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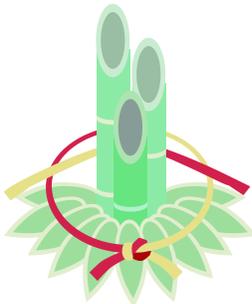
Japan Society for Dying with Dignity Newsletter No. 152, January 1, 2014

As of December 2, 2013, JSDD has 125,094 members.

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2014 Season's Greetings

By Soichiro Iwao, President of Japan Society for Dying with Dignity

Happy New Year! I wish all of you a healthy prosperous year from the bottom of my heart.

For the last several years, dealing with end-of-life issues has become one of the main social concerns. In 2011, a documentary film called "Ending Note" was released, which captured the last moments of a terminal stage cancer patient from his son's perspective. This film should have forced all viewers, not just the elderly, to think about how to approach and face the end of their lives. The shift in public views toward accepting of one's "end of life" also led to publications of one book after another capping the same title.

We have already seen many discussions taken place publicly regarding the legalization of the living will, one of which by Vice Premier Taro Aso, who slipped out what turned in to a controversial remark, "It would be horrible if I was ready to die but was administered a life prolonging measure against my will." Regardless of whether his remark will become a political issue, it is worth noting that our legislature has brought up the topic of dignified death for an open discussion.

Another significant news for us last year was the completion of the "End of Life Medical Treatment Awareness Research" and publication of its results by the Ministry of Health, Labor

and Welfare in June. Results reflect that 70% of respondents are in support of legal documentation expressing one's wishes regarding end of life medical treatments. This should lead to a statement that the majority of people recognize the need for a living will; however, why does only 3% of the respondents actually have a living will?

One of the reasons for this huge discrepancy simply may be the public's lack of knowledge about the process of preparing a living will. JSDD can do more to educate the public and help them prepare their living wills. JSDD's addition of Policy Planning & Public Affairs Division in our headquarters last year was for this purpose. Educating the public about our organization and the importance of the living will and encouraging people to plan the final stage of their lives is certainly a positive and valuable influence for everyone.

Another reason for the discrepancy may just be that people are hesitant to think about death in general; preparing a living will forces one to think about something negative--the dying process. Unlike in the pre-war era when multiple generations of family lived together, we now have people who experience death in the family for the first time when they reach their 50-60s whose parents do not even live with them. What happens to people when artificial respirators are administered at terminal stages of their lives? Why is palliative care necessary? Most people of our generation do not know the answers to these questions. Their lack of personal experiences in confronting death up close only allows them to understand the need for living will vaguely, and keeping them from taking further action.

How can we deal with this situation? I believe one of the solutions is to pass the living will act. Discussions in legislature will naturally catch media and public attention. As we saw during the process of passing the organ transplant act, it is exceptionally difficult to legalize something that deals with human life and death. As discussions deepened, a successful solution was reached to define "death" strictly for the purpose of organ transplants as "termination of brain activity" as opposed to the conventional definition of "cardiopulmonary failure."

To pursue new goals of JSDD, we founded the "Living Will Workshop of Japan" last year. Issues surrounding terminal stage or end of life cannot be resolved by the medical profession alone. The entire medical staff, nurses, counselors, care givers, social workers, patients and their families all play a part in determining what an ideal care should be for people going through the dying process.

During the first session of the workshop, we discussed topics on persistent vegetative state and senility with respect to different types of incurable and terminal illnesses.

The second session focused on dementia, a significant and invaluable topic for there is no point in discussing end of life issues without discussing this illness from which 4.6 million people suffer in Japan.

In January, JSDD will modify its homepage to improve its usefulness, as well as our Dignified Death Questionnaire and membership application forms.

Now that we have sowed the seeds, we look forward to finding out what flowers will bloom.

The 2nd Living Will Workshop of Japan topic: Dementia and Living Will



Discussions on Mental Capacity

The 2nd Living Will Workshop of Japan: Dementia and Living Will was held on November 23, 2013 in Tokyo. About 300 people including JSDD members and physicians participated, packing the conference hall with extra folding chairs. The opinions and points brought up by this group was very diverse.

During the first part of the session, people of different positions such as physicians, attorneys, and family members discussed dementia from their respective views. The second part was a debate among professionals who study behaviors of elderly people from a psychological perspective. Among the points made by and debated among the entire audience were questions such as: Are dementia patients' living wills considered genuine and legitimate? Can family members truly represent dementia patients regarding their will?

Session Part I: Importance of community involvement

The first part of the session was presided by Mr. Yutaka Suzuki, Vice President of JSDD, and Honorary President of Saitama Prefecture Social Insurance Hospital.

Known for his best seller book, "Gentle Death with Ten Conditions," as well as Vice President of JSDD, and the President of Nagao Clinic in Amagasaki City, Dr. Kazuhiro Nagao, spoke from his perspective as a small town family doctor about the importance of community involvement and compassionate healthcare professionals and family members in order for the elderly to spend the last stages of their lives comfortably and peacefully.

From the perspective of an authority, Professor of neurology, Masahiro Nomoto of Ehime University School spoke of studies that suggest that indifferent treatment of dementia patients have adverse effects on their progression. Reversely, although there is no medicine for cure, personal interactions and compassionate environment for the patients are vital to their well-being.

Mr. Takeshiro Amano, Vice President of Society for Implementing Future Social Welfare and Medical Care, shared with the audience his mother's last words on behalf of dementia patients' families:

“Dying is graceful. Dying with grace is living with grace.”

Next, from an attorney’s perspective, Ms. Hitoko Aoki, Vice President of JSDD discussed the topic, “Dementia and law: when considering dignified death.” She introduced precedents of euthanasia cases and emphasized that the individual has the sole right to make decisions regarding his or her own life. Having said that, she also pointed out the difficulty of determining whether or not an individual has the mental capacity for self-determination. Since it varies on an individual basis, each case must be thoroughly examined and decided carefully.

Finally, Dr. Soichiro Iwao, President of JSDD, and Director of the World Federation of Right to Die Societies, disclosed that the global shift is favorable toward euthanasia, and that countries around the world are also discussing how to solve issues surrounding dementia patients.

Session Part II: Heated discussions involving the audience



The second part of the session began with Dr. Nagao showing a video he had made:

Dr. Nagao: “Hi, grandma. How old are you?”

Elderly Woman: “50? Maybe 60.”

Dr. Nagao: “Do you know who I am?”

Elderly Woman: “I don’t know.” (Dr. Nagao visits her once a week to check up on her.)

Dr. Nagao: “What would you do if you couldn’t eat on your own?”

Elderly Woman: “Nothing. It doesn’t matter. Let nature take its place.”

Dr. Nagao: “How about making a hole in your stomach and be tube fed?”

Elderly Woman: “No. Don’t do anything.”

Many elderly suffering from dementia appear in the video to answer Dr. Nagao’s questions. Some are unable to express what they want, but some seem to state explicitly, “Yes, I’d like to be tube fed.” Or “No, I refuse.”

Two other professors joined Mr. Amano and Ms. Aoki from the first part of the session: Professor Shinichi Sato of Osaka University, Graduate School of Human Science Research, and Professor emeritus Koichi Nobutomo of Kyushu University.

Mr. Sato, who studies elderly behavior from a psychological perspective, made a comment from watching the video. “Since we all tend to guide dementia patients or influence their will, it is

important to take a completely different approach of interpreting their wishes from terminal cancer patients.”

Mr. Nobutomo challenged the audience with his comment: “It is perfectly normal to not know the answer or not know what to say if the topic is not something the patient is interested in. We can’t always relate it to the level of the person’s mental capacity. The main characteristic of dementia is short memory loss; the real question is whether we have enough sensitivity to detect their fear and anxiety. Maybe the key is to not look at it as solving a medical problem, but solving issues surrounding a different way of life.”

Interpreting “presumptive directive”

The main theme of this workshop session, whether a dementia patient can express his or her own living will, prompted many comments. Mr. Nobutomo opened the discussion by stating that if a dementia patient wants to express his or her own living will, there should be a meeting involving all family members. Ms. Aoki brought up the fact that she is often consulted about family members requesting to have their dementia patient become JSDD members. She stated her opinion that although it all depends on the stage of dementia, if the patient is capable of understanding the meaning of dignified death, then he or she should be able to join. Mr. Amano added, “If the person asking the question to the patient can get a thorough, reasonable response out of the patient, then yes, that person should be able to speak on the patient’s behalf.” In response, Mr. Sato stated, “Self-determination means that the person follows the rules that he or she made. The physician, the care giver, the attorney, family members must all pick up the pieces from the patient’s daily life and put them all together to draw the whole picture of what the presumptive directive of that patient really is.”

When a patient changes his or her mind after being diagnosed with dementia...

The next theme was whether family members of a dementia patient can represent a living will that had previously been prepared by the patient. Ms. Aoki stated that in all cases in which families of dementia patients requested doctors to hasten their deaths, the doctors were charged with homicide. The key point here is that self-determination must come directly from the patient.

In response, Mr. Amano brought up a situation in which there is only one sibling who can and wants to represent the patient in accordance with what the patient wanted while in good health, in which case the presumptive directive is necessary.

To counter this, Mr. Sato argued that the intent of the patient’s family is exactly that; there must be enough evidence to prove that it was in fact, the patient’s intent, not only the family’s, such as a record prepared by the patient of his or her directives for future use.

Many questions and opinions sprung from the audience as well.

“When the patient no longer has the mental capacity to make his or her own decisions, can a doctor make the decision to change the patient’s medical treatments such as termination of life prolonging measures, based on the family members’ presumptive directive?”

Ms. Aoki responded, “I believe that even if there was no record left behind, the doctor should be able to as long as they trust the family members; however, if it goes to court, it will be one’s word against another.

Another question arose from the audience, “My mother had a living will when she was in good health, but as she suffered from dementia, she started to say that she wants to live longer. What should we do?” Ms. Aoki responded to this question, “If you feel that her wish to live longer while suffering from dementia is questionable or out of her character, those comments mean nothing. However, if you feel that she really wants to live longer, she needs to renew her living will to reflect this change,” pointing out the difficulty and complexity of this problem.

Mr. Sato, who is not a member of JSDD, confessed to the audience that he had given “dignified death” a deep thought for a month leading up to this forum. He came to a conclusion that once a person reaches 50 years of age, it is that person’s responsibility to determine how to spend his or her remaining life. He asked JSDD to give every citizen a reason to think about how to live with dignity, to age with dignity and to die with dignity.

In response, Mr. Nobutomo proposed establishing a ceremony when one reaches the age of 60, or officially becomes a senior citizen, similar to the traditional ceremony when one reaches the age of 20 for becoming an adult. The ones celebrating this occasion would declare how they are going to live the rest of their lives and how they wish to die.

Discussions progressed and moved on to the topic of passing the living will act, which was not even on the original agenda.

President of the Workshop, Dr. Iwao, who is also a member of Bioethics Committee of Japan Medical Association explained some ongoing discussions within the committee. The majority consider legalization of the living will unnecessary since only 0.1% of the national population actually possesses a living will. Some argue that it is a waste of time and resources to put into law something that does not pertain to a large number of people. Dr. Iwao’s dilemma is that the legalization will prompt more people to possess living wills; however, we need more people who already possess living wills to make law.

Movement in Legislation: Liberal Democratic Party (LDP/Ruling party)

On October 23, 2013, the Liberal Democratic Party conducted a study group over the subject of “QOD: quality of death.” Led by Mr. Tsuneo Akaeda, the meeting gathered nearly 100 new legislators. Mr. Iwao made the introductory speech stating that we have been pursuing the legalization of the living will for many years and encouraging them to have a deep discussion about this in the upcoming session of legislature. Mr. Yoshitake Yokokura, President of Japan Medical Association was also present at the meeting.

In closing the meeting, Mr. Takeshi Noda, elected as one of the senior advisors on the dignified death project team, who is also the special mission chairman of the Social Security System Committee, stated that we have already begun a wide scope of discussions regarding this topic

and that we are at a point of figuring out the specific details. He showed his true commitment to the legalization process, demanding that it's time to do real decision making politics now.

On December 3, 2013, the party formed a project team to deal with dignified death issues. They elected the party's National Strategy Committee chief, Mr. Shunichi Yamaguchi, as the team chairman. Three party leaders were also elected as senior advisors: Mr. Nobutaka Machimura, Mr. Takeshi Noda, and Mr. Hidehisa Otsuji. Mr. Shunichi Suzuki became the deputy chairman, altogether 54 committee members on the project team.

At its inaugural meeting, JSDD President, Soichiro Iwao spoke on the topic of "The Elderly Society and Dignified Death," explaining that Japan is far behind other advanced countries when it came to the legalization process.

Taiwan celebrates 15th Anniversary of the "Natural Death Act"



Interview with Professor Co-Shi Chantal Chao, PhD,
Department of Nursing, Medical College, National Cheng
Kung University

Taiwan enacted the Palliative Care Act, also known as the Natural Death Act in 2000, which includes the patient's advance directive (living will) as a part of the system. Professor Cha, also a compassionate nurse, was the backbone of this successful legalization movement.

We interviewed her when she visited the JSDD headquarters on October 10, 2013 (Interpreted by Shu Chun Chien, PhD, Associate Professor, Center for Education and Research in Nursing Practice, Graduate School of Nursing, Chiba University)

Interviewer: Taiwan's Palliative Care Act is considered the first kind of Natural Death Act in Asia, but the content is not very clear from its name...

Professor Chao: Its statutory content is very similar to that of California's Natural Death Act of 1976. Ours was enacted in June 2006. In our culture, terms such as "death" or "terminal" have such a negative connotation. We would have liked to have named it Natural Death Act or Terminal Medical Treatment Decision Act, but even something as simple as agreeing on its name was one of the many hurdles we had to overcome to make this happen.

Interviewer: From your profession in research, what was the driving force that made you become so involved in the legalization movement?

Professor Chao: I am a registered nurse and studied palliative care in the United States. When I came back to Taiwan in 1993, I saw terminally ill patients with lots of tubes stuck in them because all the medical laws in Taiwan required them to be resuscitated (CPR). When a

questionnaire given to physicians came back with unexpected results, I knew that this hospital scene had to change.

6 years of personally persuading each and every legislator led to her success

Interviewer: What were the “unexpected results” you mentioned earlier?

Professor Chao: The survey was given in 1994 to 7,626 physicians, and 1,338 responded. To the question, “Would you like to be resuscitated (CPR) if you were terminally ill?” ALL doctors responded, “No.” When asked if they administered CPR to their patients, 100% responded, “Yes.” It was apparent that although none of them wanted to be administered CPR themselves, they all did it to their patients to avoid being sued by their families. I thought that there must be a law protecting them from not having to administer CPR or any other life prolonging measures when the patient doesn’t want it.

Interviewer: It took six years for legislature to pass this law. Would you share with us some of the hardship and challenges you experienced during this period?

Professor Chao: I had this photo of a terminally ill patient with 17 tubes and pipes stuck around his body. I took this photo and showed it to every single legislator, a total of 113, to make them see the reality. I also told them the results of the survey and explained the necessity of passing this law. In Taiwan, all medically related laws must be supported unanimously in order to pass. That’s why it took six years. The initial bill drafted by the legislature had to be adjusted and negotiated with the executive administration (government) so many times until all of them finally supported it. It took a long time.

Interviewer: What about public support and perception?

Professor Chao: In Taiwan, there is an old saying that if you die on a good day of the Chinese calendar, your life after will also be a good one. Sometimes, a life prolonging measure is administered so the patient can die on a good day of the calendar. To convince our people with such superstitions, it was necessary for me to make so many speeches, as many as 100 speeches in one year.

Interviewer: Were you ever opposed or threatened by any anti-campaign groups such as disabled citizens groups?

Spouse should be your primary representative in the family

Professor Chao: Not really. We received an email message from an ALS patient asking us to let them be included in this law. Unfortunately, this law only pertains to terminally ill patients.

Interviewer: How are people responding to agreeing to the patients’ decisions? Have you seen any changes in terminal care?

Professor Chao: Many religious groups (Christian and Buddhist) are promoting the effort, but there have been quite a few cases in which families did not agree with the patients’ decisions. Also, many elderly people are still unfamiliar with the law. Since 2010, Ministry of Health has

been making an effort to promote the “DNR order” (refusal of CPR) and educate people on the concept of dignified death.

Interviewer: Do families still have a strong influence on the patients’ decisions?

Professor Chao: I’m sure you have similar issues in Japan when families live far away from the patient. When the patient can’t make decisions for him or herself, the law accepts the decision of family members if they all agree. However, when there is dispute among family members in determining the patients’ wishes preventing them from reaching an agreement, the law stipulates a ranking order within the patients’ family by which one’s voice carries more than others: 1) Spouse, 2) Children or grandchildren of adult age, 3) Parents, and 4) Siblings.

Interviewer: What documents does the law recognize?

Professor Chao: There are four documents: 1) Agreement to refuse life prolonging measures, 2) Agreement to refuse CPR, 3) Medical Power of Attorney, and 4) Statement of waiver to cancel all above documents.

Interviewer: In a way, effective enforcement of this law relies on the sense of obligation and responsibility of all doctors.

Professor Chao: Absolutely. Doctors are obliged to inform patients and family members of the treatment plans and options for life prolonging measures. The contents of the agreement must be in their medical records. Doctors failing to follow these protocols face penalties.

Interviewer: In Japan, we have serious issues surrounding dementia patients, especially with tube feeding.

Professor Chao: Since advanced stage dementia patients are unable to sign agreements, laws pertaining to the problem of tube feeding has not yet been discussed. However, with the increase in number of dementia patients in Taiwan, it’s just a matter of time when we must have a discussion about this issue.

Taiwan’s Palliative Care Act Summary

- Enacted on May 23, 2000 for the purpose of honoring patient’s will and protecting patient’s rights.
- Contains 15 clauses
- A terminally ill patient, diagnosed by two physicians, can choose to die naturally by preparing an agreement (living will) to refuse any life-saving or life prolonging measures.
- A patient can designate a medical agent in advance in case he/she is incapacitated to make decisions on his/her own.
- The agreement must be submitted to the Ministry of Health, Labor and Welfare and recorded on the health insurance card to be verified at any medical facility.
- This law applies to terminally ill patients over 20 years of age with sound mental ability.
- Two witnesses must be present during preparation of the agreement.
- A family member can prepare the patient’s agreement as the agent when the patient has already been incapacitated.