

# Considering Assisted Decision Making from the Perspective of Equality with Others

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## The Situation in Japan

### Decision-Making Assistance Premised on the Adult Guardianship System

**Adult Guardianship System**  
 In order to protect impaired persons who do not possess sufficient decision-making abilities for reasons of dementia, cognitive impairment, psychological impairment etc., this system appoints individuals to assist these persons in their daily lives.

### Act Regarding the Promotion of the Use of the Adult Guardianship System

Promulgated on April 15, 2016 and enforced on May 13, 2016.

In addition to evaluating the state of assistance in 'decision-making in health care and nursing', this Act also clarifies the necessary measures to be taken.

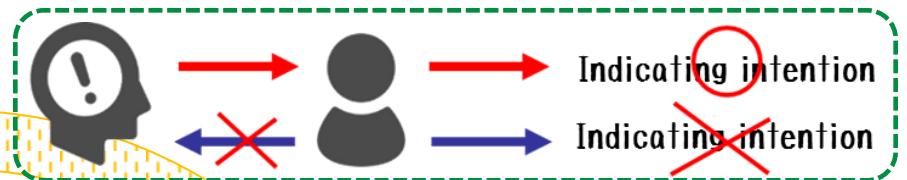
This is a system for proxy decision-making made on behalf of the impaired person by a proxy or guardian.

## Individuals impaired by ALS

### Impaired individuals gradually lose the ability to communicate their will

### ALS : Amyotrophic Lateral Sclerosis

Movement of the body gradually becomes impossible, and communicating one's will becomes more difficult. If the impaired person's intentions are not interpreted by someone else, they cannot communicate their will.



As the symptoms progress, the means of communication are lost.



The impaired person can only rely on the discretion of another to interpret their intentions.

For patients, what is awful about this disease is not only its symptoms but also having to choose between living and dying.

They want their current will to be understood, not only their will as it was in the past.



### ALS and the Adult Guardianship System

**ALS**  
 The impaired person cannot indicate their intentions.

The impaired person cannot exercise their legal abilities.

### A legal proxy through the Adult Guardianship System is required as a form of support.

Convention on the Rights of Persons with Disabilities

### Supported Decision-Making

▶ Upon deeming the impaired person's decision-making legally valid, support is then given for the equal exercise of legal abilities.

- Development of diverse means of communication.
- Advanced planning.

### Conditions Facing ALS Patients

Despite having their own will, many are left unable to have their intentions interpreted.

Through a proxy or family members

Disposal of assets

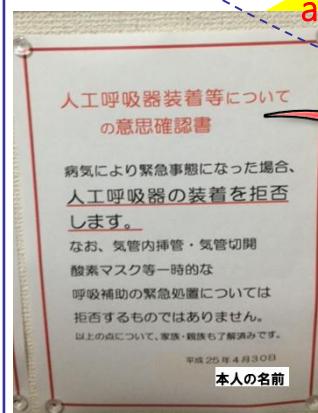
Hospitalization or change of residence against the will of the impaired person

Denial of health care on which the patient's life depends

### Advanced Living Will regarding a ventilator

**"I refuse the use of a ventilator."**

When this becomes an issue of choice, impaired persons become unequal to others.



- Depending on their physical condition, even if impaired persons make various decisions, they have no means of communicating them, or communicating changes regarding these decisions, and must entrust these decisions to another person.
- With the adoption of the framework of the Adult Guardianship System in Japan as it stands, even if assisted decision-making is sought, the lives and lifestyles of ALS patients will be adversely affected by approaches premised on the idea of 'death with dignity'.
- Abolishing the framework of the Adult Guardianship System would require the guarantee of survival through the enrichment of assistance grounded in Articles 10 and 19.