



Excerpts
From
Japan Society for Dying with Dignity Newsletter
No. 149, April 1, 2013



As of March 10, 2013, JSDD has 125,138 members.

“Living Will Needs Legal Endorsement”
Living Will Discussed in a Budget Committee Session in the House of Councilors

There was a large poster panel of JSDD’s living will template at the questioner’s table at the February 20th Budget Committee session. The questioner of this session was Mr .Satoru Umemura, a Democratic Party committee member from Osaka district. He began the session with a proposal to discuss issues of terminal care. He then introduced a template of the living will issued by JSDD and emphasized the significance of legal endorsement of this document which protects and defends the patient’s self determination (see photo).



Mr. Satoru Umemura chose this particular subject from a discussion of an integrated reform of social security, and appealed to the rest of the committee the significance of having a nationwide discussion on this topic at all levels among citizens as well as at both Houses of the legislature. When asked for his opinion at the end of the session, Prime Minister Abe replied that ending one’s life with dignity is a

fundamental human right, and that it is the responsibility of our government to protect that human right. This part of the discussion was nationally televised live by NHK, the National Broadcasting Corporation of Japan.

Legal Guarantee for “Right to Refuse Life Prolonging Measures”

Mr. Satoru Umemura Urges Legalization

At the beginning of the session, Mr. Umemura expressed his regret for having to delay this discussion on terminal care issues due to a recent controversial remark made by Mr. Aso. During a National Council session on Social Security Reform held in January this year, Mr. Aso, the Deputy Prime Minister and the Financial Minister, bluntly made a comment, “I would personally prefer to ask for a very quick death.” He denounced his comment and publicly apologized immediately afterwards and added, “I have already prepared a document expressing my own wishes for terminal care.”

Mr. Aso’s wishes for terminal care, for example, should be legally guaranteed, Mr. Umemura stated as he read to the committee the three points that appear on the Living will issued by JSDD, and introduced the JSDD Membership card to them. A large poster panel of the actual living will was displayed on his table so that everyone including the media could read it.

During the question and answer (Q&A) session, it became apparent to everyone that the living will has no legal standing by itself, and that there must also be a proxy agreement for elderly people living alone or people suffering from dementia. Mr. Umemura emphasized the importance of how we legalize the living will and pointed out to the Ministry of Health, Labor and Welfare how it should tie in with the Social Security Reform Promotion Act.

The promotion act passed last summer which integrated social security reform with tax increment explicitly states that all necessary measures will be taken to respect and honor terminally ill patients’ dignity and their wishes by providing a serene and comfortable environment for them (section 3, clause 6). “In our country, an individual’s right to prolong life is very well protected; however, the right to refuse life prolonging measures is not adequately protected.” Mr. Umemura emphasized again the importance of legalizing the living will. He further stated that he is also pushing this issue personally as a member of “The Diet Member Coalition for Dying with Dignity (DMCDD)” and asked Prime Minister Abe for his opinion on this matter.

Prime Minister Abe:

“I want a system where having a ‘Dignified End of Life’ is a reality.”

“Dying with dignity is an extremely important and complex subject,” Prime Minister Abe answered. “When discussing how one should end his/her life, we must approach it in terms of morals and values, instead of medical costs. Obviously we must carefully examine all pros and cons. In general, I want a system in which a patient is not forced to accept life prolonging measures against his/her will, while a physician is able to care for his/her patients with confidence and peace of mind.”

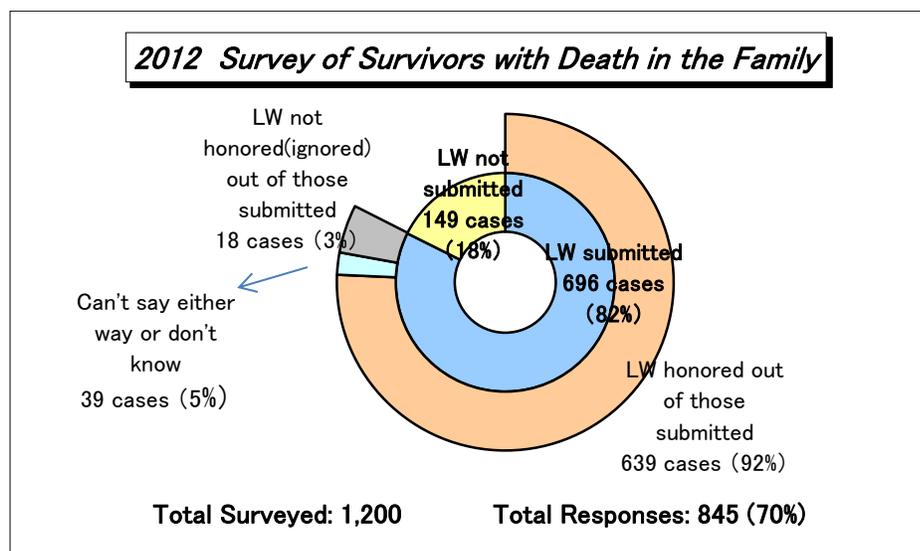
Mr. Umemura, also an internal medicine physician, is the first politician to ask a Prime Minister this question during a budget committee session. He had also asked former Prime Minister Noda the difference between a 'dignified death' and a 'gentle death' during a special committee session held in the House of Councilors in July last year.

**Number of Diet Member Coalition for Dying with Dignity (DMCDD) Members
Increases Back to 118**

As a result of general elections held in December last year, the number of members for DMCDD (headed by Mr. Teruhiko Mashiko) had dropped from 134 to 88. With the efforts of DMCDD in collaboration with JSDD, its number has increased to 118 (72 in lower House; 46 in upper House) as of March. The members have resumed their efforts to pass the two bills (proposed last year) in the general session of legislature this year.

**92% of Living Wills Honored by Physicians
= 2012 Survey of Survivors with Death in the Family =**

According to the 2012 survey of surviving families of JSDD members, 92% of those who submitted their living wills were honored, a 2% increase from last year. Ideally, 100% of all living wills should be honored; however, this number reflects the importance of advance preparation on the patients' part as well as the need for legalization of the living will. We want to take this opportunity to express our gratitude to the families for their participation and cooperation in the survey in the midst of their grieving period.



“This is XX Emergency Rescue Center!”

“Hello, this is XX from XX Hospital Emergency Rescue Center.” Our head office received an urgent call one day in March last year. “We have a patient who just arrived in an ambulance. His family says he is a member of JSDD, but he doesn’t possess a membership card; so we wanted to verify it with you.” The call was from a hospital in Aichi prefecture.

There was high tension on the other end of the phone. While our staff was checking for the patient’s membership, we could hear people shouting, “Just a minute!” “Stop, not yet!” on the other end. We verified that it was indeed our member. The caller said, “Okay, thank you. We will oblige to his intent,” then hung up the phone.

This was a successful episode of health care institutions checking to verify a patient’s living will and honoring it. It is our wish that all cases are handled in this manner in the near future.

1,200 surveys were sent to surviving families of JSDD members, and 845 responded (70%). Detailed information about this survey is found on Page 8. Out of 845 families who responded, 696 (82%) said that their members had submitted a living will; 149 families responded that the members had not submitted a living will. Out of 696 cases of living wills submitted, 639 were honored by their physicians (92%), 18 cases (3%) were not honored and 39 cases (5%) were unknown. Although we do not investigate each case, we want to introduce some specific stories received from family members.

Living Will Submitted

Living Will Submitted and Honored

- **JSDD Newsletter was a big help:**
“Our in-home healthcare physician guided us to prepare a living will. My mother was able to end her life the way she wanted, and her final departure was so peaceful that it looked like she just went into a deep sleep. We received the JSDD newsletter just in time. We learned a lot from it; it was very helpful.”—Tokyo Prefecture
- **We submitted a patient’s living will to the elderly nursing home:**
“We submitted the patient’s living will in the admission office at the nursing home where we explained explicitly the patient’s intent and family’s consent. Soon after, the patient was sent to a hospital for a treatment. Upon release from the hospital, we were asked whether the patient should have a feeding tube. We refused the feeding tube and brought the patient back to the nursing home. The physician, care manager and the entire staff understood and supported the patient’s wishes. The patient was able to have a smooth, peaceful final departure.”—Tokyo Prefecture
- **We were forced to move to a different nursing home:**

“When we decided to move my mother to a nursing home, the admission office staff seemed to understand and fully support our position regarding her living will. However, when she started having difficulty swallowing food, we had to transfer her to a hospital. We were shocked to be told that she can only be transferred back to the same nursing home if we agreed to administer a feeding tube. We requested to extend her stay at the hospital until we found another nursing home for her who will accept a patient who can’t eat and doesn’t have a feeding tube. We finally found one and transferred her there. A month later, she died very peacefully. We had read a book titled, “Refuse Medication If You Want to Die in Peace,” which was exactly our case.”—Saitama Prefecture

- **Family members’ wishes had to be verified:**

“The patient’s wishes were clear and understood by the hospital from the living will, but the family members’ wishes also had to be verified by the hospital staff, which was completely separate from the patient’s intent. Some questions were hard to answer. It was painful to realize that the family had the final say in the decision, not the patient.”—Kanagawa Prefecture

- **Nursing home attendant was reprimanded by a doctor, which made me realize the importance of the living will:**

“My mother was in a nursing home when she was sent to an emergency room. After she was resuscitated, I arrived at the hospital and submitted her living will to the doctor. He turned to my mother’s nursing home attendant and yelled, “See? Didn’t I tell you? Why didn’t you let your whole staff know that this patient was a member of JSDD and had a living will?!” My mother ended up dying soon after, but I was impressed at the importance of the living will from this experience.”—Osaka Prefecture

- **Peace of mind for the surviving family:**

“My husband and I learned of JSDD during lunch with my father when he was 72. I was a little shocked to hear about it since it was the first time I had ever heard of such an organization, but because of this I was able to precisely tell his doctor of my father’s wishes when he died seven years later. Recently when my mother passed away, I was much better prepared to deal with the situation. JSDD and the living will not only helped the person ending his/her life, but also gave the surviving family members a peace of mind. We all became members and want to spread the word to as many people as possible.”—Saitama Prefecture

- **Diagnosed with an incurable disease: Refusal of life prolonging measures:**

“My husband was diagnosed with multiple system atrophy (MSA) and fought this neurodegenerative disorder for five years as his muscles slowly deteriorated. He strongly demanded dignified death and refused all life prolonging measures when admitted to the hospital. I am so grateful for how the hospital staff respected his pride and dignity to the end. The funeral service is over now, and all the money we received from family and friends went to the Incurable Disease Organization.”—Hyogo Prefecture

- **In 10 years-Major change in society’s attitude regarding dignified death:**

“My mother’s death was truly a “dignified death.” While carrying her JSDD membership card for four and a half years, she taught me, all worried about her pneumonia and dementia, a life lesson. My

father died 14 years ago hooked to a respirator and his hands cuffed to his bed, despite submitting his JSDD membership card and his living will to the doctor. His death was not with dignity. My mother's hospital staff treated her quite differently from how my father's hospital staff treated him ten years ago. I felt that the society's view on dignified death has changed immensely over the last ten years. The living will is honored whether you have cancer, dementia or anything. JSDD has supported us for years."—Tokyo Prefecture

Living Will Submitted, But Not Honored

- **My mother's wish was ignored by family members:**

"My mother had been working in the medical field for a long time and joined JSDD in her early years. She had told both of us daughters and all of her relatives that she would not want any life prolonging measures in her terminal stage. One day, she suffered from brain hemorrhage and was sent to the hospital in an ambulance. The doctor told us that even if the surgery was successful, she would be in a permanent vegetative state. I submitted her living will and told the doctor to honor her wishes and let her die, but my sister and uncle disagreed and told the doctor to go ahead and perform the surgery, calling me inhuman and brutal.

After the surgery, my mother became a totally different person; her personality changed and body partially paralyzed. With a small child, I started taking care of her while my sister and uncle did absolutely nothing to give me a hand or help me financially. After taking care of her for one year, I was so drained mentally, physically and financially that I just wanted to run away. She died of cancer a year and a half after the surgery. I still cry when I think of how we completely ignored, rejected and dishonored her wishes."—Tochigi Prefecture

- **Unpleasant response to a request for pain medication:**

"This hospital was very hesitant to provide palliative care to minimize pain. When we asked about getting morphine for the patient, a staff responded with, "Don't complain if the patient stops breathing." Without asking for family's consent, the hospital administered high calorie nutrition fed through intravenous infusion with a central venous catheter."—Nara Prefecture

- **If only I had told them about his living will...:**

My husband collapsed at home when his lungs and heart stopped functioning. I called an ambulance and AED was administered on the way to the emergency room. An hour and a half later when I finally saw my husband, he looked like he was wrapped in tubes. When I told the doctor about his living will, he told me I should have told him that in the ambulance, and he wouldn't have been poked and cut so much."—Kanagawa Prefecture

Living Will Submitted; Neither Honored nor Ignored/Unknown

- **More individualized treatment and care:**

"My mother was already physically weak, and her wish was to refuse any surgeries or chemo and die peacefully without any more suffering. The doctor said he would support her decision and cooperated, but his only response was prescribing a higher dosage of morphine and no other treatments or care. This is probably a typical practice carried out by most hospitals. Japan faces a society of oversaturated elderly population. I strongly hope that even in a small rural town where

hospices are not available, hospitals provide medical care in support of welcoming “peaceful, gentle death” in the near future, one of the main principles of JSDD. I believe it’s one of the most respectful and honorable medical care one can provide.”—Chiba Prefecture

- **All treatments were withdrawn:**

“I don’t know if this was the right decision. The patient’s doctor told me, “Administering further active treatments would only cause more suffering for the patient. I know he is a JSDD member. Let’s form a palliative care team for him now.” All treatments were withdrawn. The patient was fully convinced, but I’m still in the midst of grief and sorrow.”—Chiba Prefecture

Living Will Not Submitted

- **Asked if we were JSDD members prior to hospital admission:**

“The hospital admission paper had a question whether or not you are a JSDD member. I was relieved and impressed to hear from the hospital staff that they are fully aware of the living will. There was no doubt in my mind this was one of the most prestigious hospitals in Japan, and I felt like I was living in such an advanced, modern world.”—Tokyo Prefecture

- **I had so much trust in the clinic that I forgot to submit it:**

“I knew that the clinic I was going to was a clinic that promotes terminal stage patients to spend quality time with their families rather than to administer life prolonging measures, so I forgot to submit my living will.”—Miyagi Prefecture

LETTERS FROM PHYSICIANS

- **Living will facilitates our medical care planning for direction and specification:**

“Terminal care is the patient’s decision to choose his/her own dying process, as well as ending his/her living process. A healthcare provider is a professional who coordinates between a patient’s life and death in accordance with his/her intent and wish. Therefore, a patient with a living will clearly demonstrates his/her intent, which facilitates our job of determining the direction and the specifics of his/her medical care plan.”

- **Too late to prepare a living will:**

“I treat mostly elderly patients and those with dementia. They usually don’t have living wills, and it is too late for them to prepare them at that point. This makes me very aware of its importance. I would like to work on teaching the young generation of its necessity.

- **Submit your living will as early as you can:**

The number of tube fed patients is growing. How does this impact patients and their families? In many cases today, parents outlive their children. Please prepare and submit your living will as soon as possible.

- **Protect good willed doctors from legal liability:**

I have been following the process of legalizing the living will closely. I expect that this will protect innocent doctors and healthcare institutions from liability until proven guilty. I am a strong opponent of meaningless and harmful life prolonging treatments.

- **We are patients’ helpers in making decisions:**

Living will is the ultimate expression of one’s completion of life to its fullest. As a physician, I accept it as the patient’s decision. However, I want to encourage curable patients to aggressively receive all available medical treatments. I think that our job is to help patients make their life decisions by providing them with our best analysis of treatments’ effectiveness.

2012 Survey of Survivors with Death in the Family Results

Questions	Responses	# people	%
Response Rate	Responded	845	70
	Did not respond	355	30
	Total	1200	100
Gender	Male	493	58
	Female	352	42
	Total	845	100
Age	Under 60	3	0
	60s	57	7
	70s	199	24
	80s	406	48
	Over 90	180	21
	Total	845	100
Cause of Death	Cancer	267	33
	Heart disease	96	11
	Stroke	61	7
	Pneumonia	164	19
	Accident	11	1
	Old age	79	9
	Other	167	20
	Total	845	100
Place of Death	Hospital	567	66
	Home	150	18
	Hospice	39	5
	Nursing home	82	10
	Other	7	1
	Total	845	100
Living Will Submission	Submitted	696	82
	Not submitted	149	18
	Total	845	100
Time of LW Submission	While in good health	137	20
	Prior to hospitalization	231	33
	During hospitalization	212	30
	During physician’s home visit	41	6
	Terminal stage/vegetative state	75	11
	Total	696	100
Physician Response	Honored patients’ LW	639	92
	Did not honor patients’ LW	18	3
	Neither/Unknown	39	5
	Total	696	100

Long Awaited: New Release Book

“Dying with Dignity is My Choice: A Proposal for the Incurable and Terminal Patient(2nd ed)”

(Compiled by JSDD)

In April this year, JSDD introduced a new book called “*Dying with Dignity is My Choice: A Proposal for the Incurable and Terminal Patient(2nd ed)*.” Publication of this book was one of the projects JSDD had been working on with the goal of helping as many people as possible to fully and accurately understand dying with dignity from different perspectives based on the illness whether physical and/or mental.

In 2007, “*Dying with Dignity is My Choice*” was published with efforts led by Tokai Chapter of JSDD. In this book, the terms “incurable” and “terminal illness” were defined by physicians specializing in different fields of medical profession. The book received great reviews and remarks. We have since made substantial changes in our society, such as advancement in medical knowledge and the movement to legalize the living will. Such improvements, especially in the field of terminal care have urged us to publish a sequel to the book.

The book is written by physicians who are experts in their specific fields of medicine, and is so well written that it is easily understood by the average reader. It is geared towards the general population and the medical community alike. It is also written from the standpoint of a person thinking about dying with dignity and dying naturally. We hope that you add this book to your home library.

Medical Professionals Demonstrate Specific Terminal Stage Illness or Condition

Table of Contents:

Preface-----Soichiro Iwao, President

1) Introduction:

Death with Dignity-----Akihiro Igata, Honorable Chairman

Revised Version of the Living Will-----Yutaka Suzuki, Vice President

In-home Medical Care and Death with Dignity-----Kazuhiro Nagao, Vice President

Artificial Hydration and Nutrition-----Masafumi Kuzuya,

Professor of Internal Medicine for the Elderly, Nagoya University Hospital

2) Incurable Persistent Vegetative State-----Sigeki Kuzuhara,

Professor, Suzuka University of Medical Science

3) Cancer-----Tadashi Watanabe, Honorable Chairman, Tokai Chuo Hospital

4) Dementia-----Hisayuki Miura, General Manager, In-Home Medical Care Department, National

Center for Geriatrics and Gerontology

5) Dying of Old Age-----Masafumi Kuzuya

6) Renal Failure-----Yuzo Watanabe, Chairman, Kasugai City Hospital

7) ALS and Other Incurable Neurodegenerative Diseases-----Reiko Nanba,
Chairman, Neurology Nanba Clinic

8) Life Prolonging Treatment after Emergency Life Saving Treatment
-----Mitsunaga Iwata, Associate Professor, Emergency Medicine Dept.,
Fujita Health University Hospital,

Epilogue-----Hitoko Aoki, Vice President-JSDD, President-Tokai Chapter