**Excerpts from**

# Japan Society for Dying with Dignity Newsletter

**No. 179, October 1, 2020**

**Main Contents:**



## Discussion on the COVID-19 pandemic and dying with dignity

### There is an increased significance to keeping a record of your own will, especially during the current situation with the coronavirus pandemic


**Dr. Soichiro Iwao, JSDD President**
**Dr. Yoshihiro Kitamura, JSDD Director**


This new type of infectious disease called coronavirus seems to transmit and aggravate quickly, leading to death while unconscious in many cases. How can we continue to honor dying with dignity against this peculiar and dangerous infectious disease? Two physicians who specialize in public hygiene and contagious diseases had this discussion: one is the JSDD president, and the other is the JSDD director.

**Dr. Iwao:** Today, we set up a special discussion about the topic, the coronavirus pandemic and dying with dignity with Dr. Yoshihiro Kitamura, the newly elected JSDD director last year.

First, I would like to quickly introduce Dr. Kitamura with his background. He graduated from Tokyo University Medical School in 1985 and received a graduate degree in Bacteriology. Lately, he has been appearing often on TV and the media as a specialist on infectious diseases since the outbreak of the coronavirus. He was the Chief of National Institute of Infectious Diseases, the former National Institute of Health in Japan. While he was a professor at Tokyo University, he was transferred to Peking University from 2006 to 2011 on a project to establish a

research center for infectious diseases. During that time, China was experiencing another terrible infectious outbreak called SARS. His efforts greatly contributed to China's preventive countermeasures from infectious diseases. After returning to Japan, he took professor position at International University of Health and Welfare, where we first met while I was the vice president. Dr. Kitamura's expertise in basic medicine and bio-ethics eventually led to his involvement in JSDD activities with terminal medical care, and was elected as the director of JSDD last year.

Dr. Kitamura is a nationally ranked Shogi (Japanese chess) player. When I was working at the International University of Health and Welfare located in Ohtawara, I was invited to attend a ceremonial event in Shogi competition. It a very exclusive, invite-only event. Isn't it right?

**Dr. Kitamura:** Yes, it is a rather closed and prestigious ceremony only for a limited number of people.

**Dr. Iwao:** I understand you hold 8$^{th}$ dan (level) which is a prestigious ranking only held by a few people.

**Dr. Kitamura:** The highest rank for amateurs is the 8$^{th}$ dan, and I was promoted by the president at the time, Koji Tanikawa. I was a strong player, but that was probably not the only reason for the promotion. I think he highly recognized and evaluated my volunteer work, teaching Shogi at the university.

**Dr. Iwao:** You are a master Shogi player, but in your medical profession, you are now undertaking in-home medical care, especially terminal medical care in Saitama City. In my past medical involvement, I was involved in revising the infectious disease prevention law as the chair of the Infectious Diseases Department in the Ministry of Welfare and Labor from 1995 to 1997. This was the very first law for infectious disease prevention, which was enacted in 1897 (123 years ago). All laws at that time were written in Katakana and neglected some basic human rights in the eyes of today's modern society. The purpose was to revise it to reflect the needs and demands of modern society emphasizing in civil rights. Revising this antique law, which had been valid for over a hundred years, and modifying it to work in today's modern era was a very sensational achievement that made some headlines in the mass media.

After that, new infectious diseases appeared one after another: a new type of influenza, the bird influenza, and now yet, another new type, the coronavirus. As of today (July 31, 2020), we want to know of any updated information about the virus and what we are facing in the future.

**"Statistically, 20% of the infected patients over the age of 80 will die"**

Dr. Kitamura, would you start by explaining what we're facing, the coronavirus?

**Dr. Kitamura:** Basically, this new type coronavirus causes pneumonia and respiratory infection which causes difficulty in breathing, and eventually in the worst case, death. If the condition suddenly worsen, the natural response is to administer an artificial respirator, then what happens is that the patient is unable to communicate his/her needs easily. It becomes difficult to send visual signals or even communicate in writing. Some patients think that they are in the dying process, but it is different from being in the terminal stage of an incurable disease such as cancer,

with no hope of recovery. Most people probably know that young people are much less likely to die from coronavirus. It is the elderly population who has the highest risk of death. According to a source, 20% of elderly patients over the age of 80 who contracted the virus will likely die. It is a serious disease, but if you look at it another way, 80% of elderly patients will recover. So, it is certainly not incurable with no hope of recovery. You can say that it is rather a curable disease, so using terms like "terminal stage" for coronavirus is totally inaccurate. However, it can be tricky if an elderly patient with an artificial respirator later wants it removed since he or she can't communicate his or her wishes. We strongly recommend that a record of how you want to be treated, known as the living will, is prepared well in advance while still in good health. Even young people, if they have diseases such as diabetes or heart disease, the same preparation is recommended because such diseases can quickly worsen. I recommend that all family members talk about this frequently before it becomes too late.

**"We are only equipped with one set of ECMO in our hospital. What should we do if ten patients rush in?"**

Extracorporeal membrane oxygenation (ECMO) which is an excellent respirator, proved to recover 60% of patients. However, only a limited number is available, and furthermore, one set requires around 20 medical staff to operate. In other words, ECMO is an extremely high cost medical equipment. When you have only one set of ECMO, and there are ten patients with severe case of pneumonia, you have to make a critical decision of which patient should be prioritized to be treated with the only ECMO. This is why we all need to talk about it always with family members and be prepared for the situation.

**Dr. Iwao:** As a matter of fact, I lost two friends recently to coronavirus. I had a conversation with one of them about ten days ago. He told me that he had a terrible cough, so I told him if it was that bad, he should go to the hospital. Two days later, he was hospitalized, and one week later he passed away. I was shocked at such a sudden advancement of his condition. A normal influenza virus doesn't aggravate this quickly. Are there any other particular characteristics of this virus?

**Dr. Kitamura:** That is a typical characteristic of the coronavirus. According to some statistics, roughly 20-25% of death occurred in patients aged over 80. It is commonly known that elderly people often die from the flu, but it is only about 1%. So, you can say that the COVID-19 is a very severe and deadly disease, especially when you look at cases in which a middle aged patient who was healthy just a minute ago can all of a sudden suffer severe breathing problems, end up in an ICU on a respirator, and then lose consciousness. Such severe symptoms of sudden advancement was not seen in any other viral diseases. The fact that one out of four patients die from the coronavirus is a very terrifying factor for elderly people.

This new type of COVID-19 is ranked the second most dangerous disease currently. If your father becomes infected, you can't hold his hand or give him words of encouragement. If he dies from it, he would be placed in a specially prepared bag and cremated so that you would not be able to watch him or stay close to him as you would normally if he had died of another disease. Basically, you are not allowed to provide COVID patients the kind of terminal care you would otherwise. This is really a cruel disease. Families are left with pain, suffering, regret and an enormous feeling of emptiness.

**"COVID-19 patients are unable to say their final farewell to their loved ones"**

**Dr. Iwao:** The motto behind JSDD's activities is "Live strongly and die peacefully." When end is near, we all want to be able to say, "I lived a great life," and be surrounded by our loved ones. Unfortunately, COVID patients are stripped of that wishful scene.

**Dr. Kitamura:** As long as it is designated as the second most contagious disease, an eternal farewell of holding hands or telling the dying patients things like, "thank you for always being there for me, dad," or "I'm so fortunate to have you as my mom."

**Dr. Iwao:** That is the saddest thing about the coronavirus. Isn't it?

**Dr. Kitamura:** Yes, it is. The coronavirus may not always be the second most dangerous disease, or it may go down to a lower risk "level 5." The normal influenza is now rated as No. 5. When COVID-19 broke out, we did not know much about it, but now we know that it will not spread if we take proper precautions. We fortunately do not have a panic situation such as the collapse of the whole medical system caused by a critical magnitude of infected cases. If the general public takes the same kind of preventive countermeasures as all medical providers do, it would be possible for family members to come closer to their patients and to hold their hands. It would be quite possible to avoid the awful farewell scenes, in my opinion.

**Dr. Iwao:** During the initial stage of this outbreak, nobody knew what this new virus was, and coupled with so many deaths all over the world, maybe we were forced to take strict countermeasures. The biggest imminent issue now is the development of a cure, both medicine and preventive vaccine. What is the current situation on this effort?

**Dr. Kitamura:** As to a cure, as of late July, two approved have been approved. One is called Remdesivir, a very expensive antiviral drug given though a drip. This is optimal for patients with 24/7 supervision and are cared for in the ICU. Another drug is called Dexamethasone, a steroid that calms the immune system. This is optimal for less severe cases, not so expensive and no serious side effects. If a balanced combination of these two drugs are administered to patients in the ICU, they should be able to leave the ICU in about two weeks now. It was necessary to keep patients in the ICU for a month early on. There's a great chance that someone will come up with other drugs that can cure COVID-19 patients in the future. So I think we have a brighter future from that aspect.

As to a vaccine, Britain, China and the US are working hard at rapid speed to develop it. They are the major countries known to be working on this, but there are actually over 140 groups globally that are also working toward developing a vaccine. We will eventually see vaccines with various degrees of effectiveness in the market. If you ask me when a vaccine will be available for the Japanese people, some experts say as early as 2021, and others say it would take longer than that. It's hard to project.

**"Some say that the coronavirus will age you by about 20 years"**

**Dr. Iwao:** From the general public's point of view, if there is no cure right now, the only thing we can do is to focus on prevention. Today, we are having this discussion with this acrylic plate between us to avoid spreading the virus. If this type of measure becomes the new norm, we will

continue to have meetings or lectures on Zoom and through other virtual means to conduct activities. Our activities will forever be forced to change and transformed into other methods and systems. However, the majority of our members are elderly people with no access to the internet, so we need to continue to have conventional lecture meetings, forums and visiting lectures while considering the risks and taking proper preventive measures such as social distancing and limiting the number of attendants.

**Dr. Kitamura:** I think so too. When we take the fraction of the number of fatality over the total number of infected cases, we call it our fatality ratio. This ratio increases drastically when the age gets up in the 60s. What I hear often is that infected patients seem to suddenly age 18 to 20 years. What they mean by that is, let's say I'm 59 years old. If I was to be infected with COVID, my body becomes as fragile and as that of a 77 year old, and as "likely to die" as a person that age. To explain it in another way, what takes 20 years in a natural process of aging and physical deterioration, it would take only one week for my body to go through the same amount of physical deterioration if I was infected with this virus.

**Dr. Iwao:** So, it's just like Urashima-taro (a Japanese fairy folk tale) who immediately transformed to an old man when he opened the forbidden holy casket.

**Dr. Kitamura:** Exactly. It is a casket virus.

**Dr. Iwao:** But it doesn't mean that you will automatically die if you open the casket, right?

**Dr. Kitamura:** Right now there is no way to sort out who gets severe symptoms and die, and who is more likely to recover. People over the age of 80 are at a high risk of developing severe symptoms from being infected, requiring a respirator in an ICU. Therefore, it is more important now than ever that we communicate with our families while we are still in good health and prepare all necessary documentation.

**Dr. Iwao:** That is why we (JSDD) issue the living will and promote ACP/Life Planning Conference. Before any of us are hooked to a respirator or in a situation in which we can't communicate our wishes, we must put down all of our wishes in writing. JSDD published a template called "My wish list," a supplementary document that includes issues of artificial nutrition and hydration. We are now in the middle of a global pandemic, so preparing such documents are absolutely necessary more than ever.

**"We are living in an era in which death is near"**

**Dr. Kitamura**: I agree. Many elderly people probably have never thought of being on a respirator until the coronavirus broke out. Nobody knows who and when it will be necessary. Even if you take precaution by wearing a mask, practice social distancing and washing hands frequently, you may still get infected, unfortunately. We must all accept the reality that tomorrow, any of us may be infected, suffer from pneumonia, our conditions become so severe that you can no longer communicate a week later, and in another week, we may die. This whole process can happen in a course of only a month. We live in a terrible era right now. "Death" and "Dying" are not something that is happening in a far distant world. We have to realize that we live in that era right now in which death is near.

**Dr. Iwao:** I think we can say that the coronavirus is sending us an urgent message of how important it is to prepare all necessary documents expressing your own wish and will. Thank you for having this talk today.

**(Photo and brief resume of Dr. Yoshihiro Kitamura)**

Dr. Kitamura was born in 1960, and graduated from Tokyo University Medical School with a Ph. D. in Bacteriology. He is a former Professor of Basic Medical Center, International University of Health and Welfare. Dr. Kitamura is currently an in-home medical care physician at the Saitama City Hikari Clinic, Chairman of KYK Medical Research Institute, Professor of Medical Education Center at Nippon Medical School, and serves as a Board Director of Japan Society for Dying with Dignity.

**(Photo and brief resume of Dr. Soichiro Iwao )**

Dr. Iwao was born in 1947. After graduating from Keio University Medical School with a Ph. D., he continued his studies at Texas University. Upon returning to Japan, he began to work for the Ministry of Health, Labor and welfare, and was promoted to the position of Director, Medical Policy Department. He then worked for the WHO as the Health Development Center Chief, and moved on to be the Vice President of International University of Health and Welfare. Dr. Iwao currently serves as the President of Japan Society for Dying with Dignity.

## Proposal by Japan Geriatrics Society regarding the coronavirus pandemic

Japan Geriatrics Society whose members are doctors specializing in elderly medical care offered the following proposal in light of the recent findings. One of the most unique characteristics of the coronavirus is its sudden development in severity and consequent loss of communication.
The proposal strictly emphasizes the avoidance of tendency to determine patient priority for the use of artificial respirators or placing restrictions on patients' healthcare directives solely based on their age or status. These incidents have been occurring more as medical facilities are flooded with COVID patients and experiencing more demand than supply.

**Major points of the proposal:**

- To guarantee the patient's right to receive the best available medical treatment and care.
- To communicate sufficiently with the patient, the patient's family and medical staff, i.e., to conduct a Life Planning Conference (ACP) well in advance of becoming infected with the coronavirus. The ACP will include topics of perception of life and death, value of life, a wish of how to spend the last days of life, and a wish of where to receive terminal care, etc.
- To permit not administering a respirator or removing it when recovery is improbable.

## Countermeasures against COVID-19: JSDD's recommendation

JSDD issued living will is a documentation and expression of the patient's will concerning the medical treatments and care choices when the patient faces the terminal stage of his or her life. Life prolonging measures stated in the living will are life prolonging medical devices such as an artificial respirator, renal replacement therapy/dialysis and gastro stoma. Therefore, the decision of accepting or refusing an artificial respirator as a life prolonging measure while in terminal stage and the decision to accept or refuse the same respirator as a medical treatment for an acute disease such as the coronavirus are two different and separate issues. However, in a case where the patient refuses a respirator due to the possibility of consequent pain and complications by considering age and other health conditions, his or her wish to refuse the respirator should be honored.

As health conditions worsen, it is often impossible for the patient to directly tell the doctor about his or her wishes. Therefore, it is imperative that we inform our families and close friends well in advance. If you are concerned that your parents or other family members are in a similar situation, you should utilize the Life Planning Conference to share their consent.

In an unfortunate case that you become infected by the coronavirus, and your conditions become severe, you must submit your living will to your doctor and explain your wishes (i.e., refusal of a respirator or pain management mediation) so that your medical care team can provide you with the care you choose and respectfully honor your wishes.

(Available on our website at www.songenshi-kyokai.or.jp uploaded 4/27/2020)

# JSDD's official statement regarding a recent media report on an ALS patient's assisted suicide

First of all, we would like to pay sincere respect to the courage of a woman who lived her life to the fullest until the end while suffering from a fatal disease, ALS (Amyotrophic Lateral Sclerosis). We wish her to rest eternally in peace. We would also like to make the following statement regarding the report of this ALS patient's assisted suicide.

We, Japan Society for Dying with Dignity, is a private organization with over 100,000 members whose mission is to educate citizens and promote the concept of the Living Will. We must first clarify that terms such as "dying with dignity" or "dignified death" are an entirely different concept from active euthanasia. We sincerely hope that these two separate concepts will be accurately and clearly differentiated from one another when discussed publicly in the future.

JSDD defines "dying with dignity" or "dignified death" as death which comes naturally in the life process by withholding any life prolonging measures and alleviating pain and suffering through sufficient palliative care. On the contrary, death resulting from active euthanasia is terminating life peacefully while being assisted by someone, and is still considered a crime in Japan. We only have the information published by the media and are not familiar with any details of this case, including the treatment the assisting doctors provided. Nonetheless, what occurred is against the social norm and an unethical medical practice, and obviously not acceptable under any circumstances.

In 1991, there was a criminal case in which an attending physician at Tokai University Hospital was charged with homicide when he provided a lethal dose of medicine to the patient who was in terminal stage of cancer. This was the only other case of active euthanasia in Japan until now. Yokohama District Court ruled in 1995 that the below four conditions must be met for physicians to legally practice active euthanasia on a patient:

1. The patient is suffering from an unbearable and severe pain that cannot be relieved.
2. The patient's condition is considered incurable with no hope of recovery; and death is imminent.
3. There is no other way of alleviating the patient's pain except for a consequent result in death.
4. The patient explicitly accepts and consents shortening of life.

Not only did the recent case not meet the above conditions, but there seemed to be no sufficient communication between the patient and the medical providers. Therefore, the conduct of the two doctors involved can be concluded as based on self-motivated judgement without social consent. In one report, the Yokohama District Court mentioned that the patient experienced some physical pain, but we suspect that there was much more pain involved that was not physical. In the professional scope of palliative care, pain consists of the following types:

1. Physical pain
2. Mental pain
3. Social pain
4. Spiritual pain

Spiritual pain is defined as pain that comes from losing value and significance of living a life. Hidden behind one's wish to die is usually neglected pain. It can be a social pain such as the feeling of not wanting to be a burden on your family or no longer being able to participate in social activities. It can also be a spiritual pain of losing the value or significance of living a life. No one can take over or substitute your pain. What is needed is a type of care management in which patients can share their pain while in search of a meaning in life. Unfortunately, our society does not have a sufficient support system for these patients and others who are vulnerable, which may have led them to assisted suicide as their only resort.

According to various research and studies, 70 to 80% of the Japanese population seems to support a legal system that allows active euthanasia. The right to active euthanasia is legally recognized in Switzerland, the Netherlands, some states in the U.S., Canada, and Australia. In Switzerland and the Netherlands, active euthanasia for physical and spiritual pain is legally recognized, as well as advanced stages of dementia if included in the patient's advance directive. JSDD supports dignified death, but opposes active euthanasia.

Some find our position to be unexpected, but our intention is that we must first make a country in which we can die with dignity by respecting and honoring the living will. Japan is the only developed country with no legal backing of the living will, and is also at the bottom globally with no profound deliberation on the topic of terminal care. The mainstream opinion currently is that sufficient palliative care should eliminate the need for active euthanasia. Some of our members proposed that we start a discussion about active euthanasia; however, our current position is that we should not recognize or approve active euthanasia so easily unless we have a sudden, drastic revolutionary change in our society.

The living will is a testament of life, a document of self-determination regarding one's terminal care. When our efforts in legislature to legalize the living will was in a deadlock, the Ministry of Health, Labor and Welfare decided to change its approach to promoting a new term, "Life Planning Conference," which is equivalent to advance care planning (ACP). JSDD started to send out messages such as, "the living will is the first step to your Life Planning Conference" and "the patient is the protagonist of this life story. Unfortunately, the reality is that people who write their living wills are still a minority in Japan, and many people in advanced stages of dementia are incapable of writing their living will.

The living will is a form of self-determination regarding one's terminal medical care. This pursuit of happiness is a constitutional right of all citizens in Japan. If we take it one step further and claim that it is also a citizen's constitutional right to die, then active euthanasia would be included. JSDD is an active member of the World Federation of Right to Die Society, which consists of organizations from 30 countries. The whole world struggles with this issue of right to die, which ultimately means to honor active euthanasia. In Japan, the discussion of right to die is still held at the level of dying with dignity by promoting the living will.

In light of this recent assisted suicide case, we want to ensure that people do not consider discussion of death to be a taboo, but rather that they expand the deliberations on topics such as the living will, dying with dignity and even the right to die. We sincerely hope that this event triggers an establishment of a unanimously supported terminal medical care system in the very near future.

# Activity Reports from JSDD Regional Chapters

## Kansai Chapter

**Regional Board of Directors meets on Zoom**

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Until last year, Kansai Chapter had its Regional Board of Directors meeting every other month at the office located in Shin Osaka. Led by Dr. Kazuhiro Nagao, Vice President of JSDD, we have gained a mutual understanding of the JSDD headquarters' purpose and deepened our knowledge of the living will. Also, we had been discussing plans for lecture meetings, living will workshops for local residents, and basic policy for Kansai area activities.

Due to the coronavirus outbreak, the Kansai Chapter Office was closed after the declaration of national emergency in April. In order to continue our activities, we held our Regional Board of Directors meeting in May and August using Zoom. Seeing familiar smiling faces of the directors brought a lively discussion about what we can do to continue our activities within the restrictions of social distancing guidelines. As younger people are more familiar with the internet and virtual settings, we hope that this situation actually brought us a great opportunity to reach out to the younger generations. Discussions are still going on, and we hope that the pandemic will be over soon so that we can see each other face to face again.

## Tohoku Chapter

**A message to JSDD members and their primary care doctors**

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What is the best solution concerning quality of life for a patient in terminal stage of cancer and receiving in-home medical and palliative care?

This was one of the questions on a National Examination for Medical Doctors in 2017. Palliative care and in-home terminal care are required subjects in our current medical education, and similar questions often appear on the exam. In addition, basic terms and concepts such as "patient's rights and obligation," "patient's right to self-determination," "informed consent," "honoring the patient's wish and will," and "patient's quality of life." These terms and concepts are also common topics on national examinations for both medical doctors and nurses. This is exactly what JSDD has been pursuing for many years. We can say that the living will issued by us is one of the basic concepts in our medical education now.

Here is a suggestion to all JSDD members. Would you take an extra step and ask this question to your primary doctor? "I am a member of JSDD. Would you honor my wish and will when I'm critically ill or severely injured?" You can ask a nurse the same question instead. Don't be passive, and take action. JSDD is now legitimately recognized by the government as a public interest corporation. We are certain that your inquiry will be received and answered amicably more than ever before. You will feel that the medical environment has changed from what it was before.

In a worst case scenario if your inquiry was not received amicably, you can select another doctor from the list of registered LW supporting physicians system, one of JSDD's top priority projects.

By the way, the correct answer to the captioned question is, "it depends on resources and support available to the patient." The 7th Tohoku Living Will Study Group Workshop will be a great opportunity to expand your understanding of supporting in-home terminal care.

## Kanto Ko Shin-Etsu Chapter

**Calling life-time JSDD members**

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There are two types of JSDD membership: one is a regular member and the other is a life-time member. A regular member pays the fee annually, and the life-time member pays a one-time fee of ¥70,000 upon enrollment.

JSDD's corporate status change to a Public Interest Corporation was accredited in April after two appeals (details are found in JSDD Newsletter #178.) During the appeals process, the court pointed out that rather than a one-time payment upon enrollment, it was much preferable to have a periodic confirmation of a member's will through recurrent payment.

Based on our responses, we decided to make a phone call to all members for their membership confirmation. JSDD has about 4,000 life-time members nationwide, and our chapter has around 2,000. All chapters started to make phone calls in June, and we closed it in August. Since many members were staying at home due to the pandemic, we had a lot of great conversations with them. On the other hand, some didn't answer the phone or were reluctant to have a conversation due to recent nation-wide scam cases targeting elderly people. We found that some members had already passed away, and some were suffering from dementia so we had to talk with their families.

The main purpose of the phone call, of course, was to confirm continuation of their memberships, but we were also able to update their information such as change of address, where they kept their membership cards, and how they were handling the pandemic. We were pleased to hear some of their responses such as, "I'm so glad to receive this phone call, "It was very instructive and meaningful to talk directly with a JSDD official."

We also realized how important it is to have direct communications with each and every life-time member.

## Tokai Hokuriku Chapter

**Report on phone calls to life-time members**
**They were happy and relieved to hear from us**

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After JSDD's status change to a Public Interest Corporation, we started calling all of our life-time members in July to update their information. Three of us, the Office clerk, Tsukasa Kobayashi (Chapter Advisor) and Yoshimi Nanpei (Chapter Director) took turns picking up the only phone in our office to call. When the call did not go through, we called again at another

time, at least twice in each case. Of all 339 life-time members in our chapter (counted one family as one), we were able to successfully communicate with 227 (66.9%), including the cases in which someone else in the household had to talk instead of the bedridden member, or the member was in a nursing home, etc. A total of 74 cases (21.8 %) were unsuccessful, of which half (38 cases) were due to a phone number no longer in service, the call went straight to voice mail, or refusing all calls because of an increasing number of spam calls.

When we were successfully connected, we asked them for any updates in personal information such as an address change, if the membership card and the living will declaration were kept in a safe place, as well as if there were any changes to their daily life. We expected some people would be surprised to receive a call from us, so we took this opportunity to thank them. We were very pleased and relieved to find that no one wanted to cancel their memberships.

Unfortunately, we found out from the calls that 20 members had passed away. It was awkward and very sad hear a wife of the member, "My husband is no longer with us." or "My father died a long ago." Of course, we expressed our sorrow and sympathy and asked for their continuous support for the dying with dignity movement. We regret that was all we could say, and can't shake the feeling that we could have said it better.

# Kyushu Chapter

**Requesting a life prolonging measure is part of the living will**

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Until today, we have regarded refusal of life prolonging measures as a basis of dying with dignity; however, if you decide to accept life prolonging measures as a result of your life planning conference, through in-depth communication with your family and medical providers, then this is also considered dying with dignity.

When I visited patients to provide in-home medical care, I had a patient suffering from a chronic heart disease, kidney disease, and dementia. He was 92 years old. He had a strong desire for living a long life, and he requested that I would give him the best available medical treatment. He said, "Cardiopulmonary resuscitation, respirator, please do so because I do not want to lose to death. Only after receiving all available treatments, I will say, okay this is it." He told me, "Doctor, please place a photo of my dead wife in my coffin and when it comes time that I'm unable to speak or express my wishes, my daughter will be my agent. Her decision will become my decision. When I die, my daughter will probably be crying. Please tell her not to cry because her father lived his life to the fullest." We used to carry on these conversations crying together with his daughter.

His wishes were well known to all of our medical staff and fully honored that he did not have any worries, fear or depression. He died in a hospital. I think that he, his daughter and all other family members were content and satisfied.

Refusal of life prolonging measures has been the mainstream statement in the living will. It is time that we open our outlook that choosing to accept all available life prolonging measures is also a viable option to be recorded in the living will. Whatever you choose, the bottom line is that the patient's self-determination is what must be honored.

# Shikoku Chapter

**Announcement: New Chairman of Shikoku chapter**

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Shikoku Chapter Main Office was moved from Matsuyama to Takamatsu in October. Masahiro Nomoto (Ehime Prefecture) also resigned, and Jun Nishiguchi (Kagawa Prefecture) became the new Chairman of Shikoku Chapter with the approval of both Chapter and Headquarters Board of Directors.

Shikoku Chapter started in Matsuyama City, Ehime Prefecture in 1994 by a group called "Consideration of dying with dignity in Ehime." The group branched out to Takamatsu city in 1995, Tokushima city in 1996, Kochi city in 1997, and eventually to all prefectures in Shikoku. The Chapter's Main Office moved from Matsuyama to Takamatsu in 2000, and back again to Matsuyama in 2010. During the last ten years, it issued biannual newsletters, then later combined it with the headquarters' quarterly newsletters. JSDD's corporate status will open new doors to further expansion. There are many organizations pursuing the best medical care for terminal stage patients, of which JSDD is the largest organization with the largest number of members.

The living will is a demonstration of an intrinsic human right, which should be honored by all people concerned. By carrying the torch of this concept, we have endeavored to create a better society in which family members, close friends, medical providers, caregivers, and everyone involved shares a common consent and support to honor the patient's will. Our endeavor will continue to create a comfortable environment for a peaceful departure.

## 9th Session of Japan Living Will Study Workshop

**Dignity in dying, a beam of light in in the midst of COVID pandemic**

Originating from Wuhan, China, the new infectious disease called the coronavirus has made a sweeping expansion in the globalized world. On March 11, 2020, the World Health Organization (WHO) declared this to be a pandemic, a disease affecting the whole world. The spread is still ongoing, and the number of infected cases world-wide was around 25,000,000, and the number of total deaths reached around 850,000 as of the end of August 2020. Due to this rapid expansion, the medical system of all countries were critically stressed for vital resources such as hospital beds, medical staff, personal protective equipment (PPE), inspection equipment and facilities, artificial respirators, ECMO, etc. Medical providers were forced to triage patients due to limited supplies of medical equipment and professional staff in many countries.

To document refusal of life prolonging measures in the living will has been to fight the nature of common medical practice to save lives at all cost, that is, the use of aggressive and invasive treatments against patients' wishes. However, the pandemic reversed this situation with an overwhelmingly large demand against limited supplies in which we are unable to save all lives. We are now facing a complete paradigm shift which we have never experienced since the establishment of Japan Society for Dying with Dignity. The environment is now telling us how to prioritize patients' self-determination.

9th Session of Japan Living will study workshop will be held as a Zoom conference, discussing the meaning of dignity in dying, how to prepare for it, and how to implement it. We hope this discussion will be like a beam of light in the currently dark, uncertain world.

## Telephonic and Email Medical Consultations No. 5

### "Should I continue or stop the cancer treatment?"

Q: I am over 80 years old. I was diagnosed with Stage 4 bladder cancer, and currently undergoing chemotherapy with UFT. I have some of the side effects such as fatigue, loss of appetite and diarrhea, but no oral ulcer. I will have a CT examination in two months to see if it is working or not, but I feel that eventually it will show no effectiveness. My concern right now is whether or not I should continue treatment with a different drug. Naturally, there will be a gradual decline of thyroid and kidney functions, and we recognize the likelihood of the cancer spread to the lungs. I am afraid that under these conditions, the new drug treatment will have a negative effect on my other organs rather than positively affecting against cancer. Please tell me your honest opinion.

Advice #1:

Sooner or later, you should stop the chemotherapy, but your choice will be whether you stop it now or continue a little bit longer with another drug. You may be inclined to choose one side, but not 100% sure about it. You will likely regret no matter which option you choose. If you stop the anticancer treatment sooner, you may be able to enjoy the rest of the time you have, but if you choose the other one, you will encounter one of the following four patterns:

- You may have a longer life; and you may have no bad side effects
- You may have a longer life; but you may have bad side effects
- No chance for a longer life; but you may have no bad side effects
- No chance for a longer life; and you may have bad side effects

You should ask your doctor's opinion as to which one of the patterns has the highest probability of occurring in your case if you chose to continue with the treatment with a different drug. If you regret over the choice of stopping the treatment regardless of the likely pattern you'll follow, you may want to make a determination to pour your remaining life time, money and physical strength by taking a risk. Sometimes your doctor is just waiting for you to tell him to stop the treatment.

I am not an expert on this, but I sense that under the current situation, you don't expect a better outcome with the next treatment. You may want to ask your doctor for an honest opinion and recommendation or you can see a palliative care team for consultation if available or ask for a referral.

## Advice #2:

The primary treatment for stage 4 bladder cancer is a drug treatment with cisplatin. However, this drug is very toxic, and you probably have a kidney problem which made your doctor chose UFT. Side effects include fatigue and loss of appetite. If these side effects are tolerable to you, you may want to continue it.

However, if this drug is not working effectively for you, you may want to stop it. Your treatment should focus on a countermeasure for the gradual loss of kidney functions and palliative care.

## Advice #3:

You should consult with a specialized physician as to the individualized selection of the anticancer drug; however, since you're in stage 4 and have fatigue and loss of appetite which are not recoverable, you may be better to stop it. I recommend having a Jinsei kaigi (Life Planning Conference) or ACP, prepare your living will, and spend the remaining days of your terminal life sorting out whatever you left unfinished. You may consider the best time for stopping this treatment and gather full information on palliative care and terminal medical care. When you are an elderly patient with multiple conditions, it may be wise not to have separate treatments from different specialists, but to have a primary doctor nearby whom you can easily talk to and who can take care of your various issues as a whole.