

## Living beyond it

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Note:

In 2004 I wrote a book called “ALS: Immovable Body and Breathing Machine.” The excerpts translated here are from Chapter 9 (pp.260-290), and the book as a whole includes twelve chapters (451 pages). I wrote about how people with advanced ALS live, and in particular how they communicate. Since then there have been several technological advances, and I am considering publishing a second edition in which I would address these developments. But the circumstances of these people have not changed very much. The accounts written in 2004 can still be thought of as capturing the state of affairs today.

One reason I had these excerpts translated was the holding of an international workshop called “Challenges of Illness Narratives” (<http://www.r-gscefs.jp/?p=8177>) by this center. At this workshop, Professor Fernando Vidal (ICREA-Catalan Institution for Research and Advanced Studies / Autonomous University of Barcelona) gave a lecture entitled “Phenomenology and Narratives of the Locked-in Syndrome.” The situation in Japan is not well known to him and others with similar research interests outside of the country. After the workshop I therefore had these excerpts translated to contribute to a better understanding of the state of affairs in Japan in the English-speaking world.

People with ALS become unable to move their bodies, but they can receive messages and in most cases are able to transmit their own messages by using several methods. And since they are able to have others slowly take down their words for them without moving their bodies, while I don’t know how it is in other countries, here in Japan there are quite a few such patients who write books and maintain blogs. I put together my book using their writings.

These people are described as having “Locked-in Syndrome” or being in a “Locked-in State.” While in the sense that they cannot move their limbs it is indeed possible to describe them as being “locked inside” their bodies, they are still able to send and receive messages. In this sense, therefore, the external world remains open to them. Some such patients do ultimately lose the ability to move even the tips of their fingers and toes and their eyelids and cheek muscles, and therefore become unable to transmit their own messages. This is referred to as a “Totally Locked-in State” (TLS). This has become a focal point in discussions of euthanasia and cessation of mechanical

ventilation, and these are also issues I consider in my book. Even in such a state, however, a person/body receives input from the world. In this sense it cannot be said that they are completely locked in, and I think this is sometimes overlooked. I believe this oversight is connected to the fact that our current society and era overemphasizes active engagement with the world, production, and speaking. An examination of this society/era is presented in my 1997 book *On Private Property*. This entire text has been translated by the same translator as this article and is available as an e-book.

Looking around the world, one gets the sense that those who have severe disabilities and have had a lot of contact with medical professionals, such as people with ALS, are still to a large extent governed by medical ideas and systems. As for private organizations, in most countries efforts to raise money to discover the causes of illnesses and develop treatments (neither of which aims, unfortunately, have been achieved in the case of ALS) make up the better part of their activities, and based on the assumption that when it comes to the state of the physical body there is nothing to be done but accept it at face value, little progress is made in the direction of how these people are to subsist and live their lives. This was also the sense I got from participating, along with Hidesaki Masuda, an ALS patient who is a visiting collaborating researcher at our center, in the 28<sup>th</sup> International Symposium on ALS/MND that was held in Boston in December of 2017. But the small number of people with ALS in attendance (the overwhelming majority of participants were medical researchers and professionals; the most influential sponsors seem to have been pharmaceutical companies) spoke about the need to create systems to facilitate living their daily lives with their bodies as they are. (We took advantage of this opportunity to conduct interviews with people from Iceland, Norway, the Netherlands, and several other countries). The movement undertaken by people in Japan has this orientation, along with the gradually assembled systems it has shaped, and in this regard the past experiences and current movement in Japan can be seen as having something to contribute. The section of my book *ALS* from Chapter 10 onward that addresses these instructive aspects of what has occurred in Japan has not been translated into English, but going forward I hope to find some way of presenting it to a foreign audience. The other article I have included in this journal also contains several points that are relevant in this regard.

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"Living beyond it"

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### 1. Danger

In the last two chapters we read the writings of Takehisa Kawaguchi, who passed away in 1994. One of the things I am thinking about while writing this book is what is to be said about the decision to die. Kawaguchi wanted to live. While saying so quite clearly, however, he also said he wanted a "natural death," and in the end realized the latter desire and passed away.

But while Kawaguchi was a patient whose disease progressed slowly, and who had therefore spent a long time living with ALS, he chose not to go on a ventilator and died of respiratory failure well before the final state produced by this illness. So while Kawaguchi was himself a person with ALS, this person as he might have been after the point at which his life ended existed only in his imagination. (There are at least three forms of experience: first, what one experiences directly; second, what one imagines may happen to oneself; third, what one simply imagines. The difference between each of them is not small. Even if you are the person in question, the first form of experience is not the same as the second).

There are people who stayed alive until this final state and people who are living in it now.

Kawaguchi died just before this state, but how have these others gone on living after the point at which he died? What were the difficulties they faced, some of which had been imagined by Kawaguchi, like in reality? And how did they live through them?

Are there cases in which being ill makes someone give up on staying alive? Yes, in reality there are. Out of what sorts of elements, then, are these experiences of illness and the decisions surrounding them composed? ALS is always described as being in the worst category of diseases. There are other diseases, such as some forms of cancer, that come with intense physical pain, but we have become able to manage physical pain itself to a considerable extent. That being the case, if we are to consider illness that may cause someone to choose to die or to not go on living, we should perhaps consider ALS, which has been described as the "nanbyo\* of nanbyo" ([2] [27] [183]), "the disease anyone would think of as the 'nanbyo of nanbyo?'" (Tsubaki [1987:1] ) and "more feared than cancer in Europe and America" (Kawaguchi [1983:46]. Also quoted in [295].

\*Nanbyo, literally "difficult disease," is a term used in the Japanese healthcare system to refer to designated diseases that are relatively rare, incurable, and cause significant difficulties in daily life).

In the previous chapter, I talked about several things that make it difficult to live. I began by briefly touching on appearance, and said that while you may never be completely at ease you eventually get used to how you look. More serious problems I covered were not being able to do things, thinking that you are causing problems for others because of this incapacity, feeling that you had lost value, and finding it difficult to stay alive because you are unable to obtain assistance. And there may be other factors as well.

With this disease, gradually (or sometimes suddenly) the entire body becomes immobile, while consciousness and perception remain. What sort of state is this? We tend to straightforwardly suppose that being unable to move would be horrendously boring, and presumably quite uncomfortable. Locked inside our bodies, there would be the discomfort of not being able to relieve our own discomfort, and surely this would be unbearable. We would also be conscious of being close to death, and the progression of the disease would remind us of the death awaiting us at its end. Thinking of being unable to get away from such thoughts is also frightening.

Like it is for me as I write this, for the people with this disease themselves, too, at first this anxiety is foreseen as a state they have not yet experienced. Of course, this prediction is one the people in question expect to become a reality, and this is completely different from simply imagining a hypothetical state, but nevertheless what they have to begin with is fear and anxiety about a future state. But they then begin to live through this in practice, and what emerges as their condition progresses is concrete discomfort, fear, and danger. I have already introduced, albeit briefly, the mental and physical states that arise as a result of respiratory distress, and the physical pain and discomfort related to poor treatment from doctors, nurses, and caregivers. How to alleviate this suffering is a major concern of those involved, but even if I were to list many methods of doing so here it would be impossible to compete with the amount of such information available from related websites and mailing lists. Rather than give a half-baked summary, I will leave the presentation of this information entirely to these sources★01. Here there are only two points I would make.

★01 - Various kinds of information are exchanged on mailing lists. Concrete information can also be found in Matsumoto [2003], published with financial support from the NHK Public Welfare Organization, and Ventilator User Network ed. [2004b]. As texts written for care providers, see Shigeru Matsumoto's *Kabegami* [Wallpaper] (Matsumoto [1995c]. Revised and expanded edition Matsumoto [2003]), and Sasaki Koichi's *Keigotsoshin* [Nursing care dispatches] (Sasaki [2000-b]). For an account of a patient living at home in dangerously bad circumstances and how this situation was remedied, see Kumagai and Kumagai [2000].

First, in many cases, although a better caregiving response exists it is not carried out because it is not known, or is not carried out in spite of being known. These can perhaps be described as small points or details, but they are matters of pivotal importance.

**[395]** Hiroshi Nagaoka [326]. "It is truly unfortunate that there are still doctors who do not demonstrate an understanding of ALS. / 'The family life of the family of an ALS patient will be destroyed' 'The patient opposes going on a ventilator, so I won't put him on one' 'You have three to five years to live after being diagnosed with this disease' 'Adjust your breathing to the motion of the mechanical ventilator' 'Even if there is nothing wrong with your organs, we cannot give you "blender food" at this hospital' 'Bedridden patients are at risk of choking on phlegm and suffocating, so you must always sleep on your side' 'A narrow feeding tube is easier to insert, and we put it in with tweezers after a liberal application of xylocaine [lidocaine] gel' 'They can't respond even if we talk to them, so unilateral, silent care is fine for tracheostomy patients' 'The reason the feeding tube won't go in is because the patient is clumsy and can't gulp properly, not because of my own lack of understanding' / I think most people [doctors] have moved beyond these sorts of beliefs, but there may still be some to whom they apply. I say this because the current state of affairs is one in which the head of a certain famous hospital doesn't even try to obtain yes/no communication with ALS patients who have lost their voice." (Nagaoka 1991:11)

Problems arise between patient and machine. If the ventilator is set up badly, its motion does not fit that of the patient's body and the patient suffers. Moreover, if the ventilator stops sending air, and if the method for the patient to communicate this to others doesn't work, the patient's life is immediately in danger. Many people have experienced this for themselves and written about it.

**[396]** "In the middle of the night it became difficult to breathe and I woke up. ... / I kicked the bell, and tried to wake up my wife. But my wife, who normally gets up right away, didn't wake up no matter how many times I rang the bell ... / My heart started pounding, and my body went cold with fright. [...] / Maybe out of a fear of death, my body started shaking. [...] / How much time had passed? My wife still hadn't noticed. I tried to kick my right leg and ring the bell, but maybe because my strength had gone my leg didn't move. The moment I realized my only means of communication had been taken away the fear of 'death' came over me, my heart started pounding so hard I thought it would burst, and my body's shaking became even worse. I was overcome by an intense feeling of isolation. / Before I knew it a thin light had entered the room. / 'Thump, thump,' I heard the sound of someone coming down the stairs. My daughter, a fourth-grader, had woken up. I kicked the bell, and got her to save me." (Nagaoka [1987:76-77]) This was written in 1987 by [241], a patient living at home who in 2001 had been receiving home care for seventeen years. We might think he would be

safe if he were in the hospital, but that isn't in fact the case. Just because a patient is in the hospital doesn't mean a member of its staff is with them; in fact it is often family members who are by their side.

**[397]** Kikuko Doi [278]. Oita Kyowa Hospital. "The last day of 1995 [...] late that night at just before one in the morning, the connection to my ventilator came out, and although the alarm continued to sound, my husband who was lying beside me had fallen into a deep sleep and didn't wake up. / There was more than an hour until rounds, so I thought I was done for, and in my dwindling consciousness I gave thanks to people I remembered, but after some unknown amount of time had passed I opened my eyes slightly and saw a nurse looking in on me, saying, "It's all right, Mrs. Doi," and as my consciousness gradually returned I realized that the doctor and nurse on duty were there and I had been saved [...]" (Doi and Doi [1998:57]. After this incident, a remote alarm connected to the nurses' station was installed.) There are also cases in which a family member notices what is happening and manages to do something about it.

**[398]** Kazuko Sugawara [280]. Iwate Prefectural Central Hospital. "The connector between the tube and the ventilator was loose. The pressure put out by the ventilator knocked it out of place. When it is not correctly positioned air is not sent into my lungs. I was surprised, and tried to communicate that it was out of place, but since air was not passing through my throat I couldn't speak. [...] Eventually my mother came back and hurriedly reattached the ventilator. The incident only lasted a few minutes, but to me it felt like a very long time. / This kind of thing happened two or three times. [...] / There was also an accident in which the ventilator became unplugged." (菅原 [1987:92-93]). If there is someone nearby but they have fallen asleep, as long as the patient can still move their body, even if only slightly, it should be possible to set things up so that they can call for assistance using whatever part of their body they can still move. But there are cases in which this doesn't work very well.

**[399]** Shigeharu Chimoto [270]. Kagoshima University Hospital. "As someone who is bedridden and unable to speak, the nurse call button is my only means of contacting the nurses, and if it stops working this can be fatal for me; if I call the nurses and the button doesn't work, there is no way for me to tell them that it is broken. In the past there have been many times when it stopped working, and the reasons for this have included problems with the electrical wiring, the thread tied to my foot not being connected to the nurse call button, and the thread coming loose from the end of my foot. For this reason I have unpleasant memories of being on the nebulizer\*, miserable memories of urinating without wanting to, memories of feeling pain in my back and shoulder from lying in the same position for too long, and of times phlegm got stuck [in my throat] and I thought would stop

breathing. There is a sense in which my life in the hospital is a thrilling adventure, and in the midst of it the nurse call [button] truly is my 'lifeline'" (Chimoto [1993:297]. \*A nebulizer is a device used to administer medicine or moisture in the form of a mist that is directed into the nose and mouth and pumped into the airway mucosa, pulmonary alveoli, or paranasal sinus.) There are also cases in which this kind of nurse call button becomes unusable but not because of an accident.

【400】 "One patient was no longer allowed to have a nurse call button. He wasn't allowed to have it even though he was clearly conscious and had the ability to push it. I think it was because if he had one he would call more often. When he was told that another hospital had been found for him to be transferred to he was so happy he cried." (Tamai [2004:109], from an interview with a nanbyo healthcare professional.) Misao Hashimoto is one of the many ALS patients receiving care at home from people who are not family members, but she has also been hospitalized several times and has knowledge of both situations.

【401】 "This might be particular to me, someone who likes to get her own way, but life in the hospital on the ventilator is more a fight against stress than a fight against disease. / When the ventilator comes loose, for example, this is fine for someone who can press the nurse call button, but for those who can't every day is a gamble. If you are unlucky you'll die alone. / I've kicked away the nurse call button in the middle of the night. For a normal person it wouldn't be a big deal, but for me, someone who can't even move a finger, just the fear of not being able to push the call button has kept me awake and left me counting my breaths to pass the time." (Matsumoto [1997f]).

【402】 "Being in the hospital after going on a ventilator is no guarantee of safety for us. Ventilators come loose easily (if they didn't it would cause problems when administering suction). In my case, for example, if the ventilator comes out my face turns red and my heart begins to pound before even two minutes have passed. It may not be an exaggeration to say I could be dead within three minutes. This year, in the same [city] Ward, two patients who were preparing to leave the hospital lost their lives." (Matsumoto [1997b])

When people are not nearby the reliability of the patient's means of communication is critical, but there are limits to what can be done. Even if someone knows the patient is in distress, if they are too far away they may not arrive in time. And if there are no parts of their body the patient can move, there is no way to send a message. If we are trying to reduce the number of deaths, the trend toward a smaller number of people looking after a larger number of people in order to cut costs is not a good approach. It should be obvious, but what is needed is to secure the connection to the ventilator, and if there is a means of communication make sure it is operating properly and there is someone who

can immediately respond. (For a very simple introduction to safety systems for people on ventilators in Canada and Denmark, see Matsui [2002:149-150]).

Particularly in cases in which these [measures] are difficult, or in which they are not reliable, it is necessary to have someone nearby (who does not go to sleep). It is in fact possible for patients to live at home using a system in which nurses stay awake beside them in shifts, and there are patients such as Ayako Takai (Tokyo) [436] who do so. Most patients do not take this approach, however, because they are not aware that it is possible.

**[403]** Kei Tamagawa [292] entered a hospital in Tokyo after having a tracheostomy and going on a ventilator in 1973. His wife, Yoshiko, was always by his side, but one day in May of 1981 she returned from a brief excursion of about two and a half hours to find that his breathing tube had come out. He passed away two days later. Ultimately the hospital did not acknowledge any fault on the part of his nurses. The doctor's account of what happened that day is recorded as follows. "At this year's meeting of the Japanese Society of Neurology, a doctor from T University presented three cases of patients like Mr. Tamagawa (ALS patients on ventilators following a tracheostomy), and two of them had died in similar accidents. The accidental death of a patient on a ventilator seems to be something like fate." (Tamagawa [1983:124]. The emphasis is Tamagawa's).

**[404]** Origasa Yoshiaki [242] discusses this while referring to Tamagawa's book. "It is also written in this book that with this disease there are many accidents in which a patient dies of suffocation when the ventilator tube comes out, and Mr. Tamagawa himself died this way when the nurses didn't notice that his tube had come out. It was a terribly sad death. / In reality, the risk of the tube coming out is part of everyday life, and there have been more than a few cases in which a caregiver has forgotten to secure the tube after having removed it in order to perform phlegm suction. It comes out easily, so in such cases I try to use my eyes and mouth to tell them, "Make sure it is securely inserted," but the day is coming when I won't be able to move my eyes or mouth anymore and will have no way to warn them when I think it is 'about to fall out.' At that point, of course, even if it comes out I may well have lost the ability to let them know by blowing on the nurse call [switch] as I have until now..." (Origasa [1989:216-217])

It is not clear exactly how many people have died like this, but every so often such incidents come to light and are reported. For example, in April of 2000 it was reported that two such accidents leading to deaths had occurred at the Okinawa National Hospital, and this was addressed in an editorial in the Ryukyu Shimpo [an Okinawan newspaper] (April 30th). As far as I can tell from reading a book written by a patient who lived at this hospital (Higa [2001]), it does not seem to have any particular deficiencies when compared to other institutions. There are several other cases in which what family



members have written about a patient's death or sudden change in condition suggests that such an accident had occurred.

Shin Yamamoto [278] points out that among long-term ventilator users, "There is a probability of more than 1% of people dying as the result of an accident every year," and wants the government to issue guidance for locks to be added to breathing tubes - when ventilators are used in intensive care units there is constant supervision, so if they fall out it will be noticed immediately and no lock is needed because it is better for it to be easy to perform phlegm suction, but this approach has also been used in regular hospital wards and homes (Yamamoto [2003]).

There are cases in which a hospital has accepted responsibility for a fatal accident and promised bereaved family members that it would take measures to stop the same thing from happening in the future (Horiuchi [2004]). These family members, however, were told by the local office of the ALS Association that they shouldn't unilaterally blame the hospital because it would stop accepting [ALS patients], and they subsequently cut their ties to this organization and collected information and negotiated on their own. When there is a structure in which party A needs party B but party B does not need party A, party A must consider party B's interests and has difficulty saying what needs to be said. It becomes difficult for people with ALS to say what needs to be said to doctors and hospitals. We also see this in other situations (Chapter 10 Section 4).

## 2. Affirmation of machines

"Ventilators whose tubes come out leaving patients unable to breathe" - the problem is these badly designed machines, the people who make them or continue to allow their use, and the people who do not try to reduce this risk. What is clear is that what is happening here does not arise out of an abstract framework of "machines" versus "nature" or "mechanical prolongation of life" versus "a natural death." Machines are not a problem because they are machines; there are badly made machines that cannot be relied on, so better machines should be built.

At the same time, neither is there any need to abstractly venerate union with machines like those who talk about new relationships between machines and human beings. To begin with, the relationship between the body and machines or artificial objects is completely concrete, and the problems that occur in relation to it are concrete inconveniences or discomforts that arise at the place where the body is connected to what is not the body. There are problems with the interface between the body and what is not the body, problems of pain, and in practice the connection between human beings and machines often does not go smoothly. Being a cyborg isn't easy. Discomfort that comes with the management of the body for the sake of treatment or what is called treatment is still

discomfort. Regarding "fertility treatment," for example, these issues have been addressed by feminism.

This is not something that is often addressed within the fields of bioethics or medical ethics, perhaps because its "ethical" dimension is seen as not being particularly deep. But this dismissal or taking lightly of simple pain or suffering is itself a problem. When someone must hand over something that is important to them for their own sake we should be sensitive to this payment being underestimated, and we can and should address how what may be obtained is weighed against what is likely to be given up as an important issue. When it is for oneself there may not be much choice, but particularly when it is (also) for someone else's benefit, there are cases (such as giving birth to a child) in which one's own time is spent, one's own space is reduced, and one must endure pain or physical discomfort. The debate over whether to accept or reject in vitro fertilization (and embryonic transplantation) is seen as having ended a long time ago. But the pain and burdens it imposes have not ended, and this technology is still not something that should be endorsed (I discuss this in Tateiwa [1997b:156-158] and repeat these assertions in Tateiwa [2004e]).

In other words, there is something the person in question gives up in order to get something else. Of course, whenever we get something we pay something in exchange, and this can be said to be unavoidable, but the problem is what is being exchanged for what, and whether what is being given up really has to be given up or not. If we don't need it we shouldn't use it, and if we have to use it the fewer inconveniences and discomforts the better.

People with ALS are urgently demanding a cure. This is completely natural, but in the case of other disabilities doubts have been expressed about curing them or their being cured. This is because too much is being given up for the sake of being cured (even when a cure is not necessarily forthcoming). In most cases, if a cure can be accomplished smoothly it should presumably be pursued. But if a great deal must be given up in exchange for a cure, then it is better to compensate for the disability using machines or human assistance. Here there is no a priori ranking of which is better, a cure or augmentation. I discuss this in Chapter 2 Section 4. If the only available method is augmentation, or if augmentation is preferable, then this augmentation should be implemented well. In the case of ALS, the suffering when a machine isn't well suited to the task at hand is great. It would be better if this suffering didn't occur, and if it has to occur it should be reduced as much as possible.

Having laid out these things that are obvious and more than obvious, it is unnecessary and indeed unhelpful to speak about the relationship between machines and the body in simply abstract, negative terms such as "merely a state of being connected to a machine" or "spaghetti syndrome." It

is obviously true that unnecessary tubes are unnecessary, and what is needed is needed. We don't have to assert that the body should be preserved exactly as it is given to us. And we should not embark on the unnatural return to nature of giving up on our own survival. We should not reject technology in and of itself, although we may reject it because of the pain it causes. Just as there are creatures who extend their tentacles to obtain nutrients, there are machines that extend natural processes. We can say to someone who loves nature that this too is a part of its workings. And to someone who loves evolution we can say that this is an example of this process in action.

In this sense machines and technology are to be affirmed. At the start of this book I advocated "cyborg feminism" and cited a passage by Donna Haraway. She also writes as follows.

**[405]** "Why should our bodies end at the skin, or include at best other beings encapsulated by skin?" (Haraway [1991: 178])

"The machine is not an it to be animated, worshipped, and dominated. The machine is us, our processes, an aspect of our embodiment" (Haraway[1991:180]).

### 3.Idleness

Moving on to the next issue, won't a person be bored if they cannot move their body at all? Won't this be painful? There are in fact people who are not bored, however, and responded as follows.

**[406]** Shigeeko Hata [200] became ill in 1988 and currently lives at home. "My child asked me if I was bored, since living with the disease means repeating the same routine every day, and I don't do anything myself. If I think of ALS as my enemy it seems very strong and I have no inclination to fight it, but since I have the anxiety of not knowing what this enemy will do in the future, my tension never subsides and I've become incapable of being bored" (Hata [2000]). These are the words of a very serious person, but there are also those who put things differently.

**[407]** Kenichi Miyashita [202]. "Four months have passed since I became bedridden and unable to move anything. This was because of my illness (ALS), so it couldn't be helped. While it is true that I want to get up and walk around, strangely enough I haven't gotten sick of lying down. / I don't know whether it's because I've always liked lying around when I have free time and enjoy sleeping when I'm tired, or because I have a natural tendency toward laziness, but in any case I don't find lying down all that unpleasant. I think if I found this lying down inescapably painful then by now I would be a ball of stress, taking it out on others indiscriminately and getting into hysterical fights just like Dr. Habu says. / On the contrary, I'd like to think of myself as someone who wants to enjoy this time I am spending lying down. I don't know what will happen, but if I'm going to live through the day either way, I'd rather hold on to some kind of hope and enjoy my life" (Miyashita [1996: 197-198]). There are also some, like the people who appear in the writings of Yaeko Shimazaki (Shimazaki

[1997-]) or are described by Misao Hashimoto [416], who stay very busy with things like overseeing housework. It depends on their circumstances and condition, but there are things they want and need to do, and they manage to do them. Hashimoto wrote [416], but I had read other writings on her website before, and the following passage stayed with me.

**[408]** "People on ventilators have clear awareness, and their state of being unable to move is one that healthy people for the most part cannot imagine. / A never ending rollercoaster, an eternally persistent sleep paralysis (nothing so enjoyable) - my vocabulary is too poor to describe it well. / The hardest thing for me in the eight months of living in the hospital after having a tracheostomy and going on a ventilator has been the fear I feel when I am alone" (Hashimoto [1997f]). There are other passages from Hashimoto's writings that can be highlighted here. In addition to the similar, "Your motor neurons have been attacked so you cannot move, and of course your voice doesn't come out. To give an analogy, it is like sleep paralysis" (Hashimoto [1997a]), she also writes as follows.

**[409]** "Unlike other illnesses, this life in the hospital can be described as a battle against loneliness and the fear of death. I have time, but I cannot read a book, write a letter, or do anything active at all. It's a fight against unlimited stress. I think there are few people who experience the fear of death on this kind of daily basis" (Hashimoto [1997b])

Reading over these passages again, however, it is apparent that [408] is a continuation of [401], in which she writes about the danger of the ventilator coming loose, and after [409] comes [402], in which she is also talking about this danger. In other words, these passages have been written based on her feelings when she was placed in specific circumstances in the hospital. Unable to communicate the flaws in the machine described above, the problem she is addressing is the concrete crisis of having her life put in jeopardy; she is not talking about having ALS in general. This is something I have only realized now, and was not aware of when I first read [408].

Nevertheless, accounts that are on the whole quite grim feature prominently in these writings by Hashimoto in her fourth year of being on a ventilator. For the most part they do not appear in her later writings. This change is not unique to Hashimoto; regarding ALS, and living on a ventilator, when you read accounts given by the people in question themselves, gradually the sense of gravity, tragedy, and pathos fades - although the difference between individuals is great, and there are some who write optimistically from the start. In the previous chapter I quoted from Hanada, Yokogawa, and Sato.

In the summer of 2002 I spoke to Hashimoto, but I had sent her an email the day before with the questions I wanted to ask.

**[410]** "About your experience of the disease called 'ALS.' / It's a blunt question, but what is it like to live or go on living in a state in which your body doesn't move (or moves less and less over time)? .../ I've had a chance to read several of your accounts, such as, 'People on ventilators have clear awareness, and their state of being unable to move is one that healthy people for the most part cannot imagine. / A never ending rollercoaster, an eternally persistent sleep paralysis (nothing so enjoyable) - my vocabulary is too poor to describe it well.' {But while I haven't been able to follow [your writings] thoroughly, I have the sense that the tone in which you write about living with ALS has changed over the years.}"

When I met Hashimoto the next day she had prepared a written answer that responded to the part in {}.

Hashimoto: "It's as you say. The passage you quoted was my candid reaction immediately after going on the ventilator. For example, even if the ventilator came out, in the hospital the nurses wouldn't come right away. Autonomous breathing was still operating, so I estimated the passage of time by the number of movements of the mechanical ventilator. It was quite thrilling. I was never into sports and always preferred not moving, so today I don't feel much stress at being immobile." She is saying that [408] describes how she felt when she was in a situation in which her life was being put in danger as noted in the previous section. How Hashimoto felt about living with ALS changed when her life at home with caregivers got on track and she was freed from this state of crisis. At this point, being unable to move is not difficult for Hashimoto to endure. Her response to my main question was as follows.

**[411]** "I've had moments of frustration, but I've also had many interesting experiences that were only possible because I have a progressive muscle disease. Maybe you can only say [you've experienced] ALS once you've lived long enough to reach the total locked-in stage." (Reply from Hashimoto, August, 2002). I discuss being "total (totally) locked-in" in Chapter 12. Even if she hadn't reached that point, she had lost the ability to do things directly by moving her body. In her response she notes that in place of this ability she had lost there were other things she had become able to do instead.

**[412]** Shigero Matsumoto [263]. "'When you have ALS you stop being able to move anything, and all of your nerves focus on your head, so your thinking should become clear and sharp.' / It? said [this]. I had been bemoaning the fact that my mind had grown dull, but I decided to believe It's words and assume that my dullness was innate and not the result of my illness. That was somehow easier to take. It? also said / 'Zen [meditation] artificially creates [a state like that of] ALS and focuses your mind. The more I look into it, the more I think Daruma [Bodhidharma] had ALS. And I

suspect the astrophysicist Stephen Hawking was only able to do such outstanding research thanks to having ALS. .../ As you'd expect from a scholar of Indian philosophy, It's arguments were persuasive. I was happy to put myself in the company of Daruma and Hawking. It's strange, but somehow it gave me courage." (Matsumoto [1995b: 181]. The "It?" he refers to is Michiya Ito, author of Ito[2002]. For other writings related to ALS, see Koinuma and Ito [1997], [1999], Ito [1996], [2004]).

**[413]** In the summer of 2002 I had another interaction reconfirming the answers received from Misao Hashimoto quoted in [410] and [411]. "Tateiwa: 'It's something a schoolchild might ask, but is not being able to move your body boring?' / Hashimoto: 'Being able to think is enough.' / Tateiwa: [...] 'I've thought about this a bit [...] I think the work I am doing now mostly just needs a head [brain], so maybe I could keep doing it.' Hashimoto: 'You could. [laughs]'" This is one answer, that you can do something else instead of moving your body, but another answer, that if you aren't bored it is actually good because there are things you can avoid doing, is also possible, and is in fact sometimes given. Not being able to do something also means being able to avoid doing it, and if someone else will do it for you - while it may cause problems for this other person who now has more things they have to do - this could in fact be a good thing for the person in question.

**[414]** Shigeru Matsumoto [412]. "I've become a 'lord' since I started suffering from ALS. [...] I'm grateful it doesn't attack my mind. Recently I've started to be glad my disease is ALS. My wife used to leave everything up to me, but thanks to my illness now she has no choice but to do everything herself. She complains, 'I'm like a widow,' 'I guess this is how a woman becomes strong,' 'Thanks to you I've fallen from heaven down into hell'" (Matsumoto [1995b: 256-257]). But there are sure to also be things you want to do yourself, things it would be pointless to have someone else do for you. It is better if you can replace the things you can only do yourself with things you can delegate to someone else. Having acknowledged this, when we think about it in a straightforward way, delegating something to someone else, as long as they agree to do it, is a good thing, like the prerogatives enjoyed by feudal "lords" in the past. (I discuss this in a bit more detail in Tateiwa [2002d].)

Of course, to never do anything but think would not be fun for most people. There are things happening around you, and it is better to be able to perceive them. Not being able to communicate your thoughts to others is painful, and a lack of communication will also cause problems in telling people what you would like them to do for you, so it is better to be able to transmit and receive messages. Even assuming it wouldn't put your life in danger, it would still be agonizing to be cut off

from other people and the world, be rendered idle, have the communication you can receive limited, and have transmitting your own messages become an arduous process.

#### 4. Being cut off

【415】 Tsuneo Taki (Tokyo). "There isn't even a curtain between beds, and patients' privacy is not protected at all. The suction machine/nebulizer is a simple device that performs both functions. The catheter had a mouth tube and an esophageal tube, and while this isn't actually hygienic I used it until I left the hospital. / This year it was unusually hot, and with the air conditioning not being very effective there were many days when my condition was poor. Not being able to make a sound or move my body even if the cockroaches in the room climbed all over me was very painful. / There was no special bath, and the hot water for a sponge bath or to rehydrate me after being cooled incurred a ¥30 gas charge each time. My electricity bill was ¥9,000 per month, my housekeeping fee was ¥36,000, my bedding changing fee was ¥15,000, my bed mat usage fee was ¥6,000, and there were quite a lot of other costs that were difficult to understand. / There was no one in the hospital who knew how to have a conversation with a letter board, and they did not try to find a way to understand me. Not being able to communicate caused stress to build up inside me. / I waited impatiently for my wife's daily visits. As soon as I saw her face I would start rattling off all kinds of things I wanted to say using the letter board. My wife would change into some modified pajamas that made giving me a sponge bath and taking care of me easier. / Knowing the lack of understanding of ALS and my inability to help myself, I begged my doctor for euthanasia" (Taki [1991:31]).

Let us assume that today there aren't many hospitals swarming with cockroaches. But hospitals are also places where there is nothing and nothing happens.

【416】 Misao Hashimoto visited Susumu Sugiyama [253] in 1997. "I've been hospitalized several times over the past ten years. I've stayed in the hospital for various lengths of time, from just four days and three nights up to eight months, but I always felt surrounded by a hustle and bustle full of sound and color during my time there, so I was shocked by your white room. I'd lived in the countryside for three years myself, and since I know how poor the rural welfare services are first hand I don't recommend living at home lightly. / Thank you, Mr. Sugiyama. If I hadn't met you I would have gone on being a carefree person who didn't know what was really happening. This visit was truly a shock. I can talk to my daughter or husband as much as I like. Of course my voice doesn't come out, so I have them read my lips or the blinking of my eyelids. While this might be inconvenient in an argument, through my caregivers I can always say what I want to say, so our daily life is like a battlefield, and my family and I have no time to think about the disease. Just like a

'mother computer' you'd see in science fiction comic book, from my bed I manage the home tutors, arrange my care schedule, and even check the contents of the refrigerator - all of this is my job. I'm sure that other patients would also have a lot of work to do and family members waiting for them if they went home, but instead they spend their time in a hospital room staring at the walls or the ceiling. This is a loss in all sorts of ways" (Hashimoto [1997b]).

Sugiyama entered a hospital in Shizuoka Prefecture in 1989 and passed away in 2000, but at least as far as can be gleaned from his writings (Sugiyama [1998]) he was not completely cut off from the outside world. He received letters from many people, sent many letters of his own, and was also actively engaged with local government and the media. Compared to other hospitalized patients such as Takehisa Kawaguchi whom I introduce in Chapters 7 and 8, he was not in an environment closed off from other people. Even so, Hashimoto was shocked to see Sugiyama in a white room. And if his posture was fixed in the hospital room, he would just be looking at the ceiling. This is often mentioned, including in [416] above, because it is indeed a reality patients face and is indeed unpleasant. This can never be enjoyable.

**[417]** Yasuaki Shikano is a person with muscular dystrophy born in 1959, and he spent his childhood between the ages of twelve and fifteen in Yakumo National Hospital. This is a hospital where children with muscular dystrophy were concentrated. He spent his time there sensing many deaths that were never talked about. After various things occurred, he was later moved to the Kinikyo Sapporo Nishiku Hospital and put on a ventilator in 1995. "Will I die counting the holes in the ceiling like this?" [...] The ceiling of the hospital room was one of those white ceilings with lots of tiny holes in it you often see. It was exactly the same as the Yakumo National Hospital where I spent my youth. / 'If I'm here, I'm going to die'" (Kazufumi Watanabe [2003:252]. Discussed in Tateiwa [2005]).

##### 5. Receiving transmissions from the world

**[418]** "No matter what sort of master you are, no one can tame 'illness' inside a hospital room surrounded by bare walls and a ceiling." (Hara [1994:199]. First published in 1991). Hiromichi Hara was born in Niigata City in 1962. In 1980 he was rushed to Niigata City Hospital and put on a ventilator as a result of his glycogen storage disease (a progressive disease in which glycogen builds up in the muscles of the limbs and heart). Hara participated in the founding of the Japan ALS Association Niigata Branch in 1987 and supported its activities. He passed away in 1993. There are people who are placed in a situation in which the only thing they can see is the ceiling. And there are doctors who say that if you go on a ventilator you will spend your days (only) staring up at the ceiling, so you should think carefully before deciding whether or not to do so, and this sort of thing



is also written in association guidelines [499]. Among those who speak more frankly, there are some who say nothing good will come of going on a ventilator (you will only be able to obtain a "low quality of life"), so it would be better not to do so (you'd be better off dying). Of course, the most straightforward response to this is to suggest making it so that the person in question has other things to look at and is given the opportunity to experience "the wonders of nature."

**[419]** Kenya Nishio [269] recalls Yukio Matsuoka, who served as Secretary of the Japan ALS Association, saying to him, "[if you go on living] you'll be able to enjoy the changing scenery of the four seasons: cherry blossoms in spring, the sea in summer, the changing leaves in autumn, and the snow-covered landscape in winter" [269]. He doesn't write about how he responded to this, but on the website that is still online after his death (Nishio [-1999]) there is a photograph of a garden in the snow and a caption that reads, "This is how my garden looks when it snows. I look out at this scenery while taking a bath."

**[420]** Toru Tsuchiya [247]. Yamanashi Prefectural Central Hospital. "Being able to see Mount Fuji from my hospital room was also my nurse's doing. When she changed the position of my bed, saying, 'You'll get depressed if you spend too long just staring at the ceiling,' a completely different world opened up for me. In it I could see Mount Fuji." (Tsuchiya [1993:9]) And of course vision is not the only sense.

**[421]** Shigeharu Chimoto [399]. July, 1988, Kagoshima University Hospital. "When tea went down my throat for the first time in four and a half years, I was as excited as I had been the first time I used this computer I'm using now. There was a sense that my 'life is expanding.'" (Chimoto [1993:135]).

August, 1992. "In the hottest part of the day, just after noon when even the crickets are still, Matsumoto, the nurse who had come to my hospital room, prepared a cool glass cup, turned off the air conditioning, and, giving the somewhat puzzling but from my perspective happy reason, "Because it's obon [a three-day summer festival when the spirits of the dead are thought to return]," she gave me a drink of beer. [...] the beer was drawn up out of the cup into a glass needle and poured into my mouth, the liquid imparting a cool sensation to my esophagus as it made its way to my stomach along with its lively bubbles. [...] I wished it could be obon every day." (Chimoto [1993:273])

That a person can drink alcohol even if they have ALS is obvious when you think about it, but it isn't something that occurs to you straight away. And alcohol does not necessarily have to be administered through the mouth.

【422】 "Of course there are also patients who enjoy beer or wine from a gastrostomy [tube], and there is absolutely nothing wrong with them drinking at home." (Yamamoto [2004:11])

【423】 Fumiko Kobayashi [251]. "Through the efforts of my doctor, I had the hospital purchase a portable respirator. I'd never imagined my range of activity would expand this much. / In early spring I put the device on my wheelchair, and, after touring the hospital, took my long-awaited first trip outdoors. The hospital where I was staying, Tsubame Rosai Hospital, was blessed with a [good] environment, surrounded by rice paddies and vegetable fields. [...] This time I attended a hanami [cherry-blossom viewing party] and spent my first night outside the hospital. [I was] at home for the first time in ten months. Being able to return home alive was truly like a dream." (Kobayashi [1987 110-111])

【424】 April of 1987, Toshiaki Tsuchiya [201]. Yamagata University Hospital. "There was a pivotal event. They bought me a portable Bird\*. The Bird I had been using belonged to the hospital and couldn't be taken outside. But the portable Bird was a great device that could be powered in three ways - by plugging it in at home, by using a car battery, or by charging its internal battery. Using this portable Bird allowed me to go on all kinds of excursions." (Tsuchiya [1989: 107]. \*A Bird is a kind of mechanical ventilator)

There are people using a ventilator at home who go on outings.

【425】 Hiroshi Nagaoka (Kanagawa Prefecture) [396] went on an outing sometime around 1988. "It has been twenty-four years since my husband was diagnosed with ALS. It has been eighteen years since he went on a ventilator, and seventeen years since he returned home after being in the hospital for ten months. / In his fourth year of receiving care at home, he was put on a stretcher and went out for the first time on a short trip to a hanami at an elementary school very close to our home. [...] It was the first time a patient on a ventilator had gone on an outing, and it was reported in newspapers and later broadcast on television. / Doctors who saw this realized a patient could go outside while on a ventilator, and took hospitalized patients who had not set foot outside their rooms on walks in hospital gardens." (Nagaoka [2001:29])

【426】 Kikuko Doi had used a letter board to say, "Why did you save me?" after being put on a ventilator [277], but in June of 1992, one year after entering Oita Kyowa Hospital, she returned to her home on a day trip. "When the doctor said, 'Would you like to try going home?', for a moment I couldn't believe my ears. This was because I'd believed that with my body hooked up to a ventilator I couldn't even leave my room, let alone go outside. /My heart leapt at hearing this news that was like a dream [...]" (Doi and Doi [1998: 74]).

Some people were no doubt happily surprised to learn that they could go outside even while on a ventilator. But there were no doubt also some who were resentful of not having been informed of this possibility sooner. I cannot present any of it here, but there is a lot of information concerning accounts of people on ventilators going on various excursions, methods of preparing to go out, behavior of airlines that impeded travel and activism in opposition to this stance, and other related topics that has been made public by people on ventilators and organizations they have created in Another Voice, the journal of the Japan Ventilator Users' Network (JVUN), this organization's website (<http://www.jvun.org>), and elsewhere. If fundamentally removable - and easily dealt with - impediments are removed, then going outside, going out to take in the world, is possible.

#### 6. Sending transmissions

Not being able to communicate or do the things you want to do is painful. Not being able to scratch when you have an itch, not being able to shoo away mosquitoes when they come flying toward you - these sorts of things are intuitively easy to understand, so they are often mentioned.

**[427]** In a series of newspaper articles focused mainly on Yoshiaki Nagao [252], (then) Director of the Tokushima Public Health Center Yuji Sano is quoted as follows. "A mosquito lands on your body. You know it is going to bite you, but you cannot shoo it away. When the disease has progressed you can only move your eyelids. You are itchy. Even if you try to call for help, you've lost the ability to speak. You keep blinking hoping someone will notice, but your appeal doesn't even reach the person standing right beside you. Understanding everything but not being able to do anything - that is the unique character of this disease."

**[428]** The following quote from Yoshiaki Nagao also appears in the same series of articles. "The misery of having to just lie there and endure it when you have an itch, and of having to just wait for a mosquito to finish sucking your blood when it lands on you. Every evening I hope to be allowed to just fall asleep that night ..." (Tokushima Shimbun [2000]).

**[429]** Shinichi Yamaguchi (Fukuoka Prefecture), who was diagnosed with ALS in 1996, has given talks with a speech synthesis device that uses his own voice, and he often opens his presentation as follows. "I'll begin by showing you a shocking photograph. This is a patient with advanced ALS. It becomes difficult to walk and difficult to speak; ALS progresses from various places [parts of the body], but everyone with the disease ends up like this. All of the muscles in the body become incapable of even the slightest movement. They look like a vegetable, but their mind is completely normal. If someone lifts their eyelids they can see. They can hear. They are well aware of itching and pain. But they cannot scratch themselves. They cannot even shoo away a fly that has landed on them. No matter how much they want to ask someone to shoo it away for them, they cannot utter a

single word. It is agony. / All of you can experience this state too. Lie down in bed in the most comfortable position you can find, and stay there for an hour without moving a muscle. I doubt you'll even be able to endure it for ten minutes. Before ten minutes are up you'll have started to itch somewhere. You can't complain to anyone. Being unable to move is hard, but the most difficult thing is not being able to express this suffering. But recently the latest advances in digital devices have made it possible for people like this to express what they are thinking. This is our salvation." (Shinichi Yamaguchi [2000])

Obtaining a means of communication is enormously important, not only for the sake of having your itches scratched. For most people this is spoken of as the biggest event in the narrative of their illness. Along with being able to say what they want and do not want to have done to or for them, being able to express their thoughts and feelings is itself very meaningful. It is also something undertaken to pass long periods of time; many pictures have been painted and many memoirs and chronicles of an individual's struggle against disease have been written by these patients.

In the following technical explanation I rely on other writings and websites, and give a very simple account of how words are conveyed.

To begin with, as for the question of whether losing the ability to speak after undergoing a tracheostomy and being put on a ventilator is inevitable, the answer is that it is not. There are some cases in which someone who uses a ventilator is still able to speak. The reason you cannot speak after going on a ventilator is that air is not flowing past your vocal chords, but it is still possible to speak when you exhale by sending air to your pharynx. There is also something called a "speech tube," and a small device called a "speaking bulb" is often used as well. The latter was invented by an American with muscular dystrophy, and involves attaching a bulb through which air can only pass in one direction.

Various other approaches exist. Seisuke Mizuno (Chiba Prefecture), a former pump technician, used his experience to develop a device called "Speaking Compression" and began using it himself (Yomiuri Shimbun [200(3)]). It was later turned into a commercial product.

**[431]** Takeshi Kamata [357] received a tracheostomy and went on a ventilator in October of 1997. "I speak using a compact compressor (Speaking Compression). When I saw an ALS patient named Mizuno from the Chiba branch using Speaking Compression to talk in his own voice at the 1995 general meeting of the Japan ALS Association, I decided that I would try to use this device too when I had a tracheostomy. Thirty-five days after my tracheostomy [...] I started using it and recovered my own voice, and while my voice is low, today I can converse normally." (Kameta [199?b]) But since speaking requires at least some muscle movement, with ALS there are cases in which it is

difficult, and cases in which it becomes progressively more difficult over time (Waku [2003-]).

Whether they are on a ventilator or not, what is to be done when a person cannot speak? I found several accounts of such situations in the 1970s.

**[432]** Words that Chiaki Suzuki, whose mother had ALS, heard from a doctor in May, 1975. A different passage from this source is quoted in [298]. "It's only a matter of time before her entire body, from her mouth to her arms and legs, becomes immobile, but her mind and eyes will continue to function, so if you put large letters on the wall and follow her line of sight she'll be able to communicate with you." (Suzuki [1978: 57])

**[433]** Ry?z? Kawai [313], around 1975. "I knew I would eventually become unable to write. I thought I had prepared myself for this. When the time came, however, I realized I had no way of communicating my thoughts to other people, and became very upset. My wife could read the subtle movements of my lips well enough to get by in routine interactions, but even she couldn't understand me when the conversation became a bit more involved... / Around half a year after I lost the ability to write, we learned that my wife could understand me by following my eyes when I looked at a page with "A, I, U, E, O [a Japanese syllabary]" written on it. Once again other people could understand me, and the path ahead suddenly became brighter." (Kawai [1987: 154])

**[434]** Ii [293], 1975. "Sounding a buzzer with a push plate at his toes and using an A, I, U, E, O character chart hung directly in front of his eyes, Mr. Ii's wife could put together his words one character at a time by counting the number of times he blinked." (A quote from Kawamura et al. [1978: 167-169] in Kinoshita [1996 - (10): 37])

**[435]** Misao Hashimoto [416] became ill in 1985, but "at that time in Japan, ALS was a hopeless disease; I was told it would lead to my death, and in the terminal phase I would only be able to communicate through Morse code signaled with my eyes. That was only fifteen years ago." (Hashimoto [2001a]) In practice, it is letter boards that are used most often. Most patients send signals with slight movements of the parts of their bodies that remain mobile, and when communicating in words they employ letter boards with a few standard phrases printed on them in addition to the fifty characters of the Japanese syllabary. If their arms or head are still mobile these movement can be used. If their eyeballs move they can spell out words by looking at each character in turn.

**[436]** By having an ALS patient look at a transparent board with a table of the fifty syllables printed on it, the character they are intending to select can be determined by following their line of sight. I saw this approach being used in the spring of 2003 when Masachi Ozawa invited Ayako Takai (Tokyo) to give a lecture at Kyoto University's Graduate School. Takai, who was diagnosed in

1982 and began using a ventilator in 1989, is an inventor who has created various devices (Takai [1998(?)] [2000]), and has also made improvements to the letter board. (For papers Ozawa has written on Takai and the people who have gathered around her see Kaneko and Ozawa [2002: 65-81], Ozawa [2002: 219-220]).

Of course, communication is affected by the body's condition. If a patient is having trouble breathing then sending a message with a letter board is difficult.

**[437]** "The feeling that he wanted to reduce his time on the ventilator as much as possible, that he must not become dependent on the ventilator seemed to undergird his will to fight the disease. So during my visits he barely used the ventilator, even when he seemed quite distressed. No matter how hard I tried to explain that putting unnecessary strain on himself would only hasten the progress of his illness, I was never able get through to him. / One day when I visited him, Mr. B. was having so much trouble breathing that I couldn't read [what he was trying to say using] the letter board. [...] Whatever he might say, we decided to put him on the ventilator just when he was using the letter board. When he actually tried going on the ventilator, reading the letter board went so smoothly we wondered where all the difficulty we had experienced before had gone. [...] / This experience changed how Mr. B. thought about the ventilator." (Okuyama [1999:31-32])

**[438]** Misao Hashimoto [435]. "Right now I operate a word processor with my right middle toe, and use a nurse call button affixed to my forehead. In ordinary conversation, I mouth a vowel shape with my lips, and when I make the 'u' shape, for example, my caregiver picks up on this and begins saying syllables with that vowel, 'u, ku, su, tsu, nu, fu mu, yu, ru,' and if I want to say 'ku' I blink when that syllable is uttered. When a patient cannot move their lips, their caregiver begins by saying the vowels, 'a, i, u, e, o,' and, after receiving a signal from the patient, then goes down the list of syllables containing the selected vowel. [...] Most people use a letter board, but as someone lacking 'diligence, drive, and patience' it doesn't seem to suit me very well. Both patients and caregivers have to memorize the syllabary chart, but as an exercise for your brain I highly recommend it." (Hashimoto [1997g] cf. Hashimoto and Anjo [1998]).

It may seem that this kind of communication would be extraordinarily time consuming, but this is not the case. I found it difficult to believe that "[such a patient] speaks very quickly, to the point that someone who talks slowly can't keep up" (Shinichi Yamaguchi [2000]), but Hashimoto speaks reasonably fast. Her interpreter, a trained caregiver, memorizes the syllables she has chosen while saying "u, ku, su, tsu, nu, ..." and then says a whole sentence aloud once it has been completed. So as long as there is any part of the body that can move, no special devices are absolutely necessary. The person doing the reading must have undergone training, however, and in most cases picking up

what the patient says takes time. At facilities that deal with many hospitalized patients, the personnel and time needed to allow patients to communicate are not provided, and the pain of not being able to communicate what is on your mind is discussed in [414].

So machines aren't absolutely necessary. There was even an era when ventilation was done using a hand-operated bag [287]. Highly advanced equipment is not required in order to go on living. But when you use a computer the degree to which you are dependent on other people having the skill and time to provide the assistance you need is lessened. Some people, like Takehisa Kawaguchi, employ various contrivances in order to use a kana typewriter or regular word processor, but once even their fingers become too weak to move these devices can no longer be used. Here computers that operate in the same way as Hashimoto's caregivers/interpreters enter the picture.

A cursor on the screen moves at a fixed pace (the speed of which can be adjusted) from one syllable to the next. The movement of a patient's eyelid is converted into a signal and used to select, for example, the "a" column. The cursor then moves across those syllables "a...i...u...e...o." The patient then chooses the character they want. On top of the fifty syllables you can also save expressions often used in daily life, allowing them to be said without spelling out each character. This sort of device seems to have begun being used around the middle of the 1980s.

**[439]** Takehisa Kawaguchi did not use such a device himself, but did obtain information about them. January, 1984. "A letter from A.'s younger brother arrived. It said that A., a patient at Tottori University Hospital, had developed a communication test using a newly developed letter composition device. / According to the letter, the new device was a set that included a word processor, computer, and electromyogram. Two thin bands (selection bands, cursors) move across the screen horizontally and vertically from left to right and from top to bottom. While looking at the screen, when the bands highlight the character you want to say you give a signal by blinking or biting down slightly with your molars. When you do so, an electrode stuck to your face picks up your subtle muscle movements, and the character you selected is displayed. / You can communicate your thoughts and desires. Could anything bring greater happiness? In A.'s case in particular he had been 'silent' for six years. Six years in which the freedom of his body had been stripped away and he had been unable to communicate a single one of his thoughts. Having endured this, he was now trying to get back his 'words.' I can only imagine A.'s happiness and how moved the members of his family must be." (Kawaguchi [1985:228])

**[440]** Shigeru Matsumoto [414] became unable to type on his word processor in September of 1986 (Shigeru Matsumoto [1985: 16]). "In October, I completely lost [the use of] words. The method of writing I had been using became impossible, and since I could only rely on my mouth I

prayed for my words [to remain]. Parting with anything is hard, but saying goodbye to language was particularly painful, and a lingering attachment remained. / My arms and legs were no good, and now that words didn't work either I had no way to communicate. I was at the end of my rope. It was depressing to think about how far [my disease] had already progressed. / One day around this time I received a phone call from Matsuoka, the general secretary of the head office, and after learning from him that there was a computer that enabled you to enter a character by operating a single switch I immediately decided to start using it. There was a very nice one I could begin using straight away if I could afford ?2,000,000, but since I was trying to reduce my expenditures as much as a possible I investigated various other options." (Matsumoto [1995b: 35] "Matsuoka" refers to Yukio Matsuoka, who at the time was serving as the general secretary of the Japan Deafblind Association. Matsumoto ended up purchasing a push-button switch, software, MSX computer, and a printer with accessories for ?140,000)

**【441】** In the case of Toshiaki Tsuchiya [424], in April of 1986 a method in which a person was responsible for part of the process was adopted. "Those of us who could not speak got a wonderful present: a word processor was purchased for us at the hospital. The only unfortunate thing was that we couldn't operate it by ourselves. We had to have someone push the button for us. We had attendants, so this was not a big deal, and in any case it was a wonderful present for us. / [...] For example, the fifty syllables would appear on the screen, and a square, bar-shaped cursor would move over them. If I wanted to write 'a,' I would signal with my eye when the bar was over the 'a' and my attendant would push the button." (Tsuchiya et al. [1998: 91-92])

**【442】** Toru Tsuchiya [247] was diagnosed in February of 1991, and entered the neurology ward of the Yamanashi Prefectural Central Hospital in August of that year. "Thanks to the efforts of Dr. Yamashita from Yamanashi University and his colleagues, a communication device called a "Pasoparu PC" was given to people who had illnesses like mine. I tried it out right away. The characters I typed appeared on the screen and were read aloud, and could also be printed like with a word processor. This was the best thing that could happen for people like us who cannot express our thoughts using our mouths or hands; I felt like a new world had been created." (Tsuchiya [1993: 182]. The "Pasoparu" was a product released by Namco in 1986.)

**【443】** Ikuro Higashimitada [197]. "About a year after leaving the hospital I got a word processor I could operate by moving my eyelids, and nothing could compare to the happiness I felt at being released from my passive existence." (Higashimitada [1998: 2-3]) As might be expected, however, this communication took time.



【444】 Shigeru Matsumoto [440]'s book (Matsumoto [1995b]) is composed of forty chapters, and "even the shorter chapters took three or four days to type out, and the longer ones more than two weeks." (Matsumoto [1995b: 20])

【445】 Kikuko Doi [426] had been using a letter board, but switched to a word processor with a blinking input system. "At the start, after just ten minutes of typing my eyes would get tired, my back would hurt, and I wondered if I would ever be able to use it for longer periods, but I gradually increased the time [I could type] to fifteen and then twenty minutes, and now if I am in a hurry I can type for seven hours at a stretch. [...] / It is a slow word processor that requires about two hours to fill a single page with approximately four hundred characters, but I keep typing in the hope that I can communicate even a few of the thoughts in my mind and have them understood. / The word processor is my life. It's amazing to be able to act on what is in my mind and heart." (Doi and Doi [1998:49]). "The joy of the day I was able to type out and display in words my thanks and gratitude, and the many things I couldn't express with the letter board, still remains today at the back of my mind." (Letter to Masayoshi Honda [385] in Doi and Doi [1998: 51])

【446】 Misao Hashimoto [438]. "At this stage, my remaining capabilities are making an expression with my face and typing on the word processor with a toe on my left foot. But don't imagine a setup in which I'm typing away with my toes on a keyboard. A light sensor picks up the very subtle movements of the first toe on my left foot, and these movements are converted [into text] on a computer by software developed for people with disabilities. With my remaining function it takes around an hour to type four hundred characters, but that doesn't mean I can type two thousand characters in five hours; after an hour severe fatigue sets in, and to finish typing eight hundred characters takes three or four hours." (Hashimoto [1998a]) Communicating like this is by no means the same as communicating through speech. 【447】 Toshiaki Tsuchiya [441]. "When I am complaining to my mother, if I use a letter board she can stop in the middle and cut me off, but using a word processor I can say, 'idiot, moron, dimwit' or whatever insults come to mind. When I actually tried writing these sorts of things, however, they just left me with a bad taste in my mouth without relieving any of my stress. It isn't worth taking the time and trouble to write something that will only make both of us feel bad. / Just once, I wish I could scream at the top of my voice, 'Idiot!' Adopting a self-centered way of thinking - it may be that the frustration at your own body not behaving as you want it to and the irritation of pent up feelings piling up inside you causes this change in your mental state." (Tsuchiya et al. [1989: 181-182]) Even so, if you can communicate in this way and people take action in response to what you say, if you can be in a place with people and things other than people around you, and if you can take trips away from this place, then you can begin to make a go

of things. If you subtract the physical pain cause by the disease, in the end what remains are the disabilities it creates, and while it may be impossible to completely get rid of them, they can be significantly reduced. Various products related to computers are constantly being released. For example, there are switches that can be connected to computers and other devices. But just having a machine does not mean you can use it. In order to communicate well with only very subtle movements of the body, the right kind of device has to be chosen and set up properly. Only after this has been done can a machine be used effectively. There are people engaged in providing this kind of support. Yasunao Nishimura has been providing this kind of assistance for many years through the Japan ALS Association's Kinki Block. There are also products developed and sold as software applications, and devices that come with software built in. There are many such products, but one of the most popular is "Dennoshin [communication heart/mind]" (Hitachi) which was released in 1997. An improved product with enhanced functionality was released in 1998 (Hotta [1998]), and in July of 2000 a product that included a connection to the Internet as a standard feature was released. Users of such products include Sadayoshi Terukawa (Katsuura City, Chiba Prefecture, Terukawa [2003b]).

**[448]** "A Hitachi employee was diagnosed with ALS. ...as a second factor, there was a joint research proposal from Kitasato University East Hospital, and I think we were extremely lucky to receive this proposal, because in terms of our own relationships we did not have much direct contact with ALS patients. As a third factor, we were able to obtain funding. In fiscal years 1995 and 1996 we received a total of ?200,000,000 in financial assistance from the Association for Technical Aids, an extra-governmental organization affiliated with the Ministry of Health. Taken together, these three factors led to the development of 'Dennoshin.'" (Ozawa [1998:26]. See also Ozawa [2002])  
There are thus various means of transmitting messages. Not being informed of their existence is naturally a source of dissatisfaction and focus of criticism.

**[449]** Yasuaki Shikano [417] went on a ventilator in 1995. His doctor introduced him to a device that spoke when you typed on a keyboard, but Shikano couldn't use it because he couldn't type. "It wasn't until around two years after leaving the hospital that I learned about an official [government] 'equipment for everyday life' benefits system that provides computers and word processors for use as communication devices by people with severe physical disabilities. [...] / I couldn't type on the Talking Aid keyboard, but I could use a computer mouse without difficulty. If I had known about this system at an earlier stage and this approach had been brought into the hospital, not only would the suffering I went through immediately after going on the ventilator have been halved, but it would have made a huge difference to the burden on the people around me." (Shikano [2001:56]. The "Talking Aid" was a product released by Namco in 1985.)

With ALS, however, there are cases in which even the movement of the eye, which is said to remain until the end, is gone. This is described as a "(totally) locked-in" state, and while consciousness remains the ability to express it is lost. What is to be done when this state arises? Obviously the patient cannot remove the ventilator themselves. Let us assume that no one else can remove it either, as this is currently the case under Japanese law. If so, the patient will go on living in this state, but this is presumably painful, and rather than having patients imagine this future and choose not to go on a ventilator - assuming this choice is allowed - and end their lives earlier, isn't it possible that patients would actually live longer if they were allowed to remove their ventilators, or have someone else remove their ventilators based on their request made in advance of becoming totally locked-in? This sort of argument is sometimes put forward. What are we to make of it? I will save this discussion for Chapter 12.

In the next chapter I discuss the process by which at least some of the resources needed in order for such patients to live without pain, without facing extreme danger, and without becoming bored have become available in this society.

Realization of this approach in today's China can be thought of as both possible and wise. This is why I decided to talk about our experiences in Japan and the systems we have created when I visited that country.

I describe and examine these movements and policies in *Ars Vivendi: Sociology of Disabled People Who Have Left Home or Institutions*, the third edition of which we published in 2012. The second edition of this book has been translated into Korean, but it has not been translated into any other languages. In the future I hope it will become possible to learn about these circumstances in Japan and the results we have achieved in English and other languages.