

Excerpts
From



Japan Society for Dying with Dignity Newsletter
No. 156, January 1, 2015

As of December 10, 2014, JSDD has 121,275 members.

Contents:

- Nation-wide discussions necessary regarding the commonly misinterpreted term, “dignified death” -1-
- Season’s Greetings... -3-
- Movement in Legislation -6-
- The World Federation of the Right to Die Societies (WFRDS) Chicago conference -7-
- Local chapters continue to organize The Living Will Study Workshops -8-

----- 0 ----- 0 ----- 0 -----

**Nation-wide discussions necessary
regarding the commonly misinterpreted term, “dignified death”**



We felt a bit of an anxiety when we heard of the shocking news in the middle of October about a young woman from Oregon, USA, who announced that she will be dying on November 1.

Brittany Maynard (29), who was diagnosed as terminally ill with brain cancer, ended her own life on November 1 as she declared, with medication prescribed to her by her doctor. Oregon has legalized physician’s assisted suicide (PAS) for certain terminally ill patients. This shocking news caused a global stir, including Japan.

ANRAKUSHI, a Japanese word for euthanasia (direct translation, PEACEFUL DEATH), is a crime: why?

Here are some of the November 4 headlines from some major Japanese newspapers:

- Declaration of dignified death by lethal dosage intake (Yomiuri Newspaper)
- Diagnosed with brain cancer; declared dignified death; died with lethal dosage (Japan Economy Newspaper)
- Declaration unchanged; died with dignity (Hokkaido Newspaper = Kyodo Tsushin)

It was an ongoing parade of “dignified death.”

Among many newspapers circulating in Japan, only Asahi Newspaper reported that the American woman died of ANRAKUSHI (euthanasia) in accordance with her declaration of dignified death (SONGENSHI), and explained the difference between the two terms, euthanasia (or active euthanasia) and dignified death (peaceful, merciful death). The Japanese language differentiates between active euthanasia (ANRAKUSHI) and dignified death (SONGENSHI), with the first act being considered a crime but not the latter.



NHK (National Broadcasting Corporation for Japan) also reported that she carried out ANRAKUSHI or active euthanasia.

Ms. Maynard’s death by PAS was clearly an act of euthanasia, but was reported widely as dignified death (SONGENSHI) in Japan. This brought great concerns for JSDD, which is often associated with supporting PAS rather than dignified death. We may further be associated with having supported the legalization of Euthanasia Act bills, rather than Dignified Death Act bills for many years.

Because the two terms have recently been used interchangeably by the mass media, we have been asked which is accurate, as well as come under many hostile accusations and attacks.

This confusion was simply caused by some cultural differences between Japan and the US. In the US, traditionally faced with strong opposition to euthanasia laws, Oregon Death with Dignity Act was legislated in 1997. This state legislation was enacted by Citizens’ Initiative (1994) with a 51% vote. The term, “Death with Dignity” sounds less aggressive than “euthanasia,” which may have given people a more positive perception.

When a euthanasia support group conducted a study of the two terms to be used legally, “Death with Dignity” was much more acceptable to the public than “euthanasia,” which had a negative connotation.

The state of Washington followed suit and adopted the term, “Death with Dignity,” and legalized PAS as one type of active euthanasia. SONGENSHI, directly translated as “dignified death,” is a concept which honors patients’ self-determination. The act of a patient withholding any life prolonging measures is considered acceptance of natural death in the US. Therefore, death resulted from following requirements and procedures in accordance with Oregon Death with Dignity Act is a legitimate case of death with dignity. However, reporting international news without considering cultural and judicial differences causes misunderstanding and confusion.

An opportunity to learn the differences and deepen our understanding between Japan and the US

The images we receive in newspaper headlines are very impressionable and influential. Once improper use of words or expressions are printed, misinterpreted stories are difficult to clarify

and unravel. Fortunately for us, some media have researched the cultural differences and reexamined their own reports to ensure proper and accurate reporting. The concept of SONGENSHI or dignified death, based on which the living will is developed, cannot be misinterpreted, or else fair and rightful discussions about Terminal Care are also moot. We hope that Ms. Maynard's death brought all of us a clear and broad understanding of dignified death and ultimately, the living will.

Season's Greetings...

Wishing for a society in which end of life discussions are not a taboo

By President Soichiro Iwao



The story of Brittany Maynard (29), who moved from her residence of California to the state of Oregon, which allowed PAS, and carried out her wish to die with dignity in accordance with its state law became a huge topic.

Our headquarters received many calls inquiring about this story. Some of them commented that this was not a case of SONGENSHI, but ANRAKUSHI, while others accused JSDD for not taking an aggressive action to clarify these wrongfully written reports.

The term, SONGENSHI, is used very differently in the international community. With regards to "Right to dignity," World Medical Association (WMA) Declaration of Lisbon on the Rights of the Patient states the following:

- a. The patient's dignity and right to privacy shall be respected at all times in medical care and teaching, as shall his/her culture and values.
- b. The patient is entitled to relief of his/her suffering according to the current state of knowledge.
- c. The patient is entitled to humane terminal care and to be provided with all available assistance in making dying as dignified and comfortable as possible.

Therefore, the concept of dignified death in the western world includes PAS, a type of euthanasia, for the purpose of respecting the dying patient's dignity and making dying as dignified and peaceful as possible. Oregon State's Death with Dignity Act does exactly this.

As you may know, a physician assisting in suicide is considered an accomplice to a felony, active euthanasia, and will be charged with such. We (JSDD) have aggressively worked with Diet members last year in our effort to pass a bill honoring patients' will to refuse administering of and terminating existing life prolonging measures. Some Diet members are strong opponents of this bill; however, since the case of Brittany Maynard, discussions about terminal care and end of life issues seemed to have become less of a taboo.

I wish for a year of building a social environment in which we can openly and freely discuss all matters regarding terminal care, and supports medical and judicial settings which will facilitate the completion of the legalization process and smooth execution. We ask for a strong support and cooperation from all members.

Take care of the invisible thread, a strong “bond”
By Vice President Yutaka Suzuki



Hearing the Buddhist temple bells ring on New Year’s Eve is so refreshing to us that any of our new year’s resolutions seem easily accomplished. We would just love to scream on top of our lungs all of our goals into the blue skies. At the end of last year, the Diet suddenly dissolved, and there was a change in our supporting Diet Coalition members. I hope that our bills will successfully be passed into legislation by the end of this year no matter what the cost.

During every New Year holiday, our family gets together for a reunion at my house. My grown children and close relatives, 20 in all, gather at my house since I’m the eldest son of my family, and enjoy the wonderful New Year meals specifically prepared for this happy occasion. This is a traditional event for our family by getting together to catch up and be thankful for everything that went on throughout the busy year. Together, we wish one another a prosperous year in good health.

There is something very special about families - something strong that is not even found in friendships, another strong relationship between people. Am I the only one who feels this strong bond generated by sharing the same blood and genes? Humans, like other animals, also have some strong instinctive traits that tie us together, make us share with one another, and help one another – our invisible thread. Some of these instinctive traits are an important part of our culture, which we must cherish and carry into the future generations.

As our society changes and the concept of “nuclear family” fades, our children are more independent with their careers and live apart from their families. Despite the physical distances, I hope that they remember the strong bond called family – the invisible bond.

Self-determination of the patient addressed in the living will should not ignore the feelings of family members who will be left in this world. Your life is not only yours. As a physician, I have always believed that when I can’t save a patient’s life, I must save the patient’s and his/her family’s hearts. I felt it was my duty to pass on these thoughts with my fellow physicians.

Patient Friendly, Good Medicine – “Morphie” the Morphine
By Vice President Hitoko Aoki



Morphie is a character in the book titled “Your Pain will be Alleviated,” with subtitles, “Morphine – the King of Painkillers” and “For Life with Dignity.” Upon our (JSDD) request, the book is scheduled for publication in February by Chunichi Newspaper in Nagoya. Morphie’s mother is “Fuuwari,” a very kind and gentle character who portrays palliative care.

The opportunity to introduce these characters came when JSDD Vice President Aoki met Dr. Keiko Kato of Tohoku Chapter last fall. With both of their support and guidance, Morphie’s main goal is to unravel any misconceptions people may have about morphine. Misconceptions typically stem from a long history of morphine being perceived as a dangerously addictive medicine that should only be used for terminal cancer patients.

Dr. Kato, who has specialized in pain management for a long time, explains that morphine works well not only for cancer patients, but also for patients with other diseases and disorders. Dr. Tadashi Watanabe, Director of Tokai Chapter and a specialist in palliative care, also talks about the role of morphine as regulating some physical conditions in the body, in addition to alleviating pain. Dr. Mitsunori Nishikawa of National Center for Geriatrics and Gerontology in Aichi Prefecture says that the medicine is available as part of in-home palliative care. Furthermore, Mr. Yasunori Iwata, a journalist for Kyodo Tsushin, reports that there is even a government policy by the Ministry of Health, Labor and Welfare specifically with regards to the use of morphine.



JSDD’s living will clause #2 is where we ask you to provide specifically the kind of palliative care you would like to receive within the realm of current medicine. Please trust Morphie; he is a good, patient friendly medicine.

Dementia and the Living Will: Japan’s Direction...
By Vice President Kazuhiro Nagao



In September, I attended the World Federation of Right to Die Societies conference in Chicago with President Soichiro Iwao. I made a speech about how in Japan, the living will is still not a legal document, but people can die peacefully in their homes. Among all the advanced countries, Japan is very unique in that it provides in-home hospice-like service, making it possible for people to die peacefully in the comfort of their own homes.

Two years ago when I attended the conference in Zurich, Switzerland, I visited a house operated by Dignitas, a Swiss group helping those with terminal illnesses and severe physical and mental illnesses to die, assisted by qualified doctors and nurses. Patients diagnosed with terminal illnesses in countries such as England and Germany, where PAS is not legal, visit Zurich with families and friends to go through a process of medical tests. If the patient is diagnosed by qualified doctors to be terminally ill (less than 6 months to live), he/she can be prescribed a lethal dosage of medicine to be administered by the patient once he/she moves into this house.

When I first saw this house, my immediate impression was, “This is too much! We don’t need this in Japan.” People can have dignified, peaceful deaths at home in Japan. We can die at home laughing, eating and living with our families until the last moment. In the western world, this practice is unknown; therefore, they must spend a lot of resources to pursue active euthanasia.

What surprised me this time in Chicago was that in the Netherlands where active euthanasia is legal, there is an increasing number of dementia patients pursuing euthanasia, not only terminal cancer patients. Every human being has the right to self-determination. When we can no longer recognize ourselves due to dementia, do we lose that right as human beings?

In Japan, there is a program called “Community Total Care System,” with the goal of making sure that dementia patients can stay in the same community where they enjoyed their lives and what they call home. Japan has become “Galapagos-ized” in that our physical isolation is generating different and independent evolution in terms of end-of-life care development, which I hope is a positive trend.

What happens to one’s living will when he/she is diagnosed with dementia? This simple question is being studied and discussed now. I personally believe that the living will should be valid to a certain level. Last year, I published two books: “Grandma, if you don’t choose the right nursing home, your dementia will get worse” and “Family members of dementia patients, don’t fight it!” If you’re interested, please read them.

Movement in Legislation

Chairman of Diet Coalition Party Members, Mashiko, pledges the bills will be passed. **Special attendance at the Tohoku Chapter, Sendai meeting**



Mr. Teruhiko Mashiko, the chairman of the Diet Member Coalition for Dying with Dignity, attended the Tohoku Chapter Forum on November 8. He expressed his firm determination for each political party to reach a unanimous resolution, and to submit the bills honoring patient’s self-determination to legislature.

Over 150 participants gathered around Sendai Park where the forum

was held to discuss the topic, “Nearing an age of ‘super’ old people and lots of deaths – Are you prepared?”

The two guest speakers were Dr. Michiya Ito, Lecturer at Tohoku University Graduate School of Medical Studies and Dr. Toshihiko Ijima, former President of Akita University School of Medicine and psychiatrist. They followed Mr. Mashiko who reported the current status of the bills. He stated that the parties have not individually reached unanimous resolutions yet, but ensured that best efforts are being made to get their resolutions as quickly as possible and to present the bills to legislature by the end of January for the upcoming session. He said there will be a full discussion on this topic and will avoid reaching any hasty conclusions.

He briefly commented on the highly publicized case of Ms. Maynard by saying that this was clearly a case of active euthanasia, or ANRAKUSHI, not SONGENSHI. He said that the use of these two terms have caused a lot of confusion, and that there is even a discussion of changing the name of the coalition to reflect its mission more accurately and correctly.

The coalition currently consists of 183 members (129 from the Lower House and 54 from the Upper House). A turnover of some members after the Lower House dissolution in November is expected.

The World Federation of the Right to Die Societies (WFRDS) Chicago conference

President Iwao reported the current status of our legislative movement



The 20th conference was held in Chicago on September 17-21, 2014. The WFRDS consists of 24 countries and 53 societies. President Iwao and Vice President Nagao attended and represented the JSDD, announcing the current situation and trend in Japan to the rest of the world.

There were many topics discussed at this conference, but the most common theme in all countries seemed to be issues surrounding dementia patients, specifically, how to protect the dignity of patients who suffer from dementia including Alzheimer Disease in their terminal care settings.

President Iwao’s speech was titled “Legalizing the living will in Japan’s elderly society.” He explained that only 0.1% of the Japanese population has a living will and is a member of JSDD. Even though one out of eight people in Japan is over the age of 75, it is still considered taboo to openly talk about death. He discussed the difficulties and struggle we faced in campaigning the legalization of



the living will.

In-home terminal care and peaceful death are part of Japanese culture
- Vice President Nagao



Vice President Nagao spoke of Japan’s National Health Insurance System, and that the concept of in-home terminal care and palliative care is growing rapidly. This idea of dying peacefully at home is most fitting to the Japanese culture, he explained with a video of in-home terminal care operated by his own clinic in Amagasaki City, Hyogo Prefecture.

An election of new board members was conducted, and Ron Plummer of Great Britain was elected as the new Chairman. Our president, Dr. Iwao remained as the board director. The WFRDS headquarters will be moving from the US to Geneva, Switzerland.

Local chapters continue to organize The Living Will Study Workshops

Patients, families, health and welfare workers all join in

The living will study workshop was founded not only for physicians, patients and their families, but also to involve workers from every field of terminal care who share the same interests to improve our care for terminally ill patients (see below chart). The idea is to expand the involvement of more people to solve issues dealing with terminal care, for which the tendency is to place the responsibility only on doctors and patients themselves.



The 3rd Living Will Study Workshop held in Tokyo triggered many local forums guided by local chapters of JSDD. There will be many more scheduled for this year. Below is our progress report since the foundation of this workshop.

Local forums held to date:

Local Chapter	Date	Location	Topic	#Participants
Hokkaido (1 st)	10/30/2013	Sapporo	Dementia, care and death with dignity	300
Hokkaido (2 nd)	10/31/2014	Sapporo	Dementia and death with dignity; dementia and living will	160
Tohoku	3/16/2014	Sendai	Can we all achieve our wish of sudden and easy death?	180
Tokai	9/14/2014	Nagoya	In search of peaceful and happy ending for patients	160

Hokuriku	10/18/2014	Kanazawa	Will the patients' wishes come true?	70
Shikoku	11/9/2014	Matsuyama	Dementia and cancer treatments	120
Kyushu	11/1/2014	Fukuoka	Why it is difficult to honor patients' wishes	220

<Don't just talk the talk; don't let it go in one ear and out the other...>

The purpose of this workshop is to bring up all the issues the patients have and to discuss and find solutions together by avoiding a typical symposium situation where the panelists speak and the audience just listens, resulting in nothing. During the Tokai Chapter workshop, the mediator frequently threw questions back at the audience after each point was addressed by a panelist, and ensured that the audience answered the questions directly without going off on tangents. One of the physician panelists commented that he was very impressed and pleased with the interactive discussions he had with the audience.

<Concerns over dementia>



In an elderly society like Japan, dementia is one of the major concerns surrounding terminal medical care. It was the main topic of the workshops in Hokkaido and Shikoku, and a part of hot discussions in many other districts' workshops. An unusual workshop topic was "Achieving our wish of sudden and easy death" by Tohoku District Chapter. Historically, people have always wanted to have sudden, unexpected, easy and quick death. Today, this still runs into the problem of dealing with a lack of mental capacity. There will need to be a

designated agent in this case, which was proposed at the local workshops.

<Spread the word to your care worker groups and other small worker groups>

Getting enough participants to attend workshops is a concern for all local chapters. Kyushu District Chapter handed out leaflets prior to their workshop to comprehensive support centers in an attempt to attract general residents' attendance, without much success. Consequently, it focused on appealing to care worker and social worker groups directly. As a result, 28% of the workers attended from those groups, implying their strong interest.



Hokkaido District Chapter enjoyed the attendance of 300 people at their first workshop; however, their attendance dropped to about half at their second workshop. It used a different approach throughout the year by sending emails to 180 people directly in addition to JSDD members – a small success story.