



Excerpts from

Japan Society for Dying with Dignity Newsletter  
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### Main Contents:

- **Little Light House Project Guide - Decision support website for healthcare choices during the last phase of life**
- **Report on the Facilitator Training Study Group**
- **Living Will Square – Like-minded people from all over the country**
- **From telephone and e-mail Medical consultations**

## Decision support website for healthcare choices during the last phase of life

### “The Little Lighthouse Project” Guide.



### “The important role of nursing in the terminal stages of life”

The most viewed page on this “Small Lighthouse” website is the “Information Box” “Can the ventilator be removed or not?” There have been times when it has received more than 5000 views per month. As the “Little Lighthouse Project” enters its third year, we wanted to delve deeper into this theme, so we planned the first feature article, “We want you to know: A dignified end - The conflict of families over ventilators.” The questionnaire on the attachment and removal of ventilators received a response of 54 responses in less than a month, and there was also a contribution from a nursing professional.

There is a great interest in attaching and detaching ventilators.

The 54 responses came from a wide range of ages, with the majority of the responders being people who were in their 50s. Around 90% were non-members of the Japan Society for Dying with Dignity. Over half were medical care professionals, and over 60% were nurses. Regarding the removal of ventilators, 43% of respondents were aware that the

Ministry of Health, Labor and Welfare had issued guidelines, 36% were unaware that there were different types of ventilators, 77% were aware that it was legally difficult to remove a ventilator once it had been attached, and 37% were unaware that it was possible to remove a ventilator after it had been attached. 34% of respondents said they would be willing to have a ventilator attached if it could be stopped at any time. The conflict seen from these results is that there is “a strong fear that once a person is on a ventilator, they cannot be taken off.”

There was a post about discontinuing life-prolonging measures in ICU wards in the US, and we also think that a “time-limited trial” (a method of trying out intensive life-support treatment for a certain period of time to see how effective it is) could be one solution to the issue of artificial ventilation. In Japan, there have also been attempts to support patients in the terminal stages of their illness, such as independent hospices, unique initiatives in palliative care wards, and the activities of ACP support coordinators and medical coordinators. Still, these initiatives have not spread due to legal and financial difficulties. It is urgent that we create a system to support the decision-making process of individuals who are shifting to end-of-life care, including the decision to utilize nurses, who can act as coordinators for the “team medicine” that is essential during the end-of-life period. It is essential to have the support of citizens’ participation as a third power in the creation of a system that will become a new option. We want to ask all our members for their interest, understanding, and support in the end-of-life care. We look forward to receiving your thoughts and ideas on gastrostomy, tracheostomy, artificial dialysis, and intravenous drip, not just artificial respiration.

(Little Lighthouse Project Leader/ Nurse: Kondo Kazuko)

## REPORT

### **5th Living-Will Facilitator training workshop in Kurume**

To realize “respect for the patient’s will”

Hold a camp to deepen cooperation and learning beyond the boundaries of professions!



Above: Participants enthusiastically listen to the latest information and lectures given by experts in various fields.



Everyone expressed their opinions and experienced the difficult process of summarizing diverse ideas in a way everyone could understand.



Group presentation

The annual workshop was held in Kurume City, Fukuoka Prefecture, from Saturday, July 27 to Sunday, July 28. Fifty-eight (58) participants, including the lecturers, engaged in classroom lectures and deepened their learning through heated discussions.

The participants learned about the current situation and decision-support issues during the “last stage of life.” They also had a group work session with a clinical ethics expert on the actual practice of ethics consulting and ethics conferences. In addition, we learned about trends in personal decision-making, death with dignity, and euthanasia in the world. We attempted to have a frank discussion about “euthanasia,” which is difficult to discuss in Japan.

### **Some flexible opinions on “euthanasia.”**

In the group work, opinions were exchanged from the perspectives of doctors, medical professionals, welfare workers, and ordinary citizens on each topic. Some flexible opinions were expressed regarding “euthanasia”, such as “maybe it should be allowed” In the question and answer session, there was a deep discussion about the dilemma those working in the field faced between respecting the patient’s wishes and saving the patient’s life.

The lecturers and their topics are as follows.

Dr. Satoru Mitsuoka (Director, Japan Society for Dying with Dignity- Kyushu Branch) “The new Living Will and ACP”

Dr. Tatsuya Morita (Deputy Chief, Seirei Mikatahara General Hospital) “Skepticism about ACP and the gray zone between life and euthanasia”

Ms. Itsumi Yamagishi (President, Research Association for Community Health: RACH) “ACP for whom and for what purpose?”

Dr. Koichiro Sakai (Professor, Faculty of Medicine, University of Miyazaki) “Ethics in clinical practice, the current state of consultation and issues.”

Dr. Yasuhiko Miura (Professor, Iwate University of Health Sciences) “Let’s try a case study of clinical ethics.”

Dr. Shinichiro Morinaga (Specially Appointed Professor, Komatsu University) “Trends in euthanasia around the world”

Let’s share another meaningful time next year.

(Written by Ms. Masako Eto)

※A facilitator is a person who, from a neutral standpoint, brings together the opinions of a meeting, etc. and leads to a better conclusion. ※ACP (Advanced Care Planning) is also called a “life conference”, and is an initiative in which patients, their families, and medical professionals discuss in advance the medical care and other support that they will receive in the final stages of their lives.



## Enjoying the rest of my life

[Ms. Noriko Okido - Age: 85, Chiba Prefecture](#)

It has been more than 20 years since I started living alone. I sometimes feel inconvenienced, but I can do most things alone. I had been teaching for 25 years, and last year I received a special award from the Ministry of Health, Labor and Welfare.

Despite the fact that all members of the group wear white canes and have audiovisual handicaps, I, as an able-bodied person, have tried to be cheerful in my activities, as I felt that I should not whine.

However, three years ago, I began to suffer from a severe hearing loss, and my communication with the members has become a bit ridiculous. We are both vulnerable, so they tend to look the other way and say, "This is just like a comical haiku poem." Apart from haiku poetry, I'm also into balcony gardening. I've been cultivating Shiki flowers on my balcony for several years, and have digging up cogon grass in the city's green belts. I often "make flowers bloom" in discussions about flowers with passers-by. As a result, I don't have time to worry about loneliness or my health. My daughter nags me to "moderate it because you're old," but I only just listen to her. I've filled in my Living Will notebook, and now I'm just relying on the gods to take care of me. "At least the freesia has a scent, even if I can't see it."

## Murmurs of a stubborn old man

Mr. Tutomu Morisaki - Age: 74, Hokkaido

I went to the doctor's office near my house for the first time in a while. A sign on the front door showed the opening hours, and it said, "Open until 12:30 p.m. on Saturdays." So, I said, "I think it should be open until p.m. 0:30.," but the woman at the reception desk was adamant that it was correct as it was. The following week, I went to a nearby hot spring spa for an event organized by the local community association. A large sign at the entrance said, "Geta (Japanese traditional wooden footwear) Boxes are here." When I said, "I think "Shoe Boxes" would be more correct.," the woman at the reception said, "We've always used the term "Geta Boxes" here," and I wasn't able to get her to listen to me either.

When I was shopping at a convenience store, a young male clerk asked me, "Was the receipt okay?" I didn't know what to say. I can understand the gist of these cases, but they are not correct expressions. One of the effects of aging is that you start to find fault with other people while ignoring your faults, and you become unable to respond appropriately because you are too stubborn to change your mind. I'm starting to get into that kind of situation, and I'm worried about the future.

One more thing that's been bothering me. There are hundreds of millions of people around the world who are suffering from anxiety, but what do you think of the scenes of "competitive eating" that appear on commercial TV? Is anything OK as long as it brings in advertising revenue?

## From the telephone and email medical consultations

17

### "The pain of having to look after a child"

This is a page where we introduce specific consultation cases and answers given over the phone or by email. A nurse will answer the questions, but sometimes, we will ask for the help of an advisor doctor.

In recent years, the number of cancer patients under the age of 50 has been increasing rapidly worldwide. According to one newspaper article, the number of new cancer patients in this age group has increased by around 80% over the past 30 years, and the number of deaths has also increased by around 20%. In particular, there have been reports that the risk is increasing in people in their 40s. In other words, the number of elderly people whose children die before them is also rising. We have also received inquiries from parents in their 40s and 50s who have children with cancer.

## (Case Study)

My 43-year-old son has terminal cancer and wants to be admitted to a palliative care ward, but because there are people on the waiting list, we are considering for home healthcare. My son is a patient and doesn't complain, but I'm worried. I don't want people to see how sad I am, but I cry every day. (Mother in her 70s)

**Q** The person in question is aware of their impending death, but we can't give up and continue to think about whether there is any hope at all. It's painful.

**A** It will be difficult to control your emotions as a parent, but it is most important to be there for your child, to share their happiness and sadness, and to give them a sense of security.

**Q** We are considering home healthcare for our son, but he doesn't want to cause us any trouble. How can we help him feel less burdened?

**A** Why not gather information with your son about what home healthcare is like and prepare to accept physical and mental support? It is also important to find a reliable home doctor and be able to discuss future treatment plans so that your parents don't have to deal with everything on their own.

**Q** Normally, it would be natural for us to be looked after by our son or daughter as we depart.... How should we live from now on when the natural order of things is not fulfilled?

**A** I can't begin to fathom the depth of your family's suffering, but please know that I'm here to help you. I'm sure it's painful that they can't all meet their end in the order they were born, and I'm sure they can't even think about what will happen in the future. While it is painful to have to face the reality of the problems you will have to deal with from now on, you need to gradually move forward with concrete steps, such as finding a family doctor who will understand your situation deeply or consider how much you can receive from the nursing care equipment service that suits your financial situation, while also building up your ability to rely on others.



It is not always the case that people die in the order in which they were born. It is heartbreaking to imagine that parents who have watched their child grow up must now count down the length of their child's life...

Long ago in the Edo period, an official who had stopped by a temple asked the Sengai monk to write some auspicious words on a hanging scroll, and the Sengai monk wrote, "Death of the grandparents, death of the parents, death of the child, death of the grandchild." The story goes that the official, who could not hide his indignation at expecting something happy, was asked by the monk, "Is it more auspicious to have the death of the grandchild, death of the child, death of the parents, or the death of the grandparents in that order?" This anecdote also shows how painful and sad it is for a parent to be preceded in death by a child.

In the future, the number of cases like this, where the elderly cannot rely on their children to look after them in their old age and even their wives cannot fulfill their role of looking after them, may increase even more. And the future may be one in which the support for a long old age comes from people other than family members. If a family member becomes ill, various problems will come at once. While it is important to think about and prepare for the "what ifs", in reality it is difficult to do so, and when the time comes, the preparations may not be useful, highlighting the complexity of the issue.

Knowing that there are cases where people do not get to meet their final moments in the order in which they were born, why not take the opportunity to discuss this with your family by picking up your "Living Will" or "My Statement of Preferences Form" again?

Medical Consultant/Ms. Michiko Sasaki