

A step toward community activities for people with ALS living at home using personal assistants

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✓What is a personal assistant?

A "personal assistant" is a person who provides assistance based on the wishes of the person with a disability. It is also referred as a 'self-nominee helper'. The more you become a good employer and the better you make use of your personal assistant, the better service you will receive and the better your quality of life will be(SATO 2014).

✓About social support systems

Two social support systems are available for people with disabilities.

Long-Term Care Insurance covers elderly people, but ALS can also be covered as a specific disease. However, the term of this coverage is too short to be adequate.

Visiting care for persons with severe disabilities is another welfare service for persons with disabilities. The desired amount of nursing care time is not always granted, **but if it is approved it is possible to receive care services 24 hours a day.**

✓What is ALS?

When someone has ALS (Amyotrophic lateral sclerosis), even though their cognition is very clear, their motor neurons (nervous system for moving your body) stop working. First, their muscle strength gradually decreases and symptoms of muscular atrophy, paralysis, and speech disorder appear. Next, their breathing muscles become weak, leading to respiratory difficulties. Even with today's modern medicine, it is impossible to provide an effective cure and expect the illness to go away. But the development of medical devices such as gastronomy tubes and artificial respirator machines are helping to extend long-term survival. However, there are only a few facilities where patients can be hospitalized for a long time, and staying at home requires nursing care 24 hours a day, 365 days a year. The physical, mental, and economic burdens on families are also heavy.

One step toward community activities:

Hideaki Masuda

✓Introduction

- 2004. Onset of ALS at 60 years old (Unable to move his body after 1 year)
 - 2006.2. Difficulty breathing, introduced a BIPAP.
Difficulty swallowing, installed a gastronomy tube
 - 2006.5. Got a tracheostomy, installed a respirator
 - 2006.8. With the respirator, started staying at home
 - 2011. Started living independently with personal assistance
- Currently 75 years old, Japan ALS Association / Kinki Block Chairman,
Japan ALS Association Vice President,
Ritsumeikan University Visiting Researcher

✓ Reasons for Choosing Personal Assistance

- As I was using only nursing insurance at that time, I couldn't go out when I wanted. When I found out about welfare services for severe disorders, I wanted to use it. I call my 'self-nominee helpers' personal assistants. Because their work is related not only to my daily life, but also to my every activity in society (Masuda 2013).
- People with ALS, patients with intractable diseases, and people with severe disabilities who are unable to move their entire body need a helper 24 hours a day in almost every aspect of their lives. Family care alone is not enough, and it is not possible to respond to the patient's needs as the illness progresses with only short-term care insurance. In order to improve the quality of life under a stable nursing care system, we have introduced an approach of finding and training helpers suited to our needs (Masuda 2019).

The progress of working with a personal assistant

Before Hiring	Recruitment (creation and distribution of flyers) → Interview at home →
Hiring	Completion of visiting care for persons with severe disabilities training → Hiring
While working	Each personal assistant submits monthly shift requests by email (by the 25 th of the previous month) → Mr. Masuda arranges the schedule and sends individual notifications by e-mail → Work is carried out
Graduation	Graduation from school marks the end of working as a personal assistant



The ways of using personal assistants

in the house (support for routines in daily life)

- **Body Assistance**: Exercise for postural change, suction, oral care, washing the face, changing clothes, eating (gastronomy tube), support in daily life such as changing diapers.
- **Work Assistance**: Set up a personal computer and mouth switch, read books and mails, print assistance.
- **Supervision**: Not possible with long-term care insurance, but possible with intensive home care.



"Eating with a gastronomy tube"

Activities outside the home

- **Cultural leisure activities**: going to music concerts and movies related to disabilities and intractable disease
- **Walking/Shopping**: Taking a walk by the river near his home or buying lottery tickets at the end of the year
- **Participation in social gatherings**
- **Overnight stays**: Especially when attending academic conferences



"2018 Birthday Party"

Community Activities

- **University and symposium lectures**: Giving lectures on communication support, intractable diseases and medical care
- **Attending and presenting at conferences**: Participating in disability symposia and overseas (Korea and Boston) academic conferences, presenting posters and giving talks
- **Research Group**: Establishing of and participating in a barrier-free research group
- **ALS Association Activities**: Attending various association activities such as the regular board meeting by traveling directly from Kansai to Tokyo or participating via Skype
- **Peer Support**: ALS and colleague consultation on intractable disease



"Poster presentation at the International Society meeting in 2017"

* All manuscript and PowerPoint documents required for these activities were created by Mr. Masuda with a mouth switch connected to a personal computer.

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Contributing to society

- **Hiring only university students as personal assistants**: Employing students from nursing departments, social welfare departments, health departments, etc. to provide a wealth of on-site experience allowing them to gain expertise and to support them in viewing people not only as patients or the disabled. Example) Practicing providing medical care with an Ambu bag
- Record so far (August 2019): 16 people are active as personal assistants for Masuda. Approximately 52 people have graduated and are working in hospitals (as nurses), government offices, and welfare organizations



"Communicating using a dial"

Conclusion

Depending on who is the agent in control of care, people with intractable diseases can perform various social activities.

This example can also motivate other people with intractable diseases to conduct new social activities.

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