

# The Catcher on the Web

-Find an ALS patient's story through the Internet

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## *Introduction*

Exactly ten years ago I was a housewife, spending my days in gardening in the suburbs of London. However, now I'm managing at a temporary employment company in Tokyo that dispatches caregivers to critically ill patients. How my life changed! This dramatic change came as the result of making a decision of using an mechanical ventilator for my mother when she was first diagnosed with ALS (amyotrophic lateral sclerosis). In 1995, it was still rare to have the home medical ventilation and there was little information available about the home health care services with the proper medical care. Therefore, with the aids of local doctors and nurses, I began – awkwardly – to take care of my mother at home. In 2003 I formally started the home health care business, which now serves 12 clients, 11 of whom use a home medical ventilator. Now my mother is in the most advanced stages of ALS causing almost all of her muscles .As my mother lies in familiar environment filled with familiar noises all day long, looking over my office desk in the living room, I am able to carry on my work while caring for her.

## ***Home Health Care in Japan and Abroad***

ALS attacks 4 or 5 people out of 100,000 equally throughout the world. As the motor neurons of the entire body selectively attacked, voluntary muscle movement declines while the perception nerves, including the senses of sight, sound, and touch, remain untouched and the brain continues to be protected from decay until the very end. Resultingly, People with ALS suffer from the loss of their communication ability. That mental anguish continues until one's last breath.

Currently in Japan there are approximately 5,700 people with ALS, and 1530 – about thirty percent – of them use the ventilator. In the West, the number of death from suffocation as the respiratory muscles become paralyzed records an overwhelming majority of patients, and in England, less than one percent of the ALS patients undergo tracheostomy. In Netherlands and Belgium where euthanasia is legal, almost twenty percent of ALS patients choose to die through the doctor-assisted suicide.

Furthermore, in some countries, patients may choose to discontinue the use of such technologies. However, in Japan, it is not legally permitted to stop using a ventilator once used. As a discussion concerning “withholding” and “withdrawing” in medical care of those close to death is just beginning, researches on Living Will and advanced directives for ALS are also following suit.

Prof. Rihito Kimura has pointed out that cultural background can play a role in the difficulties of attaining informed consent or personal decision-making since Japanese bioethics follow the Japanese characteristic of ambiguity. Certainly Japanese ambiguity is worthy of special mention, but I will not offer an explanation of it today. Furthermore, medical care's Buddhist principles, while maintaining a position separate from organized religion, have been preserved in Japan. For this reason, while in other countries it may be thought that there can be no value to a long life, ALS patients in Japan have extended their lives through medical ventilators.

### ***The ALS Village on the World Wide Web***

Even if ALS patients can hardly move their limbs, they are still able to communicate with the world via the Internet. The latest developments in communication technology have made it possible to input their messages into a computer if one can move one's fingers or toes or eyebrows or lips – any body part – just one millimeter. Using the Internet can greatly improve their quality of life, even if they can only enter information at a speed of only five to ten words per minute. Given this, a village-like ALS network has emerged on the Web, where users spend the day gathering at their homepages, bulletin boards, and mailing lists. I have met many ALS people online and there are even some who talk vigorously on the Web, although they can't move their body at all

One day I received an email from female ALS patient around forty-year-old who lived more than one hour on the train, west of Tokyo near the ocean. It had been five years since her ALS first appeared and she had decided that even though breathing had become very difficult, she would not start tracheostomy and die instead. After several email exchanges, I came to realize that Shiori (a pseudonym) had no home doctor, no regular nurse visits, and her home caregiver had quit her job due to business circumstances, and Shiori was in an extremely lonely situation. However, she did have a husband and a daughter, both of them worked in the city, so that several days a week, she was completely alone in the afternoon. When she read my homepage she said she wanted to help me. In our emails we talked about the regional differences in medicine and health services, and how to get health workers to deal more seriously with support for incurable diseases. Shiori always gave such calm and composed advice and eventually she even directly inspired the local government health center to empower the municipal staff and specialists.

Of course we also spoke about many other things through internet. And I always wanted to see Shiori's condition myself, so I decided to visit her at her home.

### ***Chance meeting with Resignation***

On a clear autumn day a half year after we began to know each other on the web, I went to meet Shiori. Just as the directions she gave me by email, I took the train to the West and left the train station, walked a short while to find a cute house facing the sea. And just as she had said, the front door was open and I was greeted by a black and brown cat in the entrance way.

I could hear Shiori's voice from inside the house saying "uh—, uh—". Following the cat's lead, I saw Shiori's appearance from behind as she typed at her computer. Her illness seemed to have progressed much further than I had thought. She wasn't even able to turn around to see if I was there. I came closer to her and peered into the computer screen on her desk where she had typed "welcome". Then she printed out for me a picture of the sea taken from her window in the early morning. It was such a beautiful sunrise that, without thinking, tears welled up in me.

I took a seat in the chair beside her as Shiori used the mouse to enter words onto the screen. Entering each letter took time. When her paralyzed hand would fall from the mouse, I would help her place it back as we continued our conversation at a slow pace. Only an animal-like groan could come from her paralyzed lips and saliva would drip from her powerless mouth to be absorbed by the towel wrapped around her neck. However, she was able to type perfect words onto the computer screen, and she explained her care chart how she used it to give instructions to her caregiver. She said she had already, on her own accord, instructed all of her care to the management of the nursing insurance. She also showed me the recipes she had written out for her daughter. As we talked I became more convinced that if Shiori used a medical ventilator she would be able to live a sufficiently independent life.

In Japan, generally the choice of using an medical ventilator depends on the personal decision of the patient, and family members are recommended not to

force the patient into a decision. Therefore, while patients feel lonely, and along with the severe pain of both the social side of ALS as well as the disease itself, their mental deliberations continue a long time. However, it is necessary to emphasize the lack of help by neural specialists, some of them believe that using a ventilator does not increase the quality of patient's life and therefore there is no value to lives using a ventilator. Furthermore, such doctors are indifferent to the inadequacies of welfare that affect the patients' decisions.

For example, formally there is a system which protects the security of patients who take a long-term medical treatment at home with a reliable medical team, However Shiori had no home doctor and the local administration neglected its policies concerning medical care for incurable diseases.

In addition, her family had to care for her 24 hours a day, largely without breaks. When asked why, it was because requesting a nurse would cost 5,000 yen per hour. Given these unfavorable social circumstances, using a medical ventilator would significantly increase the burden of the family. The choice of using a medical ventilators is not simply the matter of an individual's preferences. The circumstantial conditions of society should also come into question.

According to an ALS patient Misao, if one wants to declare that ALS is simply a disease in which one becomes unable to move, it is possible. However she also says that continuous and precise nursing care is necessary over the long term rather than medical treatments. This is essentially a problem of politics and not something patients should bear alone.

As the ability to move declines, dramatic changes in daily life are unavoidable. Confronting the changes, the patient as well as the family becomes irrational. Given this, Prof. Frank calls his first approach to the patient and family as "chaos narratives". And also If ALS patients come to believe and accept their doctor's negative attitudes toward home medical ventilation without dealing with their own body, they come to face death .At this stage, We can find "the narrative surrender" as Prof.Frank named .

However, once autonomy is temporarily lost, there are some patients who begin to search for a life path through which they supplement their lost abilities. Shiori is such a person. When I met her she already had her own narrative and was prepared for the obstacles that ALS might throw to her. She talked about her everyday life using a “quest story”, which is presented to the public on her homepage. The day we met, she wrote in her Web diary as follows,

“It is difficult for one person to understand another. But if we give up to communicate simply because it is difficult to talk and to reach mutual understanding, we become blind to the essence of the matter. When a problem arises, if we search for the causes and try to solve it, a possible path will open up.”

In the end, Shiori and I were unable to reach a perfect mutual understanding of each other’s opinions. Shiori thoroughly believed that refusing a medical ventilator was alright. And I tried to frantically convey her daughter’s feelings as well as my own thoughts on the matter. Even for me, now that the communication with my mother has become severed, having a conversation with a philosophic patient is one of the ways to listen to my mother’s “silent voice”.

However, when Shiori showed me the reality of her own life, she also showed me one of the essentials of enduring such a difficult disease as ALS. Her determination was firm and her decision was certainly different from that of the energetically living ALS patients around me. For us, that afternoon we spent together cannot be repeated and will be difficult to forget.

### ***Simply Listening***

Humans are probably the only creatures who are able to search for a value in their relationships. For example, even in the world of the Internet where we can’t see each other’s face, Shiori is an irreplaceable person for us. That is to say, because one cannot see her figure through the PC screen, we would not be able to tell the difference if the percentage of her body occupied by a machine were to change from 10 percent to 90 percent. Therefore, as I want her to continue to live

and converse, I have a one-sided wish which is different from her own, which shows the meaning of her existence for me. And, as for the people who want to die, although I cannot easily agree with them, I can learn from them. For example, for seriously ill patients persevering with a cruel life, avoiding easy sympathy, pity, and hospitality are proper manners. I simply want to affirm each and every individual existence until the end, but if that is against someone's own decision, I will not attempt to force the person to change. I just hope that as I carry on a dialogue, the patient's narrative comes to change even by a little. I have something close to a prayer – by simply listening to the stories of patients who have re-questioned their ailing bodies, they can be encouraged to narrate freely. In other words, there is no need for psychological or specialist training – just as long as there is an audience, the patient will begin to talk.

Furthermore, while narrating in order to reclaim their denied bodies, they modify “narrative theory” a little. This is something that changes greatly before my eyes.

### *Afterwards*

When the year 2005 arrived, Shiori's emails suddenly stopped. Probably as ALS progressed, it became impossible to move the computer mouse. However, Shiori should still be in the same room overlooking the sea and one can sense her presence in the conversations on her homepage and bulletin board. However, I have never called her house to check if she is still with us. It is simply that confirmation of life or death is frightening. I pray that there will be a change in her narrative from the decision “I don't want to be a burden on my family” to “I want to use a home medical ventilator and live together with my family”. If she decides to continue to live, I'm sure I will still receive emails.

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## References

- Frank, A. W. (1995). *The wounded storyteller: Body, illness, and ethics*. Chicago: University of Chicago Press  
(2002 鈴木智之(訳)『傷ついた物語の語り手』 ゆみる出版)
- Murphy, R. F. (1987). *The Body Silent*. New York: H. Holt.  
(辻信一(訳) (1997).『ボディ・サイレントー病いと障害の人類学』 新宿書房)
- Kleinman, A. (1988). *The illness narratives: Suffering, Medicine, and psychiatry*. Berkley / Los Angeles / London: University of California Press. (江口重幸・五木田紳・上野豪志(訳) (1996).『病いの語りー慢性の病いをめぐる臨床人類学』 誠信書房)
- Kimura, R. (1996). Advance Care Planning and the ALS Patients: A Cross-Cultural Perspective on Advance Directives. *Jahrbuch für Recht und Ethik [Annual Review of Law and Ethics]*, Band 4, Berlin: Duncker & Humblot. Pp. 529-552.
- Albert, S.M., Murphy, P.L., DelBene, M.L. & Rpwland, L. P. (1999). A prospective study of preferences and actual treatment choices in ALS. *Neurology*, 53, 278-283
- 川口有美子 (2005). WWWのALS村で『現代のエスプリ』, 458(特集 クリニカル・ガバナンス 共に治療に取り組む人間関係) 至文堂 Pp. 34-42.
- 川口有美子 (2004). 人工呼吸器の人間的な利用 『現代思想』, 32-14(特集 生存の争い) 青土社 Pp. 57-77.