



Excerpts from



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Ehime University School of Medicine
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NEW YEAR'S GREETINGS

**Advance Care Planning (ACP) and the right to die
How effective were our past activities?**

By Dr. Soichiro Iwao, JSDD President



Happy New Year!

In April, the current Heisei era will end and a new era will begin in May.

I hope you're all well. Currently, our membership number is at 109,000, a comprehensive total of 267,000 members. The current average age of our members is 78.5. The average age of new members has risen from 63.7 (30 years ago) to 71.7 (last five years). Data also shows that the average

membership time period from admission to withdrawal due to death is twelve years and four months.

As far as domestic events that occurred the past year, the Ministry of Health, Labor and Welfare announced the guidelines for end of life medical care decision process, which led to the implementation of Advance Care Planning (ACP).

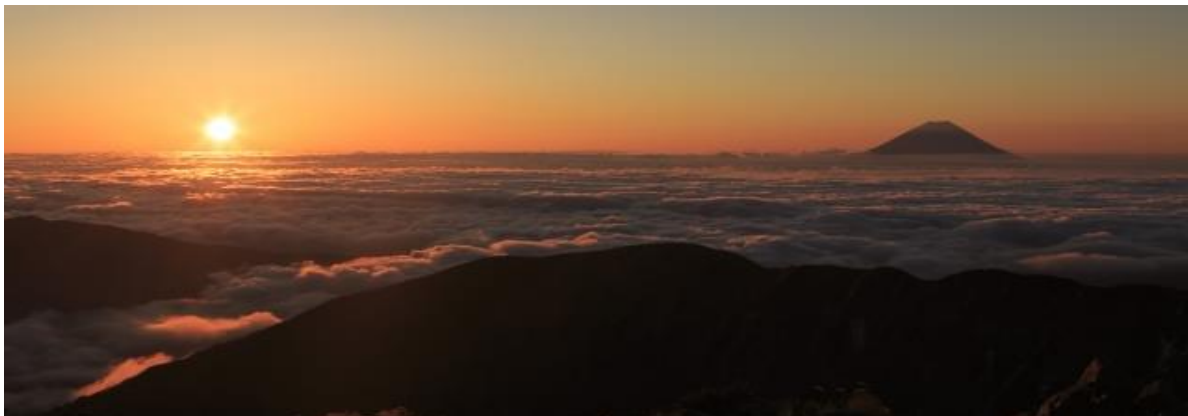
ACP requires the patient to discuss with family members, physicians and other healthcare professionals not only his or her current illness, but also about future medical care and appointment of an agent in case of mental impairment to make decisions for the patient who can no longer able to make his or her own decisions. ACP is a product of decisions you make after thoroughly discussing these matters with your family, physicians and other healthcare providers. This document becomes your advance directive for the medical facility and nursing facility.

Cooperation with local community activities

The living will (LW) issued by JSDD is a document expressing your end of life wishes in preparation for situations in which you are unable to express your own wishes. Consequently, this document does not include specific names of medical or nursing facility. You should attach your LW to the ACP and submit it to the hospital or healthcare facility upon admission.

Now, if we look at international events in the last year, I attended the biennial World Federation of Right to Die Societies conference held in Cape Town, South Africa as a director. In the last two years, Pope Francis expressed an affirmative statement supporting the idea of dying with dignity, which led to a number of movements: withdrawal of life prolonging measures was legalized in Italy; voluntary euthanasia was legalized in Canada; assisted suicide bill was passed in Victoria, Australia; and the same was almost passed with only one vote short in New South Wales. Many countries moved positively towards dying with dignity, which made us realize there is a great gap between Japan and the rest of the world. As I have reached the service limit of three terms and six years as a director of the World Federation, I recommended Dr. Masahiro Nomoto, a JSDD director and Chairman of Shikoku Chapter for the position, and he was accepted to be the next director representing Asia.

We now live in a society with a large population of the elderly and a high death rate. Many eyes will be focused on our upcoming activities. There will be many changes in our leadership positions this year, both directors and councilors. I sincerely ask all JSDD members to come out and participate in your local community activities so that more people will get to know about us.



NEW YEAR TALK

Mr. Yukio Matsuo and JSDD President, Dr. Soichiro Iwao

Is this how end of life should be?

“She spent her last eight years in the hospital, just looking at the ceiling, day and night, 24 hours every day.” Mr. Matsuo (82) talked about watching and spending time with his wife, Makiko, through her suffering and agony. This story was published and broadcasted as a television documentary drama in Japan. He shared his thoughts with Dr. Iwao about a recent controversial case of Mr. Susumu Nishibe, an established commentator who chose to end his life by committing assisted suicide, and also about his own final nest.



Photo

Yukio Matsuo (Right)

Born in 1936, in Namerikawa City, Toyama Prefecture. After graduating from Toyama High School he studied Economics at Waseda University and continued his studies in the U.S. He resided in New York for twenty years as an international trader and retired as the president of Yamatane International Corporation. Returned to Toyama in 2001, three weeks after the 9/11 attacks. In 2006, his wife (Makiko) was in a car accident which left her quadriplegic and bedridden with a respirator. Since her vocal cords were paralyzed, she was unable to talk. Later, he found a way to communicate with her using the only thing she could do: blinking. The story was written and published in the book by Mika Yanagihara, “*Makiko no Kotodama*,” translated as “*A Message from Makiko’s Soul*.” This book was made into a NHK (Japan’s National Broadcasting Corp.) documentary drama titled “*Love in the Blink of an Eye*,” and won the Creative Excellence Award at the U.S. International Video and Film Festival in 2013. Makiko

passed away in 2014, and the following year he moved to New Mexico, where his daughter and her family reside. He continues to work actively on translation. He is an accomplished martial artist with a 5th degree black belt in Kodokan Judo.

Dr. Soichiro Iwao (Left)

President of JSDD, MD. Born in 1947, he graduated from Keio University Medical School. Former director of Medical Policy Department for the Ministry of Health, Labor and Welfare. Currently a Visiting Professor at Keio University Medical Department.

Iwao: Mr. Matsuo, you translate the excerpts of our quarterly newsletters (Living Will) for our international readers. It was in 2012 when we first met at the World Federation of Right to Die Societies Conference in Zurich, Switzerland. That was when we asked you to translate for us, so it's been seven years already...

Matsuo: Yes, time flies, doesn't it? We lived in the U.S. for 20 years when I worked in international trading business, and when I was 65 years old, I retired and my wife, Makiko wanted to go back to Japan, so we returned to Toyama, the same hometown for both of us. We returned only three weeks after 9.11.2001. There had been our office in the World Trade Center until ten years prior to this terror attack. In 2006, Makiko was in a head-on collision auto accident when a car coming from the opposite direction crossed the center line into her lane. The driver was a 19 year old boy who just got his license a month prior. He fell asleep at the wheel when he collided into her car. Makiko was immediately sent to the emergency room at Toyama University Hospital and connected to a respirator. She was later administered a feeding tube and a diaphragm pacemaker implant. She was almost completely paralyzed, a quadriplegic. The only thing she could move were her eyelids. She could blink and move her mouth. She tried to talk, but her vocal cords were paralyzed also, and no words came out. She could not even move her head. She was bedridden for 24 hours in the hospital. We were just looking forward to enjoying a relaxed retirement life in our hometown together... Every day, I went to the hospital and stayed by her side. Every day was a battle.

Iwao: That was quite a tragedy. You said she was almost completely paralyzed, and her voice cords were also paralyzed. How were you able to communicate?

Matsuo: She had a clear consciousness, clear mind, and her eyes and ears were not impaired. So, we first made a rule: I told her to blink her eyes twice if the answer is YES to my question and to close her eyes if the answer is NO to my question. Later, we found a communication aid machine made by Panasonic called "LET'S CHAT." This machine was designed for patients who can push the button themselves by using a finger, but her fingers and feet were all paralyzed. So I decided to push the button for her by getting her signal of blinking. More details are in the book, *Makiko no Kotodama*, written in 2010 by Mika Yanagihara, a journalist well known for her work on issues surrounding traffic accidents. A documentary drama titled *Love in the Blink of an Eye* was broadcasted by NHK (Japan National Broadcasting Corporation) in 2012 based on this book. In the following year, NHK added English subtitles and presented it to the U.S. International Video and Film Festival in Los Angeles, and won the Creative Excellence Award in the documentary drama division.

Iwao: Yes, Midori Kiuchi, a famous Japanese actress played the role of Makiko, and another famous samurai movie actor, Isao Natsuyagi played your role. We interviewed Ms. Kiuchi a couple of years ago and published a special issue in which she said, “Mr. Matsuo made a huge contribution to the movement of establishing a support system for terminal patients and victims of traffic accidents, while caring for his wife every day. I pay a high respect for this Japanese activist.” Ironically, Mr. Natsuyagi died of pancreatic cancer in 2013 only a few months after completion of the film, and you survived pancreatic cancer after a Whipple procedure in 2010.



Matsuo: Yes, Ms. Kiuchi once said to me that playing the role of Makiko who was still alive and suffering in bed was a priceless experience which challenged her as an actress. I really appreciated her comment. One day when I walked into her hospital room, she wanted to use the communication machine by giving me a sign. I asked her, “Do you want to say something to me?” and she blinked twice. So, I set up the machine. She started picking up the letters. First, she picked “KO,” followed by “RO,” “SHI,” and “TE.” My heart started to pound faster. She said “Please kill me.” I got so scared, and next moment I found myself pushing the button for the nurse to come.

Makiko passed away in May of 2014. It had been eight years of unimaginable suffering. She had to look at the ceiling 24 hours every day for what must have been an eternity. It was during these eight years that I learned about JSDD, and my encounter with Dr. Iwao began.

Photo – “My daughter and her family live only ten houses away from me. Taking care of my grandchildren has become a part of my routine,” says Mr. Matsuo.

Iwao: That is right. In 2012, we went to Zurich, Switzerland to attend the World Federation of Right to Die Societies Conference, and you met Richard Côté, author of *In Search of Gentle Death*. You made quite an effort in translating this 400+ page book in almost 2 years. You finally finished and self-published this translated book on Amazon-Japan. What was your strong motivation?

Matsuo: Was it right the way Makiko died? Was there no other choice? Were there others in the rest of the world who died the same way my wife did? Those were the main questions to which I needed answers. Richard Côté spent over five years visiting all over the world for his research, and he met and interviewed many campaigners, movement leaders, patients and their families who either supported or opposed the concept of dying with dignity. In his book I found many examples of people who died in a similar situation as my wife’s, and I wanted everyone in Japan to know what was going on in the world. This feeling became stronger and stronger over

time. I was afraid that if I didn't translate it, no one would spread the word. Every night after I came home from the hospital, I worked on it. It took me one year and a half.

Iwao: A well-known commentator in Japan, Mr. Susumu Nishibe, recently died by assisted suicide, and this issue has caught nationwide attention. You wrote a comment on this. What was it?

Matsuo: I heard Mr. Nishibe saying "I will die on my own terms." What he said is exactly what we call "the right to choose one's death," and not his own concept. There are many who share the same concept in this world. I wish he lived to read my translated version of *In Search of Gentle Death*. Mr. Nishibe was born and raised in Hokkaido, as was his wife. I understand that he always consulted with his wife when he gave a speech or wrote an article. His wife was his true partner in every sense including in professional matters, but he lost her several years ago. I also lost my wife four years ago who was also born and raised in the same hometown as mine. I could completely empathize with his loss and strong wish to join her. I could also relate to him in a sense of having lived a full life.

Iwao: You recently self-published another translation book called *Crossing the Creek*, now sold online by Book Way (¥1,000 plus tax. Website <https://bookway.jp>), and you dedicated this book to your wife, Makiko (1943 – 2014).

Matsuo: Yes, the author was an American registered nurse. From the subtitle, *A Practical Guide to Understanding the Dying Process*, I knew that this book was not only for doctors, nurses and care managers. This book should be read by all, especially patients and their families to understand the dying process, including topics on appetite, breathing and sleeping so that we would be much more prepared and not panic when we face death. The title of the book is *Crossing the Creek*, which I associate with the river we cross when we die (Sanzu River), according to Buddhism. In his book, the author talks about playing around a creek a lot when he was a child, and that he would probably dream about it when he is in the dying process.

Iwao: You moved to America after your wife died and settled in only ten houses away from your daughter. You decided to spend the rest of your life in this city, Albuquerque, New Mexico. How do you like this part of America?



Matsuo: New Mexico is quite different from Japan. We do not have four distinct seasons here, and it is very dry. However, the cost of living is low, and the weather is mild, so living is easy and comfortable for elderly people. I only chose here because my daughter and her family happened to live here. When my wife died, I found myself all alone in Japan. I wanted to die surrounded by my daughter and grandchildren.

Photo – Mr. Matsuo surrounded by her daughter, son-in-law and two grandchildren

Iwao: In Japan, more elderly people are moving into nursing/assisted living facilities to spend the rest of their lives. How about in New Mexico?

Matsuo: I know there are assisted living facilities, but rather on a smaller scale than those in Japan.

Iwao: What about healthcare system and medical care?

Matsuo: You have a primary care doctor, and if you have specific problems, your primary care doctor gives a referral to specialists within the same hospital system. I had a hard time finding a primary doctor at first. Some of them refused because they had too many patients. I have one now.

Iwao: That is a relief. Maybe you chose the best way to live the rest of your life, surrounded by loved ones.

Matsuo: This house is the third house I bought, to be frank with you. The other two houses I bought did not fit me, and I did not feel comfortable. When I saw this house, I said to myself, "This is it!" Throughout the window of my bed room, I can see the Sandia Mountain, which is



about 3,000 meters high, similar to the Tateyama Mountain of my home town. I had a Japanese pond installed and bought six Koi and ten goldfish. By the way, Albuquerque is already 1,500 meters above sea level, so Sandia Mountain does not look like 3,000 meters high. I enjoy looking at this mountain view, similar to the one I used to enjoy in my birthplace of Toyama, and now surrounded by my daughter and grandchildren: this is my final nest. I made up my mind that I want to die in this house.

Photo – Mr. Matsuo feels comfortable and nostalgic, overlooking Sandia Mountain from his back yard with a Japanese pond.

DIRECTOR OF THE WORLD FEDERATION OF RIGHT TO DIE SOCIETIES INAUGURATION

Need more public emphasis to ensure accurate understanding of the Living Will

Dr. Masahiro Nomoto
Visiting Professor and JSDD Director
Ehime University Medical Department



Photo - Dr. Masahiro Nomoto (left) and Dr. Soichiro Iwao at the World Federation conference.

Last fall, I attended the World Federation of Right to Die Societies Biennial Conference, which has been held since 1976. This was my second attendance since the last conference held in Tokyo in 2004. This time, the conference was held in Cape Town, South Africa.

Our flight stopped in Singapore on the way to Cape Town. Singapore was just as hot as Japan, but our final destination was in the middle of the winter, and we needed to wear coats to go outside.

The conference started on September 6th. Dr. Iwao completed his maximum service of six years as a director, so I was nominated as his successor and was accepted in the general assembly held the following day. Two organizations applied for a new membership. After listening to their presentations, the board had a discussion and decided to observe their activities for two years, and then reevaluate their new membership.

I attended the several sessions and heard presentations. One was from Ms. Debbie Ziegler, the mother of Brittany Maynard (died at 29), who had moved from California to Oregon in order to qualify for physician's assisted suicide as she suffered from an incurable brain tumor.

The other presentation was from Gene Arthur who played an integral role in legalizing voluntary euthanasia in Canberra, the capital city of Australia. Both of them are extremely vigorous social activists.

Countries with legalized voluntary euthanasia are still a minority

Japan was the first to propose the formation of the World Federation of Right of Die Societies, hosting its first conference in Tokyo. Some countries have multiple organizations that are members. Although all members share the common value on the Living Will, they have different missions and pursue different goals. The main purpose of this federation is the sharing of information. The mission of Japan Society for Dying with Dignity (JSDD) is to respect and honor the living will so that people can choose peaceful and natural death without being forced to live with life prolonging measures. Currently, some of the more progressive groups are pursuing the legalization of voluntary euthanasia, which goes beyond our mission. There are many approaches to voluntary euthanasia, but the most common one is a lethal dose intake with a physician's diagnosis and assistance, and the life expectancy of the patient must be within six months.

Countries that legalized voluntary euthanasia are mainly in Europe, North America and Australia, and they are still a minority in the whole world. Compassion is the driving philosophy of this movement. Assisted suicide is a crime in many countries including Japan. It is different from the living will which only allows refusal of life prolonging measures, and is categorized as passive euthanasia. Many people are misinformed about the difference, so I feel that more emphasis is absolutely necessary to enlighten the public and deepen people's understanding on this topic.



Photo - Lively attendance from all over the world.