### **Excerpts from**





### Japan Society for Dying with Dignity Newsletter No. 184, January 1, 2022

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## **New Year's Greetings**

### By Dr. Soichiro Iwao, JSDD President

Structural changes to meet new challenges: revising the Living Will format; reinforcing promotional activities, organizing academic and scientific studies

Happy New Year!

COVID-19 changed everything during the whole past year all over the country. We hardly carried out our membership services including lectures, meetings, and study forums, and deeply apologize for that. We sincerely wish situation would become better this year.



Celebrating the 50th anniversary of JSDD foundation in the next few years, we started preparing to meet the needs of a new era. As we attained a legal title of "public-interest corporation" two years ago, we organized an advisory board consisting of philosophers, sociologists, medical providers, and attorneys to discuss JSDD's vision/goal/strategy suitable for the title. The board completed its final report in March last year. Since receiving the board's report, we have conducted 12 web meetings, with the JSDD board directors, chapter presidents and directors; four of them were held specifically to modify the living will format and to

modernize public activities which meet the needs of our current society. In the regular JSDD board meeting in November, the members accepted the proposal, based on which we start implementing our promotional campaigns through mass media, and expand our academic research as well as membership services.

Last December, we had an opportunity to make a series of five talk programs on TBS(Tokyo Broadcasting Systems Corp) radio on the topic of the living will and dying with dignity. We found most listeners unfamiliar with the term "dying with dignity." We have received quite a large amount of donations from our members after JSDD gained its legal status as a public interest corporation. We would like to utilize a part of the donation to expand our promotional programs in the mass media.

#### "Little lighthouse Project" based on years of accumulated data

As you know, we conduct a surviving family survey every year to track whether the living will was respectfully honored or not. We sorted out this accumulated data and started the "Little lighthouse Project" supported by The Nippon Foundation, an organization aimed to investigate end of life issues. This project's publication contains full of articles on how dying persons and their families think and feel about death. It not only discusses the process of suffering, regret and sorrow, but also about comfort, hope and advice. We hope you utilize this spiritual resource when facing the end of life for yourself, family, partner, or friends. Furthermore, we are carrying out a scientific research project initiated by the Ministry of Health, Labor and Welfare called the "Research on the clinical process of terminal stages and steps of the dying process."

JSDD members like you support all these activities. Unfortunately, more members die than enrollment: the total number of current members is less than 100,000. We have started looking into solutions for this situation already.

Ending this greeting, we sincerely wish all of you a good health. We also ask for your continuing support for us.

# Interview with Kunio Yanagida (non-fiction writer)



The worst part of this pandemic has been a sudden death with no closure; no chance to say good bye. Such sudden deaths do occur in disasters or accidents. How do we accept such a rare and peculiar departure without the chance to say good bye, and how do we bounce back from it?

Mr. Kunio Yanagida is a top ranked non-fiction writer in Japan who deeply deliberated and studied the issue of death and dying throughout his life. He spoke out what he had in mind. Mr. Yanagida is publishing a book called "Departing without good bye" this spring, which is based on our current pandemic restrictions of not allowing patients to say farewell to their families and friends.

# Today, we would like to ask you some questions; how we should bounce back from experiencing various types of sudden deaths including from COVID in which people don't have the chance to say good bye. What motivated you to publish this book?

**Yanagida:** What directly triggered my mind was the death of a comedian, Ken Shimura who died from Covid-19 at the end of March 2020. I was watching the news on TV where his brother stood in front of his house, holding his ashes and was being interviewed. The brother said that Ken was sent to the hospital quickly because of the Corona infection, and they did not have the chance to say their last farewell or be allowed to attend the cremation. Through the TV screen, I was able to read deep regret from his facial expression. As I watched it, I realized that this kind of departure in which people are unable to exchange farewell words with their loved ones happens all too often in life. How horrible, I thought. Dignity in dying is also dignity in life, an indispensable thing. Nothing can replace it, and it has been destroyed suddenly by a viral crisis.

# You have been deliberating on death in depth for many years. Did you feel by intuition that way people are dying during the Covid pandemic is not a natural phenomenon?

**Yanagida**: I have experienced many facing death from cancer, which is kind of a gradually approaching death. The patient and family members do have time to think about it and be prepared to accept it. Palliative care can provide the patient a peaceful ending. But the death by covid-19 is totally different. It comes suddenly without any advance notice and then the patient is separated from the outside world. You are not allowed to see the patient, and therefore you are unable to say any farewell words. You are unable to exchange any messages to say goodbye. The patient is placed in a vinyl bag and sent to the crematorium. I'm told that now the patients are allowed outside contact through smart phones or tablets.

# It seems that the situation is gradually changing now, but it is still not possible to hold hands or touch their cheek or something like that?

**Yanagida**: The situation was the same in Europe. In Italy there was a medical system collapse, and if patients die in a hospital, they are cremated and ashes are placed in lockers. I saw an image of a woman crying over the locker of her loved one on TV. Basically, there is no face to face contact at all with the Covid-19, which is supposed to be the most fundamental human communication. Prohibiting this fundamental human interaction is extremely peculiar and cruel.

#### You often said that a man's life is like a book. You are living a story you wrote, and you are now going to write the last chapter of your book. In other words, you have emphasized the importance of living the end of your life with will power and a purpose. The Covid-19 is inadvertently terminating that story, is it not?

**Yanagida**: The worst event that can destroy a person's story would be a war, followed by a natural disaster and an unexpected accident. This viral pandemic may not be a disaster, but it's

similar. One day, you suddenly feel a pain in the chest so you go to the doctor. You are diagnosed with an infection and immediately isolated in a special ward, and lastly you are placed in a bag and cremated. You go home in the form of ashes. It is a loss of human dignity, and you missed the chance to write your own last chapter.

### How to deal with an obscure loss

Speaking of the type of death that abruptly ends your story, we all remember the Japan Airlines crash in 1985. This was an instant death of 520 passengers. The Great East Japan Earth Quake was the same. Can you tell us about some specific examples?



**Yanagida:** The Great East Japan Earth Quake occurred in 2011. Almost 20,000 people died or went missing. Missing people probably have died or some lived in mental facilities because of amnesia or something. We think of all possibilities, which is what we call an obscure loss. A death without farewell and an obscure death may be overlapped. In the case of Okawa Elementary School in Miyagi prefecture. 74 school kids and 10 teachers died. There is one school kid still missing. I visited his father in the spring of 2020. He was digging the soil close to the school his son went to. Ten years had passed, but his mind was still unsettled. He was unable to accept his son's death. I also heard many people who lost their loved ones dream about them appearing on the beach. No medicine can take care of these people.

Do you think it's because our medical field doesn't have enough experience to deal with this type of

situation?

**Yanagida**: I don't think it's about not having the experience, but rather something unexplainable in the logic of medicine. In other words, our current medicine is unable to explain this kind of psychological and spiritual phenomenon with logic. Now realizing that we need religious experts to help deal with this situation, they have been working closely with medical professionals in

various activities. This has led to the start of a program at Tohoku University Graduate School as a course in Clinical Religious Studies.

#### Yes, our JSDD Tohoku Chapter is involved with that activity.

**Yanagida:** That is correct. The "form of death" is affecting people in many ways, in particular death without farewell and obscure loss. How should our leaders and as a society deal with these problems? I feel that the issue of life and death has now been brought up to the next level.

# It is not just an issue for the medical professionals and leaders, but eventually each and every individual must reach acceptance.

Yanagida: That is correct.

#### Then how can we or what steps do we need to take to reach acceptance?

**Yanagida**: I can't make a general statement, but there are many counsellors who are working with the idea of obscure loss, and they support the acceptance of the unknown situation. In other words, instead of forcefully separating the situation as them being dead or alive, it's best to appreciate the state of being obscure. The government administration, the police and the insurance industry clearly must seek confirmation of death, but what is important is that the person who died still lives in your heart even if a piece of paper says otherwise. They must keep talking about that and remember what is important. It would take a long time to heal. Like the proverb says time heals all wounds, counsellors and supporters must be patient and not be forceful.

#### So, we must wait and let them take their time to heal.

**Yanagida**: Yes. We all must be patient and wait for the right time, that includes both you and your supporters. Everyone is different and the time it takes to heal is all different also.

Let me talk about the Japan Airlines crash in 1985. I met Mrs. Kuniko Miyajima who lost her son, Ken-chan (9). He loved baseball and he really wanted to go see Koshien Yakyu in person (High School Baseball Tournament held in Koshien baseball stadium). To make his dream come true, she bought a ticket for him and sent him alone on a Japan Airlines flight. She later regretted that she did not go with him. She saw him off at the airport when he left but did not really get to say farewell to him, which has been tormenting her ever since. After the accident, surviving families formed a survivors' support group where she worked as the president. She worked full time pursuing the cause of the accident and the prosecution early on, but there was one thing she was unable to do. She was unable to forgive herself for losing her child.

One day, she received a call from someone whose daughter was sitting right next to her son on the airplane. The caller was a mother whose husband was a Buddhist temple chief priest. She said on the phone, "My daughter was very fond of children, so I am sure that she held your son's hand tightly to make him feel secure and comfortable." As soon as she heard these words, she felt like her cold and rigid heart melted away and was able to set her mind back to normal.

#### That is an overpowering story.

**Yanagida:** Around the same time, she received a carton of juice from similarly aged children of Niigata prefecture whom she did not know at all. The case came with a little note saying "Please take this juice with you the next time you go to the mountain where he died." More compassionate packages came to her, and little by little she started to open her heart again. A year later, she joined a cultural club run by a poet named Toshiko Takada who influenced her greatly. She learned how to compose poems, and when she went up to the mountain where he died, all the fond memories of him poured out in words as poems. Her words flooded like lava erupting from a volcano with a lot of emotions buried at the bottom of her chaotic heart.

#### Every time she goes up to the mountain, she releases her emotions with words in poems

**Yanagida**: During the course of mourning, she realized that he was not missing; but he was living inside of herself. She could hear him saying, "I am right here. I am not going anywhere." This has a great meaning, a decisive meaning in the process of gaining resilience out of the loss. It is a process to find one's spiritual life. It is what we call "cure" in essence, and it is a way to get rid of confusion in a chaotic state of mind. What's done cannot be undone, so the mother accepted her destiny.

Finding resilience and rediscovering a reason to live, right? Now I'd like to ask you a personal question. You lost your son (25) to suicide. How did you bounce back and resume your life from it?



you and your family. This to me is resilience.

Yanagida: Resilience, the power to come back is something that is instilled in you as you grow. This source of strength grows and builds as you observe how your parents survived various obstacles in life and how they change their mindsets to overcome these situations. In my case, I learned from my mother. My father passed away when I was ten years old, and my older brother died only six months prior to that. It was right after the end of World War II, and tuberculosis was wildly spread throughout the country. My mother was 40 years old. I had many siblings, and I was the youngest. However, my mother did not panic or get depressed. She would just say "It'll all work out in the end" or "It's no use crying over spilled milk" in her Tochigi dialect. What she meant was that fate is something you can't change. so there is no point in stressing over what you can't control. Just accept fate and move on. That is what she meant. It is not the same thing as giving up. You just accept what you face in the future for

Sounds like the image of your mother at that time when you were a boy is deeply imprinted in your mind.

**Yanagida:** In my case, the death of my older brother (25) was had a big impact on me, and I still struggle with it in many ways. However, I realize that my mother's way of life was embedded in me because I dealt with the death of my own son in the same manner as my mother did.

# In a way, Mrs. Miyajima bouncing back to her own life from her son's death was fueled by the son's life memory.

**Yanagida:** Mrs. Miyajima published a children's picture book named "Ken-chan's Fir Tree" two years ago. My wife, Hideko Ise, illustrated all the pictures. There is one scene in the book in which the mother is looking around for ken, asking "Ken-chan, where are you? Where have you gone?" His mother is wearing a white dress, holding a traditional Japanese carp streamer which Ken had made in May prior to his death, chasing a stream of white clouds shaped like an airplane in the middle of the blue sky. When she saw the white stream of clouds, she heard his voice saying "Goodbye" for the first time. For 35 years without proper farewell, his existence was in a state of "obscure loss" in her mind. To her, his words of goodbye meant "I am here. I will always be with you."

#### I see. You've written that this final "goodbye" has such a deep meaning.

**Yanagida:** Yes. The origin of the Japanese word "sayonara," (goodbye) means "if that's the way it was meant to be," but it also has another meaning "if that's how it must be." So, we use this greeting when we depart one another. There are many types of departures, one of which is for some reason you must depart your current life for another new life, such as death. When you face it, you can't just cry and say "please come back" or "bring back his or her life." When you have a situation that is beyond your power and control, you must accept it the way it is meant to be. Then you take the next step to start a new life on your own, which leads to, as I said before, writing the last chapter of your book.

#### So "Sayonara" is not just a farewell word, but also a word of connection.

Yanagida: Yes, SAYONARA is a connection or a stepping stone to start a new life.

#### By making connection, we take the first step toward a new life, correct?

**Yanagida:** Yes, a departure without farewell is something painful and cruel. While mourning and suffering, you also have to figure out what to do next and how you are going to live. It's a new issue we face.

# "Sayonara" is an important word. Thank you so much for our discussion today which was very deep and profound.

#### **Editor's comment after the interview:**

Talking with Mr. Yanagida, who spoke with a slight Tochigi dialect and has been observing and deliberating on the topic of death for many years, really touched my heart. From the suicide of his second son, the image of his mother living strongly during the post war years, and his own aging, and especially when he talked about Ken-chan from the Japan Airlines crash, my eyes

were filled with tears. "Sayonara" is a word of connection and is a stepping stone to start a new life. His passionate facial expression as he talked is still vivid in my memory.

-Gunji Takeshi, Editor



#### Photo: Kunio Yanagida

Born in 1936 in Tochigi prefecture. Non-fiction writer. After graduating from University of Tokyo, Department of Economics in 1960, he was employed by NHK (Japan National Broadcasting Corporation) as a reporter, where he covered stories including the All Nippon Airways Haneda off Shore Crash and BOAC aircraft air disassembly accident. In 1971, he published a report, "The Horror of Mach, "and won the Soichi Ohya Non-fiction award. After retiring from NHK in 1974 he worked as an airline critic and commentator. In 1995 he published a book called "Sacrifice: 11 days of my son's brain death." Later, he became more involved in writing articles about various topics such as accidents, natural disasters, life and death, and terminal medical care.

# **Telephonic and Email Medical Consultations No. 9**

### "Sincere voices from JSDD members in their 90s"



We live in an era in which the average lifespan is 100 years. We actually have many members aged over 90 who call us nowadays. As we age, it gets harder to fight back the declining mind and body, but many try to maintain an independent life style by constantly adjusting and adapting. On the other hand, some people lost their will to live when the new disease emerged.

#### **Q:** My concern is that I have no primary doctor

I am 90 years old and have lived alone so far without having any serious illnesses. Since my daughter lives nearby, I feel comfortable and safe; however, lately I've find myself physically declining and mentally weakening. I've never had a primary doctor, but now I am concerned

when I think of something happening to me. There is a few clinics nearby, but I hesitate to visit them because I'm afraid of receiving unnecessary treatments. Is there a way to live my daily life safely and peacefully? (Female, 90)

#### A: We recommend getting a referral

It is great that you have so far taken good care of yourself adjusting to change in your body and mind. But now that you are in your 90s, it is important to have a primary doctor. We will send you a list of LW Supporting Physicians near your residence so that you can visit them for consultation. We also recommend that you visit your local "consulting room for the elderly" and a "community support center" just in case you may need assistance.

#### **Q:** Commuting to the clinic is becoming difficult

I used to walk one way, and sometimes I shop and have a little chat if I see someone I know. Lately, I've find myself feeling good one day and bad the next, so commuting to the clinic is becoming difficult. (Female, 90)

#### A: There is a support system available for patients commuting to clinics

It seems like you enjoy it, which gives you relaxation both physically and mentally. It is important to have something you can enjoy. There is a volunteer support network called "Silver Support" that you can find locally. Check it out and keep doing what you are doing.

#### **Q:** I was advised to get a cataract surgery

I enjoy getting up early before my family wakes up and to read the newspaper with hot tea. Lately, I haven't been able to read small letters, and I was recommended a cataract surgery. I feel hesitant about having to spend a few days in the hospital and the surgery may not be successful. (Female 96)

#### A: Talk with doctor and get a full explanation if you have a doubt

Nowadays, many elderly people get a cataract surgery. You were advised also because your doctor assessed that you are healthy enough to endure the surgery. In general, you will stay in the hospital for a few days so they can monitor your body for recovery. You should talk with your doctor once again if you hesitate because it is important that you continue to enjoy your early morning newspaper reading.

#### **Q:** I was diagnosed with a heart disease. I would like to have a sudden death.

Six months ago, I felt dizzy so I went to urgent care. I was diagnosed with aortic valve stenosis and a complete atrioventricular blockage. I was shocked. Since I was able to live for 91 years, I want to die while I am in my sleep. I want to have a sudden death without any pain. I do not feel like doing anything anymore. (Female 91)

#### **A:** Whenever you feel pain or suffering, come to us

I understand how you feel because of this unexpected disease. As this was unexpected and sudden, you may still be experiencing an emotional roller coaster. Come and see us whenever you feel any pain or suffering.