



Excerpts from



**Japan Society for Dying with Dignity Newsletter
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“MY WISH LIST”

A supplemental document to the Living Will (LW), recently developed as a response to the increasing ways to spend one’s end of life.

The LW and Advance Health-care Directive issued by JSDD is an explicit document which includes personal choices such as one’s refusal of life prolonging measures. Lately, people have shown many more ways to spend one’s end of life and the need for a more customized format. In response, JSDD made a decision during the board of directors’ meeting held on November 25 to issue an additional documentation to the LW starting January 2018. This new supplement called “My Wish List” allows members to express their end-of-life wishes in a much more individualized and detailed manner.

Detailed wishes are in keeping with the social changes

President Iwao stated in the board of directors’ meeting that one’s terminal medical care wishes are directly related to how one wants to spend his/her end-of-life. Apart from the major decision to refuse life prolonging measures, preparing a detailed end-of-life wishes has become a global trend. This is why JSDD has decided to issue an additional separate form from the LW.

This personal manifesto (statement) is prepared as a document affixed to the living will. What is included in this document are not only the specific personalized medical treatments not covered in the living will, but also quality of life options such as where you wish to spend your last days and what you consider to be valuable.

“My Wish List” will not be registered through JSDD like the living will. This document should be in your personal possession and be submitted to anyone or any organization at any time as you see fit.

JSDD is also going to prepare a new document that explains the living will geared towards people wishing to become new members. The purpose of this document is to send them a message with main points that they must understand upon signing their living will.

Both documents will be printed again and included in the April issue of this newsletter to be cut out and maintained for your records.

JSDD Living Will (LW) Key Points and Explanation (Advance Terminal Care / Healthcare Directive = LW)

- The purpose of this LW is so that the signer can pass on his/her wishes to end life without losing his/her own identity, integrity and dignity, and those wishes can be passed onto the caregivers to be honored.
- Making one's terminal medical decision is based on the idea of self-determination, which is a basic human right.
- To prepare one's LW, the signer should receive pertinent information from JSDD and the Ministry of Health, Welfare and Labor to understand the options and make the best decisions.
- The LW can be prepared by the signer alone; however, it is strongly recommended to consult with the primary care physician, the medical team, close family members and professionally trained advisors before making decisions. This process is called "advance care planning" (ACP).
- It is extremely important to share the contents of the LW with close family members and medical providers.
- The LW protects the signer to avoid administration of any undesirable life prolonging measures; however, it is not necessarily to refuse life saving measures.
- Life prolonging measure is defined as medical measures administered only to extend imminent death. Life saving measures are defined as medical measures administered in order to resuscitate a person who is not diagnosed as terminally ill.
- Life sustaining measures such as mechanical ventilators administered to treat external wounds or neurological or cardiopulmonary diseases are not considered life prolonging measures

My Wish List

I have already declared in my living will (Advance Healthcare Directive) issued by Japan Society for Dying with Dignity. In addition, I have hereby documented my specific medical care wishes when my life comes to end. This is my wish list for spending the last days of my life without losing my identity, integrity and dignity.

Date: _____

Signature: _____

I checked the boxes of my choosing:

1. Where I wish to spend the last days of my life (mark one box):
 Home Hospital Care facility Undecided
 Other (Please specify: _____)
2. What I value the most and want to be honored (mark more than one if necessary):
 I want to live independently as long as possible.
 I want to share sufficient time with my loved ones.
 I do not want to expose my deteriorated appearance to others.
 I want to eat and discharge myself without any help.
 I want to spend time in a quiet and peaceful environment.
 I want to receive all available treatments if there is any chance for recovery.
 Other (Please specify: _____)

The following items, 3 and 4 are to be answered if you have additional comments to the statement, "I refuse life prolonging measures only to extend the dying process", and/or you need to make more clear about the statement, "I want life prolonging measures to be terminated."

3. If I am no longer able to eat/drink on my own, and I am diagnosed as terminally ill or incurable, I want to receive the following method(s) of nutrition and hydration (mark more than one if necessary or leave blank if unsure):
 Nasoenteric feeding through nasogastric tube
 Intravenous nutrition (feeding through a drip directly into the bloodstream)
 Enteral nutrition (feeding through a tube into the stomach)
 Intravenous hydration
 Fed through the mouth by a care giver
4. If I am diagnosed as terminally ill or incurable, what I don't want to receive the following treatments (mark more than one if necessary or leave blank if unsure):
 Cardio pulmonary resuscitation
 Mechanical ventilator
 Tracheotomy
 Dialysis
 Oxygen inhalation
 Blood transfusion

- Vasopressor and cardiotoxic agents
- Anticancer drugs
- I.V. dripping

5. Other wishes:

(Explanation of medical terms)

- **Cardiopulmonary Resuscitation:** A medical procedure designed to restore normal breathing after cardiac arrest that includes the clearance of air passages to the lungs, mouth-to-mouth method of artificial respiration, and heart massage by the exertion of pressure on the chest.
- **Mechanical Ventilator:** A medical device designed to move breathable air and oxygen into and out of the lungs to provide breathing for a patient who is physically unable to breathe sufficiently. It can be administered through a mask, or in more serious cases, a tube is inserted through the mouth or nose. If the condition continues for more than a week or two, a tube is inserted into the trachea by tracheotomy.
- **Enteral nutrition (feeding through a tube directly into the stomach):** A tube is surgically inserted into the stomach by a percutaneous endoscopic gastrostomy.

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A PROSPECTIVE SYSTEM FOR LW SUPPORTING PHYSICIANS



In Nasu Highlands where his clinic is deeply and solidly rooted, Dr. Taigaku Mikawa takes care of dying patients with a natural, solemn attitude.

Patients' rooms are just like a typical Japanese style family room with a kotatsu* and rice paper screen sliding doors.

Patients have access to hot springs for soaking. Though it is a hospice, the atmosphere is so similar to that of a typical Japanese onsen Inn that people refer to it as the Hospice Lodge.**

Dr. Mikawa told me “I’m a physician who keeps my patients good company until their last moment.

*A **kotatsu** is a Japanese low, wooden table frame covered by a futon, or heavy blanket, upon which a table top sits with a heat source underneath.

An **Onsen is a Japanese hot spring and the bathing facilities and inns frequently situated around them. As a volcanically active country, Japan has thousands of onsens scattered throughout all of its major islands.



Photos:
Dr.Taigaku Mikawa in his relaxed state (above).

His father Dr. Taizan, known as the Mountain Doctor, together with Dr. Taigaku when he was young (left).

Nasu Highlands, one of the famous old Onsen (hot spring) attractions in Japan, is located in the northern part of Tochigi Prefecture. Dr. Mikawa’s Clinic is located deep in the woods where you see scattered summer homes, and it looks just like one of the old Japanese style lodges.

“Yes, my mother used to run a lodge from this house. My father had a clinic at that time in the neighborhood, and later he moved his clinic to this house,” explained Dr. Taigaku Mikawa (58). There was a large wooden shoe locker in the entrance hall, and the reception window board was made of an old wood. There was classical music playing in the background. The whole atmosphere made me feel nostalgic of the Showa Era, 1930-1990. Dr. Mikawa told me, “Even though this is a medical clinic, because of the type of the house and its atmosphere, people call it the Hospice Lodge.”

The clinic’s website homepage states, “How can we recuperate our tired mind body naturally? How can we use our natural curing power that humans intrinsically inherit? How can we provide patients with a secure and peaceful environment that allows them to focus on recuperation? These are the goals of our institution.”

While he showed me through the wooden corridor, there were eight Japanese styled rooms for patients. Each room had a name such as FALCON and PHEASANT, all birds' names, and accommodated with a Kotatsu and shoji (paper screen sliding door) so that patients feel like at home. I knew it was dinner time because the kitchen employees were carrying meals to the dining room.

His father, Dr. Taizan founded this clinic during World War II when there was not a single doctor in the village.

His father, Dr. Taizan was a well-known local doctor. In 1942 here in Nasu yumoto, he opened the clinic as the only doctor in the village. Still a young doctor at age 26, he decided to bury his roots in this tourist community. Here, he met people from all over the country who came to escape the heat of summer, one of whom was a famous writer, Bunroku Shishi. He met Bunroku as a patient first, and through this friendship, he befriended many other writers over the years. He also started writing essays and short novels, altogether 14 books. A famous writer named Yukio Togawa, also known as “the Animal Writer,” took an interest in the doctor’s unusual appearance of a monk in the mountains with a beard, and wrote a series of books about him entitled “The Mountain Doctor,” which made him famous. The story was made into a TV drama with a famous actor, Hisaya Morishige playing his role, and was broadcasted on both TV and radio.

Smile is the only thing I take with me when I visit the patients

Dr. Taigaku came back to his father’s clinic in 1994 when he was 35 years old. After graduating from Kitazato University Medical School, he experienced being a hospital doctor in Amami Oshima for about three years. “At first, I was a little hesitant to come back because I wasn’t sure about all my patients being elderly who needed their diapers changed,” he recalls. Twenty three years have passed since then. His father who started this rural community medical service passed away twelve years ago.



Dr. Taigaku’s priority concern is to provide palliative care facility – a hospice – for those who are in the dying process with pain and suffering. Two years ago, he opened “Fumi Getsu An,” residential facilities for terminal stage cancer patients, which is only a few minute walk away from the clinic.

He had a patient with terminal cancer, a woman in her 70’s.

He took care of her in the clinic, and her donation contributed to the opening of the hospice. The hospice “Fumi Getsu An” is named after her. The hospice stands solemnly on top of the hill side,

with a panoramic view looking over the Grand Kanto Plain. Dr. Taigaku visits his hospice every day.

“What I take with me to visit check on my in-home patients of terminal cancer is just this smile. What more can I do than to smile and hold their hands? When they ask me how much longer they have, I just tell them, “I’ll be with you all the way through, so don’t worry,” he said.

It’s been seven years since he has become a registered LW supporting doctor. The legacy he carried from his father is rooted deeply and solidly on the grand Nasu Highlands.

LW SUPPORTING DOCTORS ACCREDITATION CERTIFICATE FORMAT FINALLY DECIDED!

The second session of the LW Supporting Doctors System Project was held on November 25 at JSDD headquarters, focusing on finalizing the format of the accreditation certificate. Certificates will be sent to all currently registered LW supporting doctors.

The President, two Vice Presidents, three Directors and the headquarters staff were among the members to decide on the wording, frame design, English wording, placement of the logo and the overall design.

Discussions continued when Director Kobayashi announced the status of ongoing projects by Tokai Chapter. In their survey conducted last summer to develop a system and process for LW supporting doctors, one of the issues identified was that the supporting doctors were never notified nor announced to the public. In conclusion, it was decided that further research and discussions will continue until the best resolution is reached on the methods and procedures of disseminating the registry of LW Supporting doctors out to the public.