

Excerpts from



**Japan Society for Dying with Dignity Newsletter
No. 165, April 1, 2017**

Special Edition: JSDD 10 years ahead and its future role

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GAZING AT THE FUTURE OF JSDD 10 YEARS AHEAD

“Let’s discuss the specific activities that are feasibly adaptable to the social changes and trends, then decide our path.”

By Soichiro Iwao (JSDD President)



JSDD celebrated its 40th anniversary in 2016 since becoming a general incorporated foundation. In the next ten years, JSDD will be facing the peak of predominantly elderly society and a large number of death. Our end-of-life medical care situation will expect to undergo some dramatic changes which we have never experienced before in our history. We must decide what path we should take after thorough, in-depth, deliberate discussions.

As much as we are proud of our 40 years of promotional activities on issuance and distribution of the Living Will (LW), we now face imminent issues of dealing with the decrease in new membership enrollment and challenges of constructing the new LW format.

High motivation recognized during discussions with the local Chapter officers

For the purpose of seeking resolutions to these issues, a meeting was held in Saga City at the end of last year. The theme was “How to prepare JSDD for ten years ahead.”

Young officers from Saga and Nagasaki Prefectures under Kyushu Chapter attended to present their candid opinions and recommendations. They are our future leaders who will be the key to successfully continue activities for the JSDD. I hereby would like to share our discussions and their suggestions regarding our current LW situation and future reorganization into a public benefit corporation.



Lately, we have noticed an increasing number of questions regarding the benefits of enrolling in JSDD and having a LW. This situation is reflected in the drop in our enrollment numbers despite the increasing number of elderly people in our population.

This reality also relates to the increased number of LWs and advanced directives prepared and submitted to medical facilities at the time of admission, and further relates to the efforts made by the local medical associations and municipalities to prepare and distribute their own advanced directives in order to increase public recognition of the LW.

Improving our LW format

JSDD is an organization with the longest history in Japan with the highest rate of LW issuance, but we are now facing a new problem of not being able to sustain the same pace of production anymore.

Advanced Care Planning (ACP) is a newly adapted concept in the Japanese medical community, in which professional medical teams provide legal agents who can assist patients with medical care decisions and establishing flexible, timely change of treatments in alliance with the changes of their medical conditions. On the other hand, JSDD issued LW is a simple and generic description of a medical directive, which is now considered outdated.

Two years ago, JSDD officially announced the committee report of the JSDD issued LW format, which identified issues to be considered. It is now time to begin revising the current LW format by clarifying the matter of witness selection and agent selection as to who can make medical decisions on behalf of the patient including family members as well as distant relatives.

Furthermore, in this digital society, the conventional way of administrative custody and management of the LW must be rectified intensively and immediately. Once we set up online membership registration, payment and administration, we may be able to see a tremendous increase of benefits for the current members as well as future members.

Maximum efforts in converting JSDD into a public benefit corporation

JSDD has made an effort to convert itself into a public benefit corporation in pursuit of improving the organization as well as expanding project development. Unfortunately, the Cabinet Office of the Government rejected our request in December last year.

For the last 40 years, we viewed our LW campaign as benefiting the public; however, this rejection possibly sends a negative message to the public as a denial of our campaign altogether. We will work continuously to convert our organization status into a public benefit corporation, especially now that we are in the midst of reinforcing the LW propagation activities for the next ten years.

A CHEERING MESSAGE TO SUPPORT JSDD

Death with Dignity: A View on Life and Death

By Kunio Yanagida (Author)



Great credit goes to JSDD in spreading the LW in the medical community. If my memory is correct, a euthanasia case in Tokai University in the early 1990s triggered a surge of JSDD membership when the public recognized the significance of having a LW.

People's concern was focused on their ability to die in peace without pain or suffering, not affected by the dominantly prevailing pro-life attitude of today's medical providers, who consider prolonging life to be their absolute moral obligation regardless of the patient's will, even when death becomes unavoidable and the patient loses his or her mental capacity. The LW may contain a number of details, but the essence of this document is simply the selection of death with dignity.

Needless to say, dignified death is very important. I wonder, however, if peaceful death as the end of life ritual is good enough when we consider death of a human being. To conclude one's life in an equally fulfilling manner as its life had been achieved, there must be another important agenda- how to spend a known quantity of one's remaining life, whether it is days, months or years.

You may have something that you want to achieve before you die, and you may want to complete the last chapter of your life in a more fulfilling manner prior to your last departure. That is what I call "dying with dignity."

The good understanding and support on the side of medical providers will be absolutely necessary. What I expect from JSDD in the next ten years is to help establish a culture in which documentation of self-determination of death with dignity is a standard.

Increased significance of JSDD

By Kozo Ishitobi, M.D.

A human life span is about 100 years, and then we go back to mother earth, handing life on earth over to the next generation. When end of life is near, we take the natural course of losing our appetite because our physical body refuses food. We go into sleep without being fed and into eternal rest. This is what I call “gentle death,” “providence of nature,” or “wisdom of God.”

We use science and technology that we developed to try to prolong our life span as much as we can. We feel that it is a crime to not administer tube feeding, intravenous nutrition, etc. when it only results in more pain and suffering for the patient. This is the wrong adaptation of medicine for natural aging, and people are starting to have doubts about our conventional medical approach.



Medicine-it is for people. What is more important is not to just prolong life, but to improve the quality of life. How to live one’s life is an individual choice which can only be determined by self, not by someone else.

What is expected of us today is to ask ourselves how we want to live our lives. If we want to live a long time, we must accept the journey ahead with bravely and courage to overcome obstacles. However, if we think the end has come, we must also accept it calmly. That is “living with dignity.”

What is expected of JSDD is to support the movement of autonomy and “living life to its fullest” for as many people as possible.

Hurray, JSDD!

SPECIAL FEATURE ARTICLE I : JSDD IN TEN YEARS

A prospect of organizing a group of LW supporting physicians

More demand for LW supporting physicians:

JSDD maintains a list of registered physicians who are in support of executing LWs, which is a great resource for all members. This registry started more than twenty years ago, and we have been seeing a gradual increase of registered physicians. Today, the list consists of close to 1,500 physicians, which may not seem like a large number. Further reinforcement of this system is in need in conjunction with the change of end-of-life medical care situation. We interviewed two registered physicians.

A system geared more towards satisfying its members

By Dai Yumino, M.D.



Dr. Yumino of Tokyo registered as a LW supporting physician a year ago. He opened his own clinic, Yumino Heart Clinic, 4 years ago near Takata-no-Baba station on JR Yamanote Line. It is well known as a busy, popular college town, filled with a lot of students and young people. He specializes in heart diseases.

The introduction of Dr. Yumino to JSDD's supporting physician registry was its annual survey of surviving families. He responded to the survey as surviving family, and we requested him to be registered in the registry as a LW supporting physician.

Dr. Yumino often met with the JSDD member patients when he was visiting in-home care patients. Outpatients coming to his clinic are questioned about their LW as a routine survey. One day, a very old female patient told him that she knew what a LW was because she was a JSDD member. This was something he never encountered before when he was working at a hospital.

He agreed to being added to the registry, as he found JSDD to be a highly reputable organization, trusted by its members for providing them with many helpful activities and resources.

Dr. Yumino said he was pleased when he found out that some of his patients had LWs. The more he met with JSDD member patients, the more he was impressed by their knowledge and their deep trust for the organization. Not only did he become a supporting physician, but he also convinced two of his colleagues to join the registry.

He believes that the spirit of supporting LWs is to provide a broad range of support to patients, enabling them to spend the last moments of life exactly the way they wish them to be. The broad range of support cannot only come from the doctors, but also the nurses, care givers, pharmacists and social workers. Physicians play only a part of that overall support, and that is what the role of a LW supporting doctors should be.

Most of us naturally think of cancer when we talk about terminal medical care, but we're starting to see more of non-cancer illnesses, such as heart failure and cardiovascular diseases in aging patients.

As we become a "high death rate" society, number of hospital beds will be extremely limited. Therefore, it will be necessary to establish a community based support system for the patients, and in-home terminal care will have to become a viable choice for them. We have been seeing more and more in-home terminal care now due to the increase in the patients' general awareness.

Yumino Heart Clinic has seen an increase of in-home care patients in the last year. According to Keiko Saito, a social worker, one out of ten patients have already made up their minds about their end of life choices and the LW when they walk in. Typically, about 30% of all of their patients end up preparing their LWs.

Dr. Yumino wants to help patients spend the last moments of their lives the way they want to live. He says that the purpose of in-home terminal care is not just to let them die at home, but it is simply the result of supporting the patients' wishes. LW supporting physicians are not merely medical caretakers who watch patients die at home, but so much more than that.

Over 20 years have passed since JSDD started the LW supporting physicians' registry. In the meantime, our medical technology rapidly progressed, and its coverage in medical care widely expanded. However, JSDD's LW support system remained relatively unchanged.

Dr. Yumino made a bold suggestion of establishing a national network of LW supporting physicians, or a national LW supporting medical body, which would be more feasible and suitable for meeting current demands of our patients. Large scaled hospitals may have a difficulty accepting this concept, but small clinics and even small scaled hospitals may have more to gain from adapting this system. We will be able to hang advertising billboards in the lobby, indicating that this clinic is a LW supporting network member registered by JSDD.

Expecting more physician-patient bonding activities

By Shimon Amemiya, M.D.



In the residential town called Takaido in Suginami, Tokyo, there is a large section of subsidized social and medical facilities owned by a social welfare corporation called Yokufu Kai. Amongst a number of specialized nursing homes and inexpensive nursing homes accommodating more than 1,000 elderly patients, there is Yokufu Kai Hospital with 13 departments.

Yokufu Kai Hospital was built immediately after the great earthquake of 1923 in order to take care of elderly earthquake victims and outpatients who came to receive treatments. The hospital has been primarily focused on providing pediatric and geriatric medical care for many years.

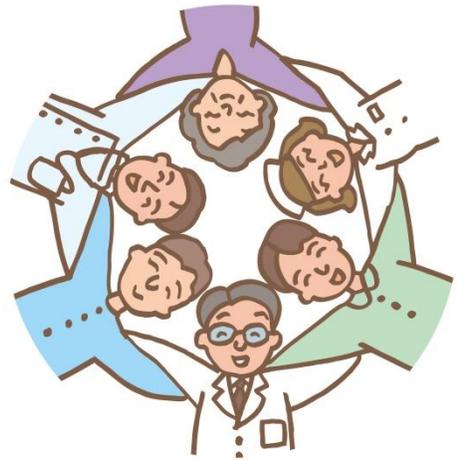
Dr. Shimon Amemiya, Department Chairman of Internal Medicine at Medical Center for Dementia Diseases, joined the JSDD LW supporting physicians' registry last fall, prompted also by our annual report on the surviving family survey.

LW supporting physicians' understanding is vital to geriatric care

When there is no more medical solution, it is important for physicians to switch their mental focus to abandon curative medical treatment and replace it with patient centered and family oriented care, says Dr. Shimon Amemiya. During his eight year tenure at this hospital, several patients have told him that they were JSDD members. They did not come out and say it on their first visits, but after accumulating several meeting opportunities and deepening our relationships, patients would start to disclose their LWs. He says that by understanding the patient's disclosed personal history, he is often struck with emotional sentiment.

Just because the patient is a JSDD member, he does not automatically support every one of his or her wishes. There are several factors he must consider before determining the patient's medical care plan, but the LW is a major decision factor, he says.

Dr. Amemiya also specializes in dementia. Japan will have over eight million dementia patients in the near future. Dealing with LWs of dementia patients with limited mental capacity will be a challenging issue. He emphasizes the importance for JSDD members to talk with their families about how they want to spend the last moments of their lives and what is documented in their LWs. What JSDD can and must do is to ensure their members understand this.



Japan will have the largest elderly population ever in the near future. With geriatric care being the highest of its priorities, decline of mental capacity in many of the citizens with LWs will certainly be a serious issue. Registering as a LW supporting physician is an individual decision. Rather than waiting for these physicians to come around, JSDD must take the initiative and aggressively seek out and bind its members with their physicians and the rest of the medical community.

Number of LW supporting physicians rapidly increase – but still only 1500

This is a registry that JSDD initiated in 1995. The LW supporting physicians are those who deeply understand the concept of the LW and are willing to support it wholeheartedly. Currently, there are 1516 doctors registered (list of names available on the JSDD website).

According to government research, 70% of all physicians claim that they support LWs prepared by their patients, but the number of registered physicians is still very small. JSDD was able to add approximately 300 physicians to the registry in the last two years by focusing on contacting in-home terminal care clinics.

SPECIAL FEATURE ARTICLE II : JSDD IN 10 YEARS

2016 Surviving Family Survey Results - Living Will: 90% honored

JSDD members who fulfilled their lives and families who were able to support them LVs not only satisfy the patients' wishes, but they also liberate their families and friends from agony and suffering. Here are some voices we heard from the surviving families:



We realized that the LW had a positive effect on all of us in avoiding pain and suffering caused by forcefully prolonging my father's life (son).



The fact that my father was a JSDD member laid a firm foundation for my decisions in various situations and phases (eldest daughter).



I was so proud of my mother's courageous and dignified decision for her last departure was so beautiful and graceful (eldest daughter).



When my husband told his doctor, "I want to live the rest of my life as human-like as I can," the doctor said to him, "I fully support your wise decision." I send my deepest gratitude to the doctor (wife).

- I took care of my mother-in-law (90) during her last stage, as the wife of her eldest son. Losing a son in his young age, she had no close relationships with her other relatives. I knew that she felt strongly about not accepting any life prolonging measures, but as her daughter-in-law and not her biological daughter, I was hesitant to speak out her wishes to the doctors and her relatives. Fortunately, she had a LW, so I could talk to them about her wishes, and she passed away peacefully (Saitama Prefecture).
- My father (93) often said openly that if he is ever unable to eat through his mouth, it would be the time to end his life. We had a courageous medical team who supported his wishes and did not administer any tube feeding, IV nutrition or respirator so that he could end his life with peace and dignity. Because he had a LW, we could honor his wishes without any emotional reservation (Tokyo).

- He was in and out of the hospital repeatedly when he finally said, “I hate going to the hospital. I want to die in my own house.” My sweet husband (79) always put other people’s needs on top of priority above his own, but he placed his end of life wishes on top. He is watching us from above, having a good time with his mother and his friends (Osaka).
- My mother-in-law (95) was a strong supporter of JSDD and always carried her membership card with her. About 1-2 years prior to her death, she was showing physical decline and early symptoms of dementia. Her biological daughter, who had been in rare contact until that time, came and started meddling with medical treatments and her living environment. However, the doctor and other professional staff in the facility who possessed her LW calmly took care of this chaotic situation. As a result, she was able to make her last departure peacefully in her sleep. Without the presence of JSDD and its membership card, we would have had to go through a terrible battle among all the family members and relatives. This piece of paper became a bond between my mother-in-law and me, like glue that closely held us together. I want to give her my deepest thanks once again (Saitama Prefecture).
- My husband (78) was always talking about JSDD to our family and his friends. About a month prior to his death, he had recommended JSDD to people attending a meeting. The people to whom he recommended JSDD came to his funeral and were shocked to find out he died unexpectedly from a brain stroke. He had a wonderful departure just like he wanted to have. I said to him in front of the Buddhist altar, “You died peacefully just as you wished. I hope you are happy,” and then found myself being in good spirits. (Chiba Prefecture).
- When my father (92) fell down at home and was taken to the hospital in an ambulance, the doctor said that his heart had stopped so we needed to resuscitate him. I realized that he was a JSDD member and had a LW, so I told the doctor. The doctor seemed surprised, but then rushed to the operating room and told the medics to stop the resuscitation. Two months have passed since he died. I still have a mixed feeling about refusing a life prolonging measure for him, but I remember that he was smiling when he signed his JSDD membership card (Hyogo Prefecture).
- The fact that my mother (71) had a choice of her end-of-life medical care turned out to be the best driving force for her to live the best last moments of her life (Tokyo).
- When I showed my JSDD membership card to my doctor, he said, “That’s great. My mother was a member too.” Thanks to JSDD, I was able to communicate smoothly with all the medical staff during treatment (Tokyo).
- I don’t know how to explain in words, but this piece of paper (LW) made the biggest difference in the world for my mother (79), who died gently and peacefully, unlike my father who didn’t have a LW (Tokyo).

- My husband (88) was a German philosophy professor. When he caught a cold, it triggered a pleural effusion and aggravated anemia. His young attending doctor was so focused to try to find the cause, to whom he said, “This is simply the infirmity of aging.” He refused medication and expressed his wish to go home. He lived the last twenty days of his life at home, and died beautifully with his eyes closed (Kyoto).
- It might have been too early, but when I was 66, and my wife was 61, we became JSDD members. Shortly after, my wife was diagnosed with Alzheimer’s disease. It was a relief to know that we were JSDD members (Kanagawa Prefecture).
- Six years ago, my mother (92) had a stroke and fell. We knew she had a LW, but we all wanted her to receive all available medical treatments, and she was forced to be in and out of the hospital repeatedly. We knew what her LW meant, but once we faced this situation, our wish for her to live longer became stronger. We knew this was against her wishes, but we hope that others can empathize (Ehime Prefecture).

Contributions made by the LW

Every year, we conduct a survey with cooperation from the surviving families to find out how the LW contributed to their loved ones’ deaths. The 2016 survey received responses from 910 surviving families.

Chart 1: 773 patients (85%) submitted their LWs to the doctor.

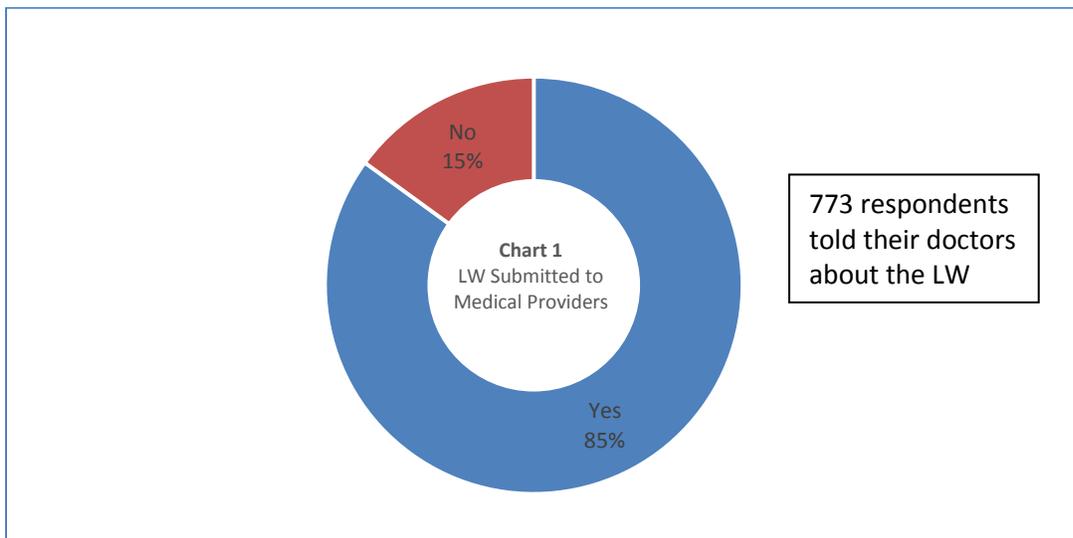


Chart 2: 60% of LWs were fully honored; 31% were somewhat honored.
 91% of the respondents admit the LW's contribution to patients' medical care.

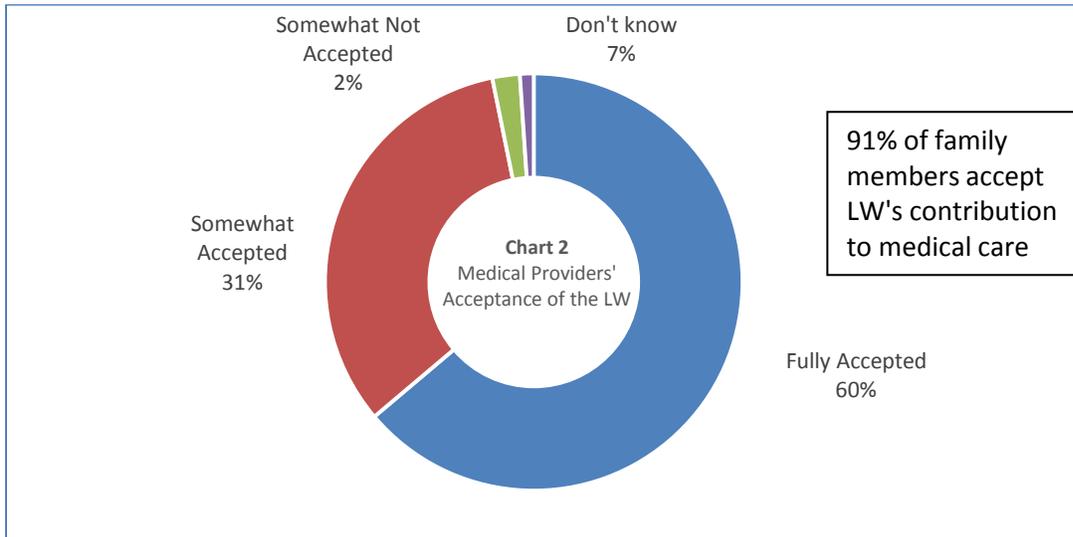
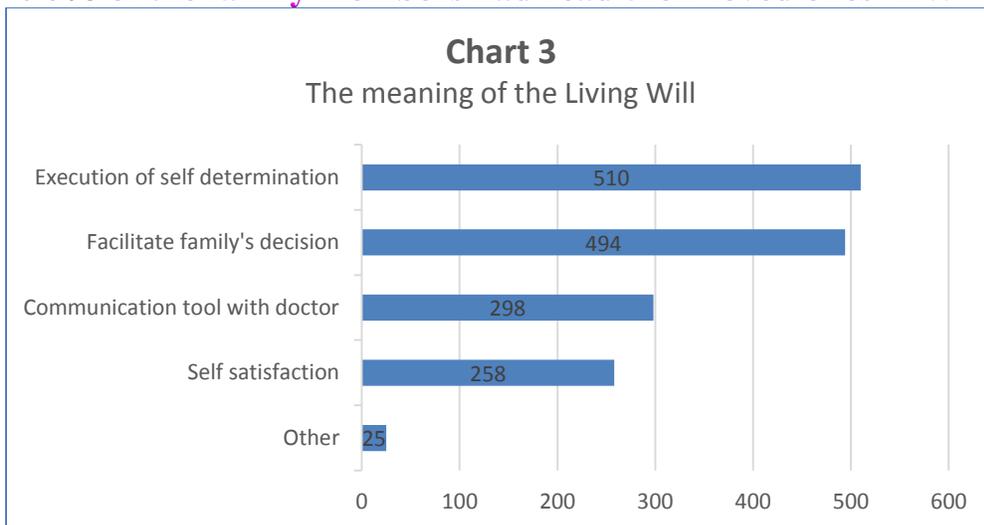


Chart 3: This time, we asked the surviving families what the LW meant to them.

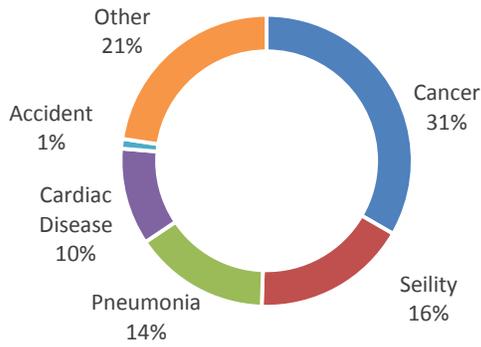
Responses:

- We felt like we understood our loved one's wishes (510 responses).
- We were able to execute our loved one's wishes in terms of terminal medical decisions (494 responses).
- The LW functioned effectively to facilitate our communication with the doctors (298 responses).
- Our awareness of having the LW allowed our loved ones to spend their remaining days in peace (258 responses).

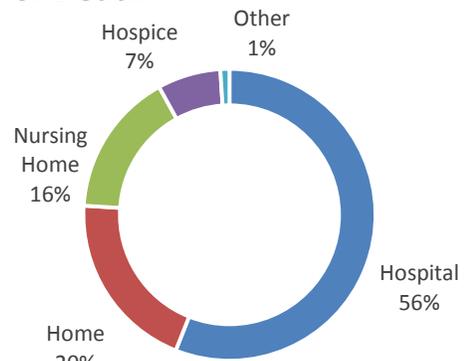
“96% of the family members had read their loved ones' LW”



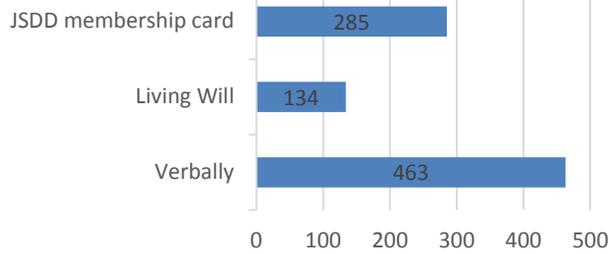
Cause of Death



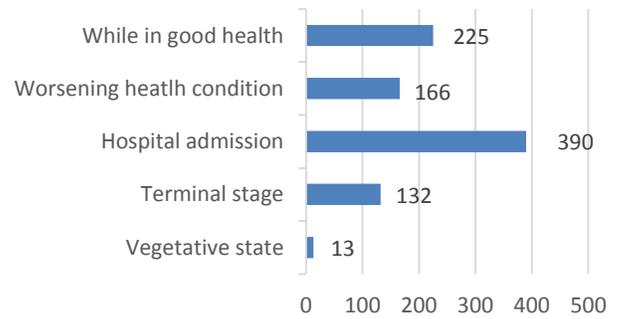
Place of Death



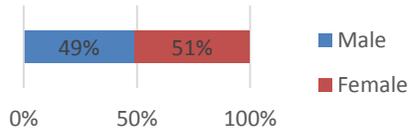
Submission Method (multiple answers)



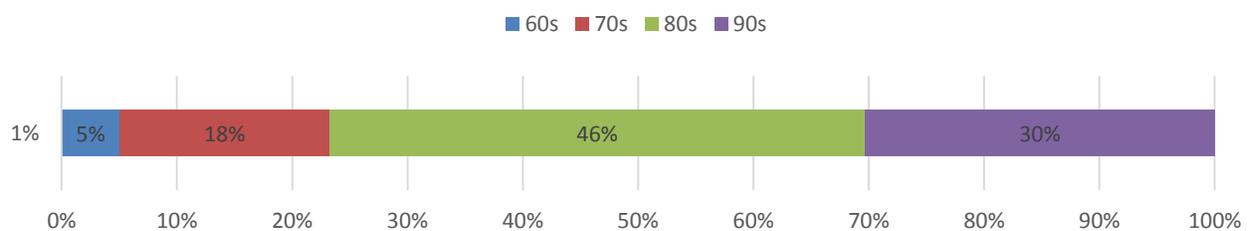
Submission Time (multiple answers)



Gender Breakdown



Age Breakdown



Our deepest gratitude to the surviving families for participating in our survey!

LOCAL CHAPTER ACTIVITIES IN 2017

The 3rd Living Will Study Shikoku Local Workshop by Shikoku Chapter Happy Ending of Life through Intimate Communications among Family

Shikoku Chapter (led by Mr. Masahiro Nomoto) held its 3rd Living Will Study Shikoku Local Workshop on February 12th (Sunday) at the Chikamori Hospital Conference Room in Kochi City. Kochi Prefectural Medical Association and Dental Association cosponsored this event with the theme, “How to end your life with “Thank you, I had a great life.” The room was packed with 140 people as audience, needing extra chairs to seat everyone.



The guest speaker was JSDD Vice President, Dr. Kazuhiro Nagao, who discussed the current terminal medical care being controlled by family members’ wishes rather than the patients’. He also showed a video of a celebrity’s terminal care as an example.

He said only 5% of the population die from “pin pin korori,” which means a healthy person dying suddenly with no suffering, and that 95% of people actually must go through a terminal process. He advised the audience, “During terminal stage, treatment based medication should be withheld, and more gentle palliative care must be implemented. That is what I call death with dignity.”

At the panel discussion, Dr. Okabayashi of Kochi Prefectural Medical Association introduced the official view of Japan Medical Association that legalization must be approached very carefully, as it may end up restricting patients’ rights. He said what must be done before the legalization is firmly establishing a thorough ground for terminal medical care based on honoring the patients’ wishes such as the living will, and a thorough practice of specific guidelines issued by the Ministry of Health, Labor and Welfare and Japan Medical Association.

Several other professionals expressed their views from their respective perspectives: Dr. Tsutomu Matsumoto of Aozora Clinic from a physician’s standpoint; Ms. Komatsu of visiting nurse station Tosa from a nurse and a care giver’s standpoint; Ms. Tsutsui of Kochi Prefectural Autonomy Study Center from a public benefit corporation standpoint; and Mr. Ueda, Shikoku Chapter Director from a patient’s standpoint.