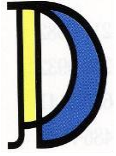


Excerpts
From



**Japan Society for Dying with Dignity Newsletter
No. 157, April 1, 2015**

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**Japan Society for Dying with Dignity starts as a general incorporated
foundation
No changes to living wills or membership**

Since April 1, 2015, JSDD started operating as a general incorporated foundation. Processing living wills, membership registration, custody, management, educational and promotional activities will all be transferred to the new General Incorporated Foundation. The declaration of living will and membership card currently held by each member will remain unchanged for continued use.

In April 2010, JSDD became a General Incorporated Association on corporate status. With expectation of all members actively involved in corporate activities, regional chapter representatives were elected by general voting. However, they realized later that the corporate status of a General Incorporated Foundation with a simpler organization and ability to conduct the same types of activities would be more suitable for JSDD.

This need for a transformation was approved by a Special Corporate Members Meeting on December 19 last year. In order to make a smooth transition, a separately formed foundation absorbed the General Incorporated Association, which became extinct on March 31.

“Living Will Study Workshop” widely developing and expanding The 4th Meeting theme: Palliative Care

It is commonly assumed that terminal medical care is a matter only between patients and doctors. Living Will Study Workshop of Japan brings together all other related professionals including nurses, care givers, and social workers. The 4th National Meeting will be held on June 20 this year in Tokyo.

Living Will Study Workshop of Japan headed by Dr. Soichiro Iwao, was established in 2013 with the intent of conducting activities beyond the scope of JSDD stipulation. Thus far, the headquarters has held a forum in Tokyo three times with themes: *The Incurable/Terminal*, *Dementia and Living Will*, and *How to best use the Living Will*. Six Chapters have held seven regional meetings with over 300 participants, and an increasing number of professionals other than JSDD members have been seen in attendance.

The 4th National Meeting will be conducted with the theme, *In Search of Painless and Suffering-Free End of Life*. Palliative care is the ultimate medical care which attempts to maintain a dying person's quality of life by removing physical pain and dullness and assisting him/her in dealing with mental aspects of pain such as anxiety, depression and fear of death.

Please join us and think about these topics with the professionals who deal with them on a daily basis.

2014 Surviving Family Survey Results Living Will supported: 90% honored

The results from the survey given to surviving families of JSDD members who passed away last year were compiled. According to the results, over 80% of the respondents said that they had submitted the deceased family members' living wills to their doctors, and over 90% of the deceased had passed away on their terms. These results were quite encouraging for all of us.

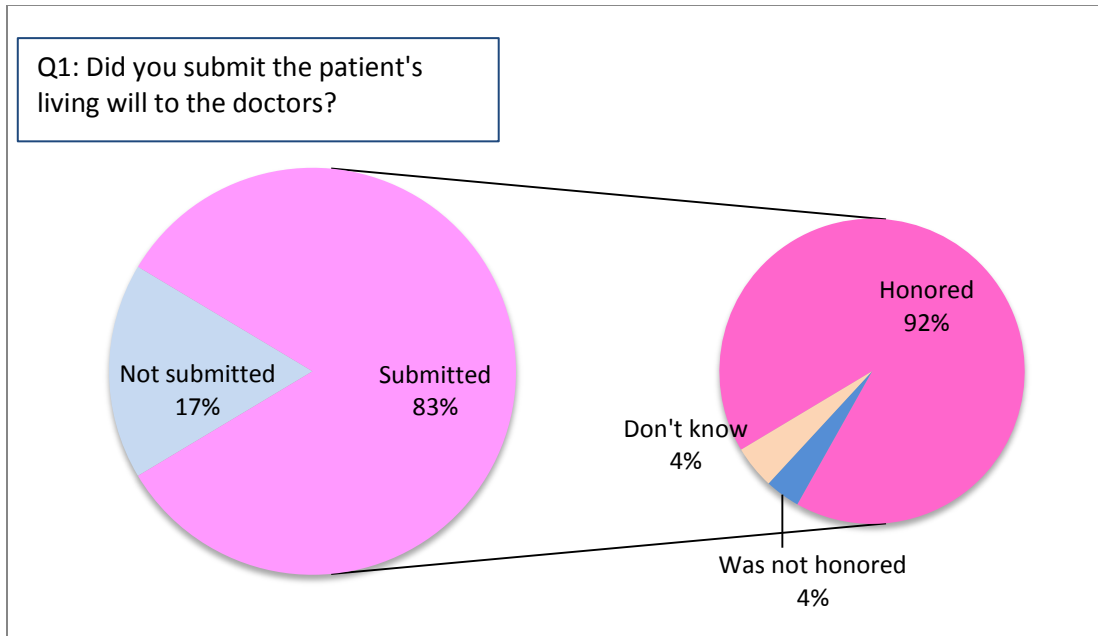
JSDD mailed the survey to 1,219 members, and 716 of them responded. The majority of the deceased was 80 to 90 years old, but the ages ranged from 103 to 50s who had suffered from a long battle of terminal illness.

Place of death was 62% in hospital, 18% in their homes, and 13% in nursing homes or assisted living institutions.

As for the timing of submitting their living will, 266 of the respondents submitted them once the patients' conditions worsened, but 271 had already submitted them in advance while in good health.

The most concerning question for everyone was whether the living will was actually honored, and how they were executed during medical treatments. To the question, “Do you think the

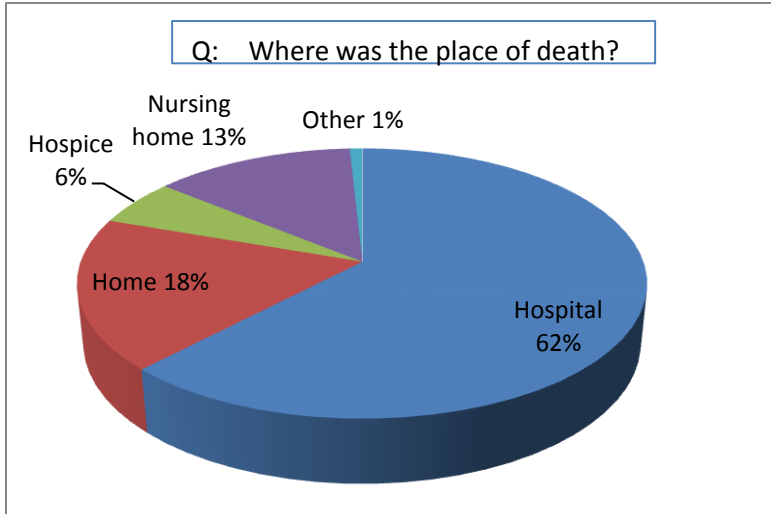
living will was fully honored and executed during patient’s terminal care?” 92% of the respondents replied either “sufficiently executed” or “somewhat executed.” Here are some responses:



“My mother lived her life vividly until her last moment.”

- Once we submitted her living will, doctors and nurses gave her the most compassionate care as if she was their own family member, which was a great support for all of us. My mother passed away as she quietly went into a deep sleep. (Miyagi Prefecture)
- When my mother became a JSDD member two years ago, my initial reaction was to ask why? I’m now convinced that by choosing her end of life style, she was able to live her life to its fullest until her last moment. (Oita Prefecture)
- On her third day of hospitalization, her doctor explained to us that our mother would be too old and physically weak to undergo any life prolonging treatments. We showed the doctor her living will which stated her refusal of all life prolonging measures. The doctor seemed relieved and told us, “Your mother is a very strong person, and I respect it.” (Saitama Prefecture)
- My father was diagnosed with prostate cancer and told us that he refused to undergo any life prolonging treatments. When he was hospitalized for the last time, he said that he had asked his deceased wife to come and welcome him and left his last note written with an old fashioned brush which stated, “I have no regrets in my life.” His last moment was gentle and peaceful, just as he wanted. (Kanagawa Prefecture)
- “I wish to go to heaven with no pain, no suffering, in high spirit.” My husband had written on a fancy paper tablet for the Seventh Night of July occasion. His condition had

worsened with intestinal obstruction, and it was impossible to relieve his pain at home. He was hospitalized in the palliative care ward, as he approved, and made his final departure while thanking us all. (Chiba Prefecture)



- My wife was diagnosed with terminal stage of liver cancer. Since severe pain was expected, I told the doctor about her living will and asked to give her the maximum amount of pain relief. The doctor took it seriously and took great care of her. She died two months later without any intolerable pain. (Tokyo)

- My father was hospitalized after in-home care was no longer an option. He

was relieved from any pain or suffering during his last stage. His living will was like a security blanket for him. (Saitama Prefecture)

- When my mother had a heart attack and was taken to the hospital in an ambulance, I was given many explanations on life prolonging devices, but I told them to please let her die quietly and peacefully. Her last words were, “Please call the Day Service (for Elderly) and tell them I’m not going to be there today.” For many years, she believed that everything was going to be OK because of her living will. (Aichi Prefecture)
- When dementia patients are already in their terminal stage with no consciousness, I believe that there is no way they would be able to express their wishes in a living will. The only reason I was able to honor my mother’s wishes on her behalf was because she was a JSDD member and had a living will. (Tokyo)

“Everyone felt serene and content at my father’s funeral because we were able to respect and honor his last wishes.”

JSDD membership was a huge spiritual support not only for the members themselves, but also for their immediate family members who surrounded their patients’ bedside during their last moment. The survey results also revealed the effects of the living will for surviving family members afterwards. We could not print everything that was written, but will emphasize that the majority of responses were filled with words of appreciation and gratitude.

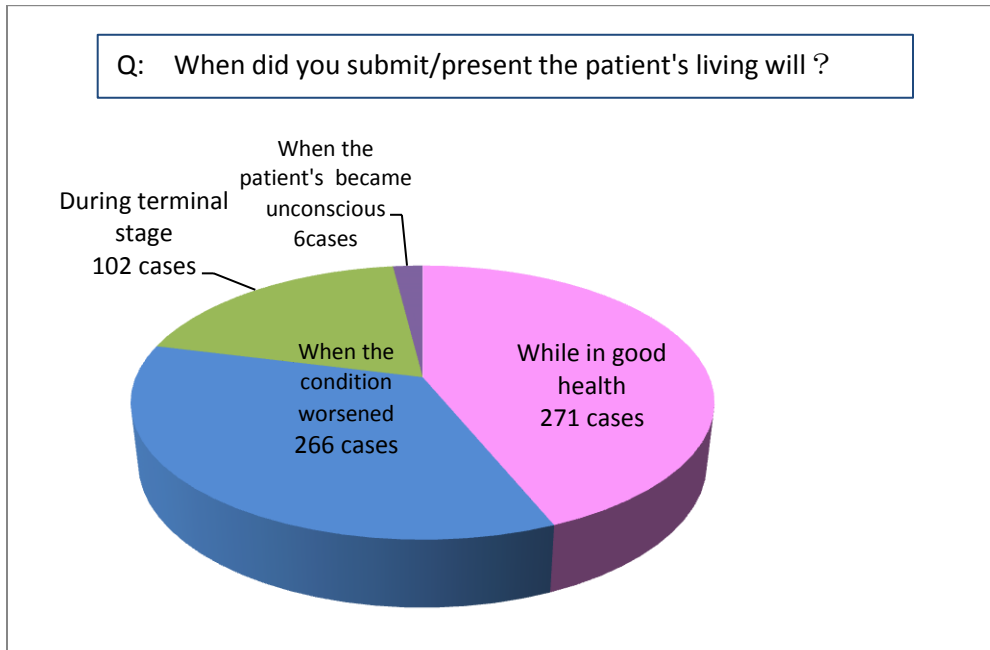
- With the combined effort of his doctor, in-home care visiting doctor, nurses and care givers, my step father was able to end his life at home as he wished. During his last stage,

to be able to watch him eating his favorite foods such as soba noodles and grilled eel was very pleasurable for us. We were able to honor his wishes to refuse all life prolonging treatments once declared he was in his terminal stage of life. Everyone felt serene and content at my father's funeral because we were able to respect and honor his last wishes. (Saitama Prefecture)

It's a natural obsession for family members to wish that their loved ones would live even one day longer or to do whatever it takes to see them live longer. Fortunately for my father, his possession of a living will issued by JSDD allowed us to carry out his end of life wishes without any hesitation or reservation. Later, we realized that he made a living will for us so that we would know exactly what to do. (Tokyo)

- Twenty years ago, my father was administered a feeding tube through an incision in his throat to prolong his life, which naturally obstructed his vocal chords and kept him from communicating. Because of this painful experience, my mother and I both decided to become JSDD members and made our living wills. When my mother was in her terminal stage, I was able to express her strong feeling to refuse any life prolonging treatments to her doctor without any hesitation. Becoming a JSDD member helped us tremendously to prepare ourselves and gave us a peace of mind. (Aichi Prefecture)
- When my mother lost her consciousness, and we were given some treatment options from her doctor, we presented him with her living will. The doctor honored her living will and took the option to provide her only with palliative care and relieving her pain. My mother alleviated our suffering by becoming a JSDD member. (Ibaraki Prefecture)
- Even when she was healthy, my mother had always said that she wanted to die at home. Fortunately, we found a doctor who could visit her at home. About 15 minutes prior to her death, she said, "I think today is the day I die. I'm not scared of dying at all." As surviving family members, we cherish those words and try to keep her serene and brave spirits in our hearts every day. We are grateful that her peaceful composure also came from knowing that she was a JSDD member and had a living will. (Tokyo)
- When we found out that my husband's cancer had metastasized, he showed his JSDD membership card to the doctor, and asked for in-home care and to relieve his pain. To reach this decision, we had many long discussions as to how to die in the style we truly want. His last words were, "Are you prepared and ready? Thank you for everything." Two days later, he died as he fell into a deep sleep. (Saitama Prefecture)
- With the strong support of the doctor and nurses from the Visiting Nurse Station, we were able to carry out my husband's wish to die at home. I feel that I will be able to stand back up and live my remaining life strongly. (Tokyo)
- When my husband lost his consciousness and was taken to the emergency room, I was told that even after surgery, he would likely be in a vegetative state, and his age wasn't in favor of having an operation. When I told the doctor that he was a JSDD member and had a living will, the doctor told me it was a good choice. As his wife, I naturally had

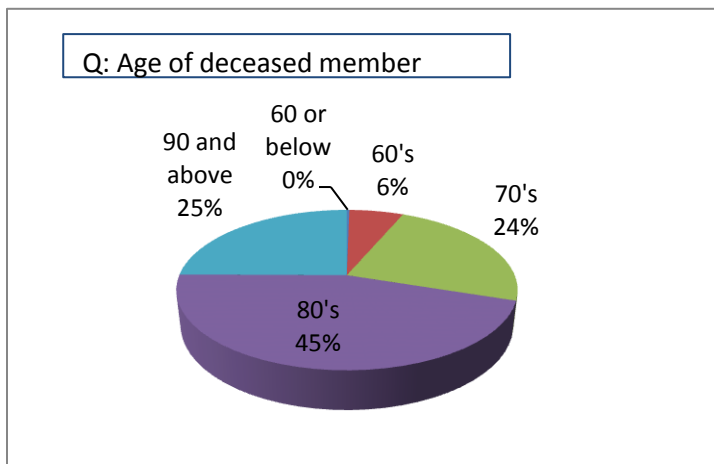
some reservation, but I knew from our daily conversations how he felt about it. I respected and honored his wishes. (Osaka Prefecture)



“Where does life prolonging treatment start and end? Results of suffering and agony.”

We received some responses expressing families’ suffering, confusion, and anger. Unfortunately, not all doctors have a good understanding of dignified death. Each case has its own circumstances also. This is an old problem we have to revisit.

- When my mother fell down at home, she was taken to the emergency room and was administered a life prolonging device immediately. I showed the doctor her living will issued by JSDD, but the doctor said that once it is administered, he could not remove it because it is considered a crime under the current law. I understood, but I felt so guilty and sorry for my mother. (Aichi Prefecture)



- The doctor returned my mother’s living will to me without even reading it, which made me feel uneasy. Her pain got worse about a week before she died. I asked the doctor to give her some medication to relieve her pain, but the doctor was very hesitant. I showed him her living will again and asked him to give her

maximum amount of pain relief, but he refused. The nurse who saw this situation understood and suggested some medication which made her drowsy. She was finally freed from the pain, but it took three days to get to that point. (Osaka Prefecture)

- It's too late to do anything now, but I feel so guilty for what we had to do to my mother that I still can't stop crying. The concept of dignified death is commonly shared, but it's difficult to find a doctor who truly understands the concept and is willing to carry it out. It was a horrible experience, and I'm next... (Toyama Prefecture)
- My husband was told that his pneumonia worsened after his surgery which caused him to have difficulty breathing, and that he will be administered a respirator. I could not watch him hooked to a respirator. He even looked painful when the mucus was being sucked out... I had his living will with me, but I debated over whether or not to submit it. In the end, I didn't submit it. (Saitama Prefecture)
- When my mother was hospitalized for the last time, the doctor said that one option was to administer a central IV nutrition, but he did not recommend it. I knew she had a living will, but when she finally became unconscious I struggled for several days to figure out if I should submit it. What is not clear is exactly when it is determined to be "life prolonging." The doctor never said what was considered a life prolonging measure and what was not. (Kanagawa Prefecture)
- The hospital crew immediately administered the life prolonging device to my husband, as if they had never heard of a living will and it was "business as usual." I thought of asking them to remove it after a while, but we could not all agree on the decision among family members. (Tokyo)
- After having pneumonia repeatedly, my father finally reached his terminal stage. Without any discussion, my brother and the doctor made the decision on their own to administer a central IV nutrition and a painful stomach testing. My father never had a chance to talk about his wishes regarding life prolonging treatments with my brother, but it seemed that his wish was never considered. (Tokyo)
- Some doctors understand the option of withdrawing life prolonging treatment, but some doctors don't and ask the family members instead for their opinions. This is the most painful moment for the family. If dignified death is legalized, both doctors and families will have a much better, mutual understanding about these decisions. (Osaka Prefecture)

The above examples are a glimpse of the responses we received from the surviving family survey. We are interested in what impressions you had from reading these live situations. Please contact our headquarters with your thoughts, with attention to the "Surviving Family Survey" department.

Last but not least, we hereby extend our deepest condolences to the families of the deceased members, at the same time, greatly appreciate their cooperation to our research during their mourning.

**The day will come when “Clinical Religion Teachers” and doctors team up
- New approach to attend to dying persons to show them the path**



Photo: Professor Suzuki guided a group of attendants at the forum held at Tohoku University to the disaster site. Statues of school children stood at an elementary school in Fukushima Prefecture. (Photo taken on 3-13-2013)

What can a person of religion do when he/she confronts a dying person?

From the relief activities conducted by Buddhist monks and Christian ministers to support the victims of the recent earthquake, The Great Earthquake of East Japan (3-11-2011), one solution arose: “Clinical Religion Teachers.”

When a Buddhist monk visits a hospital, patients tell him, “Hey, hey, don’t rush me. I haven’t died yet!” Professor Iwayumi Suzuki received a loud laughter from the audience during his speech at Tohoku University. An open forum was held at Tohoku University in Sendai on the two year anniversary of The Great Earthquake of East Japan (3-11-2011). Professor Suzuki is the chief organizer for a program to train “Clinical Religion Teachers.”

The advent of Clinical Religion Teachers was founded based on experiences from the earthquake relief activities. Not too long after the earthquake and the following tsunami, many dead bodies gathered at funeral homes in Sendai. Many Buddhist and Christian volunteers took care of the victims and conducted consultation services for grieving families of the deceased.

The dedication of these spiritual volunteers who sought nothing in return and worked beyond the boundaries of religion and sect evolved into a formation of “Heart to Heart Consultation Room,” a volunteer organization focused on taking care of victims’ hearts. Dr. Ken Okabe (passed away in 2012), a home care doctor, took the leadership role of these relief activities.

“We need a Chaplain-like professional who can fit into a religious role in Japanese culture and who can team up with a medical professional to confront dying persons.” This was Dr. Okabe’s idea. Chaplains play a large role in US hospitals for dying patients.

Currently in Japan, mental health care associated with death is the responsibility of clinical psychiatrists and psychologists. However, the ones who can answer the question, “What happens after I die?” are the religious professionals who specialize in the world after death. Dr. Okabe called these professionals who deal with spiritual pain of dying persons, “Clinical Religion Teachers.”

A Clinical Religion Teacher is a Chaplain-like professional who can provide guidance to dying Japanese people. Dr. Okabe’s dream was to see Clinical Religion Teachers in every hospital and health care institution someday. (Professor Suzuki)

Clinical Religion Teachers Course began a year after The Great Earthquake of East Japan

In pursuit of Dr. Okabe’s enthusiastic dream, Professor Suzuki conducted a lecture course at Tohoku University exactly one year after the earthquake to train people to become Clinical Religion Teachers. The training internship is three months long. People of various beliefs, Buddhism, Shinto and Christianity, gathered together for outdoors field training and rotations through hospitals and welfare institutions. The first and most important skill they acquire from this training is the skill of listening: to figure out what the people desperately need by trying to put themselves in their shoes.

Graduates are already working in the field making a difference

All religions have some type of ceremonial acts such as chanting sutra, prayers, and meditation, as well as tools and wisdom useful for spiritual care such as string of beads, rosaries, and talisman. There are lots to learn about how to make best use of them most appropriately and effectively in hospitals and other public places. There have been six courses given so far, and 96 graduates have been awarded their diplomas. One of the alumni, a Buddhist monk, visits an elderly woman living alone. He talks to her about how to deal with her fear of death and chants sutra at her home shrine. He also visits a dying Christian, and even reads the Bible to him when requested.

Their activities have been picked up by local newspapers and television nationwide. Initiated by Tohoku University, Ryukoku University in Kyoto is now following suit and offer a similar course. The advent of the elder society is in increasing need of spiritual care to mend the hearts of those facing death.

Open Plaza



My participation in terminal care **By JSDD member, Aako Ito (Sendai city)**

My 95 year old mother was struggling in her worsened situation with a difficulty in breathing, loss of appetite, and both visual and auditory hallucinations. Watching our mother slowly losing herself, the four of us all agreed to refuse the operation to administer a respirator.

She started to have difficulty sleeping on her side, so she spent her last in hospital. We embraced her gently from behind and talked about our most joyous memories with her as she passed away. We'll never forget the warmth we shared with one another.

My 97 year old mother in law had an operation for her broken hip bone, but while she was undergoing rehabilitation, she started to complain about being cold, in pain, and wanting to die. She had to have a gastric fistula operation due to a worsened case of dysphagia.

My husband could not refuse the gastric fistula operation, which only added six months of pain and suffering for his mother. After her death, I saw him sitting in front of our home shrine apologizing to her.

After we went through all of this, my husband and I learned about JSDD and became members. We were so relieved after we gave copies to our two children and discussed the matter.

When my husband turned 75, he was diagnosed with progressive liver cancer, Basehor's disease, and stage four stomach cancer. When we turned in his living will to the hospital, his physician gave us a very detailed guidance regarding terminal care at home.

The hospital established a care team for him, consisting of seven professionals including an internal medicine doctor, a surgeon, an anesthesiologist, nurses, and even a counselor who supported me, his spouse! They gave him morphine that sticks directly onto the skin, and he came home with a big smile on his face.

I saw his profound love and affection for his family in his decision to live his last days at home. He enjoyed visiting and going on trips with our children and his sisters. He enjoyed drinking after his favorite seafood, sashimi every night. We were able to cherish spending precious time together as a family.

His siblings all agreed and thanked me for following his written directives, “I refuse any unnecessary medical treatment and expensive and wasteful funeral services.” Their kind words were very rewarding to me.

My thanks go to all the medical professionals who understood and supported the concept of dying with dignity, and provided my husband with an “End-of-Life Care Team.”

Lesson learned from JSDD’s casual local chapter meeting
By JSDD member, Hiroko Tsuneto (Kawasaki city)



Twelve years ago, my mother who was living alone asked me to research JSDD so she can join. This was the first time I had heard of this organization, and I don’t even know how she found out about it. My father had a brain stroke, was paralyzed, and passed away after going back and forth between hospitals for about six years. My mother seemed to have made the decision to join JSDD led by her determination not to inconvenience me, her only daughter.

Three years ago, we placed her in a home for dementia patients. We submitted her living will to them and told them not to administer any life prolonging treatments because we believed that was her wish.

Recently, I learned from reading JSDD Newsletters that not everyone is successful in getting his/her living will executed by the doctors. I realized that it was not good enough to just submit my mother’s living will to the institution, but I needed to have a face to face discussion with her doctors and other medical staff. In order to support my mother in dying the way she wanted, I needed to learn more about what it meant to die with dignity and how it can be carried out for my mother.

When I found out through the Newsletter about an upcoming Kanto Chapter chat meeting in Tokyo, I immediately called to register. At the meeting, I learned so much from hearing directly from deceased families and patients undergoing terminal illnesses whose real stories sat deeply in my heart.

I realized that this is not just about my mother; my husband and I need to start thinking about ourselves when we reach that point. We became members and began telling my friends about the living will and how important it is for all of us.

I attend the chat meeting monthly now. Talking to other members taught me that to refuse life prolonging treatments determines how to spend the remaining days when death is imminent and is the only choice.

I don’t have any firsthand experience with terminal care in my immediate family, but how about my mother’s case? My husband’s? Mine? When that time comes, I am confident that I will be

prepared to face death exactly as written in my living will. By understanding the spirit of the living will, I have gained a peace of mind. Thank you, chat meetings.

**My thoughts on “Dying with Dignity”
By Akiko Isaji (Hiroshima city)**

September 1, 2014 was my 3.11 (The Great Earthquake of East Japan). It was the day my destiny changed, or is it more accurate to say that it was the day I saw clearly what my destiny was?

Suddenly, everything happened all at once: earthquake, tsunami, landslides, and volcano eruption. We knew that a large earthquake would come in the near future, but no one could predict exactly when it would occur. Just as an old metal bridge collapses all of a sudden, a disease appears out of nowhere.



My family has traditionally lived long lives. My uncle on my mother’s side is 100 years old and healthy. Naturally, I thought I would live a long life and would have to worry about dementia, rather than cancer. It was hard to accept the diagnosis and the fact that I only have a limited amount of time to live. I was diagnosed with pancreatic cancer with six months to live, one and a half to two years with surgery. I face life and death every day now.

It goes without saying that a patient needs physical relief, but it was only after I was diagnosed with cancer that I realized spiritual relief is even more vital. Physical relief requires medical cost which is ridiculously expensive, but spiritual relief only requires an open mind and no cost.

I belong to a casual group of women’s club. Somehow, my illness has become the center of the group’s attention. Some bring me goods when I’m hospitalized; some frequently bring me food; and some send me encouraging emails. My gardener friends bring me fresh home grown vegetables, and my chef friends bring me some of their finest gourmet dishes. My kitchen is always full of fresh flowers.

A human being is essentially a solitary being. It is such a comforting feeling to know that we all try to give a hand within our own abilities. I feel like a fish on a cutting board, exposing who I am, both good and bad, with this cancer. I am actually happy to go through my dying process surrounded by all of my friends. Even throughout this dying process, I must make choices at every step, but I feel like I know what it will be like down the road to die with dignity.

Postscript

Newsletter #157(Japanese Version) has a new format with the aim to make it easier to read. We also aimed at making this a two way message flow between JSDD and the members, not just an informational document. We hope that this newsletter is a product of all of our efforts. We opened a new column called, "Open Plaza," for our members and other readers. This is the forum for everyone to share and exchange thoughts and ideas. We encourage you to write and tell us about your ideas and opinions regarding this quarter's article about the survey conducted by surviving families of the deceased JSDD members.

We also changed the appearance of the envelope containing this newsletter. Blue envelope is regular mail, and green envelope includes the annual membership renewal fee invoice. Thank you for your participation. (Editing Office)