

Achieving **Independent Lives** for People with **ALS** Connected to **Artificial Respirators** through the Process of Accepting Care from **Non-Family Members**



Yui Hasegawa **Hideaki Masuda** **Miki Nishida** **Naoyuki Kirihara**
Yumiko Kawaguchi **Shinya Tateiwa**

Personal assistant

Hideaki Masuda's practice selecting and nurturing caregivers



He decides on a caregiver, instructs the caregiver, adjusts their shifts, and manages their pay, among other actions. A caregiver is identified among people other than housemates and family members, such as friends and acquaintances. Recruitment and interviews of caregivers and instruction and education on care and other activities are performed by Mr. Masuda himself.



Currently there are 15 personal assistants, and most of them are students. Students stop being personal assistants upon graduating. Therefore, personal assistants are constantly being recruited.

His own daily life is freely and **independently** organized by selecting a caregiver himself rather than having one dispatched by a caregiver agency.

Welfare Program

Long-term care insurance system

Personal Care (Bathing), Rehabilitation, Technical aids (Electric adjustable bed, lift, wheelchair, ramp, etc.)

Home-visit care for people with severe disabilities

(based on the Act on Comprehensive Support for Persons with Disabilities): **987.5 hours** per month

1) Personal Assistants, 2) Visiting Care from the home care agency about 80 hours per month

Daily life with a Personal assistant

- ✦ Going out
- ✦ Helping him swallow sputum
- ✦ Setting up a personal computer and switching
- ✦ Cleaning up after breakfast (managing gastric fistula) and ensuring regular hydration
- ✦ Changing positions (exercising)
- ✦ Communication through a letter board
- ✦ Dressing and placing him on a wheelchair
- ✦ Taking care of his oral cavity, face washing
- ✦ Dressing after returning; changing positions
- ✦ Dinner (managing gastric fistula)
- ✦ Changing his diaper



Personal assistant training Entrusting care to someone requires smooth communication

The personal assistant, who understands the patient's needs, and the guidance system, a team of medical professionals available to provide medical care, help share the patient's burden. This is linked to improvements in both community life and the nursing system.



Point of view from the Family



Since the patient teaches the assistant how to care for him or her, the patient's family can now leave the patient's care to the assistant. As a result, family members will have more time for themselves, which they can dedicate to their jobs, shopping, etc.

Point of view from the ALS patient

▶ The prospective **personal assistant**
 Someone with a good understanding of life's daily rhythms, with whom there is a good rapport.

Suggestions regarding **decision-making** are formed with a priority on alleviating the **family's burden of care**.

▶ The ALS patient is now receiving care from someone outside the family
 The patient frees the family from the role of caretaker while shifting to a more autonomous lifestyle.

It is important for patients to receive personalized care tailored to their needs as well as a wide range of general assistance. Having a **personal assistant** makes this possible and also allows patients to rely on someone other than family members. In this way, **I believe patients can continue to communicate even if it becomes difficult to express their wishes.**

