

Excerpts from

Japan Society for Dying with Dignity Newsletter
No. 189, April 1, 2023

Main Contents:

- Results of the 2022 “Surviving Family Members’ Questionnaire”
 - Medical consultations by phone and email



Results of the 2022 survey of surviving families
95 percent of the respondents reported that Living Will was helpful.

Every year JSDD conducts an annual survey to the surviving families of deceased members to determine if our Living Will was honored by medical professionals. The results from last year's survey are as follows. JSDD will listen to these various voices and make use of them in future promotional activities.

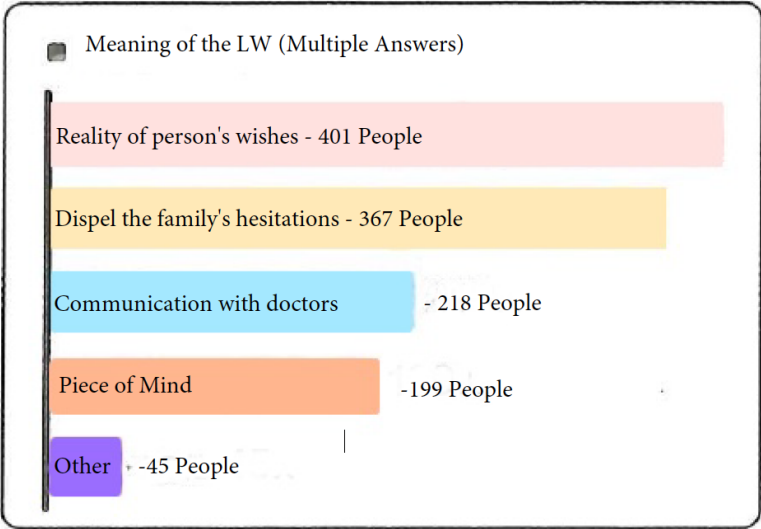
98% of the respondents listened to Living Will on a regular basis.

In the 2022 Survivors' Questionnaire, we received many comments on the gap in knowledge of the Living Will among medical professionals and their desire to provide grief care for the remaining family members. Many doctors, who are officers of the Japan Society for Dying with Dignity's headquarters and branches, have been enthusiastically communicating the significance and importance of the Living Will to medical professionals at lectures and medical education events in the region. However, it seems that this is still insufficient. However, it is also true that little by little, through such steady efforts, an environment that agrees with the Society's aims and respect for the Living Will is spreading.

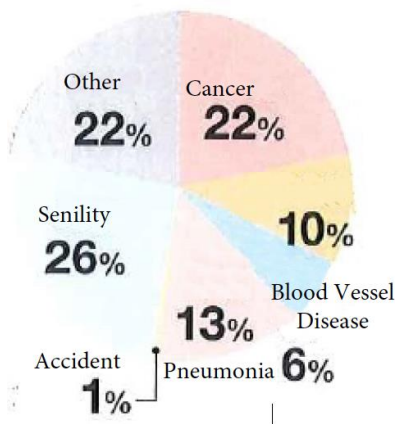
Many of the canvasses we have received strongly show that even when a departed person has achieved the dignified end that they had wished for, the remaining family members still feel a sense of satisfaction and pride, sadness, and regret. We recommend the Japan Society for Dying with Dignity's Small Lighthouse Project website. This is a healing site where like-minded friends can share their experiences and thoughts, support each other, and also help in terms of peer support (parties and occasions of the same suffering supporting each other.)

In 2022, 669 people responded to the survey: 557 (83%) presented the Living Will to their healthcare provider, 72% thought the Living Will was well accepted, and 23% thought it was rather well accepted. 95% of surviving families felt that the Living Will was practical. The graph below shows their answers when asked what the Living Will meant to their families.

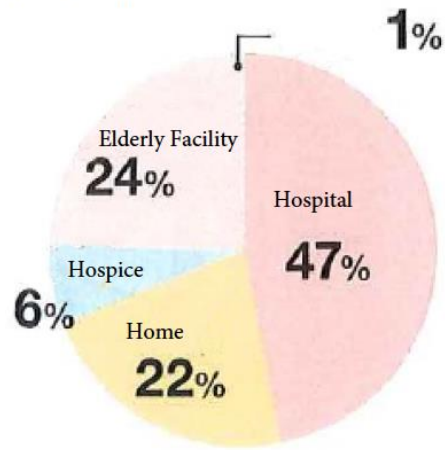
We also want to express our deepest gratitude to those who took the time to complete the survey in their time of profound grief.



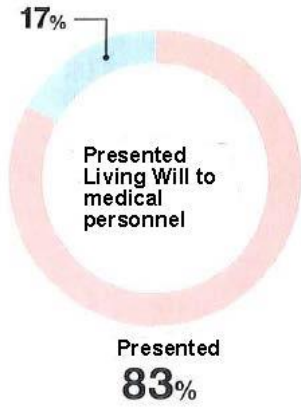
■ Cause of Death



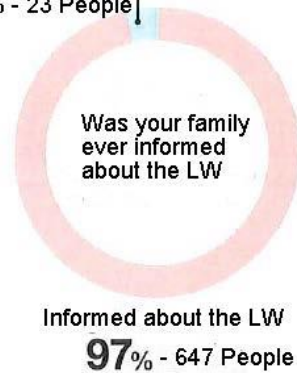
Place of Death

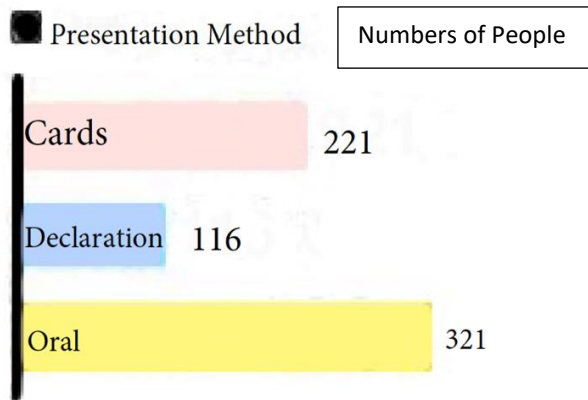
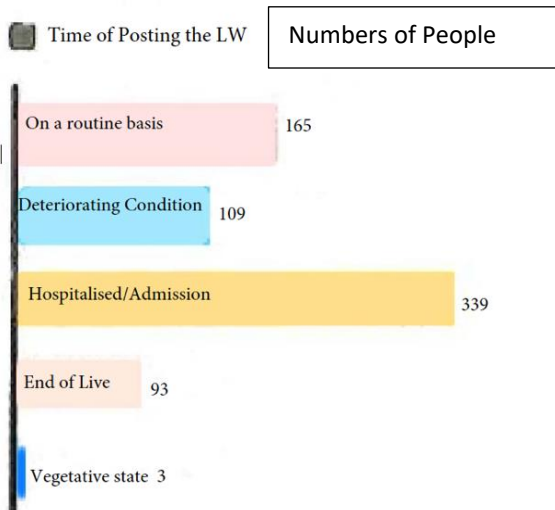
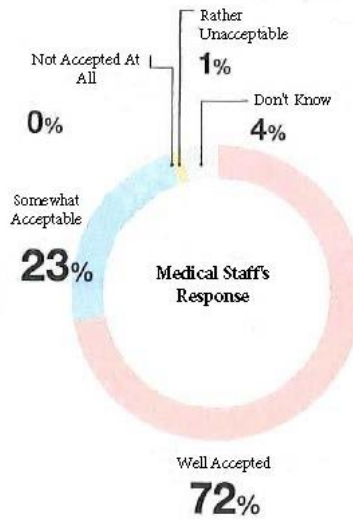
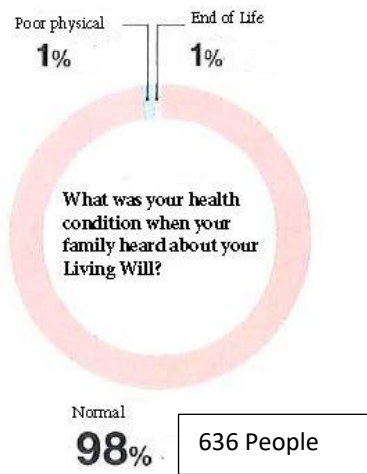


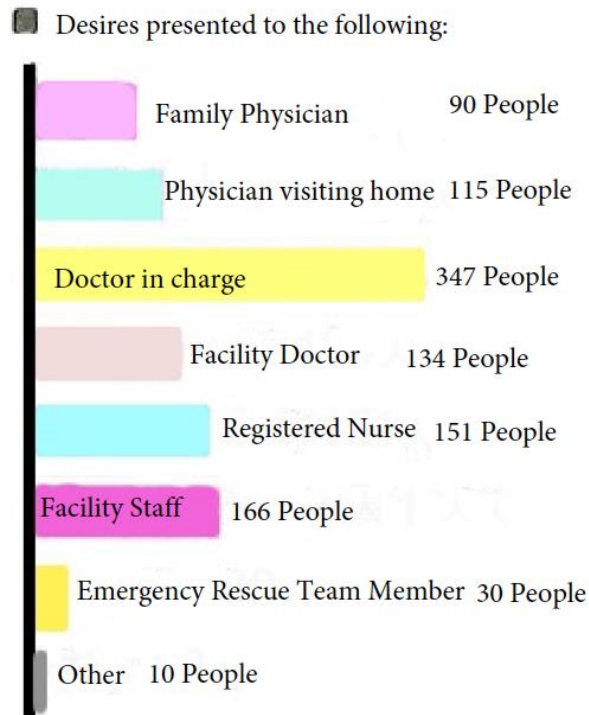
Not Presented



Were not informed about the LW
3% - 23 People







Followings are the received comments from the surviving family members.

“As a member, I was able to smoothly communicate my mother's wishes in various phases of the process. “I said “Thank you” to my membership card for watching over my mother, 92, her daughter, and me, for a long time.” (Kanagawa Prefecture)

“Decisions came suddenly and required a quick decision. However, my mother, aged 86, joined the Japan Society for Dying with Dignity to reduce our family's regrets and sadness.” (Fukuoka)

“Although I have regrets about the loss of my mother (93 years old) and what I should have done, the relief and satisfaction of fulfilling her wishes is a source of great pride. The fact that my loved one passed away with satisfaction gave those left behind the courage and hope to go on and gave me the opportunity to think about my own final days without fear.” (Akita)

“It helped me to communicate my aunt's (96 years old) wishes. This is especially necessary in the case of institutionalisation. Being a member of the JSDD gave me the opportunity to talk with my aunt on a regular basis about what she would like to see happen, and it also helped me to gain an understanding of the home visiting doctor and the contract doctor at the facility.” (Tokyo)

“My mother (86 years old) had seen her own mother's last days about 40 years ago when she was kept alive on a ventilator without consciousness and gradually began to necrosis here and there, and she said she wanted to avoid that. At that time, I found out about the Japan Society

for Dying with Dignity (JSD) and joined, and told them about my mother's wish to eat by using her mouth until the end of her life and her wish to die at home at the end of her life, but in the end, I could not fulfill either of her desires." "In the last years of my mother's life, I had told the doctors about her Living Will, so when we discussed her treatment and recuperation policy, the doctors would come up with a policy in line with her wishes. Still, I felt paranoid, as if I was being led towards terminating her treatment early. I was scared that one of our decisions could cause my mother to suffer or even determine the end of her life. I had talked with my mother about deciding what she wanted to do at the end of her life, but when it came down to it, it wasn't as simple as that, and it was as difficult as if we hadn't decided anything at all." (Tokyo)

"I took care of my mother (101 years old) at home. The years of reading articles and memoirs in the Japan Society for Dying with Dignity newsletter and practicing and preparing myself for end-of-life care were important and necessary. Now it is our turn. I don't know what will happen now, but I would like to become a life member and repeatedly build up my knowledge of how to face the coming death by reading the JSD newsletter and other information and use them as references." (Hiroshima)

"When I, an administrative secretary, was appointed guardian of a person. A card and a Living Will were found in the person's (85 years old) belongings. I presented it whenever I was notified of the person having cancer at the palliative care place or the emergency transport place; the doctors understood completely. It was helpful for both the guardian and the person themselves, as no facility would give medical consent concerning a person without relatives." (Kanagawa)

"My husband (87 years old) was able to enjoy his senior years fully, perhaps because he had the security of being a member of the Japan Society for Dying with Dignity (JSD)." (Chiba)

"The farewell to my husband (88 years old) was painful and sad, but his chosen end was admired by the younger generation, who saw him off with loud applause and cheers." (Tokyo)

"We discussed how we should live our final days and joined the Japan Society for Dying with Dignity together. Three weeks after our golden wedding anniversary, my husband (80 years old) collapsed from aspiration pneumonia, and the doctor asked him, "What are you going to do?" I was surprised when he asked me, "Your husband was talking about this!" I immediately understood, told him about the Japan Society for Dying with Dignity, showed him my husband's signature for refusal of life-prolonging measures, and asked him to do nothing and wait for a quiet departure. We were able to spend 20 peaceful days before he passed away." (Tokyo)

"When my father (89 years old) was first admitted to the emergency department, he received antibiotics and intravenous fluids. Still, his condition gradually deteriorated with no signs of recovery. As a family member who saw him frowning and suffering during regular phlegm suctioning, we felt strongly that we did not want him to go through that anymore. From the time of admission, we informed them of the JSD Living Will and asked the doctor in charge to let him have a peaceful end. The doctor was receptive to my wishes, and I was able to

see my father die peacefully and with no regrets. I have told my relatives and acquaintances about our experiences concerning the Society's Living Will, but unfortunately, they have not yet decided to join.” (Aichi Prefecture)

“My father (91 years old), after his family informed the doctor of his wish for dying with dignity on his behalf, my father said, “Don’t think that you let me die. Don't even think that I might have wanted to live longer.” He said that he wanted to die with dignity, and that is why he joined.” (Tokyo)

“When my mother (91 years old) was admitted to an elderly care facility, despite her having a Living Will, it was highly stressful to be asked again and again to confirm her and her family's wishes.” (Osaka)

“I knew the term “dying with dignity” but did not know such a society existed. I don't know how my elderly aunt (89 years old) found out about the Japan Society for Dying with Dignity and made the decision to join, and I am impressed. I wish more people had the opportunity to know about the Society.” (Hokkaido)

“In my house, we have kept the JSDD newsletter for several years, and they have been beneficial. I read through all the back editions when I had to decide on my mother's (91 years old) future plans. It was a very reassuring connection because it was multi-faceted and contained a variety of authentic voices and information.” (Ehime)

“A Living Will allows me to pass away with a peace of mind.” (Tokyo)

“Because my mother (81 years old) was a member, we were able to smoothly communicate her wishes in various situations, such as emergency hospitalisation and admission to an elderly care facility after her discharge from the former. When her health deteriorated at the facility, it helped us to make the decision to ask her to be cared for in her room at the facility instead of being transferred back to hospital.” (Miyagi)

“When my husband (94 years old) was admitted to hospital, I presented my Japan Society for Dying with Dignity membership card, and they immediately understood. During the last days of the Covid-19 Disaster, they warmly supported my husband and me by enabling us to exchange diaries, bring him delicacies, and talk on the phone. My husband's own phrase: “The last pen is complete, and I wanted to write it, the winter galaxy.” Saying goodbye to my companion is the ultimate in sadness, but I am protected by my husband's spirit and supported by my friends. In my husband's departure note, which I found later, he wrote: “It was a happy life.”

“I am now explaining the Japan Society for Dying with Dignity to my friends.” (Hokkaido)

“In 2017, my father, who had been suffering from repeated intestinal torsion, had a hole in his intestine, and the doctor told him he had 20 minutes to decide whether to have an operation or not. He was told that if he did not have the operation, he would die in about three days, so he asked for the operation. It was a major operation for a man over 90 years old, but somehow it was successful, and he was fitted with a colostomy. After the operation, he seemed to be in a

lot of pain, and my father, who was very patient, repeatedly said he wanted to die, so I wondered whether the operation a good idea. From this experience, my mother felt that it was too much to ask her family to make such a decision in such a short time, so she joined the Japan Society for Dying with Dignity. At the end of her life (90 years old), both the doctors and the facility accepted her wishes, and she was able to leave peacefully.” (Kanagawa)

“My father's mother was operated on for gastric banding even though she was unconscious and lived for ten years. My father's sister, who was forced to care for her, had a difficult time. Knowing this, my father (81 years old) said, “Don't prolong my life.” He always told us. “Don't prolong our lives because my wife and I feel the same way, so remember that.” At the end of his life, he entered a hospice and said, “I will die on 1 March, so thank you for all you have done for me”. The whole family is grateful to the hospice for protecting my father's dignity.” (Tokyo)

“Regarding the final days of my father (85 years old), both he and our family had always said that they wanted to avoid life-prolonging measures but, when it came down to it, my sister, her husband, and my mother had different opinions than me concerning my father. My mother, my sister, and her husband said, “Telling my father about his condition will discourage him from trying to live longer. My mother said, “It's okay to let the hospital take care of him. He would be happier if he didn't know anything about it.” I thought there was nothing crueller than prolonging his life in a situation from which he would not recover, so I finally persuaded them to respect my father's wishes.” (Mie)

“When my father (96 years old) passed away, I kept thinking about whether our way of caring for him was good or not. My mother also suffered from dementia, so those of us who lived outside of the prefecture, took turns going to my parent's house to take care of her. With the support of the local community, we took care of her, but my father, who had always been patient and calm, said many times, “I am tired of it. In reality, we all have our own lives, and our wishes do not always coincide.” (Iwate)

“My father (95 years old) collapsed on a road and was rushed to hospital, where he died ten days later. He always kept his JSDD membership card with him, so he was able to present it immediately to the doctor at the hospital, and the doctor understood his wishes.” (Kanagawa)

“My parents joined the Japan Society for Dying with Dignity about 18 years ago. When my mother passed away 16 years ago, I presented the Living Will to the doctor, and he said, “I didn't know this existed. I need to learn more about it”, but by the time of my father's death, they immediately understood. By saying goodbye to my parents, I felt that if they had not been members, I would not have been able to make the final decision.” (Hiroshima).

“When my sister's (85 years old) health deteriorated, I told the doctor at the local clinic that she was a member of the Japan Society for Dying with Dignity (JSDD) and that she did not wish to prolong her life; he gave me the impression that I was mistaking it for a new religion.” (Gunma)

“In the final days of my wife’s life (77), she had malignant lymphoma and I repeatedly told the doctors that I wanted to refuse treatment and move her to a palliative ward, but they did not accept my request.” (Hokkaido)

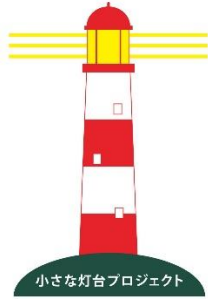
“My wife and I (aged 73) first came across the JSDD’s Living Will when our mother, who had been brain-dead for about four and a half years, died, and we told a doctor friend of ours how difficult it was, and he offered us a membership card to the Japan Society for Dying with Dignity and explained it to us. After hearing the story, my wife and I discussed it with our children and joined immediately. Five years later, in the middle of the night, my wife suddenly lost consciousness and was rushed to the emergency department. After tests, we were told that she had a cerebellar hemorrhage and that even if she underwent surgery, she would not recover and would probably continue to be brain-dead. The doctor said, “Okay.” I was touched by his compassionate response, saying, “Okay, let’s just take care of the pain and suffering. Fourteen days later, my wife passed away.” (Fukuoka)

“My husband (85 years old) suddenly became ill and was rushed to hospital in the middle of the night and presented his membership card to the doctor. The doctor immediately said: “I understand. We will meet your request. We will give him palliative care from now on. I will notify the entire medical staff concerning your decisions.” I said, “Thank you for your understanding.” The doctor said, “This is important.” I was relieved when he said, “I will do it properly.” (Ehime)

“While I was looking after and caring for my mother (94 years old), I had to make decisions quickly, worrying each moment, but after a while, she passed away. I regretted a lot what had happened afterwards and dwelled on it. This may be the path that end-of-life caregiver will always follow. I can say that the best guide for judgment and decision-making is the Living Will. In her later years, my mother suffered from dementia and was no longer able to communicate her wishes, but I am glad that she joined while she was able to express her wishes clearly.” (Shiga)

“I realized that the Living Will is the only and last way for patients to assert their freedom. Without it, I would have been at the mercy of a third party.” (Kyoto)





Decision support website for healthcare choices during the last phase of life

The Little Lighthouse Project Guide. Helping families understand Living Will

JSDD member's family wants him or her to live as long as possible.

The "Survivor Questionnaire" shows how the family members entrusted with the Living Will are torn between wanting to fulfill the person's wishes and wanting the person to live as long as possible. It takes a lot of determination for the family to fulfill the Living Will.

The only way to break the family's hesitation and encourage them to be prepared is to continue communicating their unshakable beliefs. This article presents an episode in which a family member says he or she was persuaded without giving up until the family member was convinced.

Actions by members move the family.

The idea that a long life is a good thing is a value that has been ingrained in society for centuries. It is understandably difficult to accept the idea of controlling one's own life.

That is why it is important to note that it is not just a random statement but an act of becoming a member of the Japan Society for Dying with Dignity and that this action helps to persuade the family.

By 2022, nearly 70% of the JSDD's 90,000 members were women.

We have therefore decided to run a series of informational advertisements for one year, starting with the May issue of Fujin Kōron (which is scheduled for release on 15 April.)

The informational advertisements make people who are not sure what to do think about giving it a try. Let us hope that your experiences concerning end-of-life care will influence medical choices, decisions, and actions in the final stages of life.

End-of-life care episodes

(From my experiences of end-of-life care for my husband)

I thought I was going to make preparations for my death before I turned 80, and when I sent out a Living Will card to my son and told him my thoughts, he replied, "Maybe it seems that way now because you are doing well, but when you are older, you may want to see your grandchildren's coming-of-age ceremony, and I want you to see it too. I want you to live as long as possible even if it is only one day longer!"

After much discussion, I couldn't get him to understand.

So, I showed him an essay I had written about my feelings the year before my first grandson was born and told my son, "It's not that I can't bear to be in your care, but I have had this feeling for a long time." I told him.

He then said, "I understand your intentions. I will firmly accept them." He finally agreed.

Holding the JSDD card with strong feelings and the acceleration acknowledging this has stabilized his mind."



telephone and email medical consultations



This magazine page presents specific cases of telephone and email consultations and answers. The consultant (nurse) will answer the questions, but sometimes we may also ask for the help of a consultant doctor.

Critical points “for choosing the medical care that you want”.

As a sequel to Palliative Care, this page introduces the member doctors of the Japan Society for Dying with Dignity, who have been practicing patient-oriented medicine for many years and provides critical points for patients to choose the medical treatment they want.

Thoughts of a palliative care specialist

The palliative care doctor who gave us advice on neuropathic pain caused by diabetes in the previous issue has been treating patients suffering from various types of pain for many years with a patient-centered approach to medicine. The attitude of the practice has been that consistent pain is something that only you can understand, and others cannot. For this reason, patients need to understand their bodies well, communicate the intensity of their pain and treatment effects in the correct terms, and choose the medical treatment they want. The idea is that healthcare professionals must answer this.

In the outpatient clinic setting, medical drugs' effects and side effects are explained and agreed upon. The doctor will check the effects and side effects over the phone and advise for several days, mornings and evenings, starting the next day.

Patients understand that they are the only ones who can control their pain, and they keep detailed records and reports on the time they take the medication and any changes in pain. Some patients continue to take medical narcotics for an extended period of time and yet regain the joy of being able to control their pain and continue working, and the desire to continue their hobbies, such as traditional Japanese embroidery (sashiko), and enjoy their lives vigorously while passing it on to the younger generation.

However, although medical anesthesia is said to be the best medicine if taken correctly, prejudice against those who take it is strong, and it is not uncommon for people to stop taking it halfway through.

There are regular opportunities for healthcare professionals and patients to learn medical knowledge about the safe and proper use of medical anesthesia and to exchange information with each other.

Choosing the medical care that you want

The medical treatment system has shifted in recent years from one in which patients are left to their own will to go to a hospital to be cured when they fall ill to one in which the patient is the main focus of the treatment.

This requires patients to clarify the purpose of their treatment and to make choices. However, many patients lack specialized medical knowledge and are at a loss.

Key points for seeing a doctor

- ① Tell them what you want to tell them in your own words, specifically and clearly. Make a note of when and where the symptoms started, what the symptoms are, and any problems you are having.
- ② Confirm important information given by the doctor by writing it down. Even if you think you understood the information on the spot, your understanding may be unclear.
- ③ Once you are satisfied with the purpose of the examination and treatment, decide on it. You do not have to decide on the spot. Consult with experts and others around you about any questions you have.
- ④ Ask questions as many times as you like about things you are not convinced about. Do not be rude, or stop seeing the doctor, or anything like that. You can avoid regrettable consequences later on.
- ⑤ The decision is yours to make. You can discuss the direction of your decision with your health care professionals and family members as many times as you wish (ACP, life conference.)

We hope that your medical consultation will be an opportunity to assist you in choosing the medical care you desire. We also hope that you will use our consultation service as a familiar place for you to spend your days in your own way, and not keep it to yourself.