

To be Concerned Leads to Interaction and Interaction Turns into a Lifetime Asset?!

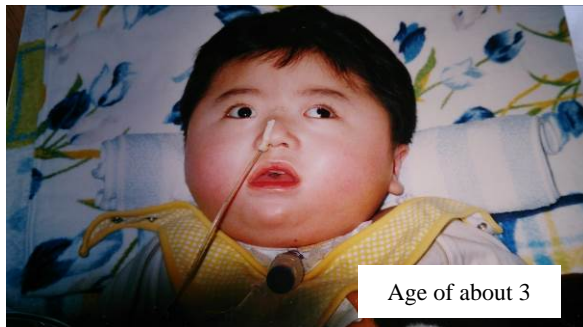
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My only son, Yutaro, is 17 years old now. He is the second year of upper secondary school. Although he can breathe spontaneously, he lives on an artificial ventilator. He is unable to cough, swallow saliva and so he needs to have sputum suctioned frequently with an apparatus. Also he is unable to chew or swallow food, he has to take in nutrition from liquid food through a gastrostomy tube. He can hardly move his limbs and when he moves from a place to another he does so in a stretcher-type wheelchair. He needs other people's support as he cannot do almost anything including excretive care. Since he cannot talk with his voice, the only way for him to have communication with other people is blinking. Even though slowly, he can move his eyeballs and eyelids and when asked something, he blinks to indicate "Yes," and does not blink to indicate, "No."

1. Birth to life at home

Yutaro was born two weeks later than the expected delivery date. When finally he was born via Caesarean section, he was not breathing. Immediately he was on artificial ventilation and was taken to another hospital's NICU (Neonatal Intensive Care Unit). For about 10 days from his birth, Yutaro did not move at all being unconscious. However, he started moving little by little and opened his eyes. Because enough oxygen was not supplied to the brain at the time of birth, he could not move



Age of about 3

his body well and the breath was weak. Accordingly, he ended up in his current condition. He repeatedly caught pneumonia and had high fever, as the result, he had to get over the high wall between life and death again and

again.

At the hospital, he received a tracheotomy when he was 4 months old and next we worked to get ready to start taking care of him at home. We practiced mucus aspiration from the windpipe, studied how to use an artificial respirator, learned emergency responses and had hands-on experience concerning how to get in and out

of a car when leaving the hospital temporarily to sleep over at home. Following this, right on his 3-year old birthday, he was released from the hospital to start living at home.

2. From staying home to attending preschool and higher schools

After having been discharged from the hospital, we started practicing on going out to get used to it little by little by utilizing the opportunity of the monthly visit to the hospital. In the next spring, Yutaro and I together began to attend a center of therapeutic care and education for infants and toddlers. When going out, we had to bring a range of equipment including artificial respirator, suction apparatus and oxygen cylinder and of course, he could not go out every day because his physical condition was not strong enough and he sometimes was unstable. Compared with the time he was at the hospital, however, Yutaro's facial expression was unmistakably livelier when he was at home or went out. He started responding well to a variety of external stimulations that occurred around him and gaining physical strength gradually. When he reached the school age after graduating from the preschool, we decided to enroll him in a school for special needs education, as we assumed, "Our son would not be able to attend any regular school because he is hooked on an artificial ventilator. He often gets sick and we are not sure even if he can commute to and from the school."

When choosing a school for special needs education, we decided that my son should have a visiting student status not an attending student status. He started a new life attending the school two days weekly and studying at home with a



teacher visiting him one day weekly. We enrolled him in the school for special needs education, expecting even a child with a severe disability like Yutaro could have education suitable to him or her as the school had nurses and staff specialized in providing appropriate education. At the school for special needs education, however, there were not many children who were on a ventilator. In fact, we, parents, had to accompany Yutaro to school to take care of mucus aspiration and nutrition support as well as take him to and from the school as he was not allowed to use the school bus service.

Meanwhile, Yutaro were getting more physically resistant after a few years of attendance as well as becoming more and more motivated to study. On the other hand, Yutaro started feeling unsatisfied with his school life, while as parents we came to question about our actual situation in which we send him to and from school and attend him all the time at school. We wondered how other users of artificial ventilator were commuting to and from school in other parts of Japan. By making searches, we were shocked to learn that there are some people who attend a local regular school rather than a school for special needs education, without parents' attending them. We for the first time noticed there was an alternative and we could have been able to choose a regular school. Later, therefore, after considering this very hard, Yutaro proceeded to attend a regular lower secondary school.

3. Life at a regular lower secondary school

Although Yutaro was admitted to a local lower secondary school as we had decided, the school principal and other teaching staff had never received a student on a ventilator and we were even given discriminatory remarks and responses by the then-principal of the school. The school side tried to let us, Yutaro's parents, take care of him and actually left him alone, by considering that students on a ventilator should not attend a local school. What we asked was just that the school should receive him as one of the students and not depend on parents to accompany him when he commutes to school. There was a very large gap between the two sides, the school and us, and we had to repeatedly have conflicts and whenever a conflict arose, we discussed with the board of education. Sometimes we felt really weary but never gave up and continued discussions. In the meantime, teachers began to gain some understanding and the relationship between us and the school was getting better every year. From the following year, our burden to attend Yutaro was reduced and in his third year at school, we were fully released from the burden of accompany him at school.

At the lower secondary school, Yutaro had to enroll in both the class for special needs education and the regular class and he sometimes studied in a special class and other times studied with other students in the regular class. In the classroom, an assistant teacher who was there to take care of Yutaro helped him by showing him textbooks and printed materials, copying what was written on the blackboard for him and holding his hand to do some works. The school had no elevator, however, and Yutaro had to move from a room to another using a stair lift. Right after Yutaro entered the school, teachers and other school staff overreacted and worried and there

was times when Yutaro could not attend the class and was sent off home early. As time passed and teachers got used to and started understanding what Yutaro needed, however, less and less unfavorable incidents occurred. However extensively we made discussions, Yutaro could not be allowed to have lunchtime with other students when he was supposed to receive nutrition injection and he also could not share a bus with other students on school excursions.



School excursion of lower secondary school

The discussions were made between the board of education concerning issues from the overnight stay study for his first year at the school to the school excursion prior to graduation (we are still discussing with the board

to make things easier for students like Yutaro entering the local school later). Teachers who depended on us, parents, to take care of Yutaro, rejected riding together in the special care taxi. But their attitude changed gradually and later they started riding the taxi together with Yutaro or taking care of Yutaro during nighttime on overnight-stay study events. Yutaro participated in such an overnight-study event near the Biwako Lake, Shiga Prefecture when he was in the first year, in a day trip to Kyoto in his second year and in a two-night trip to Nagano in his third year (it took about 7 hours by car). These events offered valuable experiences to both sides, giving a chance to realize what both of us had not known before, by being very close to each other and spending a long time with each other. These events also reduced the distance between the two sides.

Yutaro could attend all school events at lower secondary school and students sometimes helped him by pushing his wheelchair. The exchanged greetings with him, too. They



School festival of lower secondary school

even made considerations and discussions for Yutaro about how to help him attend school events together with other students. We encountered both the good and the bad. So, if asked what he thought about having entered the lower secondary school, he would reply that “he had to come through many things but, the life in the local lower

secondary school was more joyful than that of the school for special needs education.” And, even right after having entered the lower secondary school, he expressed his intention to “enter a regular upper secondary school together with other students.”

4. Entrance exam for upper secondary school

In his lower secondary school days, we participated in several study meetings to exchange information on school life or entrance exam for upper secondary school for students with disability and where we could have more chances to tell other people about Yutaro and consult on problems we encountered in relation to Yutaro. At one such meeting, we heard that if Yutaro wanted to take the entrance exam for upper secondary school, it would be better he took regular exams at lower secondary school to be given a grade even if the grade was not high enough. So, we requested the lower secondary school to “give him exams and a grade not only in writing but in quantitative scores.” Probably, everyone considered it impossible that a student with an artificial ventilator was going to take the entrance exam for upper secondary school.

Yutaro is unable to talk with his voice or write. He only can express his intentions with blinks. When taking an exam, he needs one teacher who reads questions for him and another teacher who decodes his blinks to write answers for him in a separate room. At the beginning, we requested teachers at lower secondary school to give him multiple-choice questions but in the third year he started taking the same exams as other classmates took so that he could get prepared for the future entrance exam.

We visited several fairs to consult about the entrance exam for higher schools and actually visited the schools (on open campus day) to directly see the atmosphere, teachers, students and the school’s physical structures (to learn whether there is an elevator or how he could move from a place to another), etc. to decide which school he should choose. Prior to actually taking the entrance exam, we submitted a request to the Osaka Prefectural Board of Education to make accommodations and appoint teachers who read for him, write answers for him and confirm his blinks’ intention as well as a nurse to stand by. Also, we asked the board to come to the lower secondary school to see how Yutaro took regular exams at school. There were a lot of discussions and conflicts about accommodations to be made until the last minute, Yutaro ended up in taking the entrance exam for the same upper secondary school twice, the first round (3 subjects) and the second round (5 subjects). Yutaro could not pass both of the rounds and he took the entrance exam in the secondary selection procedure, which was the last chance for him.

The test was only given in the form of an interview. Although we were concerned about the fact that Yutaro who cannot speak with his voice had to take the exam on his own, he wanted to try the interview. We let him bring photos showing his strong desire to enter a regular upper secondary school and how he was spending the lower secondary school life.



In Osaka Prefecture, we heard, no new students would be denied recently if there were less applicants than the quota. Still, we were worried that Yutaro might be rejected based on the upper secondary school side's judgment. On

the contrary, it went as the saying goes, "Third time lucky!" We could find his examinee's number, 5001, on the board announcing the exam result! Soon after the announcement was made, we were called in by the teacher of the upper secondary school because the school "wanted to hear what we had to prepare before Yutaro's entering the upper secondary school," and we were asked about his disabilities, how he spent his lower secondary school life and what the school should prepare for him.

5. Life at an upper secondary school

And the day of the upper secondary school's entrance ceremony arrived. As it is a part-time upper secondary school, the number of students is significantly smaller than that of lower secondary school. As we knew by hearsay, every student attending the



entrance ceremony looked different from each other, in terms of color of hair, appearance and age. And every student seemed to have some kind of problem (some students were non-attending students at lower secondary school). Despite their appearance, they are generally kind people. Students even in senior years give Yutaro greetings, help him when he moves from class to class or let him use the elevator first.

At the upper secondary school, where

there is no class for special needs education, Yutaro studies together with other students and during lunchtime he takes liquid food through the gastrostomy tube and has suction. Every one of his classmates treats him naturally. Yutaro had once been taken care of in a separate room “devotedly” (?). Now I wonder again what all that was about. Students with disabilities do not need to be separated from other students, if necessary care can be given.

At the upper secondary school, Yutaro can get the help of a caretaker, a nurse and an assistant teacher who takes notes for him. When two or three months passed after he entered the school, we could leave his care to those staff at school. We were very grateful about it and at the same time very surprised. The part-time upper secondary school is able to pay close attention to needs of students who have a wide range of background and academic skills. At this upper secondary school, we can find even students who were unable to attend lower secondary school regularly but now are enjoying the part-time upper secondary school.



The upper secondary school does not show rejection, a repulsive attitude or reluctance. It looks as if the school accepts students as they are. Some students are even married and have children. There are also a number of students who have a daytime job but they are also enjoying making friends, participating in extracurricular activities and learning lessons from the ground up at this school. Many students look happy attending the school as if they are reliving days they lost at lower secondary school.

6. It begins when you start interacting

Thanks to one teacher who earnestly invited Yutaro, he now is a member of a Science Club and participates in a workshop held every other Saturday. Students participating in the Science Club propose their own ideas, repeat experiments to get data and present the result at a Science Conference. When the conference comes closer, students get together to practice how to make presentation. In May, Yutaro for the first time joined other students to make presentation at the conference. In addition to this, fun events are held one after another, for example, the members of the club have Christmas and birthday parties together, they pay the year’s first visit to the