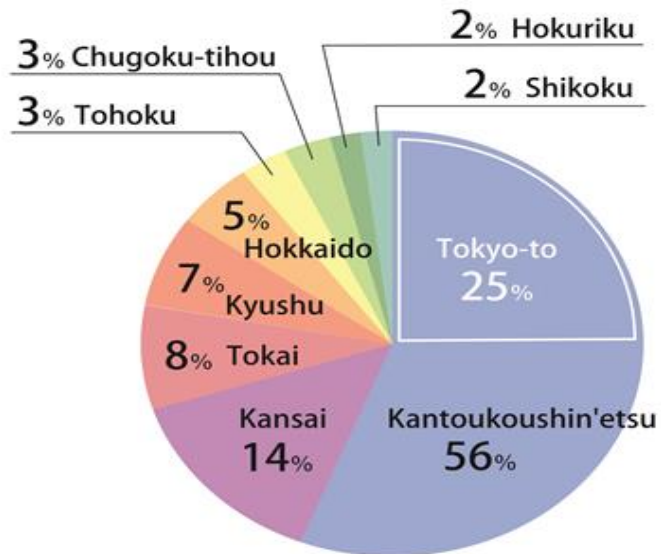
Average age 77 (Both genders)



Active generation (Pre-retirement): Less than 1/10 of the total population



Membership Composition by Regional Chapter



As of October 2015