



Excerpts
From
Japan Society for Dying with Dignity Newsletter
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As of June 10, 2013, JSDD has 125,655 members.

Contents:

- **Celebrating the 150th Commemorative Issue - 1 -**
- **The Inaugural Living Will Workshop of Japan - 3 -**
 - **The First Session: Communicating with her Eye Blinks- Six Years of Pondering the Meaning of Dignified Death by Mr. Yukio Matsuo - 4 -**
 - **The Second Session : Symposium Held by Authors of New Release Book,” Dying with Dignity Is My Choice” - 5 -**
- **“Dying with Dignity is My Choice” Book Commemoration in Nagoya - 7 -**
- **Movement in Legislation: Diet Member Coalition for Dying with Dignity - 7 -**
- **Medical Consultation: Lack of Understanding and Misunderstanding about the Living Will -8-**

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Celebrating the 150th Commemorative Issue

We celebrate the 150th commemorative issue of the JSDD quarterly newsletter, which has been providing vital information to its members continuously and forming a strong bond between the organization and its members since its beginning in 1976. There have been many changes in the medical field, especially regarding terminal care and public awareness. Even the change in this newsletter’s title reflects that we have moved on to a new era of time. The 150 newsletters only pile up to 20cm, but it packs the long and hard history of our movement with Dying with Dignity.

Here are some significant episodes from the history of the newsletter:

The First Issue Proudly Declares, “Japan Joined Other Civilized Countries...”

The first issue of “Euthanasia Newsletter” on March 10, 1976 was printed on B5 size paper and was 8 pages long. Dr. Tenrei Ohta, the president at the time, made a statement that there were only two other countries with Society of Euthanasia, the United Kingdom and the United States. Japan, being the third country, formed Japan Society of Euthanasia in January 1976 with only 150 members. The size was small, but its statements were grandeur.

The Newsletter Title Changed to “Death with Dignity”

Several years after its first print, the number of members was still at several thousand. In October 1983, the name of the organization was changed to “Japan Society for Dying with

Dignity” in order to avoid the misconception that it was a euthanasia support group. From #31 issue of the newsletter, the title was changed to “Dying with Dignity Newsletter.” In its early days, many doctors, lawyers and researchers who supported the organization reported their researches and studies in this forum. There were also many controversialists among its members.

A New Era of Honoring the Living Will

In the spring of 1990, the #57 issue, the title of the newsletter abruptly changed to “Living Will.” There is no record of why it was changed; however, it is possible that this was an effort to spread the new term, “dying with dignity,” when it was approved by the Japan Medical Association earlier in the same year.

More people started to consider the kinds of medical care they would like in their terminal stages, and JSDD’s membership reached 10,000. The term, “living will” also became more widely known, which may be why the title was also changed to “Living Will.” Twelve out of 20 pages of this issue covered an exclusive report by the Japan Medical Association and a special report on the historical paradigm shift in Japan’s medical community.

Increase in Membership: Newsletter Becomes More Personalized with Photos

Three years later, the cover of the #72 issue (late 1993) was a photo capturing an overcrowded JSDD annual general meeting with a subtitle, “membership reached over 60,000!” The newsletter expanded to 24 pages with an introduction of a new “readers’ column” in which the members could freely exchange their comments and opinions. In the #88 issue (1997), a cartoonist Mr. Yuji Nishizawa began a series of one frame cartoon with an old man as the main character, to cater to the increasing population of elderly members.

100th Issue: Business as Usual

The December 2000 issue became the 100th commemorative issue, with Mr. Michiko Yoshinaga, a journalist who has since become an advisor to JSDD, including some illustrations and advices on terminal care by members and guest columnists. It recognized that it was the 100th issue but with no bells and whistles; it was business as usual. There was a new coverage on global information, a story covering a seminar by Tokyo University at JSDD headquarters, a list of physicians honoring patients with living wills, members’ column, and a reminder of annual membership fee payment. Most of these columns are continued to this day in the 150th issue.

150 issues of the Newsletter are Valuable Resources for Study

When piled together, it only stands up to 20cm high, but it is a pile of treasure, not only for the dying with dignity movement but also for terminal care studies. There are no national archives of terminal care, especially of the old days. We have been providing support to researchers and students who request information on the topic for their researches and dissertations.

- 1976 Inauguration of the Euthanasia Society in Japan
- 1977 Enactment of California Natural Death Act
- 1983 Society changes its name to Japan Society for Dying with Dignity

- 1987 World Medical Association denies positive euthanasia
- 1990 Japan Medical Association approves the term “dying with dignity”
Newsletter title changes to “Living Will”
- 1991 Euthanasia case at Tokai University Hospital
- 1997 Enactment of Organ Transplant Law
- 2002 Membership reaches 100,000
- 2005 Inauguration of Diet Member Coalition legalizing dying with dignity
- 2010 JSDD acquires legal corporation status

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The Inaugural Living Will Workshop of Japan



On June 9, 2013, JSDD held its inaugural Living Will Workshop of Japan in Tokyo with the objective of providing healthcare professionals and patients an opportunity to discuss terminal stage and proper preparation of a living will from both perspectives. The workshop will become the primary forum where healthcare professionals and patients can openly discuss and resolve academic issues as well as issues surrounding the suffering and emotional pain of patients and their families alike. It will pursue some unresolved issues such as finalizing the definitions of “incurable illness” and “terminal stage” through the living will, which becomes the premise for dying with dignity.

The first session of Living Will Workshop of Japan was held in the auditorium at the National Graduate Institute for Policy Studies in Roppongi, Tokyo. During the meeting held in the morning prior to the Workshop, Dr. Soichiro Iwao, President of JSDD was elected as the Chairman, and Dr. Kazuhiro Nagao, Vice President of JSDD as the Deputy Chairman of the Workshop. The Workshop was originally proposed by Dr. Iwao last year when he was elected as the JSDD President. He felt that the controversial discussion of defining “incurable illness” and “terminal stage” of life had been kept within the academic circle and saw the need to include patients’ views into the discussion, which will be the main objective of this Workshop.

Bilateral Approach from Healthcare Professionals and Patients

When it comes to making decisions regarding “terminal stage” of life, something most patients and their families face for the first time with no knowledge or experience, their decisions are mainly based on their views on life as well as their own life experiences. The Workshop is expected to reveal that “terminal stage” of life takes on many different forms, as healthcare professionals and patients discuss their respective views on the subject. Consequently, these discussions will likely lead to formalizing the ultimate role of one’s living will.

Among the participants of this workshop were over 200 people including JSDD members from nationwide and physicians with interest and understanding of death with dignity. Although the Workshop will conduct its operations at JSDD Headquarters, Dr. Iwao stated that he expects it to operate independently and openly without being constrained by JSDD policies. The Workshop will hold a few sessions every year and share their progress and information through publication of its own newsletters.

The First Session: Communicating with her Eye Blinks- Six Years of Pondering the Meaning of Dignified Death by Mr. Yukio Matsuo



The first half of the workshop was a speech by guest speaker, Mr. Yukio Matsuo, a JSDD member from Toyama Prefecture. He spoke for about an hour about death with dignity, as he shared his six year experience with a quadriplegic wife who nearly lost her life from a car accident. Mr. Matsuo informed the audience of his knowledge about the living will in the United States, where he resided for many years. He explained that in the United States, another legal document called the Healthcare Proxy, commonly known as Medical Power of Attorney, encompasses the living will as a set package, and pointed out the

lack of this other document which should accompany a living will in Japan. Summary of his speech is as follows;

Summary of Speech

Returning to Japan after living in New York for 20 years, Mrs. Matsuo encountered a horrific car accident six years ago which left her entirely paralyzed. The strong bond and love shared by this couple through communication only with her eye blinks were captured in a book called “Makiko no Kotodama (“Message from Makiko’s Soul”)” by Ms. Mika Yanagihara published by Kodansha. As he talked about how he dealt with her repeated messages to him, “I want to die” and “Please kill me,” for the last six years, Mr. Matsuo sought with the audience the true meaning of dignified death.

“We lived in New York for 20 years before returning to our hometown, Toyama, in October 2001. My wife, Makiko’s car was hit head on by a car coming from the opposite lane in July 2006. She was in a coma for two weeks before she regained her consciousness and finding herself completely paralyzed from the neck down, not just her limbs. She cannot live without her life prolonging measures: a respirator, a feeding tube and a diaphragm pacemaker. When she cried, her tears did not come out of her eyes, but they flooded out of her mouth.

The only movement she could make was to blink her eyes. Communication aids are designed for patients who can push a button with any part of their bodies. One day, it came to me that she could blink to signal me to push the button; she didn’t have to push the button herself. The first time we tried it, her words were as follows: “Please kill me.” Two years and nine months had passed since her accident. Since then,

she has repeated to me many times, “I want to die.” I started recording every word she constructed in a notebook I named “Message from Makiko’s Soul.”

I had been living in New York for about ten years when I first learned about the living will. I went to a lawyer’s office to prepare my last will, when I was told to prepare a living will at the same time. In a country like the United States where medical cost is outrageous, administration of life prolonging measures would leave me and my family bankrupt. This is why about 41% of Americans have a living will.

There is another legal document called healthcare proxy, which encompasses the living will as a set. My proxy says that if I ever lose my mental capacity to make a sound decision, my wife will make the decision for me. If she is incapable, my daughter will, and so forth. This set of legal documents is so practical, effective and functional that I don’t know why Japan doesn’t come up with the same thing.

Recently, I realized that the term, “dignified death,” is used universally, but its meaning is slightly different. In Japanese, it is close to “natural death,” but in English, it can be natural or assisted death.

I hear that the bill submitted to legislature, seeking to legalize the living will and ultimately dignified death, has received many criticisms because all it does is to exempt physicians from legal liability. In the state of New Mexico, the legal liability clause of the Uniform Healthcare Decisions Act stipulates that not only are physicians exempt from legal liability by honoring a patient’s living will, they are also legally liable if they do not honor it. The patient’s self-determination right supersedes all other civil rights. I question why our bill doesn’t include this clause. How would the patient’s self-determination right be protected otherwise?

In the United States, there is yet another tool: the Physician’s Order for Life Sustaining Treatment (POLST), a document that a patient’s physician prepares to notify other healthcare professionals about the patient’s wishes regarding life sustaining treatments at the end of his or her life.

In conclusion, I would like to recite a poem composed by a pioneer Japanese Buddhist “Saint Shinran.” (Note: Shinran was a Japanese Buddhist monk and clergy who protested the trend of Japanese Buddhism in the 13th century. Monks, like Priests, could not marry and was held to a different set of standards. He felt that in order to truly understand people’s problems and sufferings, a clergy should live like the rest, and became the first married monk in Japan, starting his own sect of Buddhism.)

“Don’t assume that you will enjoy the beauty of cherry blossoms tomorrow, for a storm may come and blow them away in the middle of the night.”

The Second Session : Symposium Held by Authors of New Release Book,” Dying with Dignity Is My Choice”

The latter half of the symposium was a panel discussion by the authors of a new book titled “Dying with Dignity is My Choice,” published with efforts by JSDD Tokai Chapter. The main topic of their discussion was regarding the definition of “terminal stage” of life which may be slightly different depending on one’s type of illness.

Dr. Nagao mediated the symposium with five coauthors of the book, “Dying with Dignity is My Choice.” They each spoke for about 15 minutes on how they define “incurable illness” and “terminal stage” in their respective fields.



Dr. Mitsunaga Iwata: Associate Professor, Fujita Health University Hospital, Emergency medicine Dept.

Dr. Shigeki Kuzuhara: Professor, Suzuka University of Medical Science

Dr. Hisayuki Miura: General Manager, In-Home Medical Care Department, National Center for Geriatrics and Gerontology

Dr. Yuzo Watanabe: Chairman, Kasugai City Hospital

Dr. Reiko Nanba: Chairman, Nanba Neurology Clinic

Lively Participation Brings up Many Important Issues

There were many questions from the audience. The director of Oncology Center at a university hospital commented, “At our hospital, my impression is that the level of awareness regarding the living will is not very high among the physicians. There are not enough educational programs to gain any knowledge about the concept of the living will either during or after medical school.” Someone from the audience asked the panel, “What do you think about providing educational programs for doctors?” to which Dr. Watanabe, chairman of another hospital who specializes in clinical training said that he was surprised to learn that there is a huge gap between his generation and the young generation in terms of awareness. He brought up the following example. “Most of the DNAR (Do Not Attempt to Resuscitate) forms I have encountered were missing some basic information such as which family members confirmed or under what circumstances this was discussed with family members. This is an important topic that must be included prior to graduating medical school.”

Dr. Nagao, mediating the panel, asked Dr. Watanabe what his plans were to implement this type of education in his hospital. Dr. Watanabe replied that clinical ethics is the new course he included in his hospital medical school since this year, which will be offered to not only medical students, but also dental students, nursing students, and dental hygienists. He stated, “Clearly, I see the difference among the students in their attitudes towards medical care. Even the doctors are affected positively by this program.”

There were many questions from JSDD members as well. One asked the question, “At some point, lifesaving measures are switched to life prolonging measures; some patients want to refuse life prolonging measures, but the patients’ wishes are not fulfilled on many occasions. Is it because there is no legislature to allow it?”

In response, Dr. Iwata answered, “Technically, you can refuse life prolonging measures at the point of administering them; however, once it is administered, physicians hesitate to terminate them regardless of the legality of this matter because of his or her obligation as a physician to save lives, not end them. It’s a lot easier to stop providing higher doses of medication or to stop increasing the setting of a respirator.”

Dr. Nagao, mediator of the panel, brought up the fact the many people are confused about the difference between emergency lifesaving treatment and life prolonging treatment. It is the life prolonging treatment that is pursued in the legislature, and to make the change is very difficult. He gave an example of a well-known musician who passed away last year after 107 days in the hospital. When asked, the majority of doctors who were in the emergency room and played a part in his brain surgery said that the patient was under lifesaving treatment for the entire 107 days. The delicate difference between lifesaving and life prolonging treatments led to further discussion. Dr. Iwata said that the standard medical treatment procedure for a patient in a coma brought to his emergency room is to hook up the patient to a ventilator to go through CT scanning, then if the patient has a cerebral hemorrhage and unable to undergo surgery, any treatment given after that point is considered life prolonging treatment.

“To cease the use of a respirator under circumstances which fulfill certain conditions is legally acceptable; however, the reality is that some family members would sue the physician or the hospital so the doctors are particularly hesitant to do that unless their action is legally endorsed,” said Dr. Nanba.

Another member showed his anger, “How is it possible to administer a respirator or a feeding tube without having the consent of the patient? The patients’ wishes are not honored by healthcare providers in Japan!”

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“Dying with Dignity is My Choice” Book Commemoration in Nagoya

On April 28, 2013, about 120 people came to the commemoration of the newly released book, “Dying with Dignity is My Choice.” Dr. Iwao, President of JSDD, announced to the audience that the book is such a success that only one month after its release, a second printing was necessary. One of the guest speakers, Dr. Yamamoto, Vice President of Aichi Prefecture Medical Association, congratulated the authors on their success of the book. Of the ten authors, two of them made a short speech. One of the authors was Dr. Miura, an expert on dementia, and the other was Dr. Kuzuhara on irreversible persistent vegetative state. The book initially printed 5,000 copies on April 1, and 5,000 more copies were printed by the end of the month.

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Movement in Legislation: Diet Member Coalition for Dying with Dignity

First Meeting since Change of Leading Political Party: Second Bill Favored by DMCDD

A general meeting for the Diet Member Coalition for Dying with Dignity was held on April 23, the first since the change of the leading political party and was attended by 24 congressmen. Mr. Ishikawa was elected as the new Secretary General, as Ms. Abe was appointed as Undersecretary of Foreign Ministry.

The major topic of this meeting was on the two bills regarding the living will. The first bill addresses only the administration of life prolonging measures, whereas the second bill also deals with the termination of life prolonging measures already in place. The majority of the audience supported the second bill, some voicing their opinion that passive euthanasia including palliative care is already in practice in medical settings and that legal exemption from liabilities for physicians who honor the patients' wishes is absolutely necessary.

There was a concerned voice from new members that the definition of "terminal stage" is unclear and that they must have more discussions which are more specific and understandable. Such rudimentary statements demonstrate the difficulty of continually discussing a complex topic such as this in a rapidly changing political climate.

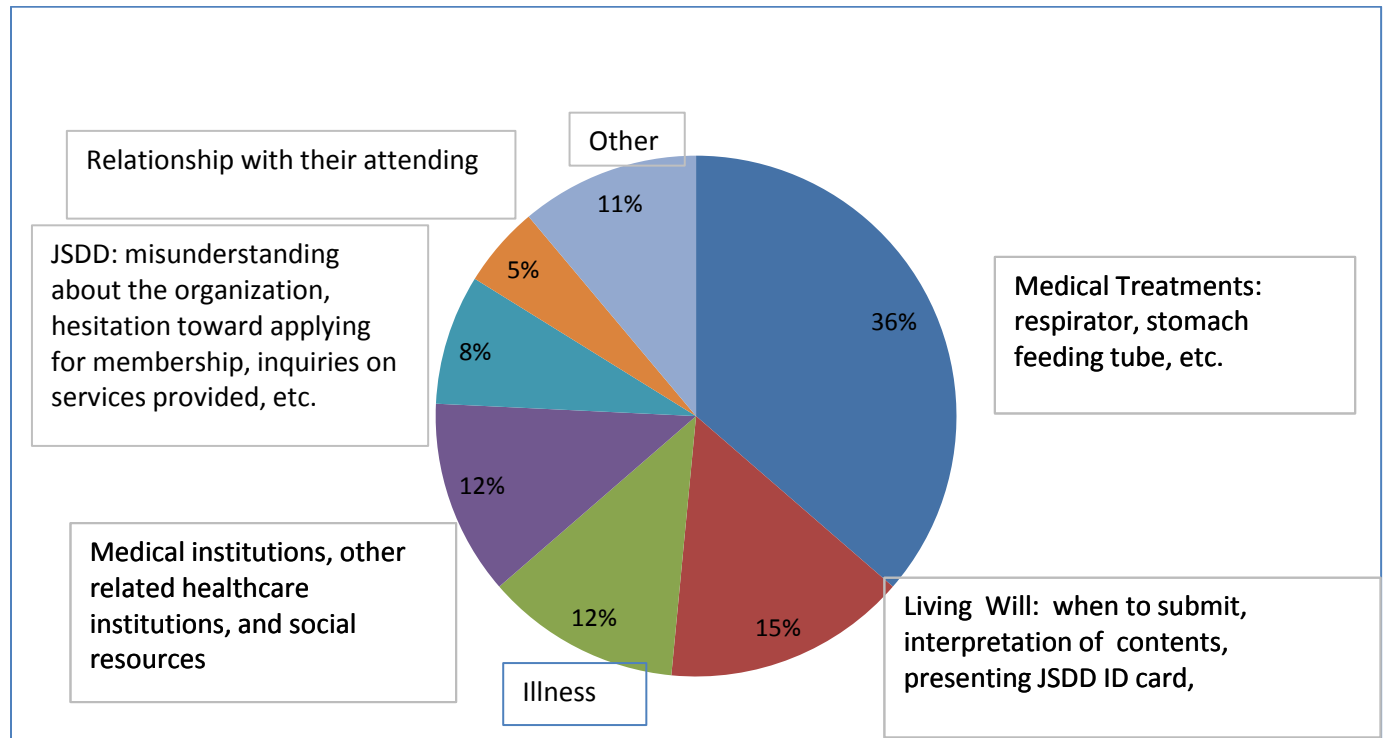
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Medical Consultation: Lack of Understanding and Misunderstanding about the Living Will

2012 Telephonic Medical Consultation Results Compiled

The compilation of medical consultation phone calls during 2012 was finally completed. There were a total of 374 phone calls; however, since some covered more than one topic, there were 532 topics total. The gender ratio was 72% women and 28% men, a much larger number of calls by women. Content based analysis indicated that 189 cases (36%) were regarding medical treatments, of which 70 cases (13%) were about life prolonging treatments, specifically about feeding tubes, followed by 50 cases (9%) on illnesses and treatments, and 43 cases (8%) on dignified death.

[Graphical Illustration of Medical Consultation Topics]



Lack of Trust in Their Physicians

In many cases, family members relayed the patients' wishes of allowing them to die naturally if they became unable to eat on their own to their physicians; however, the physicians declined. Our consultants responded by asking for more information about the patients' conditions, the exact diagnosis the doctors made, then gave them accurate information about feeding tubes including pros and cons, as well as how to communicate with their physicians.

In some cases, family members simply misunderstood the physicians' explanations, while in other cases the problem was in the relationship with their physicians. Some were afraid to ask their doctors any questions because "he may get mad" or "he seemed too busy to listen to me," indicating that they felt intimidated by them or did not trust them.

There were 81 cases dealing with the living will, of which 33 were inquiries about the interpretation of the content, 27 were regarding the timing of submitting their living wills, and seven cases were misconceptions about euthanasia. What came to our attention was the number of people who had prepared their living wills but did not understand their contents. For example, one man said "I've lived a long, fulfilling life. I don't have any goals in life. I don't want to become a burden on anyone, so please let me die quickly. I have my membership card, so would you let me die?" There seemed to be a lot of confusion about a living will and dignified death versus euthanasia. Many over 80 years of age with no families felt there was nothing else to live for and wanted to die quickly and comfortably.

Confusion Leading to Anxiety and Insecurity

There were 65 cases in which people asked for assistance in finding the next hospital or in-home care doctor because they were being forced to move out of their current hospitals. Of the 65 cases, 36 cases were requests to find them a new doctor. Many people felt abandoned by their healthcare institutions and were desperate to find a new home for their loved ones.

The majority of the callers chose JSDD medical consultation line as a last resort because they were anxious, insecure and confused, and did not have anyone else to talk to for advice. Unfortunately, since our consultants are not medical professionals, they are not in the position to provide any medical advice or answer any medical specific questions. Our consultants stated that there is a need for immediate access to doctors who can provide them with information in imminent situations. (Consultation contents that are private in nature are confidential and are strictly observed in this office.)