【 What we want you to know about ALS 】

Public interest in ALS has been heightened by celebrities who have confessed to having the disease and by the Ice Bucket Challenge, a fundraising campaign that began in 2014 in the United States.
However, we rarely get to hear the real voices of actual ALS patients. What do ALS patients really think about ?

In December 2019 we were the first in the world to perform conditioned medium therapy (CMT) for ALS. Fortunately, the course of the disease was good, and we have had the opportunity to treat and talk to many patients since then. The patient's frank and honest stories were so shocking that I often found myself at a loss for words.
We would like to introduce here the voices of such patients as they are.

What is ALS ?

First of all, we have summarized the disease of ALS in a very simple way. If you listen to the voices of patients with this in mind, you will better understand their true feelings.

1. ALS is officially called amyotrophic lateral sclerosis, a disease that causes degeneration of the motor nerves.
2. It is a very rare disease with 2.2 cases per 100,000 people.
3. Predominantly develops after middle age, from 60 to 70 years of age.
4. Degeneration of the nerves connecting the brain to the spinal cord (primary neurons) and the nerves connecting the spinal cord to the muscles (secondary neurons) results in a variety of motor impairments in the areas they innervate.
5. If primary neurons are affected, limb tightness, tendon reflexes, and muscle stiffness may occur. Secondary motor nerve damage can cause weakness in the hands, feet, or mouth, difficulty walking, grasping, speaking, and other abnormalities.
6. The disease progresses quickly, and in some cases, a wheelchair and a ventilator are required within two years. Consciousness is clear until the end.

7. Once the disease develops, it does not stop.
8. The number of patients is said to be about 10,000 in Japan (in 2020) and about 400,000 in the world (in 2019), but the number is increasing every year.
9. Approximately 5% are familial ALS and the remainder are isolated ALS with no family history.
10. The cause of the disease is largely unknown.

What is done at the hospital：

Patients who feel something is wrong with their bodies are often referred to a nearby clinic, then to a regional core hospital, and finally to a ALS hospital for examination and treatment. It often takes several months to reach a specialized hospital. It is said that the average period from the time a patient becomes aware of symptoms to the time a diagnosis is made at a specialized hospital is 13 months.

1. Needle electromyography and nerve conduction studies are always performed at specialized hospitals, and MRI, spinal fluid analysis, and blood tests are also necessary for differential diagnosis. The diagnosis is made based on these and clinical findings.
2. Once a diagnosis of ALS is made, treatment with medications begins. Medications approved in Japan for ALS include Radicat□, which neutralizes free radicals, and Rilutek□, which neutralizes excess glutamate. In the United States, a drug called Tofelsen□ has recently been approved, but both have limited efficacy.

Our treatment：

1. By administering a physiologically active substance secreted by deciduous tooth stem cells, the degeneration of nerve cells is prevented and nerve regeneration is stimulated. This bioactive substance is called “ conditioned medium”.
2. To date (as of September 2023), 10 out of 15 cases have shown improvement in symptoms and arrest or slowing of the progression of

the disease. More cases of improvement tended to be seen in patients with mild disease (severity classification 2 or 3) with low severity (reference data).

ALS subjective symptoms：

We asked the patients what kind of abnormalities they felt in their bodies for the first time. The symptoms described here can happen to anyone, but they usually resolve naturally if left untreated. If they persist for a long time, you should go to a hospital for an examination.

1. Arm

Muscle twitching and trembling.
Skinny arms.
Being unable to concentrate on what one is doing
Arm feels sluggish and heavy
Not able to do what one is told (of a superior, inferior, etc.)
Not able to control one's arms
Not able to lift the medium mug.

2. Finger

Not able my fingers are not moving
Not able to open the cap of a plastic bottle
Not able to hold my mug.
Not able to write well.
Not able to turn the key.
Hands shaking from holding cell phone.
Not able to break disposable chopsticks
Not able to get " udon noodles " between them.
I feel chopsticks heavy
Dropping the tennis racket over and over again.
Hollowed-out watermarks between the thumb and index finger of the hand
Not able to carry a buffet tray.
Grip strength dropped to half (Right 20 kg, left 13 kg)

3. Legs

I feel legs are too heavy to walk

I tried to sit down and fell on my butt.hands on the ground.

Not able to stand still and sat down to put on my clothes in changing my clothes

Not able to my toes rise and stumble easily.

Not able to take a step down a flight of stairs

Leg cramps when stretching

4. Whole body

Shortness of breath when walking

Shortness of breath on stairs

Muscle aches and pains all over the body.

Pain occurs near the shoulder blade and spreads throughout the body.

Painkillers don't work.

My whole body shape is getting poorer.

No more sneezing or coughing.

Patient's true feelings：

Starting with the hands, feet, and trunk, subjective symptoms spread from dysarthria and dysphagia to breathing problems. How did the patient feel when she experienced these symptoms? People around the patient need to provide mental support that is attuned to the patient's feelings.

1. Physical immobility

" Dressing, getting ready, driving, stairs, shopping, cooking, bathing, elimination "

" One by one, we can no longer do one thing. Every freedom is gone "

" I am very sad that I cannot live without someone's assistance "

" I'm afraid of having TLS (a condition in which a clear conscious mind is trapped in a completely immobile body) "

2. Fear of death

" ALS and was informed that life is limited "

" I want to live my life one day at a time and not be ruled by ALS "

" Life will run out someday. So I want to warmly welcome the inevitable sadness "

" All my friends who confessed wept. I felt guilty about that "

What I want you to understand：

1. To doctors

Doctors should not only explain the disease, but also give hope

Doctor should encourage me, not explain my illness in an indifferent manner.

Be doctors who can accompany the sick.

Doctors should follow up with my family who are down in the dumps.

It was a relief to know the cause of his poor health, although he was very worried that he would not be diagnosed anytime soon.

Doctors should explain about long-term care insurance and specific disease medical beneficiaries.

2. To caregivers

If a gastrostomy is performed, the main nutritional intake will come from the gastric tube. The patient will lose the enjoyment of taste.

I want to be fitted with a ventilator (NPPV) because I have difficulty　I have no choice but to choose to have a tracheotomy myself.

3. To administration

The government should work with patients, not on an application basis.

Instead of "Please let me know if you have a problem,"　you should ask, "Do you have a problem?"

You should understand to uncover needs in conversations with patients.

ALS Severity Classification：

1. housework and employment are generally possible.
2. difficulty with housework and employment, but generally independent in daily living (personal care).
3. the patient is unable to eat, excrete, or move around on his/her own and requires assistance in daily living.
4. dyspnea, difficulty in sputum expectoration, or dysphagia.
5. tracheostomy, parenteral nutrition (tube feeding, central venous

nutrition, etc.), ventilator use.