

Excerpts from



## Japan Society for Dying with Dignity Newsletter No. 159, October 1, 2015

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### **Editorials: The era of 8 million dementia patients and the living will -Fighting with declining mental capacity-**

The rate at which the number of elderly dementia patients has been increasing is beyond our expectation. We have entered an era in which more than 8 million people in Japan have dementia. How do we predict and determine the will of elderly people who are gradually losing their mental capacity in both memory and judgment? How do we approach their end of life medical care? Discussions during the Living Will Study Workshop held by a regional chapter of JSDD were intense and endless. This particular topic was also on top of the list for our committee deliberating on the living will modification.



Facing reality that the average age of our members is 78 years old, the issue of dementia is not something any of us can or would like to ignore. Is a living will prepared prior to being diagnosed with dementia legally valid? What if the patient forgets that he/she had prepared a living will well in advance? Can a patient who is already diagnosed with dementia legally prepare his/her living will?

JSDD does not consider dementia as a disqualifying condition for its membership. We

take into consideration the existence of basic level of mental capacity which gradually declines in the case of dementia. We also do not require a doctor's note of diagnosis and leave it to the individual's own judgement.

We do occasionally receive calls asking the question of whether a dementia patient qualifies for JSDD membership. Our response is always a simple but accurate definition of dignified death, and that the individual can become a member as long as he/she comprehends it. This is how Nagoya Chapter deals with this type of question, according to Hitoko Aoki, Vice President of JSDD.

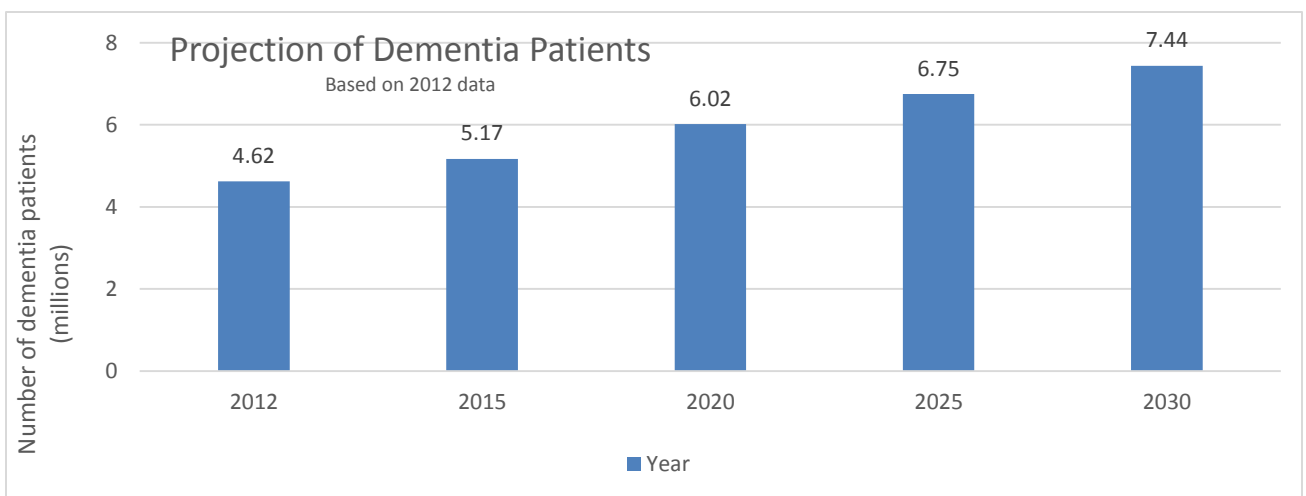
### **Living Will must be honored even after dementia diagnosis**

When doctors must determine whether or not to administer a patient with a life prolonging measure, they often wonder, "we know what the patient wanted when he/she prepared the living will, but what does he/she want now?" After all, it is only human nature to change one's mind.

In most cases, dementia patients who are already losing their mental capacity are losing their speech capacity at the same time.

JSDD's Living Will Study Workshop compiled results from the 2014-2015 research and published a report that recommends what the living will should look like once it is enacted by legislature. After a long deliberation on this topic, Dr. Soichiro Iwao, JSDD President, strongly stated that a living will prepared by an individual who is later diagnosed with dementia should still be honored as the will of that individual.

The purpose of a living will is to have an official written document prepared in advance to protect yourself for a possible future situation in which you are no longer able to express your will in a clear and concise manner. Therefore, our interpretation is that the living will is valid unless the individual revokes it.



Speaking of life prolonging measures, respirators have been the main point of discussion in the past; now the major topic is tube feeding due to a rapid increase in the number of dementia

patients. The medical intervention of tube feeding patients who are unable to obtain nutrition through the mouth has become the stage of a major social issue.

### **Hot topic of discussion within our Study workshop**

According to *National Strategy on Dementia*, a government publication, the number of diagnosed dementia patients over the age of 65 was 4.62 million as of 2012. The projected number in the year 2025 when all baby boomers reach their senior citizen age is approximately 7 million. Within ten years, one out of five elderly people will be diagnosed with dementia.

Even now, there are approximately 4 million people who are in the pre-stage of dementia.

The 2<sup>nd</sup> Living Will Study Workshop Symposium (held in November 2013) selected as its main topic this common issue with which everyone is concerned.

With regards to qualification criteria for JSDD membership, one of the external panelists remarked that it may be possible to somehow derive the will of dementia patients from themselves without giving them any guidance or persuasion. The common understanding among the panelists was that patients should still have a level of mental capacity to allow them to make some decisions during early stages of dementia. Once diagnosed with dementia, patients' mental capacity gradually declines. The further along the patients are, the harder it is for them to make clear self-determination.



### **Key point is that self-determination is still possible during early stages**

*Dementia: Care and Dignified Death* was the topic during the 1<sup>st</sup> Living Will Study Workshop Forum conducted by the regional chapter of Hokkaido in June 2012. Ryuichi Denno, Professor at Sapporo Medical School lectured the audience that it is crucial to express and convey your wishes to your family and loved ones to reach a mutual agreement during early stages of dementia while you're still capable of making those decisions.

During the 2<sup>nd</sup> Living Will Study Workshop Forum, the following examples were introduced:

“I met my mother’s doctor to tell him about her JSDD membership. She is in a late stage of dementia, so her statements vary every day from “I want to live” to answering “yes, yes” to whatever question she is asked. Eight members of our family told the doctor that she is no longer mentally capable to make decisions, but we would like to respect and honor her living will which she prepared when she was in good mental health. The doctor agreed.”

This is an excellent example of how the living will should be used on behalf of a dementia patient.

Japan has an adult guardianship program (2000) to support people lacking mental capacity. The appointed guardian does not possess power of attorney over matters regarding medical care and preparation of a living will, but there is a perfect example of a guardian who continued to pay the annual fees on behalf of the member, who remains a valid JSDD member even after conditions worsened.

We continue to deliberate in pursuit of improving the living will format that is feasible and practical from every aspect of the matter. We recognize the fact that we will be living with 8 million dementia patients, and that there is an immediate need to have a standardized living will format which is both detailed and flexible enough to deal with the declining mental capacity of dementia patients. We have an enormous issue at hand.

## **The Living Will Study Workshop**

### **[1] The 4<sup>th</sup> Living Will Study Workshop in Tokyo** **-In pursuit of painless end of life-**

The 4<sup>th</sup> Living Will Study Workshop Forum was held on June 20, 2015 at the Graduate Institute for Policy Studies (Roppongi, Tokyo). Roughly 30 of the 300 total attendants were medical professionals.

JSDD and Kanto Koshin Etsu Chapter cohosted the event with the theme of “In pursuit of painless end of life.” The forum was broken into two sessions: physical pain and spiritual pain, for which an expert from each field spoke on the subject.

#### **The First Session:**



**Ms. Yoshiko Kato**, Chair of Palliative Care Department at Sanyudo Hospital (Yonezawa, Yamagata Prefecture) emphasized in her lecture that in order to live with dignity, one must bring back his/her daily routine that is painless. “Pain can be controlled by palliative medication; pain killers such as morphine are legitimate palliative medication and not illegal drugs,” she stated.

Morphine works not only for cancer related pain, but also other types of pain. For example, a patient with a compression fracture who couldn’t walk for three months suddenly was able to walk for 15 minutes only after taking one dose of morphine. After continuing to take morphine for six months, the pain was completely gone.



**Mr. Daien Oshita**, a Buddhist priest at Hida Senkoji Temple (Takayama, Gifu Prefecture) works with a number of terminally ill patients through spiritual consultation, training, lecturing and educational activities based on clinical meditation and providing care and support. He stressed the fact that when a person encounters very last moment in life, he/she realizes that there is no one to rely on, not even doctors and families. Then, he asked, who and what can be completely reliable? “It is the other existence that is connected to yourself... some call it God, Buddha, the Universe, or just some great existence. This awareness and connection is the way to alleviate pain in your soul.”

### **Bring pleasure to your heart and soul**

In conclusion, Mr. Oshita stated, “When you think about what will be left behind in this life, the ultimate happiness exists in the simplicity of everyday living. The way to enhance the quality of life, to truly please your heart and soul, is by doing one little thing every day.

**The second session** was about palliative care needed for the new era. The following four panelists shared their respective experiences and fields of expertise:



- Setsuko Yonezawa – JSDD member who took care of both parents and husband in their terminal stages
- Kimiko Tanaka – nurse at Special Care Nursing Home (Setagaya, Tokyo) (Photo)
- Hiro Hanabusa – visiting physician (in-home terminal care) and founder of Shinjuku Hiro Clinic
- Yuichi Maruki – president, Saitama Psychiatry and Neurology Center who works with ALS patients

## [2] Kansai chapter Living Will Study Workshop

### -Living Will acts as a barometer of intimacy between parent and child-



The 1<sup>st</sup> Kansai Living Will Study Workshop was held at the New Osaka Hotel in Shin Osaka on July 12, 2015 with the theme, “terminal stage of dementia,” with 250 people attending. The following panelists participated in the forum:

- Kazuo Ozawa – Chief at Kansai chapter, JSDD
- Kazuo Nagao – Vice President of JSDD
- Yasuo Okuni – President of a social welfare corporation
- Tomoki Kataoka – President of Listen/Care Center
- Taeko Maruo – President of a Non-profit organization
- Fumio Tsuji – Physician at Suita City Hospital

### **63% of deaths from aspiration pneumonia are caused by dementia**

Dr. Tsuji talked about the relationships among dementia, being bed ridden, and aspiration pneumonia, and emphasized the importance of the living will. 63% of deaths from aspiration pneumonia was attributed by dementia, of which 66% of patients were permanently bed ridden. In such cases, many families regret having brought their patients to the hospital.

Ms. Maruo’s organization not only takes care of patients, but also their families who are taking care of the patients. She emphasized that whether or not the patient can die according to his/her wishes is an indication of the trusting relationship the patient (parent) and family (children) had developed over the years – like a report card. She also emphasized the importance of parents passing on to their children how they wish to die, especially during casual conversations over dinner for instance.

Mr. Kataoka repeatedly emphasized the significance of preparing an official notarized document conveying the individual’s will while Mr. Okuni highlighted the importance of in-home terminal care.

## **Chairman of Diet Coalition Members Federation, Mr. Mashiko, explains the draft bill**

**-Lecture meeting by Kanto Koshin Etsu Chapter, June 4, 2015-**



On June 4, 110 people attended the lecture meeting held at Edo Tokyo Museum (Sumida, Tokyo). About 20% of the attendees were non-members.

Mr. Teruhiko Mashiko, Chairman of Diet Coalition Members Federation (194 members from both upper and lower houses) explained for the first time to the public regarding the outcome of the general meeting held only nine days prior.

During this general meeting, the phrase “legislating dignified death” was omitted from the federation title. Also, the two draft bills to honor patients’ will at terminal stage were consolidated into one bill (for details, please refer to Newsletter #158).

Mr. Mashiko emphasized, “We are now at a milestone of submitting the draft bill once approval from all respective parties are obtained. It is important that each member makes his/her own decision without any party influence or coercion.”

### **“Successful legalization hopeful”**

Followed by Mr. Mashiko’s speech, JSDD president, Dr. Soichiro Iwao explained the details of the living will being modified by JSDD, and discussed the current situation and future prospect of dignified death.

The majority of the audience expressed their strong wishes for the bill to be enacted as soon as possible. They requested for the next meeting to cover more about detailed personal family experiences with regards to how their loved ones were cared for at the end of their lives, as well

as information on current palliative care and medical terminal care facilities and their services. Another request was to provide a clear and concise definition of the term, “terminal stage.”

## Topic of issues

### [1] JSDD supports physically challenged patients

#### ① Lectures accompanied by sign language interpretation



How do you express the term dignified death in sign language? Do you just combine the term “respect” and “death?”

This is just an example of how a sign language interpreter prepared for our lecture catered with sign language service by Kanto Koshin Etsu Chapter in Yokohama on July 26, 2015.

Requested by a group for the hearing impaired, the Chapter director Kenkichi

Yoshinari presented a lecture to about 20 elderly participants from this 140-member group on a hot, humid Sunday.

Mr. Yoshinari felt uneasy at first, as he had no prior experience lecturing in front of hearing impaired people, but he spoke for an hour and a half as he normally does, covering full explanation of the living will and the current status and efforts being made to bring the bill to legislation.

#### **Living Will reached out to the hearing impaired**

Sign language interpretation is not the only support service we provide. Four other professionals were hired by the hearing impaired group to timely type into the computer Mr. Yoshinari’s lecture which was projected onto a large screen in large print. This made it much easier for people who lost their hearing as adults to read and understand quickly.

The lecture was followed by a question and answer session. Seven people raised their hands to ask questions. Mr. Yoshinari said that he gained the same sense of pleasure and satisfaction from the reaction of this audience as usual.



Ms. Toshiko Wakabayashi (83), a JSDD member, made the comment that she often attended these forums but never could understand the content due to her difficulty in hearing. She was very appreciative of the support which allowed her to actually follow the lecture.

Mr. Yasuharu Akabane (87) commented that he was so glad to be a member of JSDD with his late wife, Ayako, when she passed away. He wanted to spread the knowledge about the living will and JSDD to all of his friends, which led them to this forum.

## ② Our newsletter's 23 year history of supporting the vision impaired

Our service to the vision impaired goes back to 1980's when Ms. Atsuko Matsune, JSDD Councilor and ex-president of Kanagawa Prefecture Braille Service, started translating our membership application into Braille.



The *Braille Everyday* newspaper announced the introduction of our membership available in Braille, which brought light to the blind who had concerns about dignified death.

At the annual meeting in 1990, a member from Kagoshima Prefecture, Ms. Shizuko Taniyama, expressed her joy by mentioning that she could finally join JSDD by registering in Braille. She and her husband had always talked about wanting to die without any life prolonging measures if something ever happened to them. They were finally able to have their peace of mind.

Our newsletter in Braille started two years later, initially a hand-made newsletter by Ms. Matsune herself. Today, we can order them from the Japan Braille Library, and 38 copies are delivered to our vision impaired members.

## [2] Issues of the elderly – concern goes beyond its generation -Death with dignity according to middle school students-

“What happens when the living will is not clear enough?”

“What is JSDD's response to people who do not support dignified death?”

These were questions Ryunosuke Takaoka (15), a Kaijo Middle School student (Shinjuku, Tokyo) asked the chapter president when he visited the regional chapter office of Kanto Koshin Etsu (Hongo, Tokyo).

### **From a pet's death**

Ryunosuke chose “dying with dignity” as his middle school graduation thesis in social studies which led him to visit JSDD's chapter office. He chose this topic from an experience he had with a tragic death of his pet cat, “Felice” (“Happy” in Italian) with whom he grew up since he was an infant. “It was so shocking. My first experience of death. Since then, I found myself

pondering what an ideal death would be for a human.” He had learned the meaning of the term “dignified death” in 4<sup>th</sup> grade as an example of self-determination.

He decided to attend the 4<sup>th</sup> Living Will Study Workshop Forum held on June 20, 2015 to learn more about dignified death. He was surprised to find that this profound concern was shared by so many old people. “What I found was that services are well provided to take care of patients and their families. What I found surprising was that even your last days of life can be spent in a fulfilling and peaceful way” (Photo – Ryunosuke and his mother).

### **Student challenges legislation by developing his own draft bill**



Ryunosuke is also planning to visit the opponent groups of the dignified death legislation for personal interviews. “I want to give more depth to my thoughts by looking into all the pros and cons for dignified death before I reach my own conviction,” the teenager says.

He has a dream of becoming a doctor. According to Mr. Nariyuki Yokoi, Ryunosuke’s social studies teacher, one of his classmates is already working on developing his own draft bill for protecting dignified death based on his visit with ALS patients. He hopes that his student’s draft will be much more flexible than the draft developed by the Diet Coalition

members.

For more than 20 years, Kaijo Middle School has given its students the assignment of a graduation thesis. About 20 students have chosen the topic of dignified death thus far. For Kanto Koshin Etsu chapter office, these visits by students are a normal occurrence.

“Deaths of grandparents or pets trigger these kids’ concern over dignified death or grow initial motivation for becoming a doctor, which lead to more concerns over matters of life and death,” explained Mr. Yokoi.

Topics such as “Care,” “Solitary death,” and “Challenges of shopping by elderly people” stand out when looking through a compilation of all graduation theses, reflecting the growing elderly society of Japan.

### **Lectures catered to school classes**

This chapter office also receives student visitors from Hibiya High School and nearby nursing schools. Requested by private schools (both middle and high school in Setagaya, Tokyo), this chapter provided them with lectures during class to teach students about dignified death. Each year, more and more students are interested in taking elective classes about dignified death.