Excerpts from

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Eighth Session of Japan Living Will Study Workshop
Keynote speech “Our Life as a Memoir”
“You write the last chapter of your life story”
By Mr. Kunio Yanagida (non-fiction writer)

The eighth session of Japan Living Will Study Workshop was held in Tokyo on November 30, 2019. The topic was “Life Planning Conference (Advanced Care Planning): the Living Will is the Start.” Coincidentally, November 30th = 1130; which is phonetically read in Japanese as yiyi (11) mitori (30), defined as good terminal nursing care.

The first keynote speaker was Mr. Kunio Yanagida, one of the bestselling non-fiction writers in Japan. He told the audience that they are now going to write the last chapter of their own books. He emphasized that no one will write it for you, and that only you can write your own last chapter. It was as if he was talking to every person individually. Everyone was deeply touched. Below is the summary of his speech:

Hello, everyone.
When I was asked to make a keynote speech with the title, “Our life as a memoir,” I was very delighted to be honest with you. Because no matter whose life it is, 40 years or 80 years, it is full of ups and downs. It is quite an overwhelming accomplishment that any human being accomplishes by living an entire life. That is the way I view life as a writer. Dr. Hayao Kawai, a clinical psychologist and a close friend of mine, often told me that a man or a man’s life can never be fully comprehended in a true sense of the word unless it is clearly and openly exposed either vocally or literally. Somehow, his professional perceptions and theories of the human mind through his own observations of people suffering from various worries and anxieties matched my perceptions as a writer through my experiences with people. Again, life is not understood or comprehended unless it is fully, clearly and openly expressed.

Position of death is placed in the context of life

Japan Society of Dying with Dignity (JSDD) developed a model of the living will, which is now spread nationwide, and used as an official expression of self-determined wish in the medical community.

However, when I first read the itemized contents in the living will, it seemed like most people viewed death as a momentary event, which they wished to be peaceful and painless. Does death equate to only the last moment that passes like the wind? In other words, are you fully satisfied if you can just spend the moment painlessly and peacefully? Is that how we should approach death? Those are my questions.

What is important in the living will is that death be placed in the context of many decades of life. It is how you live the last chapter of your life that leaves you with no regrets or remorse. In that case, death is not a matter of how you take your last breath, but it is the last chapter of a long life process. We should review the living will with this outlook of death as part of a long span of life. That has been my view on how to create your living will; however, let me move on with the rest of my speech.

Photo: Mr. Kunio Yanagida
Born in 1936. Graduated from Tokyo University with an Economics degree. After working in the social news section of NHK (national broadcast of Japan), he became a non-fiction writer. Many of his work are on how to face death in pursuit of issues surrounding the mind, quality of life and quality of death. One of the bestseller non-fiction writers in Japan.

It seems to me that people's attitudes toward how we die started to change in the 1980's. Cancer became a central point on the matter of death in the 1970's. By looking at death from both medical professionals and suffering patients, my growing impression was that we were entering a new era. To symbolize this trend, many people started to write memoirs of how they fought against cancer. Before then, only celebrities and famous people wrote books, such as authors, commentators and scholars. It was in the 1980's when people regardless of professions or genders started writing books. In the early 1990's, I took on a role of compiling 12 volumes of "Contemporary Selection of Non-Fiction Stories."

The first volume was a compilation of writings about life and death. I added a chronological table covering all work after the end of WWII at the end of the volume. I was fortunate to be able to compile this table from my own collection of relevant books and materials as I was immensely interested in topics related to medical science, life versus death and fighting against fatal illnesses since I started this line of work in the 1970's.

This table shows that there was very little in terms of records of fighting illnesses, medical and nursing care for terminally ill patients and medical policy on terminal medical care in the 1970's. A lot more work was documented in the 1980's, and even more in the 1990's. This trend indicates the change in people's awareness. More books written means that more people read them. Book publishing of this sort is now a solid business. The day came when the general population was interested and concerned about the topic, so they started to read more books about death. I call this time period, "The Era of Socialized Death."

Prior to this period, people died quietly either in their homes or hospitals surrounded by their families. Death was a private. Now we are posting and sharing messages with the public about how we lived our lives or how we ended our lives. We are in that era. I even created a key word, "socialized death" to indicate this new norm.

Resilience generated from writing

Why did people start writing about their fight against fatal diseases? Looking back, a lot of books came out about people's war experience, especially about enduring the air raids the first 20 years after the end of WWII. As time went by, such books became less popular and instead, books about fighting fatal diseases replaced them. The books or journals were about letting others know how they are suffering; how lonely they are; what they found out about the fatal disease; how they would live the rest of their lives after accepting the inevitable; and how they let their medical providers know the pain and suffering they endured. All those things caused them to pick up a pen and start writing.

Another trend was that families who took care of patients by their sides started to write books about their mourning. The action of “picking up a pen and start writing” brings an enormous power and resilience when facing death.

Recently the word “resilience” has been used often in regards to disaster events, medical community and welfare. It means the power to revive, recover and regenerate; in other words, the power to live for tomorrow.

The next question is how these books and journals of fighting against fatal diseases can turn into resilience. When you find out that you only have another month or six months to live, how can you be resilient? According to my study, it seems that nobody wants to die depressed, under mental distress, desperate or in grief. Most people would rather attempt to complete their lives by making the best of their remaining days.

Humans usually fall into a state of shock when we face an incurable disease for ourselves or we lose our loved ones. For example, you plan to enjoy your retired life comfortably with your spouse, and then suddenly your spouse may have a stroke and die or you are diagnosed with a progressive type of cancer. When something similar happens that put you in a state of confusion and shock, expressing your thoughts and feelings, namely by writing a book, a journal, or a poem, becomes of great importance. Writing brings out context, which forces you to organize and clear your chaotic mind. If you do not write it down, you continue to be in a chaotic state of mind and end up suffering for a long time.

For instance, let’s say that you write a self-published book. Someone will read it and provide you feedback. The reaction from others makes you objective, allowing yourself to look at yourself from the outside. Through this process, you will learn to accept the meaning of your life as you face death.

I believe that if you take a bird's-eye view of your life no matter who you are, the story is as great as the most popular drama series on TV or a bestselling novel. Regardless of how high or low, life is full of ups and downs. There are many chapters, and there may be a chapter that is full of winding roads. If you look back on your own life, you realize that life is composed of many chapters; you just didn't consciously write it down.

If you become seriously ill or when you reach old age, realizing you only have a year or six months remaining, you will be writing your last chapter by yourself. Is everyone on board?

What is the purpose of writing? Part of it is to confirm what is most important to you in life. Human beings are very greedy. We never stop saying, "I want this, I want to do that, etc." But maybe out of 20 things you want to do, you might narrow it down to only two or three things that you really want to do if you have to choose. By writing down your thoughts and feelings, you will narrow it down. I believe that you can make your last chapter well worthy and convincing.

The highlight of your life is ahead

I would like to talk about other people's last chapters: about people whom I have personally interviewed, written about or taken from their books about fighting fatal diseases.

In 1979, a book was published by Ms. Momoko Harasaki who died of lung cancer in her 40's. While being under in-home care, fighting a progressing cancer, she started writing a journal. In those days, terminal medical care was not a common terminology. When her cancer recurred and reached an incurable point, her husband said to her, "Your cancer recurred and is spreading. The prognosis is not good." She told him, "Thank you. Thank you. I am very glad you told me the truth. I know how hard it was for you to decide to tell me. Thank you, and now I can see a lot of things. The highlight of my life is still ahead of me. The past of my life so far was for preparation of the upcoming highlight," she wrote. What she meant by "the highlight of my life is still ahead of me" was that she was ready to wrap up her life as a complete memoir by writing the last chapter of it.

What is the highlight of life? She was a wife, a mother and a Christian. Her two boys were in middle school. She continued, "I will not be around much longer, but I am going to plant an apple tree and devote myself to teach and mentor my children.

"Planting an apple tree" is from a quote by Martin Luther in which he said, "Even if I knew that tomorrow the world would go to pieces, I would still plant my apple tree." It means that tomorrow I may die, but I will plant an apple tree by believing in the eternity of life. This is her firm determination of fulfilling her life to the very last moment. While she received in-home terminal medical care, she continued to give motherly care to her children from her bed. Even through pain and suffering, she lived her life fully at the end. What a magnificent life she had completed!

The trend of writing your own last chapter appeared a gradually in the 1980's. By year 2000, this awareness had spread widely. I believe that JSDD has played a major role in spreading this trend. I call this era “The Era of Designing Your Own Death,” meaning that you prepare for death in your own way by writing your own last chapter.

How to support those who are writing their last chapters?

How to best support the people who are designing their own deaths is another challenge. Since the 1990’s, in-home hospice care has been booming as a support concept. As an example, I would like to talk about Ms. Mitsuko Akiyama who was diagnosed with liver cancer in 1989 in her 40’s and only had six months to live.

(2) Awareness of how to live
“the last chapter of your life”

- Life is full of ups and downs
- Life is composed of many chapters

“Even if I knew that tomorrow
the world would go to pieces,
I would still plant my apple tree.”

-Martin Luther

Mr. Yanagida used power point slides to talk to his audience as if he was talking to every person individually. There were wiping off their tears with handkerchiefs.

Her end of life was very meaningful. She had two children, one in middle school and the other one in elementary school. As a mother and wife, she chose to fight cancer from home. Her family doctor was one of the pioneers of in-home hospice care in Japan. Her husband was working for a major food company. He decided to take a long leave of absence to be with her and make her last days better. Taking long leaves were not allowed in those days, but he chose it with such firm conviction of staying with her valuable enough to risk losing his job that his company later adopted a long term care leave in the company regulation. His firm determination changed his company policy.

Furthermore, her younger sister who was teaching at a nursing school commuted a long way from Kyoto to Kanagawa once a week, to help provide terminal care to her older sister. This experience changed her life, and she later established her own in-home care system and even received the Nightingale award.

Her elderly mother even came to Tokyo from Akita Prefecture to care for her. She said to her daughter who was gradually losing her consciousness, “You must say everything you need to say before you totally lose your consciousness.” She also told her grandchildren, “Your mother may lose her consciousness, but she can still hear you so you have to keep talking to her frequently.” With death being the unspoken understanding, her family started to work together as a family to support her daily in her last months.

Today, a social support system for those designing their last chapter is being developed in many forms nationwide. We are now entering yet, another new era. I hereby would like to close my speech. Thank you for listening.

2019 Surviving Families Survey Results:
94% of living wills were honored
Living will is an important guidepost for end of life nursing care

Patient enrollment in Japan Society for Dying with Dignity was like a litmus test for the family moving forward. This experience made us realize that there were lots of things indescribable, sensible and emotional associated with the dying process. Below are some of the feedback from surviving families:

“Living will was my support for eight long years of staying by my wife’s (62) side.” (Kanagawa Prefecture)

“The doctor told us that he respected and honored the patient’s dignity (83) who was deeply loved.” (Kyoto prefecture)

- My husband (87) was very particular and stubborn about how to spend the end of his life. He had already told all of our family about his enrollment to JSDD at the beginning of the year. He organized and cleaned up almost all of his things, and his departure was so elegant just as he planned it. (Mie Prefecture)

- My thought after losing my wife was how strong and powerful women are. I was not aware of how bad my wife's (81) condition was until she fell. One day, she did not come out of the bathroom for a while, so I went to check on her. She was lying on the corridor floor with cold hands and feet. I panicked and called the ambulance. Then, she raised her head a little and said, "We promised not to call the ambulance" while she was half unconscious. She recovered later and moved to a nursing home, but died of an infection. (Kanagawa Prefecture)

- In the case of my mother (100), both of her two daughters' families were JSDD members and had a great, rational understanding about the topic. I wonder how people with no families can extend their wishes to someone, especially now as we face a large elderly population. I hope that a system will be established to take good care of the elderly population. (Kyoto Prefecture)

- I was able to provide nursing care for my father (95) at the end, thanks to his firm will power to refuse all life prolonging medical measures. As his daughter, I worried so much and felt so insecure about being able to give him comfort and peace. With the support of everyone around me, I was able to give the best terminal nursing care for my father. After my mother passed away, he did his best to organize and clear things around him and lived his remaining life without depending on anybody. He was so great. I am sure that JSDD supported him. (Ibaragi Prefecture)

- Unless you experience the same situation, you can never foresee people's minds and behaviors: this is the lesson I learned after I lost my mother (73). I am so glad that she was enrolled in JSDD; otherwise, there would have been a lot of family disputes. (Tokushima prefecture)

- My husband (66) died of lung cancer. He didn't seem to be sure whether he was in terminal stage or not, because his doctor did not say anything about it. He struggled between the thought of surviving through treatments and spending his last days peacefully with only palliative care. I really felt that even if you're prepared, it is awfully difficult to recognize when your last day will be or if it's in front of you now. (Osaka Prefecture)

- The last two weeks of nursing care was a sequence of choices and decisions. Though I had a pretty good knowledge of life prolonging measures, I was not confident about making each decision for real. It was very important for me to gain validation from the care givers, nurses, doctors and all family members. When he was in his terminal stage, it was not easy to confirm his clear wishes; however, we all worked together to place patient's wish as the top priority. We only knew because he was enrolled in JSDD, and his living will was a clear guidepost for all of us to make decisions for him. We never realized it until we had gone through this experience. There were lots of sensible, emotional, all indescribable decisions involved in the end of life nursing care process. The presence of his living will through JSDD was a guidepost in all of this. (Kanagawa Prefecture)

- When the emergency staff called me to confirm how to treat my mother (89), I was able to tell them without any reservation to not administer any life prolonging measures she can’t be cured. I received this confirmation call five times, but I was able to answer clearly each time. However, I have to admit that later I felt unsure if I was right or not. To learn that she was a JSDD member saved my conscience. (Tokyo)

- The living will my father (80) had did not lead to smooth admission at the hospital or the nursing home. I was told that as medical professionals they could not just leave him to die untreated. However, there were some doctors who told me that there are ways to help meet the patient’s wish. They also felt the dilemma between the oath they took as doctors to do everything possible to save the patient and honoring the wish of the patient as a compassionate human being. When the time came, even I, his son, wanted to give in to the emotion of wanting to prolong his life. (Fukuoka prefecture)

- My father and I didn’t talk much in our relationship. Naturally, I didn’t know that he (83) was enrolled in JSDD. I found his living will and his “My Wish List” only when I was going through his personal belongings. His “My Wish List” showed all the items he checked off on for “I do not want to receive the following treatments…” I understood exactly what he wanted, but I found myself crying for him at the same time. I am grateful for JSDD because “My Wish List” let me know what he really wanted. (Tokyo)

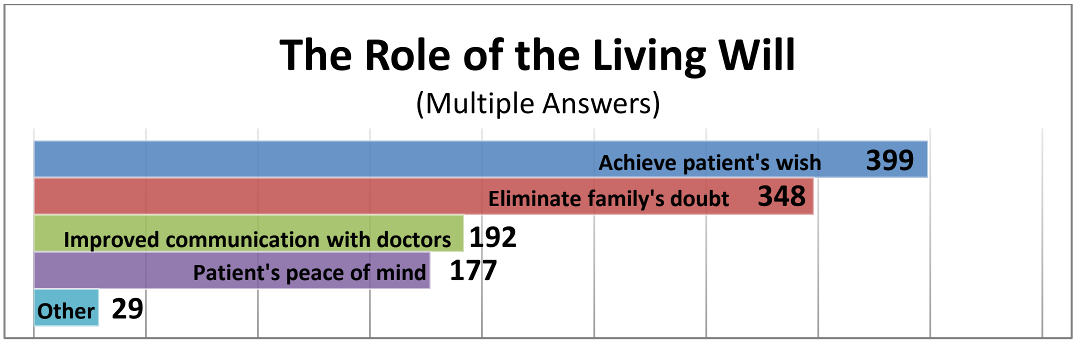
- On one hand, I was happy to see my husband (86) in his last days without tubes or needles all over him, but at the same time I still question myself it was really the best for him. The selfish idea that I just wanted him to be alive still won’t go away. (Tokyo)

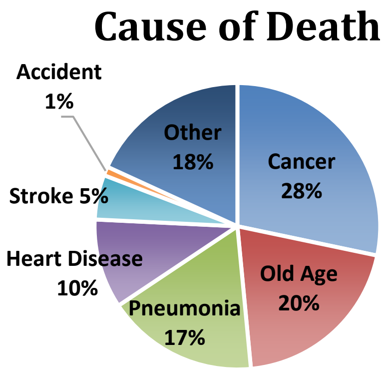
The majority responded that the patient’s wish was achieved

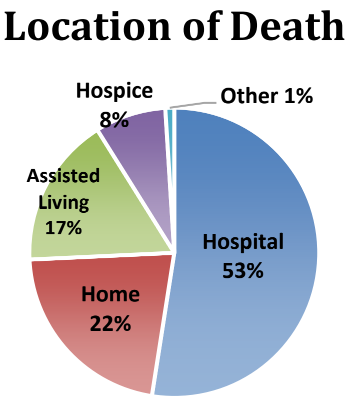
Every year we conduct a survey to assess the effectiveness of the living will with cooperation from surviving families. In 2019, we received responses from 640 families.

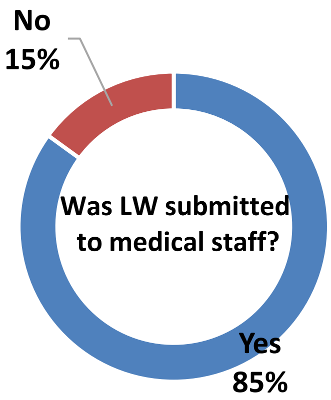
541 respondents (85 %) said the patient’s living will was submitted to medical providers; 70% responded that the living will was fully honored; 24 % answered that the living will was somewhat honored. Overall, 94% confirmed the effectiveness of the living will.

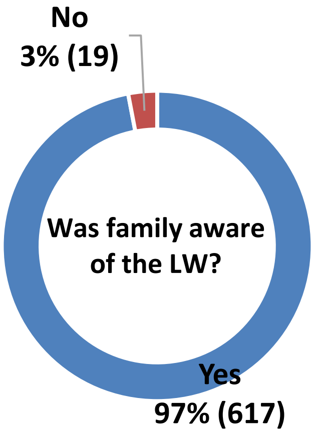
The following results are from the survey we started three years ago starting with the question, “What does the living will mean to your family?”

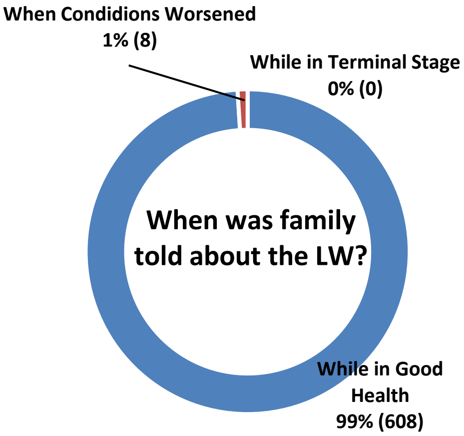


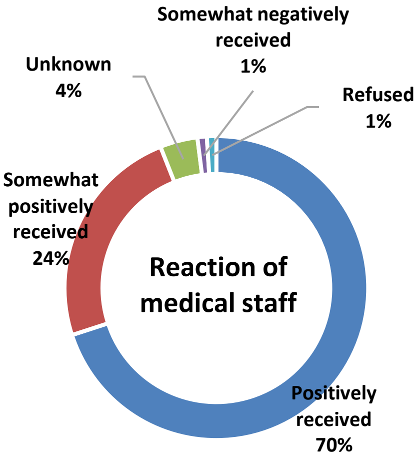


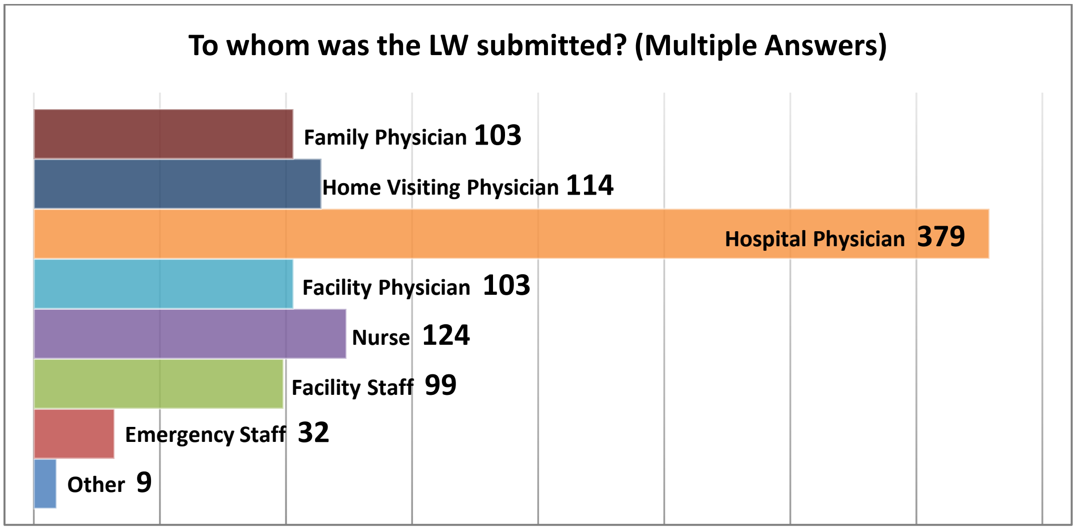


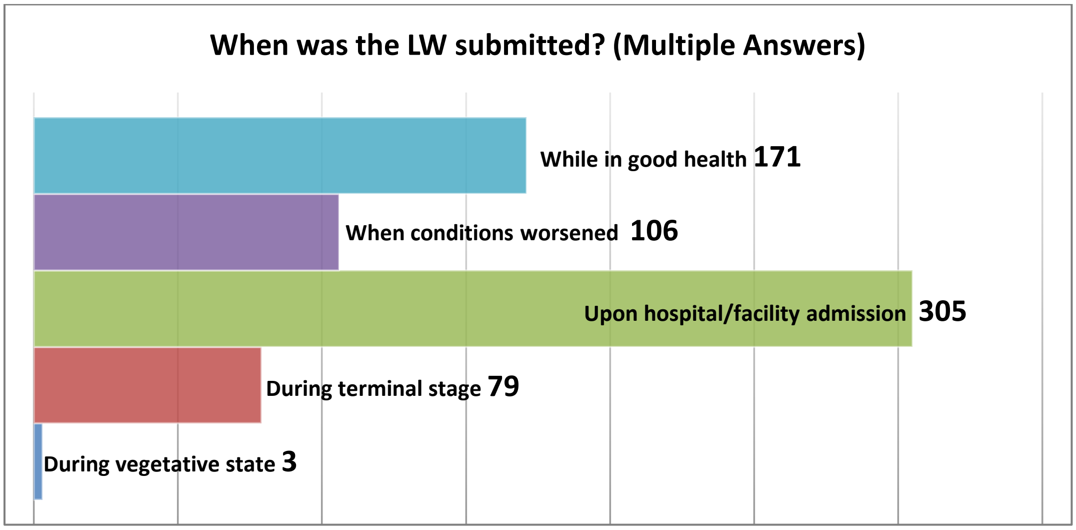


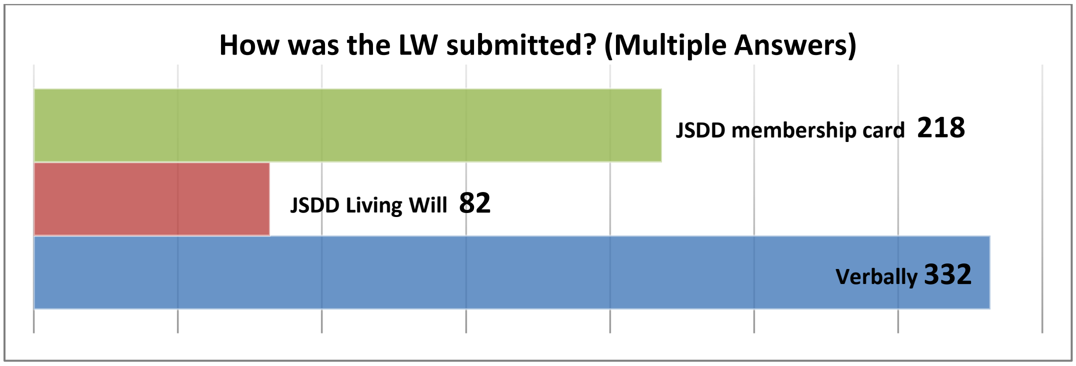



When was family told about the LW?
When Condidions Worsened
1% (8)
While in Terminal Stage
0% (0)
While in Good Health
99% (608)


Reaction of medical staff
Somewhat negatively received
1%
Unknown
4%
Refused
1%
Somewhat positively received
24%
Positively received
70%


To whom was the LW submitted? (Multiple Answers)
Family Physician 103
Home Visiting Physician 114
Hospital Physician 379
Facility Physician 103
Nurse 124
Facility Staff 99
Emergency Staff 32
Other 9


When was the LW submitted? (Multiple Answers)
While in good health 171
When conditions worsened 106
Upon hospital/facility admission 305
During terminal stage 79
During vegetative state 3


How was the LW submitted? (Multiple Answers)
JSDD membership card 218
JSDD Living Will 82
Verbally 332

Telephonic and Email Medical Consultations No. 3

Questions from JSDD Members and Answers by Consulting Nurses and Doctors
“I want to have his nutrition tube removed…”

Q: Fourteen years ago my father (85) became a JSDD member, and a few years ago he was diagnosed with dementia. Late last year, he was hospitalized due to dehydration. After about one week in the hospital, he no longer could feed himself. Now he is receiving parenteral nutrition and has a difficult time communicating. My mother wants to have the nutrition tube removed, but will the hospital agree to it?

A: When dementia progresses, it becomes harder to eat and drink through the mouth. If the patient depends on parenteral nutrition, and there has been no communication for some time, he should be diagnosed with terminal stage of dementia. To continue with the nutrition tube in this condition would be against his wish, and obviously his quality of life is not improving at all. Assuming the family’s opinion is in favor of honoring the patient’s wishes, it is very considerable to have the nutrition tube removed. If there is full support from all family members, it is likely that they will carry out the patient’s wish.

Q: If the primary care physician says that the patient’s condition is expected to improve by taking in sufficient hydration and nutrition, since the current condition seems to be temporary, is this considered a life prolonging measure?

A: If this is a curable and recoverable condition with an IV of hydration and nutrition over a week or so, this treatment is not considered a life prolonging measure.

Q: If there are no signs of recovery, will they continue with the IV?

A: You should probably ask the primary care physician first. An IV improves the condition of hydration temporarily. However, if the patient is still unable to self-feed through the mouth and is not expected to do so in the future, it shouldn’t be a problem to ask the doctor to remove the nutrition tube. If the patient is given central venous nutrition, his nutrition will improve. However, if your father has no chance of feeding himself through the mouth, this treatment would be considered a life prolonging measure. If he has a LW and an advance directive with family’s consent, it would be quite adequate to talk about the withdrawal of the nutrition tube.

Q: If the primary care physician says that the patient’s recovery is not expected, but he can’t stop the nutrition tube that has already been administered as long as he is in the hospital, what should we do? The patient’s LW would not be respected and honored.

A: In many cases, terminating the treatment that has already been administered is impossible even if the patient is in terminal stage, and his death is imminent. We can make one suggestion to propose reducing the volume of the hydration/nutrition to 500-250 ml by slowing down the drip speed. Japan Geriatrics Society has recently issued guidelines stating that it is permissible to reduce the volume of hydration/nutrition if consented by family members, medical providers and caregivers.

Q: When the doctor says that recovery is impossible, is it okay to take the patient back home and provide nursing care at home?

A: It is necessary to consider the following: (1) there are enough family members willing and able to take care of the patient at home; (2) there is an in-home terminal care doctor available; and (3) there is a nurse station or a walk-in clinic locally available. If the patient is currently under hospital care or medical consultation, you can contact the primary care manager and ask if the patient is eligible to receive medical care from a local vising doctor as well as nursing care.