Excerpts from





Japan Society for Dying with Dignity Newsletter No. 182, July 1, 2021

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In pursuit of legalizing dying with dignity Diet Member Coalition for Dying with Dignity restarted



The Federation of Diet members to consider honoring of end of life self-determination restarted on March 24th. A total of 165 bipartisan diet members participated (five more participants joined later). Takeshi Noda, former Minister of Domestic Affairs, was elected as the new chairman. In his inauguration speech, he said that the rapidly increasing elderly population is becoming an extremely important topic in the medical community.

(Photo: Newly elected chairman, Takeshi Noda, making his introductory speech)

Looking back at the progress of the legalization

movement thus far, October 1983 was when JSDD first introduced the bill, Special Measures for Terminal Medical Care Act. However, it was rejected and set aside due to the sentiment that the topic was not mature yet, and the timing of it was not right. In December 2003, a petition to seek legalization of dying with dignity was submitted to the Minister of Health, Labor and Welfare, at the same time we started a campaign to gain support of the Diet from both upper and lower houses for the legalization process. In response, 60 diet members from both houses attended the initial meeting. Between then and 2012, several versions of the bill were drafted. In 2015, the

final bill was developed which accepts the patient's refusal to commence and terminate existing life prolonging measures. This bill was meant to exempt physicians from making legal decisions and becoming liable by honoring the terminal patient's self-determination to refuse or terminate life prolonging treatments.

The latest bill prepared by the Diet Members Coalition contains an explicit wording about the patient's self-determination when it comes to the refusal or termination of life prolonging measures. In other words, the legal preparation has begun once again to guarantee the protection of patient's self-determination and dignity to the fullest.

In commemoration of this grand start, former vice president of JSDD, Dr. Yutaka Suzuki, made a speech with the title, "In pursuit of legalizing everyone's desire of a gentle departure."

An urgent message from Soh Kuramoto, a playwright, director, screen writer and JSDD advisor

"To prolong human life" is the ultimate goal of the medical community, but there is another crucial medical mission that we are all forgetting, "to liberate patients from pain and suffering." He had to watch one of his staff members go through his last moments of joy and sorrow in Furano city, Hokkaido, who ended up experiencing a merciless death. We have to ask the question, "What is dignity in dying?" He now shares his feelings about the loss of his friend in tears.

"And Koji Died"

By Mr. Soh Kuramoto

[Profile]

Soh Kuramoto, born in Tokyo in 1935, is one of the most famous and respected Japanese screenwriter, playwright, and director. Graduated from the University of Tokyo. Free after Nippon Broadcasting System, he moved to Furano, Hokkaido in 1977. From movies to screenplays for TV dramas. He produced many hit works such as "From the Northern Country" and received numerous awards, the Order of the Rising Sun and the Medal of Honour. Since 2006, he has presided over the NPO Furano Nature School and is also focusing on environmental conservation.



My close friend died of cancer.

He was 62 years old and a JSDD member, but the membership card didn't help at all. I am writing now with a feeling full of sorrow, anger and emptiness in my heart.

My dear friend. I'll just call him Koji.

Koji was on my staff since the founding days of the Furano School. We had a close friendship for nearly forty years. His dream was to become a log cabin builder, so I sent him to Canada to train. Through hard work and steady efforts, he became the leader of all builders. He built over ten houses including some log cabins. A stone house I am living in now and a drill hall which I call a studio were also built by him.

He was a brawny, patient, and delightful man from Kyushu. It was nearly two and a half years ago when he was diagnosed with cancer. He told me the news with an awkward expression on his face that he was already in Stage 4. His remaining life was about two years or so. He was 60 years old, unmarried, and was in the middle of building his last nest. He wanted to die in his own nest, definitely not in a hospital. Between his visits to the hospital for treatments and being in pain, he was trying to finish building his last house. I introduced him to a University Hospital in Asahikawa city, and suggested enrolling in JSDD.

City of Furano's population is 22,000. There is a local hospital, and many doctors are sent there from the Asahikawa Medical University(AMU) Hospital.

Several years ago, I was writing a drama script called "Garden of the Wind," which is about a doctor who was diagnosed with terminal cancer. I researched and learned quite a bit about pancreatic cancer and palliative care. I became very close to Dr. I who specialized in palliative

care at the AMU Hospital. I even asked him to review and edit the draft of the script. He was already retired, but one of his colleagues had taken over the Palliative Care Clinic, with whom Koji's primary care doctor had close contact. Through this connection, Koji was able to receive cancer treatment that was not available at his hospital in Furano. When he felt good, he continued his house building work.

One year had passed from his first cancer treatment. During the second year, side effects of cancer pills started to surface, so they switched him to steroids. It was around that time that his pain reached a fairly high level, but being the quiet and patient man that he was, he did not show any signs of pain. Because of that, we mistakenly overlooked how severe his pain actually was.

In November of that year, he suddenly attempted to commit suicide.

He made two cuts in his neck unsuccessfully, and then he tried to drill a hole into his heart with an electric drill. Another staff member who happened to be there found him bleeding and immediately called for an ambulance to take him to the emergency room. Luckily, his life was saved.

I was terribly shocked, and asked the doctor in charge of palliative care who rushed from Asahikawa to relieve him from the pain. I showed him Koji's JSDD membership card and begged him to give him morphine if he was not able to save his life. Here's my confession.

My brother in law, my younger sister's husband, died of bone marrow cancer more than ten years ago. They were living in Osaka, and were devout Christians. The pain from bone marrow cancer is known to be quite severe. After suffering for two full years, they decided to move him to a Christian hospice run by a church located in Arima Hot Springs.

It is known that a large amount of morphine is given to patients in a hospice. Relief from pain is possible, but death is unavoidable. They reached this decision after a long discussion. This was the first time that I learned about the hospice.

Soon after he was moved to a hospice, I visited him. I noticed that my brother in law's facial expression was of joy, quite different from when he was in pain. He was unbelievably talkative as if he was a whole different person. His conversation was inconsistent from time to time and confusing, but the pain seemed to have completely disappeared from him. My sister happily told me that they sang hymns together last night, still in disbelief and trying to hide her happy tears with a big smile. He lived nine more months afterwards. At his funeral, his graceful and peaceful facial expression gave me a strong impression.

Unfortunately, there is no such facility in Furano. There is only a few hospices in the whole island of Hokkaido. I spoke to the palliative care doctor at the AMU Hospital, and he agreed to support my request. I was still uncertain, so I contacted my internal medicine physician. His response was, there is still hope for a new medicine, so don't give up yet. I called the palliative care doctor of Sapporo and told him what my internal medicine doctor had said to me. He was furious to hear that this doctor was still saying such a thing.

Being 86 years old, I can sense that death is near and real. I am digging deep into my soul and seriously hoping of dying without pain. I am not scared of dying, but I don't want to be in pain and suffer. I want to die in a hospice. Anyone, please build me a hospice!

In January, Koji's cancer spread to his stomach. He was still enduring pain with in-home terminal care. He seemed overwhelmed by the thought of his suicide attempt in November last year. He was ashamed that he failed to kill himself, which consequently distressed many people around him. He became even quieter than before and continued to receive steroids at home. He was receiving morphine, but it didn't seem to be working because his face showed no relief from the pain. His blood oxygen level which should be 97 to 98 was rapidly decreasing. Even though he was using an oxygen tank, his appearance became worse and worse.

On March 14th, his blood oxygen level dropped down to 60. He could no longer withstand this condition, so he finally called for an ambulance to be hospitalized in Furano city. Due to the COVID-19 lockdown, the hospital was in an alert posture. Despite hospital restrictions of no visitors, I requested my selected staff to attend to him 24/7 which was approved.

As I was unable to do anything for him, I decided to write a long letter to him. I wrote about our long, close relationship, remembering all the joyful memories we shared, and my deepest gratitude for his friendship. At the end, I wrote that I just prayed for him to be liberated from the pain as soon as possible. While I was writing, my mind was confused as it felt like I was writing his eulogy.

The next morning, my staff who was attending him called me and said that after reading just the first page, he started crying and had a hard time finishing the rest of the letter. When he finally read the last sentence, he murmured "Sensei understands my mind and feeling."

At 1:00 am on the 17th, a call from my staff awakened me. "Koji is struggling in bed with pain and calling your name. Please come right away! I already asked the night shift nurse to allow you to come and see him."

When I arrived, Koji was wrestling in his bed like a fish out of water. He was wearing a mask and a pipe through the nose, but it seemed like the oxygen was not going into his lungs. He was trying to scream, but no sound came out. He was trying his best to inhale. When I grabbed his hand, he tried to hold my hand tightly, but without much strength. I could only rub his rough hand that reflected years of his hard labor. Koji was trying to tell me something, but his voice just sounded like noise. He was trying to pump air into his lung by inhaling to his fullest, but only an empty breathing sound filled up the whole room.

His blood oxygen level had dropped down to 40!

"Isn't there anything you can do to relieve his pain? Please do something!" I begged the nurse who had been adjusting a dial on the equipment near his bed. Obviously, there was no change on Koji's condition. This young night shift nurse was probably not allowed to give him more morphine or make any medical decisions. Most likely, she was just trying to do what she was instructed to do. I reluctantly gave up on asking her for anything, and found myself just rubbing Koji's rough hand helplessly.

"Hang in there! Hang in there! You'll feel better soon!"

Koji glared at the ceiling, took off his mask to inhale roughly and deeply, and then he put it back on. He repeated it many times.

"How can we allow such cruelty in this world?" I thought aloud in my head while I attempted to hold the tears trickling down my nose.

Even when we swallow a stomach camera for a checkup, any hospital will provide patients drowsing drip to reduce the level of consciousness so that the camera goes down smoothly into the stomach without any pain or discomfort. This is the level of comfort that modern medicine can provide for our patients. Meanwhile, Koji is tussling in pain like a fish out of water. He is fully conscious, so his pain must be at its peak. The ultimate goal of medical science is to save human lives; however, what was going on in this hospital room was far from being humane. Even though our advancement in medicine can alleviate pain, what this situation seemed to me was nothing but torture. This is such a brutal, cruel and inhumane practice! How can we allow this kind of cruel practice?

For about two hours, I kept rubbing his hand. When I heard his rough breathing sound to calm down, I had to leave the room. I couldn't stand watching him like this anymore.

I went home, but I was unable to sleep.

So many things were going through my mind.

In the 86 years of living my life, I have witnessed many deaths. The death of my grandfather, my father, my grandmother and then my aunt. In all deaths I observed, there was a struggle for each breath until finally the last breaths were taken because they no longer had the physical strength to inhale. Unlike any of these deaths, Koji's process of his last stage was of cruelty, brutality and mercilessness; something I have never witnessed in my life.

Some may say that this happened in a remote hospital in a rural area in the middle of the night under unusual circumstances due to the Covid-19 pandemic; therefore, it was inevitable and is just an isolated, rare case.

I don't think so at all.

I have to emphasize that I have no intentions of accusing the nurse who attended him that night, a doctor who gave advice and instructions from afar, or all other healthcare professionals who were involved in his care.

What bothers me the most is that the current medical community seems to consider saving human life as the definitive rule, and rather ignores another important obligation for the medical profession; that is, liberating patients from pain and suffering.

We have made great advancements in prolonging the human life through artificial respiration, tube feeding, dialysis, ECMO etc. Naturally, I acknowledge this achievement. However, this blind emphasis to prolong life consequently produced many patients in a vegetative state,

resulting. This led to the topics of dignity in dying and euthanasia to become a taboo and the avoidance of having open and serious public discussions on death.

Is this the right path?

Let's take a look at the near collapse of our medical system due to the Covid-19 pandemic.

We saw many patients who were unable to find a hospital who would accept them and who were bounced from one hospital to another. Some patients strictly followed the stay home order and died without a doctor's care. One can only imagine how sadly they died. Some may have died like Koji, struggling and suffering in a lot of pain.

If our current medical science didn't have the ability or resources to deal with this issue, we would have to accept it. However, the truth is that we do, but we are unable to execute make it happen in a timely manner. In the case of Koji, it was possible to reduce his level of consciousness, but they were not allowed to use this medicine for the purpose of prolonging life. This is why I decided to become a JSDD member. This is why Koji became a JSDD member.

Early that afternoon, Koji was finally able to die.

Good job!
Way to hang in there!
Those were the only words I could think of.

More than forty years ago when I decided to settle in Furano, the first thing I did was to walk around town to find out where the closest hospital was.

In the center of town, I found a local hospital. It was not a big hospital you often see in large cities. I figured its medical equipment and level of expertise were several years behind the big city hospitals. But once I decided this was going to be my hospital, I accepted to end my life in the hands of medical professionals at this hospital, whatever its level was.

This Hospital is now renovated and equipped with all modern systems, tools and technical services, quite different from forty some years ago. However, it was in this modernized hospital I witnessed that the medical professionals were not able to relieve Koji's tremendous pain. I don't think this tragedy occurred because the hospital was located in a remote, rural area. It has nothing to do with its locale. I feel that 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.

I feel a great deal of regret and anger about this issue.

The End

The Living Will/JSDD Membership Card not being honored The status quo must be changed By Dr. Soichiro Iwao, JSDD President

A JSDD Advisor, Mr. Soh Kuramoto called me on Friday, April 16th and said that he would like to write an article about how his friend, a JSDD member, died horribly in pain. It was an example of how the living will or the JSDD membership card was absolutely useless. In our annual surviving family surveys, over 10% typically respond that the living will was not supported. The reasons of why they were not accepted vary, but we take this fact seriously. We received Mr. Kuramoto's consent to publicly share his writing and would like to send this message out to all the readers.

He said that what's most troubling for the living will not to be honored is that the philosophy of the current medical community revolves around saving lives as the ultimate goal, but ignores the other important mission of liberating patients from pain. We should not overlook another point he made. "It 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."

For the last 45 years since JSDD was founded, we have been issuing the living will, an advance healthcare directive which expresses the patients' wishes to be honored at the end of their lives. We have also established and endeavored a networking campaign of the LW Supporting Physicians Registry System. However, we have not reached a satisfactory outcome in which all people feel comfortable and secure about this system. The reality is that right now, it is more about luck to come across a good doctor who supports the philosophy of JSDD and carries out the patient's wishes with top of the line medical technology.

Patients can prepare detailed living wills and present them to their doctors, but if the medical providers are out of touch, patients will never be able to die in peace. There is no self-determination for the patients. The right to die with dignity should be one of the most fundamental human rights. We are currently campaigning the concept of "Jinsei kaigi" or ACP to educate and enlighten all of our citizens. Unless the medical community raises its awareness while improving the quality of care, it is only a one sided campaign.

I think we are seeing a shift in our culture which encourages open discussions of death and one's end of life wishes without fear of judgement.

We pledge to continue our efforts to approach the Diet members, medical providers and medical educators to pursue a society in which everyone can experience a sense of security, peace and dignity, and finally a gentle death.

JSDD Board Directors and Medical Advisors' Corner = Palliative Care Team undeniably needed =

By Dr. Satoru Mitsuoka, a clinic owner and JSDD board director

As an in-home palliative care clinic owner, I would like to offer my views on various circumstances. It is common practice to gradually transition from an aggressive treatment to palliative care when cancer treatment drugs are not working effectively. It is not an abrupt switch from one to the other type of care. Palliative care starts when one is diagnosed with cancer or other terminal illnesses. It means to start caring for the patient's physical, mental, social and spiritual pain.

In Koji's case, he thought that committing suicide was better than dying with pain. That means his pain was unimaginably unbearable. When the function of the lungs deteriorate from lung cancer or metastasized lung cancer, one has difficulties breathing. In such cases, a sedative can be prescribed if the patient wishes to be put to sleep with family's support. I wonder if such discussion even occurred with Koji.

Spiritual pain occurs when these three aspects of self-being are diminished; the autonomous existence (the ability to make your own decisions), the time existence (acceptance of the present self because there is hope for the future), and the relationship existence (experience your existence by supporting and being supported by others). In Koji's situation, he of course, lost himself; he was isolated from other people as he had no family, and the pandemic restricted all contact with friends. Since the cancer treatment was not working, he lost all hope for any kind of future.

In terms of spiritual pain, it is likely that he was also suffering from depression. From the time he attempted to commit suicide, he should have been placed in therapy with a professional counselor.

For sufficient palliative care, there needs to be a consolidated effort by a team of experienced professionals: a doctor specializing in palliative care, a nurse, a pharmacist, a caregiver, a social worker, a clinical psychologist, a dentist, and other volunteers. If Koji was able to receive such care, he would have been able to spend the last days of his life in comfort and peace. However in reality, such care is limited to only a small number of very fortunate people.

It is important for an individual to prepare a living will and keep it nearby; however, if a team of medical professionals is not available, it is wasted effort. What we must strive to do is not only to promote the living will, but also to promote palliative care to the medical community. Koji's case taught me the importance of it.

By Dr. Keiko Kato, palliative care specialist and JSDD Tohoku Chapter advisor

I drew three conclusions from Mr. Kuramoto's message.

- They should have started planning for Koji's terminal care and his dying process from the moment he was diagnosed with stage 4 lung cancer. He needed to make use of all local medical resources, not only consultation from a palliative care doctor at the university hospital, especially since Koji had expressed that he wanted to die at home and would hate to die in a hospital.
- Some JSDD members say that they have acquired a sense of security and peace of mind by becoming a JSDD member, but in a real medical setting, a JSDD membership does not guarantee full security. It is imperative to have detailed discussions with people who are close to you and document your advance care planning (ACP). In Koji's case, the perfect opportunity would have been when he stopped his cancer treatment due to severe side effects.
- I wonder if Koji had any contact or close communication with his palliative care team. Palliative care is not only for cancer but is a medical foundation for any illness. Therefore, it is important that the patient assertively requests palliative care at an early stage when initially discussing options for treatment. Palliative care is a team effort that not only consists of medical professionals but of many other related fields. Palliative care also helps prevent tragic incidents such as suicide.

By Dr. Yoshihiko Nomura, clinician and JSDD medical advisor

For stage 4 lung cancer patients like Koji, anticancer drug treatment does not give him any hope, but it is more of a torture that damages the body. If he was also receiving sufficient palliative care at the same time he was receiving the anticancer drug treatment, he would have had much less pain. Anticancer drug side effects for stage 4 cancer patients usually include loss of appetite, anemia, loss of hair, bodily fatigue, infection from reduced white cell count, etc. Some patients ask to stop the treatment even if it meant that they would die. Therefore, anticancer drugs should not be given a priority to a stage 4 cancer patient.

In Japan, a hospice is known to be a facility that is attached to a hospital to provide palliative care for terminal patients, but a hospice does not necessarily have to be associated with a building or a facility. Hospice care is a philosophical concept that provides quality of life during the dying process. Koji made an extra effort to build his own final nest. He should have received proper palliative care and compassion that would support him to die in his last nest, not in a hospital.

FY2021 Business and Budget Plans finalized

Reinforcing surveys and research activities associated with end of life issues Drastic reduction of business projects and a large amount of donation during the pandemic

FY2021 Business and Budget Plans for the Public Interest Corporation, Japan Society for Dying with Dignity were finalized on March 13th by the board directors. On June 12th, FY2020 financial statements were reviewed and approved during a virtual council meeting.

Dr. Soichiro Iwao, president of JSDD, stated that since April last year, JSDD has made a fresh start as a public interest corporation. We were scheduled to substantially expand both promotional and educational activities, but many lectures and regional chapter activities were forced to cancel because of stay home order due to the pandemic. In order to avoid being stagnant, our headquarters initiated a new trend of video dispatch through a team of board directors. Furthermore, JSDD intends to reinforce its focus on conducting surveys and research activities associated with end of life issues.

Current Membership Status

There were 100,645 members at the end of FY 2020, and we lost 5,563 members in the past year. We are seeing quite a drop in the total number of members as we only lost about 1,000 in the previous FY. The new enrollment was 2,664, which was 2,610 less than the previous year. The number of cancellations was 8,227 (the previous year's cancellation was 8,221). We think that the decrease in promotional and educational activities due to the pandemic was a major contributing factor. As to new enrollment, 39% of total membership was in the 70s age group, which remained unchanged for over a decade. In comparison, the average age of new enrollment was 57 years old during the period of 1976-1980; and jumped to 72 years old during the period of 2016- 2020.

FY2020 Business Report and Plan

We had three business objectives:

- 1) To expand and educate the population about the concept of the living will
- 2) To conduct national registry and maintain custody of the living will
- 3) To research and propose new projects

As to objective #1, we were forced to reduce our activities due to the emergency declaration and stay home order during the pandemic. Only 62 lectures and seminars were conducted with 636 total number of attendees, compared to the previous year of 199 lectures and 8,067 attendees. During the pandemic, we dispatched online promotional videos and conducted virtual study activities. The total number of registered LW Supporting physicians was 2,012, which was only a 24 increase. We are far behind our target of 2,393. The total number of phone calls for medical consultation was 557, and consultation cases on multiple topics was 1,313; compared to the previous year of 500 medical consultations and 1,182 consultations on multiple topics. During the pandemic, there was an increase of mental health related consultations, further endorsing the importance of telephonic consultations.

As to objective #2, please refer back to the Current Membership Status.

As to objective #3, an advisory committee formed in September 2019 called "Living Will Study Group" consisting of JSDD board directors and other subject matter experts submitted a proposal to make revisions on: the articles of the association, the living will template, and JSDD's future strategy. These topics will be discussed in detail during the FY2021 board directors' meetings. A new project to issue guidelines on optimal terminal patient medical care was launched with financial support from the Nippon Foundation.

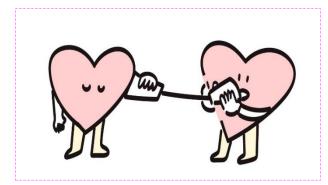
FY2021 Budget Plan

FY2020 Financial Report

We had projected a deficit of \$2,048,000, but instead, we had an unexpected profit of \$13,700,000 since most of business activities were canceled due to the pandemic. There was also a total donation of \$15,520,000, which was more than double the previous year.

FY2020 Summary of telephonic and email medical consultations Increase of mental health issues due to the pandemic Expectations and requests to the LW Supporting Physicians

- My husband (75) is currently hospitalized for pneumonia, and was administered a tracheostomy and a nasogastric tube. He is fully consciousness and strongly wishes to be discharged from the hospital. My wish is that he will receive care at home from one of the registered members of JSDD LW supporting physicians. (female, 70)
- My wife (74) has been suffering from chronic pain of unknown cause for a long time. I
 want her to have morphine to relieve the pain. Would you give me a referral to a clinic
 that specializes in palliative care with a doctor on the JSDD LW supporting physicians
 list? (male, 88)
- My mother (99) was told at the senior facility that she is in the dying process. She has been receiving IV drip therapy for nutrition once or twice a week. Our family and her siblings all consent to stop this treatment, and the senior facility also supports this decision and told us that they would remove it at any time. However, we are not allowed to see her because of the pandemic. What should we do? (male, 70)
- Under this prolonged situation with the pandemic, my everyday life is very dull and pathetic. I have collagen vascular disease, but the test value indicated normal. I also have malaise and was diagnosed with athetosis, but I am unable to find treatments to reduce the symptoms. (female, 76)



From April 2020 to March 2021, Telephonic Medical Consultations played an important role during the pandemic. JSDD typically provides two nurses alternating shifts as an advisory staff. When the stay home order was announced in the beginning of the pandemic from early April to May, this consultation service was canceled temporarily, but resumed from the staff's homes until today.

Here is the summary of this service for FY2020. The number of consultation cases was 557 total, a slight increase from the past two years (461 and 500). The total number of itemized inquiry was 1,313 cases (one call with multiple inquires), another gradual increase from the last two years (1,006 and 1,182).

Stay home order causing a feeling of isolation

The breakdown of itemized inquiries was as follows:

- Questions regarding medical treatment options to die with dignity: 604 (46%)
- Questions regarding mental health issues: 271 (21%)

Every year, we provide consultation regarding medical treatment options to die with dignity in close to 50% of the total calls, but consultation regarding mental health issues shows an increase from the last two years (13% and 19%). Due to the pandemic, people seemed to build anxiety and fear, a sense of isolation from not being able to leave home, physical decline and even reluctance to visit doctors. Although the number of people who called regarding mental health issues was merely 1% of the total number of membership enrollment, they had no other outlet and considered JSDD as their last resort. The callers' desperate desire to talk to someone and have someone to listen to them was deeply felt by the advisory staff, as they confessed.

The advisory staff agreed that the data showing an increase of mental health issue consultations reflects the considerable amount of expectations and requests that people have for the LW supporting physicians.

