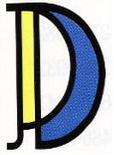


Excerpts from



**Japan Society for Dying with Dignity Newsletter**  
**No. 187, October 1, 2022**

**Main Contents:**

- Changes to the Living Will
- Detailed explanation of the new Living Will and how to prepare one
- Explanation of important terms



**Changes to the Living Will: Revisions and explanations**  
**Dr. Soichiro Iwao, President of JSDD, Public Interest Corporation**

The Living Will or Advance Directive for Terminal Medical Care issued by JSDD has been highly evaluated for nearly half a century as an official documentation of patient's will and intent for terminal medical care based on self-determination. However, recent social shift against terminal medical care and wide expansion of a phenomenon called "end of life activity culture" have generated publications of so many documents similar to our Living Will.

In the meantime, we have continued to push for the legalization of dying with dignity. The Diet Member Coalition for dying with dignity which was established in 2012 presented a draft bill honoring self-determination for terminal medical care. This draft was meant to protect physicians who exercise termination of life prolonging procedures in order to honor their terminally ill patients' self-determination from criminal liability.

Once the bill is passed, the Living Will issued by JSDD, which has been promoting the concept of self-determination for terminally ill patients, will play a major role as a new model for expressing patients' will and intent. We have also considered the importance of legal integration and conformity for confirming patient's will and intent. For the last three years, our team including the board directors and the staff, had multiple discussions and came up with seven points for further study.



1. Does the current Living Will we issue, a simple form that includes comprehensive declaration and patient's signature, fully convey the patient's will and intent under all medical settings?
2. Is it necessary to document that the patient had sufficient information with a full understanding of the information, and undergone a process to prepare the Living Will?
3. The receiving physician will likely question the patient's mental capacity upon preparation of the Living Will and if it was strictly a voluntary action by the patient with no coercion. Is this nature of trust that is currently endorsed by JSDD sufficient? Does this statement need to be explicitly written in the document?
4. It is important to confirm if there are any changes to the patients' will and intent. We do this at JSDD upon receipt of annual membership fee, but is this the best process of confirming their continued intent?
5. Most living wills (or advance directives) issued by organizations other than JSDD include a column for family consent. Is this considered an indispensable condition to protect the physician's decision or does it damage the patient's autonomy? Is it necessary to add this to our Living Will?

6. How can we protect the patients' will and intent when their mental capacity declines? The concept of appointing a medical agent, which is common in other countries, is not commonly practiced in Japan. How should we protect the patients' will?
7. Our rapidly increasing population of elderly people and dementia patients is becoming a serious issue. Should the JSDD consider incorporating this specific aspect to our Living Will?

Since 2017, we have conducted multiple committee meetings with professionals in the fields of ethics, philosophy, medicine, nursing, welfare and law to discuss the contents of the Living Will. In 2021, the board of directors meeting formulated the following observations.

1. The JSDD issued Living Will will be a directive, an important tool for confirming the patient's will and intent, as well as supporting the physician's discretion and medical reasonability.
2. Moving forward, two other documents will accompany the basic Living Will document: Living Will Preparation and Explanation of important terms. These will enforce the awareness that just having the Living Will in person is not good enough, and emphasizes that the Living Will was prepared based on full understanding and is valid uninterruptedly.
3. The requirement to have patient and witness signatures on the JSDD issued Living Will ensures its authenticity. The membership application form comprises of a remark emphasizing autonomy.
4. Since autonomy and mental capacity of the patient are constantly questioned, requiring a witness during Living Will preparation is appropriate from a legal perspective. The witness will prove the patient's autonomous intent and the mental capacity.
5. Under such sophisticated social circumstances, it is imperative to increase the level of security and oversight of the process. At the same time, we must ensure that it does not inhibit the patient's autonomy in doing so. Family consent and involvement in medical settings are deeply embedded in the Japanese culture and will continue to be included in the terminal medical care setting; however, family consent will not be a decisive factor for the execution of the Living Will.
6. In the case of declining mental capacity after preparation of the Living Will, it is important to establish and promote the government endorsed system of advance care planning (ACP) in order to continue honoring patient's will and intent with the Living Will as the base document.
7. As we acknowledge the fact that eight million of our population has dementia, and that number is quickly rising, the Living Will must reflect the likelihood of people with declined or loss of mental capacity. See "Explanation of important terms" for more details.

Based on these conclusions drawn by our board directors and referencing advance directives issued by other organizations, the draft of the new Living Will was finalized. The new Living

Will safeguards the mission that JSDD has continuously worked on for a half century by adapting to our projected future to meet our members’ wishes that are acceptable to the medical care community. We will explain the new Living Will more in depth with easier language below.

## Detailed Explanation of the New Living Will

The new Living Will is available as of November with more comprehensible instructions and reflect the current trends and needs. Below are the comparisons of the old and new Living Wills and the two other parts of the new Living Will (Living Will Preparation and Explanation of Important Terms). Another separate document, “My wish list,” was also modified which is shown in the following pages. Similar to the previous form, these pages in the newsletter can be separated and used as an official document.

### -New Format-

#### Living Will

#### 1 -Advance Directive for the final stage of my life-

Membership Number	
Date of Registration	

This directive expresses my wish to maintain my dignity until the end of life, and will be valid unless revoked by myself.

- If my death is imminent, or if I am in an unconscious state for a long period, I do not wish to receive any medical treatments for the sole purpose of extending my life.
- 2 • However, I wish to receive sufficient amount of palliative care to alleviate any physical and emotional pain or suffering, to include medical opium.
- 3 • I wish for my representative and medical care providers to have full discussions on the above two points to plan and fully execute my wishes.

I hereby state that I take full responsibility for the actions of those who support my end of life wishes and am deeply gratified.

### -Required information-

#### Applicant

Name:	Date:
Address:	Date of Birth:
	Home Phone:
	Cell Phone:
Email Address:	

**Witness** (a person who can prove the signature of the applicant. If you do not have a witness available, you may skip) 4

6	Name:	5	Relationship to you:
7	Contact information:		

**Representative** (a person who will convey your wishes on your behalf in case you are unable to do so. If you do not have an appropriate person available, you may skip) 4

6	1) Name:	5	Relationship to you:
7	Contact information:		
6	2) Name:	5	Relationship to you:
7	Contact information:		

**-Optional information-**

**Primary Care Physician**

6	Name:	Affiliated Clinic:
7	Contact information:	

**Care Manager, etc.**

6	Name:	Specialty:
		Employer:
7	Contact information:	

**【New Living Will key points】**

- 1 The term, “terminal medical care” is changed to “final stage of life” which broadly encompasses multiple aspects of “end of life.”
- 2 Statements will emphasize the wish for comprehensive and humane palliative care to deal with not only physical pain, but also mental and social suffering.
- 3 Expressions which hinder autonomy such as “consent of the family” are replaced with expressions that are more of supportive of the patient’s will and intent, which consequently leads to self-determination.
- 4 Best to find someone, but if you do not have an appropriate person, you may skip it.
- 5 Relationship to you, the applicant.
- 6 Optional columns: You do not have to renew the with each change.  
Contact JSDD to provide any changes to the information.
- 7 Cell phone numbers are recommended for immediate contact.

## My Wish List (Part 1)

[This portion is optional. Fill in when it is the right time for you. If not, you may skip it.]

In addition to block #3 in my Living Will, I hereby state my thoughts and wishes regarding specific medical care at the end of my life. My wish is to spend the last days of my life as myself with dignity.

Date: \_\_\_\_\_

Signature: \_\_\_\_\_

### Medical care I wish to receive

- Intravenous (IV) dripping       Blood transfusion       Oxygen inhalation  
 Artificial respirator       Dialysis       Anti-cancer drugs  
 Cardio pulmonary resuscitation       Vasopressor and cardiac stimulant

### Nutrition and hydration

- I wish to be fed through the mouth only       Small amount of IV dripping  
 Nutrition through stomach tube       Nutrition through nasogastric tube  
 Total parenteral nutrition - TPN

### Palliative care

- I wish to experience no pain or suffering with maximum palliative care including medical opium and strongest pain medication.  
 I wish to receive comprehensive palliative care for not only physical pain, but also for mental and emotional pain and suffering.  
 I wish for those who suffer from a sense of loss and grief upon confronting my death to receive comprehensive palliative care

### When I can no longer express my own will

- If there is a situation in which my Living Will and My Wish List are not sufficient to make sound medical judgement, I wish for my representative and medical care providers to have discussions and find the best solution for my end of life welfare.  
 When I am able to show even a slightest expression as to my will and intent, I wish for all parties involved to make their best efforts to clarify my will and intent.

### How I would like to spend my last days

#### Location:

- My residence (my own home, my children's house, my grandchildren's house, etc.) Provide the specific name: \_\_\_\_\_  
 Other than my residence: \_\_\_\_\_  
 Assisted Living Facility for the elderly  
 Hospital       Hospice or Palliative Care Facility name:  
 Undecided       Other: \_\_\_\_\_

**With whom: (including pets)**

1. \_\_\_\_\_
2. \_\_\_\_\_
3. \_\_\_\_\_

**How?**

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**My Wish List (Part 2)**

**What I care about the most**

**Medical care:**

- I wish to remove all pain, suffering and discomfort.
- I wish to know all the details of the process that I expect to go through
- I wish to build a positive and trusting relationship with my medical and care providers.
- I wish for everyone around me to amicably embrace my unstable emotions

**Autonomy:**

- I wish to spend the last days of my life independently and self-supported.
- I wish to eat by myself without any help.
- I wish to relieve myself as much as possible.

**Dignity:**

- I do not wish to be seen as being old and weak by others.
- I do not wish to bother and inconvenience other people.
- I wish to have a role or be a part of my community and my family.
- I wish to be recognized for all the accomplishments I've made in life.
- I wish to be treated sincerely and respectfully.

**Human relations:**

- I wish to convey my thoughts to people who are important to me.
- I wish to spend as much time as possible with my family and friends.

**Environment:**

- I wish to spend the last days of my life in a comfortable, peaceful and tranquil atmosphere.
- I wish to spend the last days of my life in a cheerful and lively atmosphere.
- I wish to spend the last days of my life in a sanitary and clean atmosphere.

**Emotion:**

- I wish to spend the last days of my life with feeling joy and happiness filled with laughter and humor.
- I wish to spend the last days of my life without thinking about illness or death.
- I wish to spend the last days of my life supported by faith and trust.

**Other:**

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## **Living Will Preparation**

### **Significance and purpose of the Living Will**

JSDD pursues a society in which all people have the right to choose their own end of life medical care and live with dignity until the end. The JSDD issued Living Will is an official document which allows patients to express their will and intent regarding their choice of medical care in advance. By preparing and registering your Living Will, your wish is clearly communicated to the medical professionals so that they can honor and execute your wishes until the end. The top priority in the preparation of your Living Will is that it is your own will and intent, and the second most important element is that you can share it with your medical and care providers and your family and anyone who supports you. If you do not wish to prepare a Living Will, that is a perfectly fine decision. You can prepare it at any time whenever and if you feel ready.

### **The right to self-determination**

It is up to you to decide what medical care you wish to receive or reject. The Constitution guarantees your right to self-determination as a fundamental human right.

### **To those who have been administered a life-prolonging device**

To those who have already been administered a life prolonging device such as an artificial respirator or dialysis as a result of external injuries or illnesses such as nerve, heart and lung or hereditary in nature, it is not considered life prolonging. JSDD does recommend complete removal of such devices which would consequently have a fatal outcome.

### **It is not for refusal of emergency or critical care**

The purpose of the Living Will is to avoid life prolonging measures administered solely sustain your life against your will in case you are unable to express your own wish and intent when something happens. The Living Will is not for refusing treatments aimed to temporarily sustain life.

## **Information gathering and decision making**

You can make the best decision when you can obtain all appropriate information from JSDD and other trustworthy organizations on various medical conditions and treatments. Make sure you fully understand the information before preparing your Living Will.

## **Advance Care Planning (ACP)**

We recommend that you obtain sufficient information and explanations from your medical care team and advisors to make informed decisions. Meet with them on multiple occasions including your family members to go over the Living Will you prepared. This consultation process is called Advance Care Planning (ACP).

## **Changing your mind**

You can always revoke it whenever you feel like it. Your condition, changes in your environment and medical evaluation may bring changes to your feelings. It may be a good idea to check your own feelings on holidays such as New Year's or your birthday. Please contact us when you wish to revoke it.

## **(Key points)**

We assume that you joined JSDD with a good understanding of important terms and concepts such as the purpose of the Living Will and the meaning of dying with dignity. With that understanding, we endorse and protect your Living Wills from external interferences. Please read it carefully once again and further deepen your understanding.

## **-Explanation of Important Terms -**

### **Son gen shi: Dying with Dignity**

It is not giving up on living. It means that you keep living robustly without losing your character and spend the last days of your life with dignity, grace and peace. For example, if your death is near due to an existing illness/disability or you are unconscious for a long time, you can refuse medical treatments which will only prolong your life and accept a natural dying process.

Note: In Japan, there are two terms with two separate meanings which the rest of the world considers as legal euthanasia. One is "Son gen shi" which is explained above, and the other is the legal aspect of euthanasia.

### **An raku shi: Euthanasia**

Death by which a physician administers lethal medicine directly to the patient or the patient intakes prescribed lethal medicine as requested by the patient who suffers from a painful and incurable disease or condition. In Japan, this is not typically legal.

### **End of life stage:**

It is a period of time when prescribed medical treatments for recovery have not been effective, are unlikely to stop the dying process, and the patient is nearing death. The length of time

depends on the disease. The prognosis for cancer is usually more predictable, but chronic diseases can suddenly get better or worse. Some unpredictable cases can be after having a cerebrovascular disease or aging, in which this stage can last for a long time. Conditions such as acute heart failure, cerebral hemorrhage, and external injury from an accident can have a rather short stage of several days. It is important for medical care team to make proper judgement.

### **Dementia and end of life Stage:**

Regardless of the condition of dementia, the patient has his will and intent. One cannot assume that all dementia patients are incapable of making sound judgement on all matters, or they are unable to express right or wrong on all matters. Proper support can lead to sound judgement. The medical care team and family must collaborate to determine the best treatment for the patient based on the Living Will which was prepared prior to the upsurge of dementia and the will and intent that the patient expresses. The end of life stage for a patient who suffers from dementia is the same as any other patients whose conditions get worse and there is no way back to recovery.

### **Tranquility:**

Medication given to patients to lower their consciousness or to maintain a lowered level of consciousness for the purpose of alleviating pain and suffering.

### **Artificial respirator:**

When patients are unable to breathe sufficiently on their own, oxygen is pumped in and out of their lungs. This may be done through a mask, but in serious situations a tube is inserted into the patient's mouth or nose. If it needs to continue for more than two weeks, an incision is made in the throat to insert a tube into the trachea through an artificial opening (tracheotomy).

### **Stomach tube feeding:**

An artificial opening is made with an endoscope, and a tube is inserted. All hydration and nutrition are given through this tube.

### **Nasal tube feeding:**

A soft, narrow tube is inserted into the nose. All hydration and nutrition are given through the throat and esophagus.

### **Total Parenteral Nutrition (TPN):**

A catheter is inserted into a large vein such as one near the groin leading to the heart to provide liquid nutrients including carbohydrates, proteins, fats, vitamins, minerals and electrolytes. In some cases, a needle is only inserted to embed a small 3 cm port under the skin for feeding.

### **Peripheral Venous Nutrition (PPN) or Intravenous (IV) Dripping:**

Nutrition is given through a small vein of a hand or a leg.

### **Cardio pulmonary resuscitation:**

Medical treatment or device administered when the heart stops such as a heart massage, electrical defibrillation, artificial respirator, and vasopressor.