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Public Interest Corporation  
Japan Society for Dying with Dignity

## **JSDD's official statement regarding a recent media report on an ALS patient's assisted suicide**

First of all, we would like to pay sincere respect to the courage of a woman who lived her life to the fullest until the end while suffering from a fatal disease, ALS (Amyotrophic Lateral Sclerosis). We wish her to rest eternally in peace. We would also like to make the following statement regarding the report of this ALS patient's assisted suicide.

We, Japan Society for Dying with Dignity, is a private organization with over 100,000 members whose mission is to educate citizens and promote the concept of the Living Will. We must first clarify that terms such as "dying with dignity" or "dignified death" are an entirely different concept from active euthanasia. We sincerely hope that these two separate concepts will be accurately and clearly differentiated from one another when discussed publicly in the future.

JSDD defines "dying with dignity" or "dignified death" as death which comes naturally in the life process by withholding any life prolonging measures and alleviating pain and suffering through sufficient palliative care. On the contrary, death resulting from active euthanasia is terminating life peacefully while being assisted by someone, and is still considered a crime in Japan. We only have the information published by the media and are not familiar with any details of this case, including the treatment the assisting doctors provided. Nonetheless, what occurred is against the social norm and an unethical medical practice, and obviously not acceptable under any circumstances.

In 1991, there was a criminal case in which an attending physician at Tokai University Hospital was charged with homicide when he provided a lethal dose of medicine to the patient who was in terminal stage of cancer. This was the only other case of active euthanasia in Japan until now. Yokohama District Court ruled in 1995 that the below four conditions must be met for physicians to legally practice active euthanasia on a patient:

1. The patient is suffering from an unbearable and severe pain that cannot be relieved.
2. The patient's condition is considered incurable with no hope of recovery; and death is imminent.
3. There is no other way of alleviating the patient's pain except for a consequent result in death.
4. The patient explicitly accepts and consents shortening of life.

Not only did the recent case not meet the above conditions, but there seemed to be no sufficient communication between the patient and the medical providers. Therefore, the conduct of the two doctors involved can be concluded as based on self-motivated judgement without social consent.

In one report, the Yokohama District Court mentioned that the patient experienced some physical pain, but we suspect that there was much more pain involved that was not physical. In the professional scope of palliative care, pain consists of the following types:

1. Physical pain
2. Mental pain
3. Social pain
4. Spiritual pain

Spiritual pain is defined as pain that comes from losing value and significance of living a life. Hidden behind one's wish to die is usually neglected pain. It can be a social pain such as the feeling of not wanting to be a burden on your family or no longer being able to participate in social activities. It can also be a spiritual pain of losing the value or significance of living a life. No one can take over or substitute your pain. What is needed is a type of care management in which patients can share their pain while in search of a meaning in life. Unfortunately, our society does not have a sufficient support system for these patients and others who are vulnerable, which may have led them to assisted suicide as their only resort.

According to various research and studies, 70 to 80% of the Japanese population seems to support a legal system that allows active euthanasia. The right to active euthanasia is legally recognized in Switzerland, the Netherlands, some states in the U.S., Canada, and Australia. In Switzerland and the Netherlands, active euthanasia for physical and spiritual pain is legally recognized, as well as advanced stages of dementia if included in the patient's advance directive. JSDD supports dignified death, but opposes active euthanasia.

Some find our position to be unexpected, but our intention is that we must first make a country in which we can die with dignity by respecting and honoring the living will. Japan is the only developed country with no legal backing of the living will, and is also at the bottom globally with no profound deliberation on the topic of terminal care. The mainstream opinion currently is that sufficient palliative care should eliminate the need for active euthanasia. Some of our members proposed that we start a discussion about active euthanasia; however, our current position is that we should not recognize or approve active euthanasia so easily unless we have a sudden, drastic revolutionary change in our society.

The living will is a testament of life, a document of self-determination regarding one's terminal care. When our efforts in legislature to legalize the living will was in a deadlock, the Ministry of Health, Labor and Welfare decided to change its approach to promoting a new term, "Life Planning Conference," which is equivalent to advance care planning (ACP). JSDD started to send out messages such as, "the living will is the first step to your Life Planning Conference" and "the patient is the protagonist of this life story. Unfortunately, the reality is that people who write their living wills are still a minority in Japan, and many people in advanced stages of dementia are incapable of writing their living will.

The living will is a form of self-determination regarding one's terminal medical care. This pursuit of happiness is a constitutional right of all citizens in Japan. If we take it one step further and claim that it is also a citizen's constitutional right to die, then active euthanasia would be included. JSDD is an active member of the World Federation of Right to Die Society, which consists of organizations from 30 countries. The whole world struggles with this issue of right to die, which ultimately means to honor active euthanasia. In Japan, the discussion of right to die is still held at the level of dying with dignity by promoting the living will.

In light of this recent assisted suicide case, we want to ensure that people do not consider discussion of death to be a taboo, but rather that they expand the deliberations on topics such as the living will, dying with dignity and even the right to die. We sincerely hope that this event triggers an establishment of a unanimously supported terminal medical care system in the very near future.