

Excerpts from



**Japan Society for Dying with Dignity Newsletter
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**2018 SURVIVING FAMILIES SURVEY RESULTS:
93% OF LIVING WILLS (LWS) WERE HONORED**



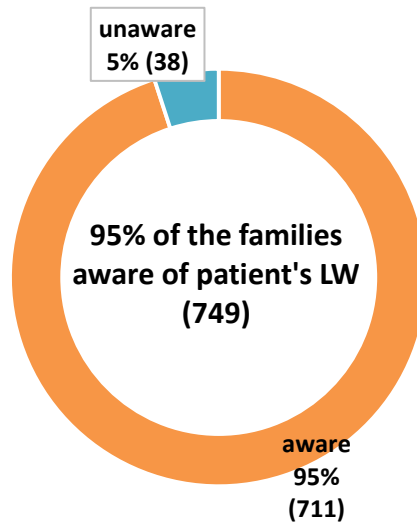
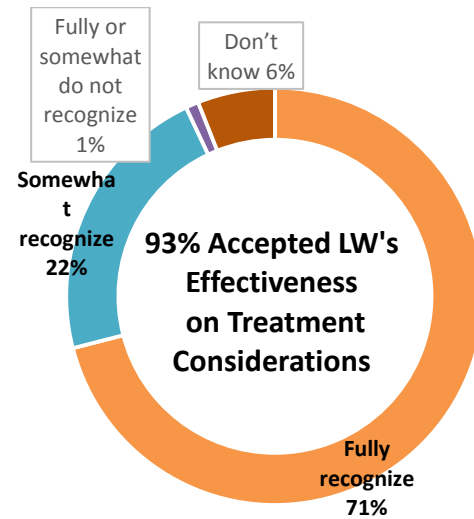
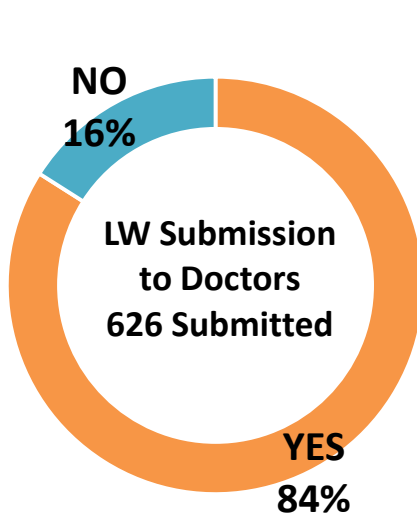
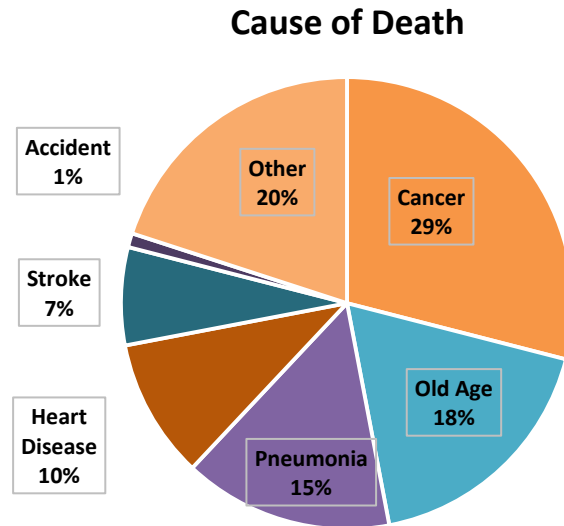
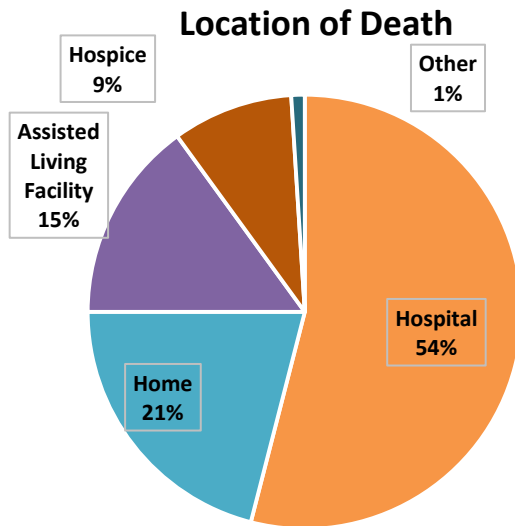
The role of the Living Will

Every year we conduct a survey to assess the effectiveness of the LW with cooperation from the surviving families. In 2018, we received responses from 749 families, of which 626 respondents (84%) had submitted their LWs to their medical providers; 71% responded that LWs seemed to be fully honored; 22% answered that it was somewhat honored. Overall, 93% of all surviving families recognized the effectiveness of the LW.

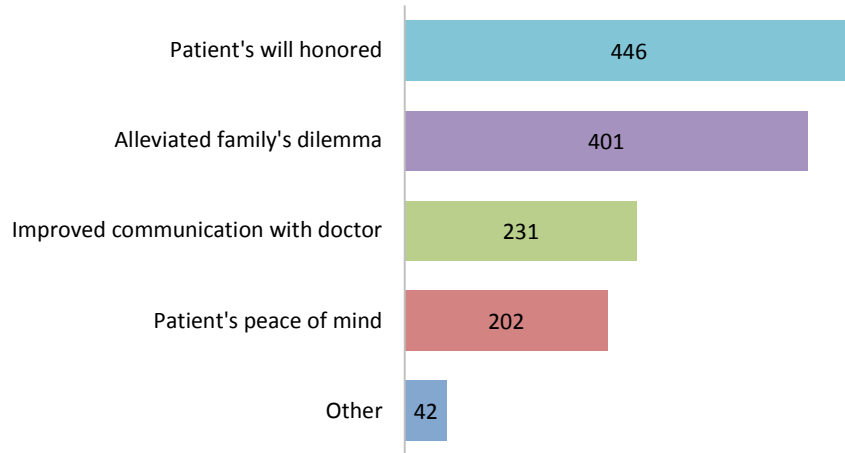
The following results are from the survey we started two years ago questioning, “What does the LW mean to your family?”

446 responded that they were able to achieve and satisfy the patient’s will; 401 responded that the LW made it easier for the family to make the patient’s medical decision; 231 responded that

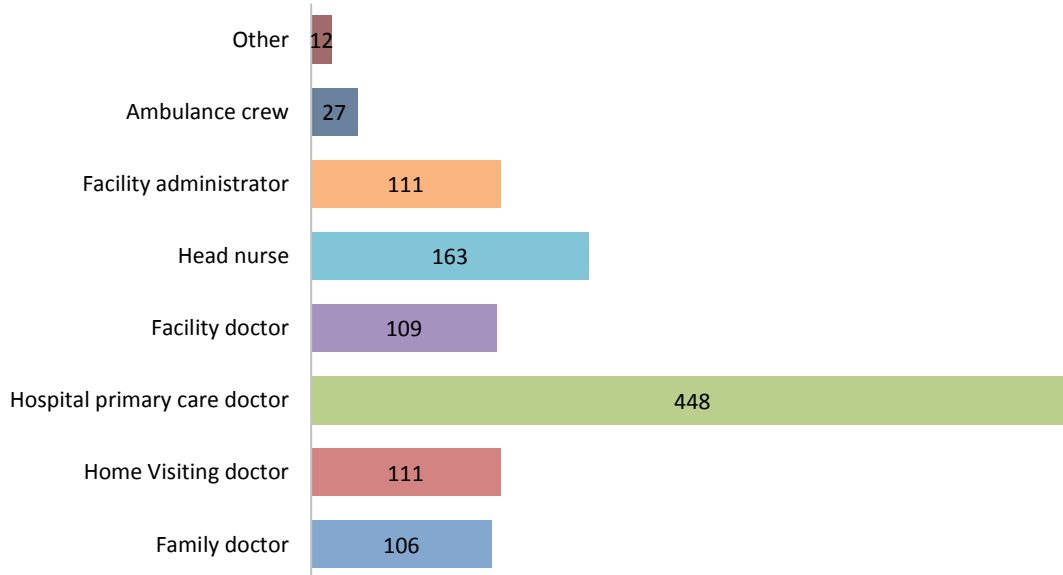
the LW facilitated their communication with the doctor; 202 responded that the patient was able to live his/her last moments in peace because of the LW.



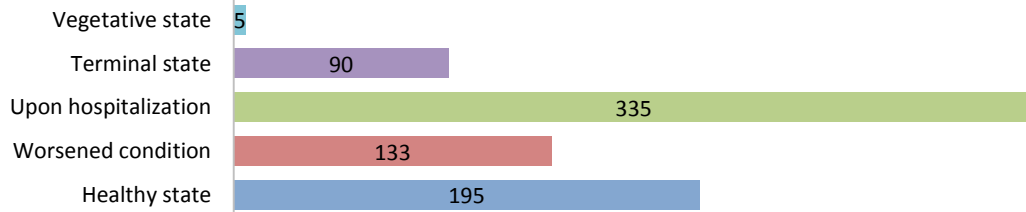
LW'S ROLE (MULTIPLE ANSWERS)



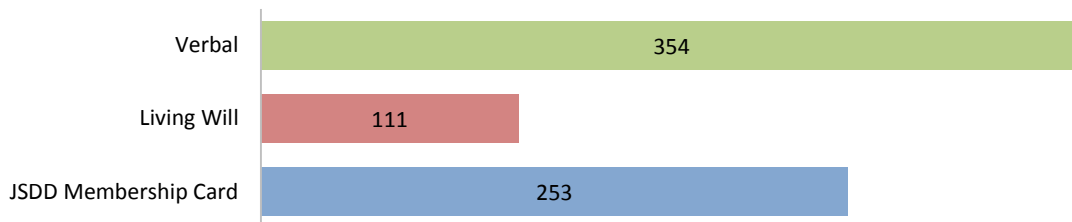
LW SUBMISSION DESTINATION (MULTIPLE ANSWERS)



LW SUBMISSION TIME (MULTIPLE ANSWERS)



LW SUBMISSION FORMAT (MULTIPLE ANSWERS)



Surviving families find peace and relief

Below are some voices from the surviving families:

My father was a JSDD member. It did not just mean that he refused life prolonging measures, but it also meant that he gave me courage and confidence to face his death. -an eldest daughter

It is not just a lip service, but a proof of magnitude to be a JSDD member. -an eldest daughter



- My husband (75) was determined to have his terminal care at home. We presented his LW and wish list to the home doctor and discussed it with him. The doctor confessed that this was the first time he received such documents, and said later that he could take better care of my husband because his wish was clearly confirmed by the documents. The doctor and his care team treated my husband with compassion in accordance with his wish list. (Tokyo)
- My wife (82) died as she wished, and as her husband and family, we accepted her death with peace. However, as time went by, we found ourselves in more grief, emptiness, doubt, as well as regret of not welcoming her wishes earlier. Both my wife and her family clearly wished her to die with dignity*, but when that wish became reality, our hearts were broken. We recognized the difficulty of facing this decision, which was a lot harder than we expected. We are convinced that having a clear declaration of dignified death* was the greatest support for the surviving family members in alleviating some pain and confusion during this difficult time. (Ibaragi prefecture)
- My husband (82) died a natural death. All his family members had read his LW and were fully aware of what he wished for, so no one mentioned any life prolonging measures. However, someone told me, “I will never join JSDD no matter what because I want the latest and the best treatment and care available. If I become a member, I would never receive the latest and the best treatment and care.” I realized that everybody has a different view. (Tochigi Prefecture)
- My husband (93) who died peacefully in his sleep had left me this letter 15 days prior to his death. It said, “My life has been full of ups and downs, but I have somehow overcome various troubles and hardships. I feel truly lucky and happy. There is a saying that if the ending is good, all is good. I thank you all.” (Tokyo)

Remarks: *The expression used in this entire newsletter such as Dying with Dignity or Dignified Death do not refer to active euthanasia commonly used in Europe and USA. This expression in Japan refers only to passive euthanasia such as refusing life prolonging measures.



For my husband who was a clinical doctor, the LW was the foundation on which his heart rests for a long time. - a wife

We have no words but to express our appreciation for the way the doctor treated my wife and honored her wishes in accordance with her LW – a husband

My husband had told me that his JSDD membership card was his identity to prove his aesthetic mind – a wife

- When we received the upcoming medical treatments from the doctor, we told him that my husband (83) was a JSDD member. The doctor nodded quietly. My husband always said to us that he was going to die suddenly without having any pain. I now feel like he's telling me, "See, I told you!" - (Ibaragi Prefecture)
- My husband (81) was a pharmacist. He took every chance to explain to me and his customers what LW was. He disseminated pamphlets that he made and often gave lectures to spread the concept of LW. His ideal way to die was a sudden death without any pain. He actually died only one day and three hours after becoming ill. I want to tell him, well done! – (Okinawa Prefecture)
- When my husband (87) suffered an acute fever and was hospitalized, I noticed the bulletin board that said "To JSDD members: If you do not wish to receive excessive life-prolonging measures, please come to the admission window." This was exactly what we wanted, so we were so glad and relieved. (Aichi Prefecture)
- We were overwhelmed by the strength of her will power (56). She would have survived her breast cancer if it was detected earlier. Unfortunately, she had to accept it and endured its pain and didn't disclose the news to her family until she was in terminal stage. We did everything as she wished for in her LW including her funeral service. We just wished that she could have lived longer. (Kanagawa Prefecture)



- Medical providers, medical facility, and all the family members knew and understood the wishes of my mother-in-law (88). However, her biological children living in distant places requested to let her live as long as medically possible. As a result, they administered her life prolonging measures. Of course, we all wanted her to live longer, but I wanted to say, “Please stop her pain and suffering now.” Unfortunately, it wasn’t my place as her daughter-in-law. (Toyama Prefecture)

Thank you for your cooperation if you participated in this survey.



ACTIVITY REPORT

KANSAI CHAPTER:

Two doctors’ lectures a great success

On Saturday, February 2nd on the 5th floor of the Grand Hall at Nara City Central Public Hall, a special public lecture event was held in commemoration of Nara Chapter. It was a successful event with over 300 participants.

This event had two main purposes: one was for JSDD to provide the information services that was tailored to the needs of specific local community in order to enlighten and materialize the concept of the LW and death with dignity. Dr. Nobuyuki Miyagi, the first president of Nara chapter, first made a speech with the title “Living Will: an ounce of prevention is worth a pound of cure.”

The other purpose was to deepen the understanding of the concept of ACP (Advance Care Planning), which is a way of determining your terminal medical care by repeatedly discussing all possibilities with all parties concerned. How is ACP different from informed consent or planning conducted in assisted facilities or at home?” a visiting nurse questioned from a specific work perspective. Dr. Nagao, vice president of JSDD, made a speech on “Life Planning Conference: the ACP,” and highlighted some disputable points. The ACP’s center of gravity is the patient’s will. What is important is the process that involves time dedicated to communication, he emphasized.

Kanto-Ko-Shin-Etsu Chapter

Audience deeply nodded to two doctors' lectures

On Saturday, March 2nd at Sonic Citizens' Hall of Omiya, Saitama City, two key speakers presented their lectures during this public event. Dr. Yutaka Suzuki, vice president of JSDD lectured on "How to welcome the end of your life peacefully," who gave a specific example of a famous TV script writer, Sugako Hashida to explain the difference between dignified death and active euthanasia. He also pointed out the changes in our fast paced society in which we do not have the opportunity to learn about what death is all about.

Toshiyuki Sugiura, a clinical physician in Kawaguchi City, and the director of its chapter, gave his speech on "How to complete your life peacefully in the community where you grow roots." Dr. Sugiura, who is also an in-home terminal care doctor, explained the difference between ordinary healthcare through home visitation vs. in-home terminal care by providing details of medical care, as well as advantages and disadvantages of each respective care. No matter what treatment and care the patient and family choose, there is no way to avoid death. Since it is often inevitable to leave behind regret, grief and sorrow, it is important to remember the following: (1) it is healthy to openly discuss death; (2) establish a relationship with your primary care physician; and (3) talk about your ACP with family and close friends as often as possible in your everyday life.

Over 160 participants in the audience nodded and seemed fully convinced by these two speakers.

Tohoku Chapter

Registry of dignified death and legal document: your Last Will and Testament

According to mass media, an increasing number of people are preparing to notarize documents expressing their will for end of life. We hear many voices from Japan National Notaries Association. Are notarized documents better and have more merit than the LW issued by JSDD? Is this just a recent phenomenon?

We had a serious debate in January at the "Sendai LW Communication Exchange," discussing the difference between the JSDD Living Will registry and other notarized documents. We did not expect a large audience due to the level of legal expertise seemingly required by the topic, but we found out that there was a lot of interest and concern on this matter on the contrary. One participant, a former college professor, complained about being charged ¥400,000 for notarizing his documents.

The discussion concluded that notarized documents were best for matters such as estate distribution, but the LW registry is much more valid and effective for honoring the patient's will regarding dying with dignity and ACP agreed by all family members, not to mention more convenient and less costly. Everyone agreed that it is a much superior product as a whole.
-Chapter President Hashimura

Chugoku Chapter

This lecture's title was "What does old age mean to you?" Over 100 participants filled the hall. The details of the lecture is on our Chapter's homepage; however, we would like to introduce some of the comments here:

1. As I am now in my 80's, I feel like I can think and decide for myself how I would like to live the rest of my life.
2. I wish to see more doctors registered in the LW supporting physicians system.
3. My target is to visit the Osaka International Exhibition that is coming after the 2020 Tokyo Olympic.
4. I received many advices about the LW on a broader scale.
5. Please have another lecture like this soon because I would like to bring my friends.
6. As I am now considered an elderly person, the contents of the lecture deeply penetrated into my whole body.
7. I was so relieved to hear a wonderful lecture endorsed by positive results.
8. Thanks for the wonderful lecture. I can now start living my life each day as a gift.
9. I brought my mother with me. I hope that she has a better understanding of the ACP.
10. I feel a great joy in living. I was able to grasp facts and reality in a delightful lecture.

58% of the comments column was filled, which is a record so far.

-Chapter President Masaki

Tokai-Hokuriku Chapter

Let's talk about ACP

5th Japan LW Workshop Tokai-Hokuriku Regional Forum was held on November 25th last year at the Aichi Prefectural Medical Association Grand Hall. The theme was ACP, which has recently been highlighted as important as a national policy. The attendance this year was 127 people, nearly 50% more than last year. Dr. Iwao, president of JSDD was also present. Dr. Mitsunori Nishikawa of National Center for Geriatrics and Gerontology was the lecturer. He emphasized that ACP places heavy weight on the patient's sense of value, and the doctor is merely the executor. Another lecturer, Dr. Ryota Mori of Nagoya City, an in-home terminal care

doctor, said that ACP is not just something of the medical community, but has to be addressed and rooted in the patient's social community.

Someone from the audience mentioned that ACP is an abbreviation of the English term, Advance Care Planning, and that not many Japanese people would understand what it is. We need a simple and concise term in Japanese to be understood by everyone.

The Ministry of Health, Labor and Welfare officially announced on November 30th, five days after this event that ACP will also be known as "Life Planning Conference" (in Japanese).

The attendees consisted of 30 JSDD members, 87 non-JSDD members, and 10 doctors.
- Chapter President Tsukasa Kobayashi

Shikoku Chapter

Necessity for Advance Healthcare Directive

On February 3rd, Kochi Lecture Meeting was held with the topic, "How to prepare and ensure that end of life medical care provided is based on the patient's wishes." The speaker was Mr. Tatsuhiko Kitamura representing Kochi, and Vice President of Shikoku Chapter. He explained that the Ministry of Health, Labor and Welfare recently took a big step forward by implementing terminal medical care programs such as the "community total care system" and propagating the concept of ACP by calling it a "Life Planning Conference." In response to this movement, he asserted that it is necessary for all citizens to decide how they want to live the rest of their lives and how they want their end of life to be, and then to prepare an advance health care directive accordingly.

Later during the round table discussion, all attendants were requested to fill out their wish lists about their end of life instructions and terminal medical care requests.

On the same day, a public meeting sponsored by Gender Equality Promotion Center was held. Dr. Masahiro Nomoto, Shikoku Chapter President made a speech titled "How to die without suffering or putting a strain on your family." He explained the current status and guidelines on terminal medical care established by the Ministry of Health, Labor and Welfare, as well as ACP or "Life Planning Conference," emphasizing the importance of close and repeated communication with family, relatives and close friends.

Kyushu Chapter

Visiting Lecturer Program implemented in Miyako Jima

On February 22, upon request of a JSDD member in Miyako Jima, the Visiting Lecturer Program was finally materialized. The title was “How to support self-determination of elderly and dementia patients: how to provide terminal medical care and confirm patient’s will?”

The lecturer, Dr. Uema, addressed from his own experiences in providing terminal care and in-home care how difficult it is to determine patients’ terminal stage based on the illness and whether the medical judgement was correct. He also explained the ACP and introduced the “Living Will Notes” at this event. This was a great opportunity for attendees to become familiar with JSDD, especially for healthcare professionals who support in-home care in Miyako Jima.

ACP (ADVANCE CARE PLANNING) NEWLY KNOWN AS “LIFE PLANNING CONFERENCE”

Living Will is absolutely necessary



In November 2018, ACP (Advance care planning) officially became known as “Life Planning Conference.” ACP has been promoted in the medical world, but unfortunately it has not been well known among the main population. The Ministry of Health, Labor and Welfare decided to rename it to appeal more to the general public and selected “Life Planning Conference” from a list of possible names. How is “Life Planning Conference” different from the Living will, and what are its uses?

Q – Please explain what an ACP is.

A – ACP is the frequent meetings the patient has with family members and medical providers in advance regarding his or her remaining life and in case something happens, and to plan on medical treatment and care with the purpose of supporting the patient’s wishes. The contents describe in detail how and with whom the patient wants to share the rest of his or her life and the type of medical care to be received. The patient’s sense of value has to be on top priority which must be determined through repeated discussions. An ACP was a term used only among medical professionals, but others started using the same term in the recent years.

Q – Is it true that the term “Life Planning Conference” was adopted to popularize the concept of ACP?

A – Yes, the purpose of renaming the term ACP was to appeal more to the general public by providing an image of the patient, family, and medical providers getting together to share and

exchange opinions and come up with the best atmosphere for the patient together. This term was proposed by a registered nurse from Hamamatsu City to reflect a more comfortable and caring environment.

Q – Is it true that a certain day will be designated as the national Life Planning Conference Day?

A – Yes, November 30th will be officially designated as the national Life Planning Conference Day. The number 11 is associated with something good, and 30 is associated with nurturing in the Japanese culture, so 11/30 is the day we all think about terminal medical care. Of course, the New Year holidays and Obon festival days (in Buddhism) when all families get together would be a good time to have this planning conference about your life. We strongly recommend it.

Q – How is the Living Will issued by JSDD different from Life Planning Conference?

A – Living Will is a voluntary expression of your self-determination such as not wanting to receive excessive life prolonging measures, or wanting to receive full amount of palliative medical care to alleviate pain. On the other hand, Life Planning Conference is having communications with those in your life from a much broader aspect to guide and confirm what kind of care the patient wants to receive and not want to receive.

By the way, JSDD added another clause to the LW designating a witness and an agent last year. Furthermore, an additional document called “My Wish List” is included in every JSDD newsletter to be completed and kept in your custody. “My Wish List” can be modified as often as needed as you change your mind. JSDD issued another document called “Living Will Notes” in which you can describe in your own words very specifically how you want to live the last part of your life.

Q – Is it correct to say that the living will itself is also revolving to be suitable with the changes in our society?

A – Yes, it is. You’re not choosing either the living will or the Life Planning Conference, but the living will must be prepared first because you have to express your own wishes before you can discuss them with others. If you do not express or clarify your own wishes first, having a conference may be misguided against your will or you may be hesitant to express your own wishes in front of them. Your wishes may not be the same permanently and change, too. Therefore, confirming what you express is very important.



Picture: "Living Will Notes" issued by JSDD last January. It has many blank spaces to write down topics such as how you want to spend the last part of your life and what you wish when you are unable to feed yourself, etc. Please keep a copy near you at all times.