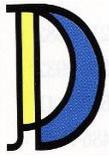


Excerpts from



Japan Society for Dying with Dignity Newsletter No. 161, April 1, 2016

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2015 Surviving Family Survey Results

Living Will honored: 90%

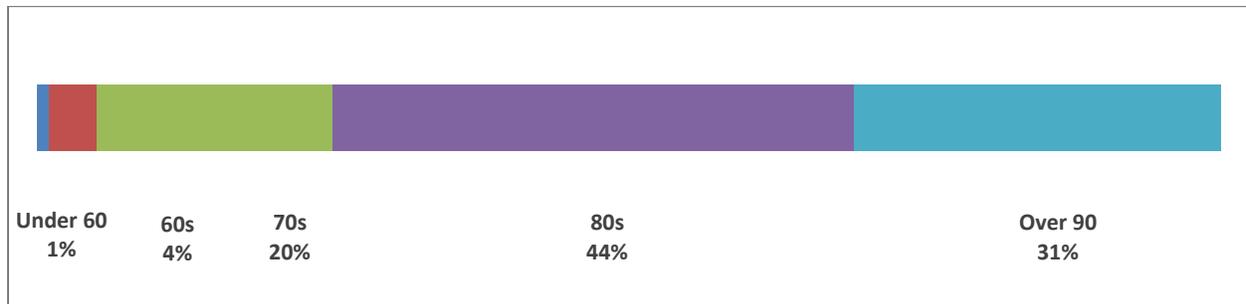
JSDD enrollment alleviates agony and suffering of family members

« When you decide how you want your end of life to be, it will not only give you a peace of mind, but also help your family in healing after your departure. »

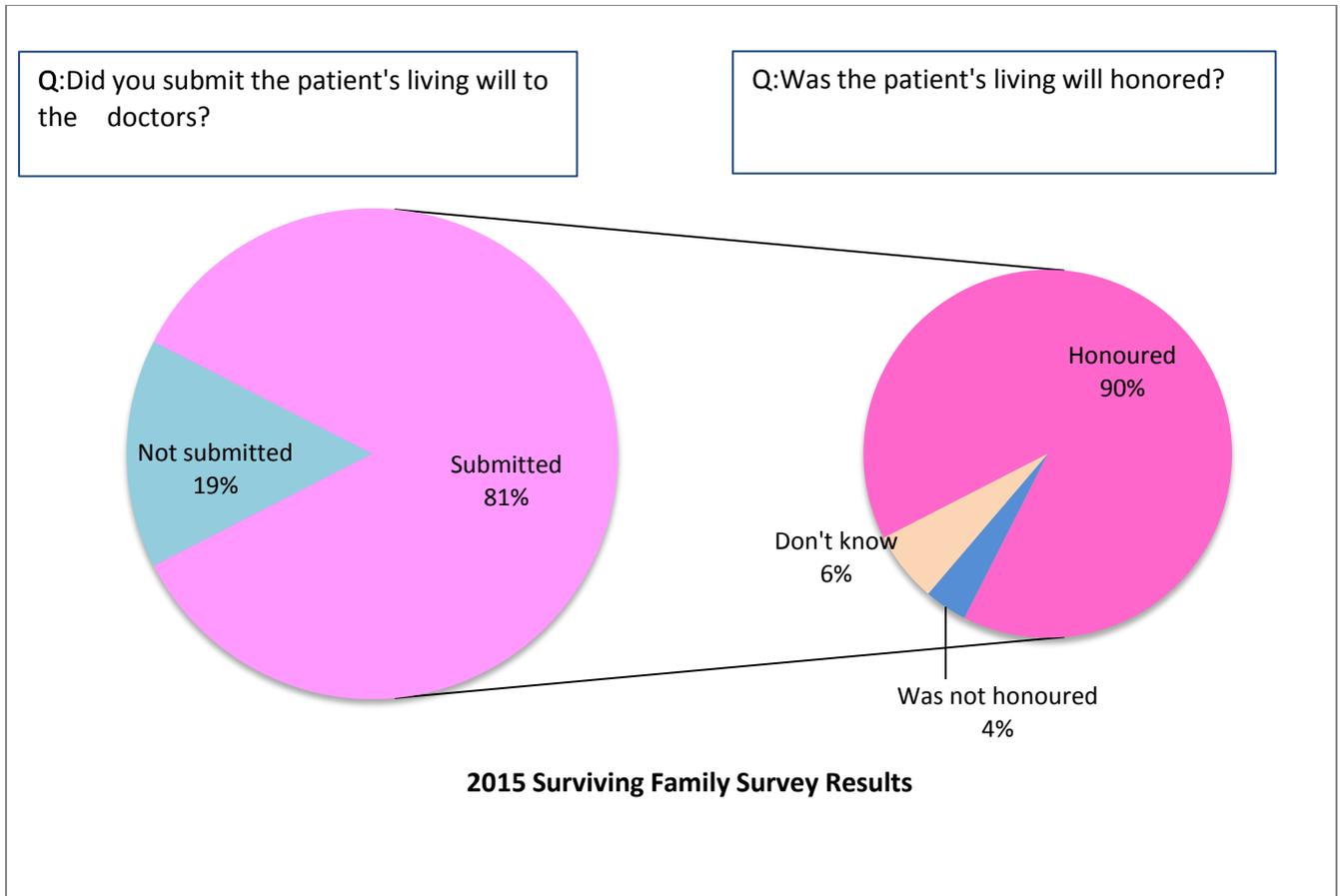
JSDD conducts an annual survey with cooperation from surviving family members to see if the members’ living wills were actually used. From the 2015 survey, 851 responses were received with similar results from that of last year.

The highest number of dying members were in their upper 80s, followed by over 90, and 70s. Location of death was topped by 63% hospital, followed by 18% home, and 14% nursing home. Of 851 respondents, 692 members had submitted their living wills to their medical providers.

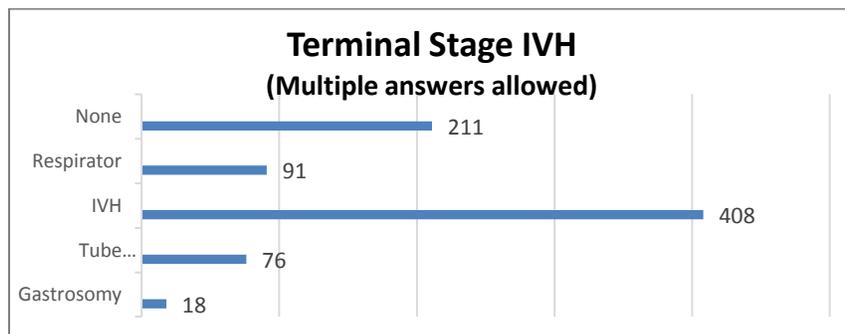
Age Comparison of Respondents



To the question, “Do you think the living will was honored?” 54% answered “Definitely yes,” which was 7 points less than the previous year. 36% answered “Somewhat yes,” 5 points more than the previous year. We concluded that a total of 90% living wills were honored in 2015, compared to 92% the previous year.



To another question, “What kind of treatment was given during the patient’s terminally-ill stage?” 211 responded “No treatments,” and 408 responded “IVH”, Intravenous Hyperalimentionation (either morphine or nutrition/water.” In addition to the IVH, other treatment answers included artificial respirator, feeding tube either central, nostril or stomach.



What should be highlighted is that there were more communication between doctors and patients and/or their families (83%) and treatments were continuous throughout the end (69%). Interestingly, of the 377 respondents who said their living wills were definitely honored, one out of ten still continued with life prolonging measures such as artificial respirator and/or intake of nose/central tube nutrition.

Here are some voices from surviving family members according to the survey:



Focusing on respecting and honoring mother's wishes brought our family together--
-by an eldest son



I have deep respect for my father who told me his thoughts about death---by an eldest daughter



My grandmother taught me a valuable lesson about dying with dignity---by a grandchild



Because my father was a JSDD member, we were able to share our journey to death together---by a daughter

- A male JSDD member (87) who had refused to receive artificial respirator and feeding tube was able to welcome a natural end of life after his physician explained it to him. “Since he was surrounded by patients with life prolonging devices, he would not have had the end of life he wished for, had he not submitted his JSDD membership card to the hospital,” stated the man’s daughter.
- “Rather than just refusing life prolonging measures verbally, my mother’s (96) JSDD membership allowed us to express her wishes without any problems or regrets. I am so glad of the outcome.”
- “My father (86) lived with artificial dialysis for a long time. Death was something very close and intimate to him, as he often told me about his living will. He died with a smile, saying “thank you.” He had no other life prolonging devices or tubes at all. He told all of his family about what he thought about his own death, for which I completely respect him from the bottom of my heart. I became a JSDD member after he died. I now have a peace of mind about my own death.”

- “I lost my father (72) to bile duct cancer. We were all so ambivalent about our wishes for him to live longer while not wishing to see him in so much pain. His JSDD membership led us onto a right path, his dying path, and allowed us to share it with him peacefully together.”
- “When it was time to face our mother’s (85) death, our whole family came together to support her. In a way, focusing on her wishes gave us all a peace of mind and played a main role in bringing us close together. It made me realize the importance of all family members being prepared by discussing death before it happens, which guides us in the right direction.” The eldest son even contacted JSDD twice for consultation, and said that our advice and service gave him great emotional relief.
- “My grandmother (87) died of lung cancer. She did not accept any invasive or physically painful medical examinations or treatments. My son and I spent the last two days with her. She had told us about her living will quite some time ago, so we knew exactly what she wanted and were able to adhere to her wishes. We learned a great lesson from her.”
- “Being her eldest daughter, I took care of my mother (94) at a nursing home towards the end of her life. She used to tell us all four children about her JSDD membership so often that we had no emotional conflicts among us when she was going through her dying process. I was so impressed and moved by her deep thoughts about her own death.”
- Another eldest daughter who took care of her mother (94) at a nursing home said, “We found such peace and compassion for our mother in giving her adequate care, spending quality time for the last time, and finally seeing her graceful departure.”
- Another daughter said of her mother (91) who was clear minded until her last moment, “We had it set up so that she was always with at least one of the family members. At one point she was having a conversation with two of her grandchildren. Her last days were spent full of love and peace.”

*Thank you for those who participated in the survey.



Taiwan passes “Patient’s Autonomy Act”

The new dignified death bill applies to mentally incapacitated patients with dementia and in persistent vegetative state as well. How is Taiwan different from Japan? -Taiwan is an advanced society with regards to legalization of dignified death. What does Taiwan envision to achieve in its future society?

In January this year, Taiwan’s legislature passed a new bill called “Patient’s Autonomy Act,” the new dignified death act, which will be enacted in three years. In 2000, Taiwan enacted its first bill related to death of terminally ill

patients called “Palliative Care Act,” based on the government’s formal advance directive regulation. Taiwan spent 16 years to pass this new bill with recorded results, which expanded its scope of coverage to terminally ill patients to include those with severe dementia and in persistent vegetative state. This is an epoch in a sense that sovereignty is placed on the rights of the patient.

Late January, one of our staff members visited the national legislative building in Taipei to interview Ms. Gyuxing Yan(41), a Member of Parliament who led the submission of this new bill to legislature.



Photo left – Legislators approached Ms. Yan to extend their congratulations on passing a bill she initiated, many Taiwan newspapers reported on December 19th 2015.

The initiator of the bill was a Member of Parliament on a wheel chair

Ms. Yan suffered from muscle dystrophy when she was 19. Assisted by a care giver, she worked hard as a Member of Parliament for the last four years, focusing her political activities on making laws to support socially vulnerable people like herself. A great credit goes to her for taking the lead for this movement of legislation while being disabled. She welcomed our staff by saying “I hope that Japan will succeed in its enactment of the law very soon. I will do whatever I can to help.” The new law aims

to honor the right of patient’s self-determination and ending one’s life with grace and dignity.

She kindly explained the details of procedures that are regulated by law. The first step is to conduct an Advance Care Preparation meeting where the patient, physicians, family members and medical agent gather to discuss such matters as acceptance or refusal of life prolonging measures, intake of nutrition/water when the patient becomes unconscious or mentally incompetent.

If the meeting reaches an optimal conclusion most beneficial to the patient, the next step is the documentation of the outcome (Advance Directive) which must be signed in front of two witnesses and the certifying physician who stamps his seal. Next, the document is electronically coded and placed into the patient’s health insurance card (IC card), which completes the technical procedure. She says that the main feature of the new bill is the expansion of targeted audience.

The bill allows people the options of withholding, refusal and withdrawal of life prolonging measures in the following five conditions:

1. Terminally ill stage
2. Unrecoverable coma
3. Persistent vegetative state
4. Severe dementia
5. Other

Conditions defining terminally ill stage was intentionally left out because physicians strongly pointed out the number of patients who are not in their terminal stage, yet undergo long term excruciating pain and suffering. This point was also supported by a general public poll at 99%.

The decision to place a patient in one of the five conditions listed above must be made by two medical specialists who agree on the diagnosis, and two consultation sessions by a palliative medical team. The Ministry of Health and Welfare plans to develop detailed regulations for enforcement of specific advance directive for each category based on guidelines and cooperation from the academic community.

Why is there such a large gap between Taiwan and Japan in terms of legislation concerning this issue?



Let's take a look at this new law from Japan's point of view. JSDD places high emphasis on patient's self-determination with regards to terminal medical care. This law does exactly that; however, the main difference is that this law clearly spells out that family members have no authority over a decision made by the patient, and their consent is not necessary. Diet Member Coalition for Legalization of Dignified Death (DMCLDD) also

drafted a bill which allows withholding and withdrawing of life prolonging measures for terminally ill patients. The Taiwanese bill has the same stipulation as one drafted by DMCLDD: immunity clause for civil, criminal and administrative liabilities. The Taiwanese bill also includes patients in persistent vegetative state as one of the five conditions. JSDD's living will includes this point except for one slight difference, "irrecoverable" instead of "persistent" vegetative state.

Let's look at emergency situations where the patient is brought in by an ambulance, one of concerns many JSDD members have voiced. As mentioned earlier, the advance directive data is encoded in the patient's health insurance card, so as long as the patient has the card in his/her possession available to rescue workers, there should be no questions whether or not life prolonging devices should be administered. Worst case, even if they mistakenly administer a life prolonging device, it can be withdrawn at any time. This patient autonomy act has an area that we (in Japan) have not covered, in the case of severe dementia. Ms. Yan says that in light of increasing number of dementia patients due to a growing elderly population, it was necessary to cover it. Mr. Lee Yu Tan, director of Taiwan Dementia Society, which is a support group for family members of dementia patients, highly evaluates this law. He says it is very important for families to send off their loved ones with grace, dignity and a natural farewell.

The last of the five conditions, "other" refers to a state or condition, rather than a specific illness, in which patients experience excruciating pain and suffering which is incurable. She had discussions with many patients with fatal diseases, such as ALS, for consideration of inclusion into the bill. Bioethics Professor of National Taiwan University School of Medicine speaks highly of this law, stating that it recognizes basic human birth right by



expanding the coverage to patients not in terminally ill stage to be able to choose their own terminal medical treatments.

Palliative Care Act (currently in effect) creates society of good endings

Palliative Care Act (enacted in 2000) will remain valid until the new Patient Autonomy Act will be enacted in 2019 since there are no conflicts between the two laws. Former director of National Taiwan University Hospital, who also helped legislating the new law, says that the title of the law may be difficult to interpret, but it is simply a natural death law which guarantees every citizen the right to refuse and/or withdraw life prolonging measures until his/her last moment in life.

In 1990, the first hospice ward was established in Ma Choi Memorial Hospital. Professor Ku Shi Chao, PhD, of Department of Nursing at National Cheng Kung University School of Medicine started and successfully spread the idea of in-home hospice care. However, they quickly found out that there was no legal basis or support for terminal medical care. A group of medical providers spent six years of tireless efforts, reaching out to legislators to gain their support before a successful legislation of Palliative Care Act finally took place.

When mentally competent adults over the age of 20 are diagnosed as incurable and terminally ill, they can decide to accept life prolonging measures, hospice care, or refuse all care. The decision will be documented as an Advance Directive, regulated by the Ministry of Health and Welfare, for submission, which is electronically added to their national health insurance cards which can be verified by any medical institution.

With a statutory revision five years ago, electronic health insurance cards became a standard, tremendously increasing the number of registrants. Presently, approximately 340,000 people are registered under the new national health insurance system, which is only 1.4% of the population. The administration for this system is Taiwan Hospice Care Society (a general incorporated association), under the Ministry of Health and Welfare. According to the director of the society (also Senior Physician at Ma Choi Memorial Hospital, Department of Psychiatry) announced that their goal is to reach 400,000 registrants by the end of 2016, targeting 3 million people in their 50-60s who are taking care of elderly parents and are highly concerned about dignified death and natural ending of life.

Photo right –an example of national health insurance card with advance directive information electronically embedded (private information such as birthday and social security number have been deleted)



Living Will situation: Comparison of US vs. Japan deepens discussion

**Diet Member Coalition holds a symposium to expedite submission of the “Living Will bill”
Many Diet members assemble at the Lower House in midst of a heated deliberation on budget plan.**



The Diet Member Coalition held a symposium on February 25th in Tokyo to deliberate on honoring patients’ will at end of life (196 members, chaired by Teruhiko Mashiko). Approximately 200 people attended including 30 Diet members and members from related groups including JSDD. In his opening remarks, Chairman Mashiko said that he wanted to take this opportunity to deepen their in-party discussions and to compile a draft bill in time for submission during the current session of legislature. Dr. Mutsuko Ohnishi,

currently residing in Boston, MA (USA), was one of the guest speakers who talked about “The state of Living Will in America.” Another guest speaker was Ms. Hiromi Tarui, director of Department of Health and Welfare, Susaka City, Nagano Prefecture, who discussed “Our town’s determination toward improved terminal medical care.”

30% of US citizens possess living wills; can be issued by municipal offices

In the U.S., each state government establishes regulations, legal procedures, and issues advance healthcare directives including living wills. The American culture is known for its emphasis on self-determination. 30% of its citizens possess living wills, majority of whom are considered to be in the higher income brackets.

Dr. Ohnishi explained that U.S. experienced series of trial and errors repetitively to get to this point. The issue of determining mental competence associated with the surge of elderly dementia population is ongoing. Since the cultures and people’s attitudes toward life and death are different between the two countries, some aspects of what the Americans have gained may not apply to the Japanese. However, terminal medical care is a very important matter in any aging society, therefore, these discussions are absolutely necessary.

Recently in Japan, some municipal offices started to issue living wills. Ms. Tarui reported how her district of 70,000 population succeeded in tackling this matter with in-home medical care still being in its promotional stage. They used this opportunity to expand the concept of in-home medical care to include end of life medical care.

In 2013, their district published a legal document for patients to choose their own end of life medical care, very much like the living will. This document consists of six items to be checked off with options for end of life medical care with a detachable card. To date, 1,800 copies have been issued. In addition, the district published and distributed several hundred copies of a

booklet entitled “Sending off your loved one with grace and dignity” intended for families and friends. Ms. Tarui has not yet compiled any statistical data from their efforts, but wishes to grow a culture in which young, active people start to think and plan for their own end of life. The intimate design of the booklet’s front cover portrays her vision of a new culture.

After the speeches by both guest speakers, a Diet member stated his opinion on how important for the patient to initiate a line of communication with family members, and his optimism for when Ms. Tarui’s activities can be mirrored by the entire medical care system nationwide. The Diet Member Coalition is now looking forward to meeting each party’s deadline to compile their own versions of the bill for submission to legislature during its current session.

2016 Frontline: Local Chapter Activities

Tokai Chapter’s Think Tank Association -Professionals discuss legalization-

Six years ago, Tokai Chapter established “Study Group for Legalizing End of Life Medical Care,” commonly known as “Think Tank Association.” The purpose of this group is to identify specific terminal medical care issues for JSDD to resolve, and apply those solutions to the enactment of our “dignified death law” once it passes legislature. Their annual meetings include participation of physicians and other medical professionals, attorneys, researchers and legislators, a total of about 50 professionals. Since its third annual meeting, the group has been combining few topics such as “Tube feeding / Dementia / Persistent Vegetative State.” During the sixth annual meeting this year on February 14, cosponsored by Aichi Prefecture Medical Association and Nagoya City Medical Association, multiple topics, “Terminal Stage and Medical Rescue / Physician’s decision vs. Patient’s wishes” were chosen.

Dr. Mitsunaga Iwata, Professor of Emergency Medicine at Fujita Health University, presented two exemplary cases from medical rescue team perspective. The first case was an ALS patient who had a heart attack but refused resuscitation. The other case was a heavy smoker who passed out, but was known to tell everyone on a regular basis, “Don’t take me to the doctor. I’d rather die happily than to have to stop smoking.” He explained honestly how difficult it is for medical emergency rescuers to make quick decisions on the spot.

The possibility of withdrawing life prolonging measures

The next speaker was Mr. Kunio Aoyama, an attorney and director of Tokai Chapter (also a retired judge of Nagoya High Court). He also talked about the same topic of medical rescue, but from a judicial point of view. He said that Japanese Association of Acute Medicine (JAAM) establishes guidelines on emergency / intensive care medicine specifically regarding terminal medical care. He also said that there seems to be a mutual understanding in the judicial community that there is no prosecution for withdrawing life prolonging measures as long as it meets the above mentioned guidelines.

After the two speeches, there was an opinion exchange session among the audience. Medical professionals such as paramedics, hospital physicians, and in-home care physicians, shared their

different perspectives and provided constructive suggestions on how they can work closer together to improve their situations. Dr. Soichiro Iwao, President of JSDD, explained about the living will issued by JSDD, and expressed his goal of spreading the simple concept of “deciding yourself what is yours” nationwide.

Tokai Chapter has another association separate from the Think Tank Association called “Study Group for Terminal Medical Care and Jurisdiction,” which comprises of physicians and attorneys and meets about six times annually. The group proclaimed the necessity of physicians and attorneys all working together to build a social system in which end of life is what the patient wishes: a legal, graceful and dignified one.