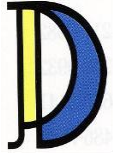


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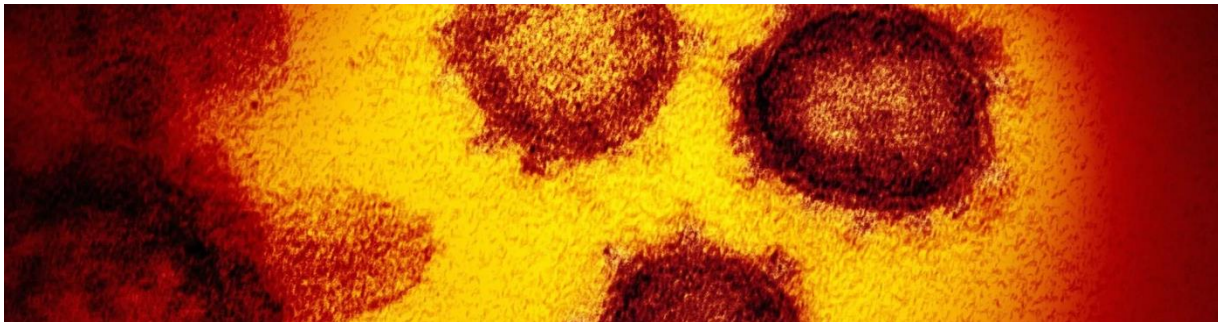
**Japan Society for Dying with Dignity Newsletter
No. 183, October 1, 2021**

Main Contents:

- 10th session of the Japan Living Will Study Workshop: Resilience and strength to overcome the pandemic through adaptability
- Special Edition: Responses to Mr. Soh Kuramoto's urgent message
- Regional Chapters' Activity Reports
- Telephonic and Email Medical Consultations

10th Session of Japan Living Will Study Workshop

Resilience = the strength to bounce back from the pandemic



A year and a half have passed since the WHO announced the new type of the Corona virus infection as a pandemic. During this period, many studies have been conducted as toward its prevention and treatments. With the compilation of all global experiences and knowledge, the vaccination became widely offered and a curable medicine finally developed. However, we are still far away from ending it.

This virus tested our trust in the healthcare system which has been available any time and easily accessible to anyone; and now we are unable to provide adequate life prolonging measures and not even emergency lifesaving rescues. This is the first paradigm shift since the foundation of Japan Society for Dying with Dignity. The Corona virus has obliged us to take action and execute self-determination upon crises of our own lives. Consequently, we have been forced to realize the importance of the living will prepared well in advance.

Japan Society for Dying with Dignity has conducted eleven workshops in the last two years to determine how our society should be, what direction it needs to go, and what the living will should include. Members were invited from outside of our organization, mostly philosophers, sociologists, medical professionals and attorneys. Through these workshops, we reached the conclusion that dying with dignity is not just about rejecting life prolonging measures and/or providing sufficient palliative care, but it is an event that comes after living with dignity.

What does it mean to live a life with dignity? Many events occur in life such as death, divorce, illness, poverty, solitude, discrimination, not being recognized, not being loved; all those events are heart breaking. Then there are natural disasters such as earth quakes, tsunami and over floods. Some people are able to maintain a positive outlook and self-respect, and some cannot unfortunately. Where do we find the strength and the courage to overcome life's cruel occurrences and obstacles, and get back up when we're down? In other words, how do we find resilience in ourselves?

Life is a sequence of unexpected happenings. The endings of your own life or your family members rarely happen as you wish them to be. We would like to have this discussion by placing the focus on resilience, the power to recover from despair.

Date: December 11 (Saturday) from 1 pm to 4 pm

Meeting medium: Online conference (closed session: The contents of the conference will be posted on the newsletter and our website.)

Lecturers (tentative):

- Shabbot Akane (The Netherlands; author of "Positive Health;" and researcher of euthanasia related issues)
- Jun Matsuda (Honorary professor at University of Shizuoka; philosopher; and author of "Status of Euthanasia, Death with Dignity, Medical Treatments and Self-determination During the Final Stage")
- Yusuke Takamiya (Professor at Showa University Medical School)
- Chihoko Hirabayashi (Nurse; Medical Consultant for JSDD)

Coordinator: Satoru Mitsuoka (Owner of Mitsuoka Clinic, JSDD board director)

For updated information regarding this session, please refer to: <https://www.songenshi-kyokai.oj.jp/>

“Special edition” Responses to Soh Kuramoto’s Urgent Message (Newsletter #182)

We need a lot of more LW supporting physicians!

Sensational responses came from JSDD members who read last quarter’s urgent message about dying with dignity with the title, “And Koji Died” by Mr. Soh Kuramoto. Some responses include the following:

“I couldn’t read it without crying.”

“Memories of how my late husband spent his last days came back to me.”

“I hope more and more people read this article.”

“Poor Koji... his story broke my heart.”

Here are some of the responses we would like to share and present our proposal for future solutions.

“Spread this message to more people”

Nobumasa Ohtsuka (81), Nara Prefecture

I was deeply impressed with Mr. Kuramoto’s message of “And Koji Died.” and would like to express here my wish. I have often questioned some statements commonly shared among people such as “the life of a person weighs more than earth” or “a life must be saved no matter what.” What Mr. Kuramoto said has stuck with me, “...the problem is the lack of philosophical standard within the medical community, which is a crime committed in one of the most modern academic fields, the science of medicine.” My friend’s father was staying in a privately operated assisted living home. Last year, he suffered from a severe case of emphysema and was treated by the clinician contracted by the nursing home. He often told his friends and siblings specifically to not give him any life prolonging measures; however, the clinician who treated him said that he would be able to recover after administering an artificial respirator for two to three weeks. Naturally, his siblings all agreed to it. Unfortunately, his conditions did not get any better, and he suffered excruciating pain and discomfort much worse than dying for the last two months. He was upset with his siblings for not doing what he told them to do, and even begged them to just kill him.

JSDD’s position is that it does not support euthanasia, but what is the difference between dying with dignity and euthanasia? The essence of the matter is that when a patient is still mentally clear about his or her wishes and makes a statement such as, “do not administer any life prolonging measures, but provide me palliative care to alleviate pain and suffering,” the doctor should respect it and follow it accordingly. The doctor should not be held legally responsible for acting on the patient’s decision. In my opinion, legalizing this process is the only thing that needs to be done. Dying with dignity sounds like only noble people deserve it, but most people just want to die peacefully without any pain. Mr. Kuramoto’s message had a strongly persuasive power. JSDD should take an advantage of it for its promotional campaign and other activities. I am sure there will be a lot of support and agreement.

“Overwhelmed with my late husband’s final days, I read it in tears”

Sakiko Kobayashi (90), Fukuoka Prefecture

I read “And Koji Died” twice. I found myself drowning in tears. I was thinking of how my late husband died. It was over twenty years ago, but it seemed like only yesterday. It hurt my heart. He was wrapped in tubes. He wanted to go home to die, but his wish was ignored. He was just breathing, and I wanted so badly to help him out of the pain. I still believe to this day that he was angry with me because I did not do what he wanted us to do.

As I watched how he died, I immediately joined JSDD because I did not want to end up like him. I have been telling my children that when my time comes, all I want them to do is to get rid of all

the pain, and that's all. I believe that our medical technology has made great progress; however, it does not and never will change the dignity of human beings. I feel strongly about being able to end my life as a human being, not merely existing in this world as a living body. I speak highly of JSDD to my friends. Mr. Kuramoto's pain pierced my heart, so I picked up this pen to write to you. I sincerely wish for a continuous growth for JSDD.

“I read it holding back tears”

Teruko Umekawa (82), Kanagawa Prefecture

Having a hard time holding back tears, I somehow managed to read Mr. Kuramoto's urgent message which made my heart feel heavy. I want many people to read this message and share this reality with each other. I agree with what the JSDD president said, which was that we must change our current status that the only people who can die with dignity are those lucky enough to find a good doctor. It is unfair to rely on luck.

I joined JSDD because I did not want to extend my life with pain and suffering. I am now aware that merely being a member of JSDD is not good enough. At my age, the main topic of conversation among friends is what our life endings will be like. I was rather proud to tell them that I joined JSDD and always kept my membership card handy, but I now realize that is not good enough. I need to do more. I found that not many people know about JSDD. As I want to start letting more people know about JSDD, please send me some pamphlets so I can distribute them and help in my own way.

“I feel like a fog cleared up”

Chieko Futoh (89), Tokushima Prefecture

I read this message by putting myself in Koji's shoes. I realized that just being a member of JSDD does not give me a complete peace of mind. After I read this piece, I really felt like a fog had lifted from my view.

Since being a JSDD member for the last several years, it didn't seem like there has been much increase or decrease in membership. If a high percentage of doctors in Japan were supporting JSDD, Koji would not have finished his life with that much pain and suffering. Imagine if an old lonely woman living in a rural place believing that showing her JSDD membership card would automatically guarantee her final exit without any pain. This is not reality. I have now realized it. I must find my own way to make it happen.

I have gone through many surgeries; eye, knee, thyroid gland and a broken bone. Every time I have a surgery, I showed them my card. The doctors glanced at the card, but no more than that. JSDD has many highly reputable doctors as directors and advisors. I request them to have more influence over increasing its members and supporting doctors. I sincerely beg all doctors throughout the country to place top priority on the dignity of patients. I'd like to start with my primary doctor and ask him to become a LW supporting doctor. I now realize that I must make every attempt to have a peaceful ending for myself. Thank you, Mr. Soh Kuramoto. You opened my eyes widely.

Expanding the Network of LW Supporting Physicians



Increasing the number of LW supporting physicians will be JSDD's top priority considering the fact that despite how well the patients prepare their Living Wills, they are unable to receive their expected peaceful exit unless their provider is aware and willing to execute it. As Director Mitsuoka pointed out, we must promote the importance of palliative care and expand its use. JSDD endorses the

above points and promise to work closely with each and every member of JSDD as a true public interest cooperation.

Activity Reports from JSDD Regional Chapters

Hokkaido Chapter

Homepage Video Seminar

Topic: Terminal Medical Care offered by Continuing Care Retirement Community (CCRC), United States

Lecturer: Reiko Miyamoto (MD, Chapter Chief)

*In Japan, senior citizens are forced to change hospitals or facilities depending on their need for hospitalization or care service, and often receive undesirable aggressive medical treatments and/or life prolonging measures.



In contrast, there are around 1900 CCRCs in the United States where seniors can receive any level of medical treatments and care while enjoying their retirement until the end without having to move around. Palliative care is the major terminal medical care given and they do not administer any aggressive medical treatments or life prolonging measures. Dr. Miyamoto visited a CCRC in 2015, and she talks about her observations.

Photo: CCRC Hillcrest Meeting house lobby

Tohoku Chapter

New Project: Living Will Information Exchange via conference call

How do we communicate freely with one another during the pandemic without the internet or email that is easy access to everyone? This is how we came up with the Living Will Information Exchange Conference Call. Our first call occurred on Friday, July 16th from 2:00-4:00pm. Our Branch Chief initiated the call at the booked time. This is literally a person to person opinion exchange and consultation. Eight people from Miyagi prefecture, one person from Iwate prefecture and one person from Akita prefecture, altogether ten members. They had about 15 minutes per person to talk, and the conversations were very deep and intimate.

There were comments and opinions about the urgent message from Mr. Kuramoto which appeared in the previous newsletter #182. Some questioned if the living will was not useful. Some had different opinions that it was an unfortunate case, but could have been an anomaly or if the patient had made a different approach, maybe different life-ending could have been possible.

I also explained about the survey report from the surviving families which showed 94% effectiveness of the living will. Of course we are not satisfied with this result and will further endeavor to go and break thru. Someone mentioned that he recalled the heartless comment made by the doctor did hurt him a lot and I explained that the medical community is a lot different from the past days. In the medical examination for the medical students the honoring of the patient's wish is adopted as a questionnaire in the examination. One request from this conference call was a list of LW supporting physicians in the local areas. As we were able to have a very intimate conversation, some made offers such as "I will reach out to see if there's an interest in incorporating seminars or lectures during town meetings;" "Our local administration office may be interested in having a joint seminar with JSDD on the topic such as Living Will and Terminal Care," or "Some funeral service firms are serious about promotional campaigns. Maybe we can have a joint event. I will reach out to them." I feel they became more positive and involved because of the intimate person to person conversation we had. We will further exert this idea so that we can be more open and productive. They all told me that this project was really a good trial. We will try to expand this project over to all six prefectures in the future. Please feel free to contact us at Tohoku chapter.

Takao Ami, Chapter Chief

Kanto-Koh-Shin-Etsu Chapter

Online Lecture Meeting (Title: Stay true to yourself until the very end)

The new variant of the Corona virus is widely spreading, and the infection rate is rapidly increasing. Many patients are forced to stay at home since hospitalization is rarely available. Consequently some died without receiving proper medical care. The risk of this fifth wave is greater. Under such circumstances, there was an online lecture held by Dr. Suzuki on August 28th. Dr. Suzuki is a pioneer in-home terminal care doctor who followed his father's career path in terminal medical care, currently taking care of Covid patients at their homes. He operates Suzuki Internal Medicine Clinic in Ohta-ku, Tokyo and is also the vice president of National In-home Care Support Clinic Association. Although this meeting had the maximum capacity of 80, the attendance exceeded to 125.

According to Dr. Suzuki, we are in a transition stage of providing in-home medical care for support rather than for cure. In-home physicians deal with various types of illnesses and must provide appropriate medical care including palliative care. We found out in this lecture that healthcare professionals of multiple sectors are working together to create this joint support team system. He also mentioned that there are limits to what in-home medical care can do, and integrating palliative care hospitals is part of today's in-home medical care system. This lecture was a great opportunity to learn about today's in-home medical care system. I believe that many people who attended this lecture realized that in-home care is becoming something more intimate, friendly and acceptable than what they originally thought. Life is a sequence of making choices until the very last moment. Of course, spending your last days in the hospital is one of those choices. However, if in-home terminal care is something that was more open, accepting and embracing all ideas to support the wishes of the patients and their families with no pressure or rejection, everyone would probably completely trust the in-home terminal medical care system and leave everything to the team. Through this lecture, Dr. Suzuki made us all feel strongly that we need a lot more in-home doctors. Before closing, I would like to conclude that in-home terminal medical care is something that should be seamlessly integrated into the patient's daily life, not something that controls it.

Michiko Sasaki, Nurse and Chapter Director

Tokai-Hokuriku Chapter

A common platform for sharing thoughts

We have conducted a lecture five times per year in the past, but it became difficult to hold meetings with a large number of attendants due to the pandemic. Instead we decided to conduct the Living Will Information Exchange in each prefecture. In addition to the usual chapter directors, the telephonic exchange in Gifu prefecture was held with additional five selected members: 1) a husband who was concerned that his wife is unable to express her own wish, 2) a single female looking for a LW supporting physician, 3) a female care manager working in a nursing home, 4) a female with an opinion that Advance Care Planning (ACP) is not gaining any attention in our society, 5) an independently minded female currently working as a care giver. We asked them to discuss their wished medical care and the kind of end of life, as well as any concerns or anxieties in their own lifestyles.

We introduced Ms. Kato (42), who lectured during the meeting last July. She emphasized her philosophy that your medical care should revolve around you, and if something is lacking, you need to find it or make it yourself. Ms. Kato was diagnosed with breast cancer at age 31 and is currently under treatment. She started up a support group for cancer patients and those who support them. Her story of fighting cancer for 11 years can be seen on her website.

Getting together on the same platform and exchanging opinions and sharing information allowed us to confirm that your own self-determination requires a combination of correct information, making reasonable decisions, and tough mental preparedness.

Mr. Yohei Nojima, Chapter Chief

Telephonic and Email Medical Consultations No. 8

“We were very impressed by the high level of concern over palliative Care”



The living will (advanced directive concerning end of life medical care) has one paragraph that states “I want to have sufficient palliative care with proper amount of morphine to alleviate any pain.” People’s concern over palliative medical care is very high, and we receive a lot of inquiry regarding this subject. Below are some of the inquiries, answers and explanations.

What is the current situation on palliative care as part of in-home terminal care?

- I am in terminal stage of cancer. The medical patch was not working well, so now I’m taking sublingual tablets, but the side effect of nausea and vomiting are terrible. Can I take morphine to oppress the pain and vomiting? I am thinking of receiving in-home terminal care in the future. Please give me some information on local LW supporting physicians who also provide palliative care.
- I was diagnosed with lung cancer by a CT and a tumor marker. I have been taking steroids for a connective tissue disease for a long time. Because of this, I was told that surgery and radiation treatment would not be recommendable. Is it possible for me to receive in-home terminal care?
- My father is very old and in the last stage of pancreatic cancer and currently receiving in-home palliative care. If I call his name, he reacts by nodding or squeezing his hand over my hand. Fortunately, he doesn’t seem to be in much pain and is on oxygen tank if needed. Since he developed edema, he will be removed from dripping. The doctor said that only has a few more days to live. I want to see him off without any pain.
- I have been taking pain killers since six months ago when I was diagnosed with spinal stenosis, but the pain is still unbearable. I think morphine is the last resort, but my doctor is negative about it. I would like to switch to a pain clinic specialist.
- I have been depressed for a long time and I am unable to sleep some nights due to unbearable amount of pain. Consequently, the volume of my medication is increasing. My family is doing their best to comfort me which I appreciate, but not any more than that. Can I have any palliative care medicine to alleviate the pain?

“Don’t keep it to yourself. Talk to your doctor.”

Q: From what stage should we start palliative care?

A: The Ministry of Health, Labor and Welfare recommends that upon diagnosis with cancer, both medical treatment and palliative care should start simultaneously. Regardless of the progress of the condition, it is recommendable to start it at an early stage. There is no need to be in pain. It is also important to maintain physical and mental stability by alleviating the pain with palliative care for the continued treatment to work.

Q: Is palliative care only available to cancer patients?

A: Palliative care has been mainly provided for cancer patients, but lately it was recognized that it is an important treatment for other illnesses. So, it is no longer only for cancer patients. There are many diseases causing severe pain, and we see many patients suffering every day. You can consult with the palliative care department of your hospital, or a pain specialist at the pain clinic.

Q: Do you have to be hospitalized to receive palliative care?

A: Patients are sometimes admitted to a palliative care ward, but that is not always the case. In-home care team programs provide home visiting doctors and nurses and also provide in-home palliative care. A single person living at home can be eligible for the service.

Q: I am afraid that palliative care is costly and expensive.

A: Whether the palliative care is provided in hospitalization or in-home, the national / public health insurance will take care of it. When it comes up to a high cost, there is the national high cost reduction program which you can apply. When hospitalized, uncovered bed cost, meals and others may become high cost. When serviced by the in-home care team the care insurance apart from health insurance will be available.

Q: I am concerned about addiction and side effects of morphine.

A: As long as morphine is properly used for medical treatment purpose only, it is reported that addiction cases are almost none. If you feel sleepy or foggy in some cases, talk with your doctor and adjust the volume depending on your situation and condition. There are many types of pain medication besides morphine in the forms of pills, patches, suppository and injection. Don't hesitate to consult your doctor at an early stage.

Pain includes discomfort

The pain you feel physically is not the only kind of pain. Any and all levels of discomfort is in the category of pain. If people are asking you repeatedly if it is really painful, such heartless words can hurt both physically and mentally. Do not tolerate it because it will eventually cause sleep deprivation and loss of appetite; or in the worst case, it can lead to depression. There are many ways of dealing with this. Do not try to disguise it or keep it to yourself. Get the treatment at an early stage and eliminate the pain before it even starts.