

14 years old- My family

Mary died...

Today is my birthday. I grew quite a lot.

I think I need to thank my mom and dad.

I need to get much better grades, and be more healthy so I won't make them sad. In order to do that, I want to make this beginning of my youth important, without any regrets.

I'm going camping the day after tomorrow. I need to finish my homework so I won't have to worry about it.

Go! Go! Aya!

Tiger, the fierce dog next door ripped Mary's head off, killing her.

Mary who was very small, approached the monstrous Tiger with a friendly wagging tail.

I yelled with all my might, "Mary no! Come back over here!" but...

Mary must be frustrated... she died without being able to say a word. If she wasn't born a dog, she wouldn't have died so fast. Mary please be happy somewhere else!

The new house is finished.

The large room on the east side of the second floor is me and my sister's room. The ceiling is white. The wall is wooden brown. The scenery outside the window looks different than usual. I'm happy that I have my own room, but it seems too spacious and lonely. I wonder if I'll be able to sleep tonight.

Starting off all refreshed!

1. I'll wear t-shirts and pants (it's easier to move around).
2. Chores to do everyday-- water the lawn, pick weeds, check for bugs behind the leaves of the one tomato vine I planted. Also check the leaves of the chrysanthemum for cockroaches, and if I find any, take care of it right away.
3. Not to slack on my homework
4. Other than that, write in my diary everyday.

I'm going to make sure I do all of these.

My Family

Dad, 41 years old. Sometimes he has a bad temper, but he's nice.

Mom, 40 years old. I look up to her, but her straight forwardness scares me.

Me, 14 years old. In the beginning stage of adolescence. The age that's hard to deal with. If I describe myself with one word it would be, crybaby. I'm full of emotions. I'm naive and I easily get mad and easily start laughing.

My little sister, 12 years old. I see her as a rival in both school and personality...although lately I've been pushed around by her.

My little brother 11 years old. He's a tricky one... a little scary. He's younger than me but sometimes turns into an older brother. He's also like a parent to Koro (the dog).

My youngest brother, 10 years old. He has a wild imagination, but he can be a little careless.

My youngest sister, 2 years old. She has curly hair that she got from my mom, and her face is from my dad (especially her eyes... its what it looks like when the clock hits 8:20) She is very cute.

15 years old- The sickness creeping up

Sign

I think I've been losing weight lately.

Is it from skipping meals because of the loads of homework and science project?

I can't put my thought into action so I worry.

I blame myself but there seems to be no progress.

My energy just continues to drain.

I want to gain a little more weight.

Starting tomorrow, I need to act more according to the plan I wrote out before.

It was drizzling today. Walking to school holding a heavy bag and to make that worse, an umbrella, is a pain. As I was having these negative thoughts, my knees popped and I fell forward at a narrow road about 100 meters from my house. I hit my chin pretty badly. As I gently slid my hand on my chin, I felt the sticky blood covering my hands. I picked up the scattered bag and umbrella, turned back, and headed home.

My mom came out from the inside saying, "Did you forget something? You better hurry or you're going to be late."

"What's wrong?"

No words came out and all I could do was cry.

My mom quickly got a towel and wiped my face which was covered with blood. I felt the sand cutting through the wound.

She said, "We're gonna have to go to the doctor," and quickly helped me change into clean clothes, placed a band aid over my cut, and jumped into the car.

I got 2 stitches without any pain killer.

I grit my teeth and dealt with the pain, because it was my fault for being clumsy.

But more than that... I'm sorry mom for making you take a day off work.

I thought to myself that maybe my hands didn't help me when I fell, because I'm kind of slow... as I looked at my aching chin in the mirror.

But I'm glad it was under my chin. My future would be dark if a scar was left in a place where people can see.

My grades in P.E.

7th grade= B

8th grade= C

9th grade= D

I'm so frustrated! I guess I need to try harder.

I was hoping that the circuit training I did during summer vacation would help a little, but I guess not. Well, I suppose it's because I didn't continue it long enough (the voice from the shadow= Exactly!)

In the morning, inside the kitchen where a slight light and breeze was slipping through the window with the yellow lace curtain, I cried.

"How come I'm the only one who is not athletic?"

Today, there is going to be a test on the balance beam.

My mom covered her eyes and said, "But Aya, it's okay because you are smart. You can just stick to whatever subject you enjoy and make use of that in the future. You're good at English, so you should master that. English is an international language so I'm sure it will be of good use. So don't worry if you get a D in P.E..."

My tears had stopped falling. There was something left for me.

I shouldn't be such a crybaby.

My body won't move the way I want it to. Is it being anxious, because I skipped doing my homework that I can finish in 5 hours each day? No, that's not it, something in my body is starting to breaking down. I'm scared!

My heart feels as though it's being squeezed. I wanna exercise. I wanna run. I wanna study. I wanna write neatly.

"Namida no Toka-ta (A tear's toccata)" is such a good song. I fell in love with it. When I eat while listening to that song, it makes the food taste even more delicious.

This is a discussion about my little sister.

All this time, I only noticed my sister's mean side, but I started to think that she is actually really nice. The reason for this, is because when we walk to school, my little brother leaves me behind and he just walks his own pace, but my sister walks with me.

Even when we cross the bridge, she holds my bag for me and says, "Make sure to hold onto the rails."

Slowly, my summer vacation mood is fading away.

After cleaning up dinner, I was about to go upstairs and my mom said, "Aya, come sit over here."

My mom looked very serious and I was getting nervous, thinking about what I was going to get punished for.

"Aya, lately your body is constantly looking like you're going to fall forward, and you walk very unsteadily moving from side to side, do you notice that? I've been watching and I'm worried. Let's go see a doctor."

I asked, "...which hospital?"

"Just leave it to me, I'll look for a trustworthy place."

My tears started to fall endlessly. I wanted to say "Thank you so much mom, and I'm sorry to make you worried," but I could not make any words come out of my mouth.

I wondered if my clumsiness is from staying up late at night, eating at different times, but thinking that there is something wrong with me and that's why I have to go see a doctor, left me to do nothing but cry.

My eyes are starting to hurt from crying too much.

The medical examination

I go to the hospital in Nagoya with my mother (she wrote this in English).

Left the house at 9 AM. My little sister wasn't feeling well. She went to pre-school anyways, so that I can go to the doctor....poor sister.

11 AM, arrived at the hospital (Kokuritsu Nagoya Daigaku Fuzoku Byouin). I read a book while waiting for 3 hours, but I was nervous. I couldn't concentrate as usual, because I was so worried and scared. My mom tried to reassure me saying "I called Dr. Eitsurou so there's nothing to worry," but...

I was finally called. My heart was beating fast.

My mom explains to the doctor,

1. I fell and cut my chin (people would usually fall on their hands, but I fell on my face).
2. I walk wobbly (my knees don't bend well).
3. I lost weight.
4. My movement is slow (I can't react quickly).

While listening, I became scared. My busy mom had been watching me so carefully...I guess she noticed everything...but I'm a little relieved.

Now, the small things that I was worried about has been informed to the doctor. Finally, all my worries will be gone.

I sat on the round seat and looked into the doctor's face. I was relieved, because she wore glasses and had a gentle smile. I closed my eyes and lifted up my hands and brought my index finger closer to my face. I stood on one foot. I lay down on the bed and repeatedly bent and straightened my legs. The doctor hit my knee with the hammer. The medical examination was finally over.

"Let's have a CT scan," the doctor said.

"Aya, it doesn't hurt or itch. It's just a machine that slices your head so they can look inside your head.

"Ehh, slicing my head!?"

This is really important to me, so I didn't find what my mom said funny. The large machine slowly came down. My head fit perfectly as if I was in outer space.

"You can just lay there, don't move now," a lady in a white gown said, so I laid there, but I became sleepy.

I had to wait a long time, and after given a medicine, I got to go home.

Another task was added for me to do. If I can get better by drinking medicine, then I don't mind drinking a stomach full of them. Please doctor. If I'm a flower, please help from ruining the life of the bud, that hasn't blossomed yet.

The hospital is pretty far and I have school, so the doctor said I only have to come once a month. I promise to go and do as you say, so please make me better. The world's best, Nagoya Daigaku! Dr. Eitsurou! Please!

Repentance

The only plant we harvest at Seiryu Junior High is Chinese citron.

When I went to go pick weeds where all these trees were, the guys made fun of my walking.

"What kind of walking is that? You look like a kindergartener."

"Haha you seem eager, your feet are bowlegged."

They laugh saying every possible thing to make me mad. Of course, I ignored them. If I put up with all this, the water in the ocean would be gone. But it was really hard not to cry. Luckily, I was able to keep the tears from falling...

Today something very frustrating happened.

During P.E., I changed and went out to the field.

The teacher said, "Today we'll be running to the park 1km away. Then we'll practice making basketball passes."

My heart thumped. Running, passing...I can't do either.

"Kitou what are you gonna do?"

I dropped my head low and the teacher continued,

"Well, you can have a study hall with O-san." (O-san forgot her P.E. clothes).

Hearing this, I immediately hear my classmate's voices.

"Aww study hall, how lucky."

I was boiling with anger.

"If you want study hall so much, I'll trade places with you. Even if it's only a day, I wanna switch bodies. Then maybe you'll understand the feeling of a person who can't do anything they want to do."

Everytime I walk, in every step I take, I can feel my unsteady body, it makes me feel weak, and I feel humiliated and miserable not being able to do what everyone else is capable of doing. Is that something you can't understand unless you experience it? Even if you can't feel what that person is feeling, I want you to at least try to think in my point of view.

But I think that's hard to do.

Even for me, I only first realized this after it happened to me.

Fever

I guess I caught a cold. I have a fever, but I feel fine and I have a good appetite. But I don't have any confidence with my body anymore.

I want a thermometer (since I broke it). I want to see my health in numbers. I'll ask my dad. Aya gets sick a lot. She uses up twice more money than her siblings. When I become an adult, when I become stronger, I'll let you guys live an easier life. I'll take good care of you guys like you took good care of me.

When I sleep, I think of lots of things.

The things my history teacher talked about.

Being made fun of is a good experience for me, because it helps me to become a stronger person. The schoolwork in junior high is easily done, if I study little by little everyday. It's not too late if I start now. I'm gonna try really hard.

...but on the other hand, my bad health makes me really worried.

"Don't cry you cry baby" The tough times are when a human is growing. If I can overcome this, a beautiful morning will be waiting for me. The peaceful morning full of light, with birds singing and the smell of the white rose...

I wonder where happiness is.

I wonder what happiness is.

"Aya are you happy right now?"

"Of course not. I'm in the bottomless pit of sadness. It's so hard. Mentally and physically..."

The truth is that I'm a step away from becoming weird!

Because the crow that was crying is already laughing.

Characteristic

I look up to people with strong personality traits, because I myself have nothing special.

I'm attracted to the idea of each individuals putting out their own unique characteristics.

Maybe even in the world that we live in, our uniqueness and talents are used to make the most out of life, like the movie "007."

The world is in need of people with strong character traits.

However, characteristics only belong to you, so it's not something you shove and give away to others.

But people take things in a different way, so it gets complicated.

When I was leaving school, I met Eiko at the bicycle shed. As I held onto "Yamato" and "Last Concert" records, Eiko put my heavy bag inside the bicycle basket.

Eiko said she had something to do so we parted at the crosswalk.

I really like how Eiko is so straight forward, but other people think she is cold hearted.

Path

There was a meeting to talk about what high school to apply to, with my teacher, my mom, and I.

1. Ability = I can still go to public school.

2. about my body = Right now it's only my unsteady walking, but we don't know how this situation is going to change, so I have to pick a high school that is close to my house. This school is connected to couple of high schools so I have to right a letter explaining how I won't be able to go to a school far away.

3. I will also apply to a back up school(private school)= my mom and I were only thinking about public school, but my teacher said it will be good to be able to get a feel of applying to different schools, so we decided on that.

Leaving the nest

An ant to ant, a flower to flower, a bird to a bird. -Kouji

On the back of this magnificent paper it said, "In celebration of Kitou-kun's graduation." Okamoto sen-sei wrote it for you, only for Aya... I was really happy.

He's a little scary, but he's a nice teacher who likes flowers.

I thanked him with all my heart and smiled with gratitude. My teacher taught me the meaning of this song.

"An ant to ant means to be straight forward and clear. It means that there are such things as 'flower' that humans call a flower, 'bird that flies' that humans call a bird."

It shook up the soaring blue sky, the tiled roof of the school, and the dark green tree.

I didn't understand half of the meaning of the song, but I can tell that my teacher was trying to say "do your best." The feeling of "I'm gonna do it!" stirred up inside me.

"What do you think he wrote that with?"

"It's probably not with a brush..."

My teacher smiled and said, "Actually, I wrote it with a chewed up toothpick, using an ink stone and ink." I was awed at the idea.

"Did you notice that there was a ribbon so you can hang it up on the wall?"

"Yup!"

My teacher smiled and left.

I will never forget that I had a wonderful encounter on my graduation day. Please continue to be my mental support.

Public school entrance exam

I had "daikon" miso soup as I requested in the morning. It was the same on the morning of the entrance exam for the private school. Well, I didn't request it that time, but I passed the exam when I had this, so for good luck I requested it this time.

Am I being too concerned?

I went to the bathroom twice, and my mom drove me to the high school, where the exam was being held. Everyone looked smart to me, making me feel hesitant and impatient.

The teachers escorted to our own classrooms where we were to take the test.

As I was going up the stairs, I fell and sprained my feet. I ended up taking the test alone in the nurse's office. This is so miserable, super miserable.

I pressed the watch I borrowed from my mom against my ears, and tried to relax.

Departure

Yay, I passed! Both mine and my mom's faces were messy with tears.

I'm going to put forth all my strength, and try my best to make lots of friends, and to be careful not to fall! Dinner was hamburger as my request.

I'm so happy as if I'm the hero.

I forgot all about the pain of forcing a body that I could not control, to study like mad. Oh this is such a wonderful feeling.

But there's some loneliness. I have to start out with a handicap. My inability of controlling myself is becoming more obvious. Even my walking is unsteady. When I'm about to bump into someone, I can't quickly move away.

I'm going to walk on the side of the hallway. I'll probably be the center of attention with my new friends. This isn't something I can hide, so I guess I should just show my true self from the beginning.-or so I think inside my head, but I'm worried. I don't know if I'll be able to keep up. I wonder what's going to happen with P.E.

That one word from my mom

"Your high school life isn't going to be easy. There will probably be more of hardships, being restricted from simple things and being seen as different from other people. But everyone lives with at least one or two hardship in their life. Don't think of yourself as unfortunate. You can pull through if you think that there are people who are more unfortunate than you."

I thought to myself, hmm I see. My mom is probably in more pain than I am in. My mom works thinking about people who need help and are in pain. When I think about that, I can put up with my troubles. For

my parents, myself, and for the society, I decided to continue doing my best with the hope of being able to live.

Hospitalization

My first check up after starting high school. It still takes 2 hours by taking the freeway, so we left early in the morning.

I think I'll write down some things I want to tell the doctor.

1. It's getting harder for me to walk. I fall without holding on to something. It's hard to lift up my feet.
2. I start choking when I eat or drink in a hurry.
3. I laugh to myself a lot (It's like a grin. I realized after my brother asking me what's so funny about that).
4. What's the illness that I have?

After having to wait a long time like usual, I had a check-up with one old doctor and three young doctors. I guess to check on my athletic ability, I had to straighten and bend my legs, hit my knees, and walk like the usual.

My mom briefly talked about what I wrote down earlier to the doctor and also told her that I'm attending a normal high school with the help of my close friends.

After the check-up the doctor said, "Let's get you hospitalized during your summer break, for the treatment and also so we can take tests. Please go through the hospitalization procedure before leaving today."

Eeeek I'm gonna be hospitalized? Oh man. If I can get rid of this then I'll just have to pull through! I easily accepted it like that but, I really wonder what's going to happen to my body.

Something is on the verge of breaking down. It's going to get worse unless we fix it as soon as possible. I'm scared. I was told that I have to wait until I get hospitalized to get the answer to the fourth question. On the way home, I asked my mom.

"Is Nagodai (Nagoya Daigaku Fuzoku Byouin) a good hospital? Will they cure me? This is my first summer break being in high school and I wanna do so many things, so I want the hospitalization to be short."

"Aya, make sure to write down things that you notice about your body. It doesn't matter how small it is. It'll help with your treatment. That way your hospitalization might be short. If you think of this hospitalization as a short period in life, you can remember it as a good experience. Anyways, I'll only be able to check on you on Sundays so you have to do laundry on your own, without overdoing yourself. I'll buy you lots of underwear, but when you go home start writing down things you'll need and start getting ready."

On the way, we got out of Okazaki Interchange and we stopped by my aunt's (my mom's younger sister) house. I started crying while listening to my mom explains to her about my situation.

"I want to heal her no matter what it takes. If Meidai Byouin can't do it, then I'll go to Tokyo or America or search everywhere to find someone to cure her."

Then my aunt replied, "Aya-chan let's get better soon ok? Nowadays most illnesses are curable and plus you're still so young. But, you have to keep your faith and tell yourself "I'm going to get better." If you just sit there and cry then even the strongest medicine won't do any good. I'll occasionally come visit you. If you need anything just call me. I'll rush over there, so don't worry and just hang in there." She got out a tissue saying, "Come on, blow your nose and drink this juice. The juice is gonna taste salty if the tears get in," and made me laugh.

I know it's still 2 months away but please time, stop! Aya's illnesses please stop as well!

16 years old- The beginning of agony

My life in the hospital

My new life, first time away from home is starting.

I'm in a room with a lady who seems to be around 50 yrs old. My mom said, "Pleased to meet you," so I bowed my head with her. She looked like a quiet lady with lonely eyes. I was nervous not knowing what kind of life was ahead of me.

In the afternoon, I went on a walk with the lady. We sat on the bench under the cherry blossom tree. The sunlight looked like it was dancing between the leaves. Since I'm really near-sighted, I couldn't see clearly but I sensed "beauty" within the green and the light. Then, I sensed "oddness" in the leaves that were being blown, casually by the wind.

I've gotten used to the life in the hospital, but lights out at 9 and dinner at 4:30 is a little too early. The pace has changed, and a day seems to run past me.

I have to go through lots of tests like the electromyogram (owww this hurts!!), electrocardiogram, x-rays, and hearing tests.

I am taken from one place to the next in this big hospital, which is easy to get lost. I just can't stand the dark hallways. It even makes my mood dark.

My doctor, Yamamoto Hiroko sensei* (now a professor at the Fujita Hokeneisei Daigaku in the Shinkeinaika**) said that finally, I'm gonna get the shot that's gonna make me better. To see the before and after of the effects of the shot, we recorded my walking, walking up the stairs, buttoning, into a 16mm camera.

I wonder what I'm going to be when I grow up, or actually what can I be?

The 3 requirements that I have to meet:

1. Something that does not involve my body.
2. Something that I can do using my brain.
3. Something that gives me a decent pay.

This is hard. I wonder if there is such a job that meets all these requirements.

Some number of young doctors play around with me. Stand on your tiptoes! Close your eyes! Can you do this? Then something about my pelvis... After all that, they ask me "Was it fun?" I can't deal with this. I wanted to yell, I'm not a guinea pig, so stop it!

Sunday, the day I've been looking forward to is finally here. My mom and my two sisters came. We all went to the roof to do the laundry. The blue sky was really pretty. The clouds were white and pretty as well. The wind was a little warm, but it still felt good. It felt like I became a human again. They took some spinal liquid. My head hurts. It hurts terribly. Is it because of the shot?

Michan's family (my mom's younger brother's family) came. My grandpa's eyes were red. I was going to tell him, but I couldn't and so I was staring...then my grandpa said, "Do I look weird? I got a tan from working and I stayed up late last night."

It was so black that I felt bad. His eyes were like a rabbit. It looked like he was crying.

"Aya do your best. I'll bring you some good food next time. What do you want?"

"I want a book. Sagan's "Kanashimiyo Konnichiwa"*** I've wanted to read this."

I went to the Physiotherapy room underground.

I'm going to take a test from PT Kawabashi and Imaeda (PT=physiotherapist).

At that moment I said something stupid. I can't believe I told them that I like Japanese and English and that I have lots of confidence in these subjects, and how my grades were in the top of the class. This should be the last time I boast about my grades...it makes me look more miserable and will make me want to rob a bank or something. In any case, you can't really determine how smart you are by the grades on a report card.

PT. Kawabashi said he was a troublemaker when he was a student.

Actually, I think that's better...it's much more healthy.

I'm still so young and look at my body...

I felt so miserable that my tears started to fall.

I shouldn't say anything anymore. After writing what I wanted to write, I felt alot better.

The reason why I study so hard is because this is the only thing I'm good at. If you take studying away from me, all that's left is this useless body. I don't want to feel this way.

It's sad, and harsh, but this is reality.

I don't care if I'm stupid; I just want a healthy body.

*Sensei – teacher/doctor (in this case it's used as doctor).

**Shinkeinaika – department of neurology.

***"Kanashimiyo Konnichiwa" – commonly translated as “Hello Sadness”

Research

- 1) Test. I had to move my hands according to the song, twinkle twinkle little star.
Before getting my shot R(right) 12 times L(left) 17 times.
3 mins after my shot R(right) 18 times L(left) 22 times
5 mins after my shot R(right) 18 times L(left) 21 times

2) Rehabilitation

1. I had to stand on my hands and knees.
I had to move my body by keeping my balance (like making half a circle)
[rotating my pelvis]
I had to bend my leg, rotate my pelvis, go on my hands, rotate my pelvis again, and then lift up my hands.
*I'm not supposed to let my feet go, and my shoulder blade isn't supposed to move inwardly.
2. Reflex movement
As soon as I lift my leg, I have to catch my body with my hands. This will help me when I fall.
*My shoulder blades moved inwardly, and my weight pulls me back.
3. Exercising by swinging my hands
I have to swing my hands back and forth and watch how my pelvis moves.
When my right hand is in the front = my right pelvis has to go back
When my right hand goes back = my right pelvis has to come forward.

So basically, I have to alternate my hands and feet when I walk. For me...
When my right hand is in the front = my right pelvis goes back
When my right hand goes back = my right pelvis goes back

This is weird. Both my leg and hand goes back at the same time.
4. After standing on my legs and knees, I have to stand on my knees alone.
5. Making it right. I had to lean back my shoulders and straighten my body by lining up my knees with my spine.
6. I had to practice crawling.
Putting my right hand out->Putting my left feet out->putting my left hand out->Putting my right feet out
I have to keep my legs straight when I put it out.
Walking normal is a really hard thing...
7. Getting up

Dr. Yamamoto said to me, "A boy named K-kun is going to be hospitalized from today. He has a similar illness as you."

I passed by him in the hallway.

He was skinny and seemed to be in the 6th or 7th grade. He looked like an innocent and cheerful boy, who didn't seem to let his illness bother him.

I told him inside my heart, "I hope the shot will help you. Get better soon."

After getting the shot, I got a headache and became nauseous, but maybe because the medicine is actually working, or I'm getting used to it, there is less pain.

They recorded my voice. I wonder if they're testing my throat and tongue.

Rehabilitation is very important! That's what Dr. Yamamoto said. I knew I had to try my best, but it was really hard. I'm not normal...mom, I could almost cry.

We went up to the roof again and they took pictures of me with the 16mm camera. My body felt miserable.

PT. Kawabashi, I can only walk like a robot. This is sad. While we rested, PT. Kawabashi told me one of his childhood stories.

"I peed on a teacher's head from the roof and got beaten up." Wow...that's a dynamic prank... I can't do the same, but this feeling of wanting to do something, boiled up inside me. He also told me the trick to catching a cicada (both female) that's on a tree. He called the cicada's shedding of the skin, semi-nude! I thought to myself... I guess he's a guy too.

I got a fever. 102 degrees. Am I going to die? No! I can't lose to an illness! I miss my mom and family. Man, every time I try to take a step forward this always happens! It seems like this mental and physical unbalance is gonna last forever. I'm scared of getting old. I'm only 16 years old.

I only have couple more shots to go. Then I'll finally be able to get out of the hospital...supposedly.

Usually, it's a happy thing but it's different with me. When I first started the shots, I suffered from the side effects (nausea/headaches). My doctor said that the shots helped, but my expectation of being able to walk as I used to, doesn't seem like it was met. Now I have another notebook to keep other than my school diary... the notebook for physically handicapped people. My illness is where the cerebellum's cell takes over me physically, making it hard for me to move, and this illness was discovered about one hundred years ago.

Why did the illness choose me?

The word fate isn't a good enough explanation!

2nd Semester

My mom's teaching: It's okay to be slow, it's ok to make mistakes, and the important thing is to try your best.

I wanted to say, I'm always serious! My behavior may be....but when it comes to my inside... i felt a little sting.

After the opening ceremony, my mom and my teacher had a conference.

1. Although the treatment during the hospitalization helped me a little, recovery is difficult, since it is a complicated illness.
2. My mom asked for consideration for I might trouble people around me when I walk from one class to the next, and that problems may rise, but to let me do as much as I can.

My mom's idea.

1. To take the textbook apart and only bring the necessary pages. Take only one notebook and put tabs, to separate the subjects.
2. Change my school bag to a backpack.
3. To take the taxi to school, because the rush hours in the morning is dangerous. For going home, I have to choose to either take the bus or the taxi, depending on my condition.

"Don't do anything rash. I already talked to the taxi company, so you don't have to pay any money," said my mom.

Gosh, how much of a money eater bug am I going to be...I cause so much trouble, I'm sorry.

The evil 13th

I rode the bus from the gate of the school. I had to switch onto another bus so I got off at Asahibashi, crossed the street, and walked to the next bus stop. The light turned green. It's sprinkling. An elementary school boy shared his umbrella with me. I tried to walk fast trying to keep up with his pace. All of a sudden, I fell flat forward. Blood flowed from my mouth and stained the wet asphalt in red. There was so much blood gushing out, that I became worried that I might die, and started crying. The lady from the bakery in the corner of the street rushed out and helped me get up. She let me inside and wiped my mouth with a towel. She took me inside her car and drove me to a nearby hospital. She saw my student notebook, so she called the school for me and my teacher came. After the treatment, my teacher took me home. Lady from the bakery, teacher, thank you.

Aya's lip was swollen and her 3 front teeth were broken and gone. When I touch it with my hankerchief, it still stains in red. I'm a "girl." My 3 big front teeth are gone, and now I look ugly.

My illness is worse than cancer!

It stole the beauty of my youth.

If I didn't have this weird illness, I could have had a love life...I just want someone to rely on.

I just can't take this anymore!

Kaoru no Kimi ([To my brother...]Ikeda Riyoko)* said "I love you!" and left the person he loved. Do I not have the freedom to love or be loved by someone?

In my dream, I can walk, run, and move freely... In reality, I can't do any of that.

When I read the part where Nanako** starts to run, it makes me think how much I wish I can do that. Is this servile?

I slept the whole day thinking about when I fell. K-ko-san called me asking "Are you okay?" It made me happy. I probably have to be absent for a while.

I woke up at 7:30. My sister Ako-chan is going to Nagoya. She looked so cute that I kinda sulked.

It's good to wake up early. I got to eat the last cream puff. It was so good with the cream spreading through the inside of my mouth. It's hard to eat without my front teeth. I had to hold my mouth close to keep it from coming out.

I have to start going to the dentist from tomorrow. I want to hurry and be the old Aya again. I put the mirror away, which used to be on my desk.

I was reading a knitting book with my mom. This white dress that my mom used to knit for me when I was little was on there. "Mom, did you read this and make it?"

"Yupp, remember how you wore this on New Years with a pretty hair band and took a picture in front of the front door?"

If I was healthy, we would be talking happily saying "Oh yah, back then..." but it would get upsetting so we ended the conversation there.

*"Kaoru no Kimi ([To my brother...]Ikeda Riyoko)" – a character from a book called "To my brother..." by Ikeda Riyoko.

**Nanako is also a character from the book as well.

About my future

My mom and I talked about my future.

According to my mom, "Unlike people who cannot see or are handicapped, the things you were able to do before doesn't leave your mind. You think hard about why you can't do it anymore, and your emotions come out. So it always starts with the struggle with your mind. Even if others may view it merely as a machine-like radio exercise, its actually a struggle with your mind, it's a training. Aya, I think that as long as you live every day to its fullest, you'll have a future. Aya, you cry a lot, and when I see you cry, I feel so sorry. But looking at reality, you have to understand where you are right now and make your life full, or else you'll never live with your feet on the ground. Mom and your siblings will help you with things you absolutely cannot do. But when we talk about our opinions, or argue we're straight forward aren't we? That's because we think of you as a real live normal person and a sister. So take it as words full of love that will help you grow stronger mentally. This is a training as well, so that you will be able to go on when someone tells you something that stabs you in the heart. You learn love, and love what you know...basically you're surrounded by love and knowledge as the name of the place where you were born, Aichi-ken.*"

As I listened and took in the fact of my illness, I thought I should start thinking about my future.

"I want to be a librarian. To do that, I wanna go to college. Then I can get a degree as a social worker..."

"It'll be hard to go out. You should think about something you can do at home. For example, translating."

"I wanna write a novel, but my life in society is pretty poor so I guess that won't work."

"You can decide that later, but for now do what you can do right now, and put the effort! Yes the effort."

"Okay, I guess the only thing I can rely on is my scholastic ability."

*The place where Aya was born, Aichi-ken is made up of two kanji characters, ai (love) and shiru (to know), so that's what her mom was referring to.

Friends

I saw the sunset. The big red....

It quickly sank like a small sparkler firework that falls quickly, but it had a clear brightness to it.

The color was really beautiful. It was the color of an apple. Y-ko-chan and I said "Isn't it so pretty?" to each other and we're speechless after that. We saw a trail of an airplane shining in the red sunset.

I think Y-ko-chan is a really good person.

When I told her I wanted to study at her house, she strictly said no. I was so sure that she was going to say yes.

If I was in her shoes, I wouldn't be able to turn her down, and I wouldn't be able to study at my own pace, later regretting that I had said yes.

Basically, I lack self-control.

If I said that my physical handicap and my self-control is connected, would that be considered an excuse? It makes me happy that there is someone that can say what they think and that there is someone who listens to what you have to say.

Friends treat each other equally so I'm grateful.

S-chan told me, "I started reading because of you."

That made me feel happy. It's okay if I feel that I wasn't just a trouble to my friends...right?

"Aya-chan, you were crying a lot that one time remember? You were so cute."

"Really? Wow... no one has ever told me that before. But I saw myself in the mirror when I was crying before...and that wasn't a pretty sight."

"Well, I didn't see your face. The way you cried was cute."

"Haha that was harsh!"

What was cute wasn't my face, but the atmosphere I gave when I was crying. We both laughed.

Friends are so cool. I wanna be with them forever.

Agony

A thalidomide lady gave birth to a healthy baby girl. She changes the diaper and breast feeds, using her feet. I'm not sure if I'm supposed to feel happy for her, but only worry comes to me.

The Achilles tendon on the right leg feels stiff. I became depressed.

The most difficult thing for me is walking from one class to the next. I have to accept the help from classmates or hold onto something as I walk through the long hallways and stairs. It takes so much time, that I make my friends late to class.

Lunch time is a hassle too. Everyone finishes in like 5 minutes. I only get one bite or two in 5 minutes. Not only that, I even have medicine to drink. When I feel like I won't finish eating in time, I drink down the medicine, look around, and if I see that there's someone else still eating, I try to eat as fast as possible. I wonder how many times I was able to finish eating my lunch. I feel bad not being able to finish the lunch that was made for me, but I just don't have enough time.

When I try to eat the leftover at home, "Give it to Koro. You can eat alot at dinner."

Aww, what a waste. My lunch is like Aya + Koro.

Y-ko-chan and S-chan* always helps me like they're my shadow.

"Sorry for always causing trouble."

"We're friends aren't we?"

This really makes me feel alot better.

"Friends are equal." But not always. Especially for me, I have to be carried and such or else I cannot survive school life.

I finally understand why the teachers sourly tell me, "Put in more effort to walk on your own."

There is only one road for me.

I don't have the right to pick my options. I can never go onto the same path as my friends.

If I make myself feel better by thinking that I'm going to walk the same paths as my friends, my own path will disappear...

I wanna go somewhere...

I wanna hit something really hard, yell and scream like crazy, fall down laughing....

*Aya's friend's names Y-ko-chan and S-chan are used to keep their identities from the public, like using Person A and Person B in English.

Where I want to go.

Library, movie theatre, café (I wanna sit in the corner seat and drink lemon squash). But in the end, I can't go anywhere on my own. I feel so pathetic, miserable, and can't do anything about it, that I just cry.

I'm a big baby. But I can't help it. A crybaby and I have been together for 2 years now. Something little can't tear us apart.

Now, I can cry without making any noise and my nose won't turn red as long as I don't cry too much. There's nothing good about crying. It only makes me tired, makes my eyes puffy, plugs my nose, and takes away my appetite...

Lately I've been picking fights with people. Relationships with people are complicated. It's not like someone is wrong, but it just becomes worse without realization. I guess it's like my sickness. *tears*

My Diagnosis

I can't make loud noises anymore. I dunno if my abdominal muscle got weaker or if my breathing capacity is getting smaller.

Maybe because I'm limited with where I can go, but I don't even know what I want anymore. But... I want to do something. I wanna do something so badly that I can't stand it. My hands and feet are being tightly bounded. People being nice to me is a pain for me.

Y-ko-chan came with me to the bathroom. I made her 5 minutes late. After my feelings of "I'm so sorry! I'm really sorry!" this frustrating feeling of "Why can't I do this simple thing on my own? I feel so stupid and frustrated!" just builds up inside me.

A victim is a human that has a heart too!

Not being able to hear is not a misfortune. It's convenient.

I want to be happy, so I have to find something that I can compete equally, with a normal person. You're only 16. You're still young so try harder!

During homeroom, we had the picking of the different officers. 45 classmates, 44 officers.

I didn't want to think that I was left out, so I decided to do an angel's job*. I can pick up trash that's left on the ground, and even close the window. If I put myself into it, I can do a lot of things.

I'm about to lose to the sickness.

No! I'm not gonna lose! No matter how hard I try and act happy, when I see my teacher, sisters, brother, and my friends walking normally, I feel miserable.

I wanted to see something that would touch my heart, so I went to go watch a marathon by myself. But, it only made me feel more depressed. I felt a melancholy feeling in "Running." My friends are going to leave me. I started to realize what a big handicap it is to have a unhealthy body.

I decided to read my favorite book while sitting out during P.E.

I try to copy what I can get out from the book, "Hello Miss (Ojyousan Konnichiwa)," (Kusanagi Taizou). Right now, I'm reading "I'm 20years old (Bokuwa 20sai)," (Oka Shinji) with the thought that I will never commit suicide.

I cannot live without thinking. I can't just simply say, "Oh well."

Even walking....I think about what the best way of walking for me is, or if the path I'm taking isn't too rough for me, or cleaning as well... I think of ways I can do it on my own, in the most efficient way...

Even I feel pity for Aya.

But on the other hand there are good things too!

I can't go on without thinking that.

My body is becoming stiffer. I dunno if it's because it's getting colder, or because my sickness is getting worse, but I fall even when I'm holding onto something. It's too dangerous for me to go out into the road. Now my mom has to drive me to school. Before going to work, she drops me off at school. I hang onto her shoulder for support and she takes me to the shoe cupboard. While I put on the uwagutsu** (Everyone else has slippers), my mom runs to my classroom on the second floor to drop off my school bag and lunch.

Then I just slowly walk up to my class hanging onto the rail.

After school I wait until 6 'o clock at the candy shop across the street from school. The lady at the candy shop kindly told me, "You can go inside and do your homework or read."

Kids who are just going home from school, because of sports, come to the shop so it's a little embarrassing, but I put up with it because there's no other choice.

I fell again while walking to my class. I got a slight cut on my right temple.

S-chan helped me up. Before I can say "Thank you," tears started falling out of my eyes and I couldn't make it into words.

*The officers mentioned in this entry is kind of similar to a class cabinet except it's like, there's 2 people in charge for each thing (cleaning committee, cleaning committee...) Since Aya can't do any of it, she calls her job an angel job, where she does little things to help out.

**Uwagutsu – a shoe worn inside a school (worn in elementary school), different from slippers.

I don't wanna grow-up

Harsh words come out of my mom's mouth as I cry endlessly.

"Showing thoughts through crying is what a baby does! You're making high school students look bad!"

I became even more miserable and continued to cry (like a small lamb in the forest).

Dear Emi-chan (my cousin),

Emi-chan, why is Aya such a crybaby? Why can't I laugh naturally like I used to? I want to go back to the past!

I wanna make a time machine and ride it to go back to the past. Watch myself run, walk, roll around, and play with you... but then I come back to reality.

Do I really have to come back to reality?

I don't wanna grow up!

Time...please stop! Tears...stop falling!

Ahh...Aya just can't seem to stop crying.

It's already 9PM. Time will continue to move even if I break all the clocks in the world.

I can't stop time as long as I live.

It's not about giving up... I just can't do anything about it.

I love walking on the road.

In 7th grade, I walked 5km from my house to the audio-visual center.

If I pick up flowers as I walk, and look up at the blue sky, it's not a pain to walk at all.

I loved walking more than riding a bicycle or a car.

Only if I can walk on my own...

One friend says that she feels like a bad kid when she's alone. Another friend says that she feels most like her human-self, when she's alone just day dreaming.

When I'm alone...I don't like being alone, being alone is scary!

I wonder what my purpose of life is.

People always help me, but I can't do anything in return.

To me, studying is my source of life, but I can't find anything that is more important.

I can't walk the hallway which is only 3 meters.

Can't a human live only with their mind?

Can't I walk using only my upper half of the body?

I wanna be like the air. The good-hearted person whose kindness overflows and people realize how important she was to them, once she is gone.

I wanna be that kind of person.

We had a seat change in class, and now I'm sitting in the front row.

I need to plan out which path to take when I'm late for class. I need to be careful with my health or else I'll yawn, get a stuffy nose, and feel sick.

For snack, I ate baked sweet potato. It was really good.

It's only 2:30 but it seems like the sun is setting.

I didn't notice how most of the sakura leaves from the Inari Mountain had fallen.

Oh that reminds me! The school's maidenhair (ichou no ki) tree is turning!!*

Walking... by holding onto my friend's shoulders and the wall of the hallway, I fall when I look up.

Today is open house. I'm glad my parents didn't come. I just don't seem to like the mothers.

I get frustrated and my tears start to drop when they look at me from top to bottom with those discriminating eyes that say "There's a handicap person."

Who would ever choose to have this kind of body! I couldn't help it, but to cry at dinner, when I was thinking about those mothers who came to open house.

I know its no use crying, I'm sorry mother.

I went to parent-teacher conference with my mom. If I try a little harder in math, I would be in top class!
Let's do it Aya-chan!

It's 11:00. I can see the half moon smiling through the east window.

I wonder if I can pray if I turn off the light.

Living with my healthy classmates, I sometimes feel an uncontrollable frustration. It sucks.

But, when you look at it in another way, this frustration becomes a motivation for me to study harder.
I love Higashi-kou (Aichiken-ritsu Toyohashi Higashi High School), my teacher, S-chan, Y-ko-chan, M-e-chan, I love everyone.

I also love my senpai** who gave me a chocolate when I was waiting at the candy shop!

*“The maidenhair tree is turning,” – the leaves are turning into different colors, like red, orange, yellow, also signals autumn.

**Senpai – uppper-classman. If Aya is a freshman, then her senpai would be any sophomores, juniors, or seniors.

My Decision

My mom went to visit a school for the handicapped, in Okazaki. She told me about it, and for some reason, I couldn't stop crying.

My sister is studying very hard, because its exam week. I'm doing nothing. I can't get the school for handicapped children out of my mind.

Honestly, I know that I can't stay at Higashikou* for 3 years. I don't know anything about handicap school. It's an unknown world for me. Columbus and Gama must have gone into the unknown world with 4 hopes and 6 fears.

Hope

1. I will be able to see a clearer future.
2. I will be able to live my own life.
3. The facilities and the system seem to be very good.
4. I will be able to make handicapped friends.

Fear

1. I will be less like a human.
2. I don't know if I'll be able to live with other people.
3. Saying goodbye to my high school friends.
4. How the people (society) will look at me (because of the image of handicap school).
5. Boys.
6. A change within the family.

I wonder if my little sister will remember me, even if I go away and stay in the dorm. And my brother... Will he at least sometimes think about me? (This seems like I'm gonna go commit suicide or something).

S-chan has been living alone since freshman year, because her house is far and can't commute to school. The reason may be different from me, but I can understand her loneliness.

A big fly is buzzing by the window. Flies in the winter need to be killed. But when I thought about them giving birth to many children in the summer, I couldn't kill it, feeling the importance of "life."

I was looking at the new classroom building from the window. I became emotional as I thought to myself, "Aww this is Higashikou."

When I looked up at the sky, there was a white moon.

"You didn't choose to be sick. There are many things you can do, even if you are handicapped. If you were a person who didn't have the power to think, you wouldn't have been able to feel the kindness, and the warmth that people have, which you first realized after getting sick," says mom.

S-chan and I talked in the sunshine by the lakeside, listening to the birds singing.

"Aya-chan, you're one strange girl. You say, 'The sky is beautiful, it's so blue,' and is easily amazed. Your heart must be very pure," says S-chan.

I asked her, "Is there anyone that lets you be yourself when you're with them?"

"Hmm maybe my little sister or brother, because I can be arrogant. But I can be myself the most when I'm alone."

S-chan chose to live on her own. Aya is torn away from her family.

This is a big difference...

*Higashikou is a short-hand way of saying Higashi High School.

A High School Senior with a Canine Tooth

There is a girl in Biology Cub with braids who love mice. I walked with her to the library. I walked all on my own! I was very slow...but she walked with me adjusting her speed to my pace. She has 44 mice at home. She told me about the first time she got a mouse.

"Her name was Nana. She was a girl. She died from breast cancer. A mouse becomes like a human when they get sick, and then die. It's very sad, seeing an animal die."

I don't know anything about her. I could ask the upperclassmen or the teachers, but I don't intend on asking them, because I want to get to know more about her through her stories.

I was able to talk to her again.

People call her Sa-chan.

Her family consists of her father, mother, younger sister, and the 44 mice. In her own yard, there is a graveyard for her mice and she puts grasses on their graves.

In French, the forget-me-not is translated as a mouse. Sa-chan told me that this was because the forget-me-not looks like a mouse.

"I (she uses Boku* when she talks, even though she is a girl) think that when someone dies, they have died instead of me. You (Aya) have a bad leg. So, I think that I need to live my life earnestly for you."

"I believe that people have special power (I just nod and listen to her). To an amoeba, we are people with special powers, so for a blind person, aren't people who are able to see, people with supernatural powers?"

Sa-chan doesn't toil. I love her! But neither Sa-chan nor Aya will be in Higashikou next year.

In English grammar class, K-chan cried saying she was disappointed. (She had gotten a low grade on her test).

The teacher became frantic and said, "Don't cry! If you're gonna cry, you should have tried harder in the first place."

It was scary. Thinking that I would never get in trouble like that no matter how bad my grade would be, made me sad.

I was telling Sa-chan about the time when my body became warm from doing sports.

"Playing push-and-shove is the best!"

"Even in soccer and basketball, you don't need to touch the ball, all you need to do is run."

I was a little embarrassed when I rambled on about the things I cannot do anymore.

I watched the movie, "The Lily in the Field" on TV.

I believe in God. Thinking that God is probably testing me through these hardships, made me feel a lot better. Somehow, I do not want to forget this feeling.

It's almost New Year. Many people helped and cared for me this year. It seems like next year is going to be a tough year... fighting against myself. This is because the Aya right now cannot admit that she is a handicap. I don't want to. It's scary. But I can't keep running away! If I go to handicap school...

It scares me to think about attending the handicap school. It may be true that it would be a great place for a handicap person like me, but I want to stay in Higashikou.

I want to study with everyone.

I want to learn about many things and become a big person.

I don't want to think about my healthy classmates leaving me behind.

My mother sometimes talks about the handicap school.

Aya is capable of doing things on her own even though it may take a lot of time.

She told me how I can change from a person being helped, to a person giving help.

I am on the cliff of making a huge decision and that time is coming soon.

*Sa-chan uses the word, Boku which are used by boys for the word, "I." Therefore, Aya makes a comment about her using that word.

Revolution

I wanted to transfer schools by making the decision all on my own.

I have been telling myself that I would put an end to it by the third semester.

<Memory 1>

Mr. N, until today I have respected you and trusted you. It disgusts me how; he can just put an end to it like this.

He could have just told me directly, "Go to the handicap school, because this school can't take care of you any longer," instead of telling my mom, "It is taking her longer to get from class to class."

If he would just tell me straight forward, then it would be much easier for me to make my decision.

Stop staring at me!! Gosh this is so irritating.

He asked me, "Has your mother told you anything yet?"

Why do you have to hint everything! Just tell me!

Although my life is a continuation of hardships everyday, why couldn't you listen to what I had to say, so that I can leave this school feeling a little better?

If you would have let me talk, I could have easily said I will be transferring schools from junior year...

I was planning to go to the handicap school from April but...

I wanted to leave this school with confidence but I can't even do that now.

I can't leave feeling like this....

<Memory 2>

I talked to S-chan.

"At the handicap school you'll no longer be special, so you won't have to feel as distressed as you used to. But... if you have the desire to do things quickly, you can do it, so why don't you put some effort into it?"

I felt a sharp knife go through me.

Our friendship stays strong because of her 99% kindness and 1% strictness, so I didn't cry.

My emotions become numb when I'm in a great shock.

S-chan taught me to "think."

I was re-born.

Although I am physically handicapped, I thought my intelligence were the same as any healthy person.

Missing a step while climbing the stairs and falling all the way down...that's what it feels like.

My friends and teachers are all healthy. This truth makes me sad, but there is nothing I can do about this difference.

I am going to leave Higashikou and I will live "alone" carrying this heavy package called handicap.

I at least needed 1 liter of tears to make this decision and I will need more in the future.

I don't want to cry anymore.

Losing makes me frustrated.

If you feel frustrated, do something about it!

I can't continue to lose.

My first visit to the doctors after New Year's.

I was a little relieved after talking with Dr. Yamamoto.

Enthusiasm stirred up inside me.

My mother quickly talks about transferring to the handicap school.

My doctor said she would ask the board of education.

I started to get my hopes up, but even that was easily popped like a bubble.

I suddenly remembered myself being very rebellious these past few days.

You (as in myself) have been relying too much on people.

I just realized this.

You have been taking advantage of the people around you.

That's why your friends got tired. It's too late to realize now.

We ate out at "Asakuma" (restaurant), which we haven't gone to in a while. My mother told my siblings about me transferring to the handicap school. I became irritated and said, "They already know, so don't talk about it!"

"It's true that Aya, you're the one transferring, but it's not just about you. It's important for all of us to think, help, and cheer up one another, in order to solve family problems. This connection is very important," my mother said.

It's better to be naked once*. I started to think that there is no need to feel the excitement.

Hamburger steak was really good. I ate ice-cream, which was for dessert in a second.

W-kun, O-kun, D-kun, thank you for always saying "hi" to me. It really made me happy.

M-kun thank you for carrying my bag.

I was finally able to say "Hi!" to H-kun...

This year was very long.

I really enjoyed this year with everyone. I'm finally ready.

Goodbye and take care...

*"It's better to be naked once" – once someone is naked (not literally, more like emotionally, mentally, inwardly), they can see something new.

Organizing My Feelings

The class distribution for the junior class was announced.

My name is no longer there.

I was able to make a decision, but it still makes me sad.

Only if I could just be healthy...

Get over it already! How long are you going to stay like that!?

You have to be able to have confidence that you yourself CAN overcome this illness!

I can't write as well anymore...is this a sign that the illness is getting worse?

It's okay if you fall.

You can just get up again.

Why don't you look up at the sky, while you're down there.

The blue sky spreads across above you.

Can you see it smiling at you?

You are alive.

I cried in front of my friends.

It made me very sad when my club teacher asked me, "Are you quitting school?"

Does it make you feel good to be crying? Not only does it make the people around you feel bad, but doesn't it make you feel empty?

Then stop crying! You're cuter when you smile.

And if you have something to say, just say it before you start crying!

Right now I feel worthless.

I'm gonna skip shower and go to sleep.

Tomorrow, I'm going to the handicap school for an interview.

Make the decision and don't cry anymore.

I continue to hope and pray to become someone great.

Handicap school...this name has a dark image...

Why can't it have a different name?

There may be nursing help inside a school, but there are no nursing society...

Conference with my teacher.

"I think that you could continue your studies at Higashikou with this small degree of handicap.... I wonder if something can be done if you don't have trouble with actually taking the classes. Are you really satisfied? Because the average of the academic ability at a handicap school is pretty low."

I cried inside myself, "I don't wanna hear it anymore! I don't want any sympathy!"

I actually had a slight hope when Dr. Yamamoto called the Board of Education. But their answer was that they have left the decisions up to the principal.

My mother said, "We were told that Higashikou cannot take care of her any longer, so there's nothing we can do about it. Coming to this decision was very difficult for Aya, but I want her to have hope and start a new life. Aya herself has already made the decision. Please carry on with this decision that we have made."

Honestly I still had a connection with Higashikou, but listening word for word, to what my mother was saying, my feelings became one with my mother.

As long as she is my support, I will be able to go on.

God, I will listen to my mother. I felt a deep love in her action. I'm going to become a better and stronger person.

On the way home, I stopped by Emi-chan's house. I had called before I went, so my aunt had great food ready for me, and when I got there, everyone was waiting for me.

I ate until I was full, and I was so sleepy I couldn't even think about studying.

I was planning to do my best on my last final exam, but so many things were happening that I couldn't concentrate.

I couldn't help but to think about the "flowering quince"* inside the classroom...the color is really pretty, but why was it given such a name?

Ms.Motoko said,

"Whether you choose to go to handicap school or stay at Higashikou, the ultimate decision lies in your hands. That's what it means to live."

But I thought to myself,

"I have no choice, but to go to handicap school. I wanna stay in Higashikou, but the school won't let me, because they say I can't keep up with the school life. So, it's not really my decision. You're just saying things in a nicer way."

Ms.Motoko continued, saying,

1. Stay clean. Be very strict to yourself and don't let anyone think that handicap people are dirty.
2. Treasure your friends.
3. In the future, you should master typing.
4. Don't forget about Higashikou."

I didn't tell her, but I kept repeating what she said and how I felt, over and over again in my mind.

The people around me surround me, attacking me with the word "handicap." I forced myself to think that the handicap school was the only place for me, trying to calm myself, and made the decision to transfer. I looked back a couple months since the path of handicap school came about.

Emotionally, I had made the decision, but I realized that nothing was really organized in my mind. That's why my emotions were always so unstable.

I read the Bible. I accepted Jesus' words and calmly thought to myself... I'm sorry God, I still lack faith. It's very difficult to become a devout Christian.

Alright, I will put my feet firmly on the ground and think rationally.

<Advantages about Higashikou>

1. Allows people to see that there are people like me through our daily school life. (Gain the kindness to help each other)
2. Having many complex by comparing my handicap self with the normal healthy people, becomes a power for me to try harder.
3. I can learn a lot from my teachers and friends.

<The drawbacks>

1. I cannot keep up with the class schedule.
2. I have the habit of relying on my friends and teachers.
3. I only hang out with the same group of friends and cannot join other larger groups. (My abilities has limitations).
4. I become a burden to people because I cannot help during cleaning time.

<Advantages about going to a handicap school> This is just my image.

1. I can live independently.
2. Become less of a burden to the people around me.
3. I can think about my future.
4. Gain skills needed in life.
5. Between the handicapped students, we will be able to understand each other.

<Drawbacks about going to a handicap school>

1. Start to use the term "handicap" as an excuse.
2. Have fewer opportunities to interact with my healthy friends.
3. My learning speed will slow down.

*A "flowering quince" is called "boke" in Japanese. This word boke means to be a little stupid, silly, or dense, so that is why Aya asks herself why the pretty flower is given such a name.

The Farewell

4 more days until the closing ceremony.*

It seems like they are folding 1000 cranes for me (This is just my guess).**

I will always keep it in my heart that I-san and G-san were folding those cranes for me, so that I will not forget even if we have to say goodbye.

It makes me happy that they are wishing for my happiness...but I wanted them to say, "Aya-chan, please don't go!"

My heart is full of hatred to my friends who didn't say that to me and to myself, for not trying harder so that people would say that to me.

But...to keep my promise with Mrs. Motoko (which is to not think badly of my friends), I didn't say anything.

When I told my mom, she started singing, "Forget about the past. If you keep looking back, you won't be able to move forward. Walk three steps forward, then two steps back. Life is~"

I started to laugh.

A friend gave me a cycad fruit. Its color is orange.

I love this color...it's such a really warm color.

I talked with Mrs. Motoko for the last time.

She listened to all my complaints.

"Don't be so harsh on yourself. Life isn't just about studying and school. What can you do if you're thrown into society when you only have academic skills? Studying was merely an escape route for you. You've avoided carrying your own bag, and washing dishes and only concentrated on studying... am I right? That's why your view of life is so narrow. You need to create a revolution. You should be happy that you were at least able to go to a normal school for a year. At the handicap school, there are children who have lived in hospitals all their life. Compared to them, you've been hit with the harshness of society, so you know not to always rely on people. For a 16 year old, you have an immature side and a mature side. You're an unbalanced person. This is because you haven't experienced enough of life for a 16 year old. It's not too late yet, so don't give up. Go and gain lots of things at handicap school that you couldn't gain at Higashikou. You can even cause mischief. You can do it! But, it would have been better for Higashikou if you would have stayed."

I was really thankful to be able to meet such a great teacher. I'm going to tell her "goodbye" with a big smile.

When exams are over, there's no school until the closing ceremony.

My parents planned a small party for my friends, and all the people who helped and supported me this year.

We talked, played poker, and played gomoku narabe.***

S-chan gave me a coffee cup, Y-ko-chan gave me a music box, and A-ko-chan gave me a dry flower.

My mom each gave us a fountain pen saying, "Goodluck with your studies and I would be happy if you would sometimes remember Aya when you look at this pen."

We all became silent. When I realized that the time for "goodbye" had finally come, my tears started to flow, but I tried hard to keep it from falling. I had promised myself to not say goodbye in tears.

I had a really fun time, but once everyone left, I became lonely and cried like a baby.

*Closing Ceremony is when all the students of the school get together in the auditorium and the principal gives a speech. It is similar to a graduation, but different, since there is a closing ceremony on the last day of every semester.

**There is a custom to fold 1000 cranes out of origami, to wish for the health of the sick people.

***Gomoku narabe(5 stones in a row) is a board game with white and black stones and the point of the game is to get 5 stones of your color in a row.

Reflecting and Regretting

The time has finally come!

It's March 22. The closing ceremony breezed by and I went inside the classroom. Everyone wrote me farewell messages on a paper.

I wanted to shout saying, "Thank you for always helping me! I will never forget you all. I'm going to be transferring to a new school, but I will try my best. I hope that you all won't forget me, Aya the handicapped girl," ...but I couldn't stop crying.

S-chan, Y-ko-chan...

"It's a hassle sometimes trying to help Aya all the time." My teacher told me what my friends had said one day.

I don't know why I never realized it. I was always only focused on myself. It's all my fault that I have made everyone feel this way.

Aah don't say anything anymore! I've already reflected on my wrong-doings enough...

During the Star Festival,* I wrote "I want to be a normal girl" and my sister got mad at me and asked me, "What makes you so different from a normal girl?"

I wanted to fight back saying, "What's so wrong about writing the truth?"

I realized that it's very difficult to admit that you are handicapped, even though you know that you are.

*Star Festival, known as Tanaba in Japanese is celebrated on July 7th. People usually write their wishes on a small piece of paper and hang it on a bamboo.

Direct Appeal

Dr. Hiroko Yamamoto's Profile.

She is small with short hair, and glasses. She is always wearing a white robe, but she wears earrings and rings that are not too fancy, which makes her look fashionable but not too gaudy.

She has been my doctor since I stayed at Nagoya University Hospital. When she transferred to Fujita (Nagoya) Hoken Eisei University, she contacted me so I changed hospitals with her.

She is quick-minded, prompt, and quick with anything she does. She is reliable and sometimes she would drive me to different universities for physical examinations. She is an amazing person.

When I asked her, "What high school did you graduate from?"

She simply answered, "Meiwa."

Even I knew that Meiwa is a school for the elite. She told me that after Meiwa, she entered Nagoya University. I love her because she never boasts and is always so warm. When I'm with her, I cannot be my lazy self.

For a year and a half, I have continued to go to the hospital and at times was hospitalized, but I knew that my illness was getting worse.

Maybe because the cells in my cerebellum were being destroyed, but my body movements have become awkward and I have trouble moving my legs, since my knees would not bend.

I can't even talk loud anymore, and can only say one word at a time. I can't even laugh Wahahaha and when I try to, it comes out as Wawawa.

I still tend to swallow accidentally without chewing and I am losing my strength to move my tongue.

Next time when I go to the hospital, I'm going to ask the doctor, "Without hiding the truth, please tell me what's going to happen to me."

It's scary to ask, but I need to think about my future. Depending on her answer, I might need to re-think about how I'm going to live my life.

Shopping

My mom was making phone calls to different places and suddenly shouted from downstairs, "Let's take Aya to Yuni (a shopping center). They said they have a wheelchair so Aya, you can go too!"

It was during spring break and we were all at home. After taking forever for me to get ready, they put me in the car and off we went. We arrived at Yuni in 15 minutes.

With my favorite pochette* hanging from my neck, I looked around the apparel section with my sister pushing the wheelchair from the back.

Everything looked interesting to me.

There was a pretty skirt and I wanted to wear it.

Since I always crawl, wearing a skirt would hurt my knee so I have always worn pants.

Wearing a skirt was a dream for me.

I grabbed some courage and pointed to the skirt.

My mom said, "It would be nice if you had one. It's going to get warmer soon," and bought me the skirt.

I was really happy. If I wore a white laced blouse with this flower printed skirt, and stood up straight and tall, I wonder if everyone would tell me I look cute. Just once... I would like to be told that.

We bought a lot of underwear, socks, and towels for my new life in the dorm.

Suddenly, I became sad. I'm going to the dorm in a few days and live away from my family. I had promised myself not to cry anymore, but I just can't help it. Be strong. Be a strong person who can overcome anything.

*Pochette – a small bag carried around the shoulder.

The wheelchair

"Aya," said Mom, "we're going to buy you a vehicle!"

"What!?"

She started explaining slowly. "The corridor has a handrail, but it may be dangerous when you want to go across. From a stand position, you'll have to sit down, crawl across, and then stand up again. This may cause you some anxiety when you're in hurry. And you often all over when you're changing your position. You won't be able to go outside, either, even if you want to. But it would be different if you had an electric wheelchair. You could easily operate it despite the weakness of your arms, and you won't have any problems even on slopes. It can move at speed of 5 kilometers per hour - the same as walking. So there's no danger, and it's very easy to operate. I think it would be perfect for you. But that doesn't mean you should get lazy, you know. It's not good to start relying on a wheel chair. You'll have to try to move using your own efforts as well. You mustn't neglect that. Have you been training properly?"

I was so pleased with the thought that I could freely go out. My world suddenly seemed to get wider. I've always wanted to act at my own direction. Up to now at a bookstore, I've had to show someone a memo with the title of a book written on it and ask them to go and find it for me. Fancy being able to pick up any book with my own hands! It's like a dream.

Great! I'll master the operation of the wheel chair and go out in it before I enter the school for handicapped.

Two men from a car maker delivered my wheelchair. I watched them assemble it. The wheels are moved by a motor. It has two batteries installed next to each other down below the seat.

"Aya, you have a ride. All you have to do is hold this bar and move it in the direction you want to go."

I tried sitting in the wheelchair. I pushed the bar forward slightly and the wheelchair slowly moved forward. It only makes a slight wound when it moves and turns. I practiced hard, but after a while, the tears started to flow-that's my nature, and I hate it!

"What's the matter?" Mom asked.

"I'm just so happy because I can move around again freely after such a long time!" I answered. But I couldn't express my complicated feelings very well.

I'm determined to practice until I can to get a bookstore. When I looked out through window, it was raining.

I worked very hard, including wiping the kitchen floor and cleaning the toilet. I wanted to vent my energy on something. My study is making a little progress. (I smile in glee, finding that I still have the spirit to study.) Rika calls my wheelchair 'The Chair' and my father calls it 'The Car'. And that's what it is in Japanese-kurumaisu-'a car-chair'!

I still remember something that happened when I was in the first grade of high school. Rika was about to play around with some wheelchairs lined up the corridor of the hospital. Mom said to her, "You shouldn't play around with wheelchairs. It's an insult to those who can only get around but riding in one/

I read about the prisoners in the German concentration camp of Auschwitz in the book Man's Search for Meaning. The book's a record of their experiences. Somehow, as a disabled person, I empathize with them. My experience seems to resemble theirs in terms of gradually becoming numbed.

Friends of The Disabled

'Tanpopo no Kai' (The Dandelion Association) is a group of disabled people who got together somehow or other. They took me to a coffee shop called Baroque which has a harpsichord. When I said, "I'd like to come here again when it's being played," Yamaguchi-san smiled.

I dropped by Jun's house. She's deaf, but she actively communicates through sign language. Her facial expressions are very cute. I've learned a little sign language. I want to become better at it and become a close friend. Jun's mother gives an impression very similar to Mom's.

What I've Learned from My Friends

1. If I remain timid, thinking I'm disabled, I'll never be able to change myself!
2. Rather than seeking after what you've lost, improve what you've been left with.
3. Don't think you're smart or you'll only feel miserable.

Changing Schools, Life in A Dormitory

I arrived at the dormitory with a car full of household goods. The other students were also returning ready for the new term. The school has big rooms laid out like classrooms. Inside each one, there's an aisle running down the middle. It divides the room into left and right parts, on which there are tatami mats. Each student is provided with a cupboard and a fixed desk with a lamp. My new castle is the place nearest to the closet. Mom sorted out the things we'd taken to make my place comfortable.

"You won't need this yet," she said, "so I'll put it in the upper cabinet. But I'll put this near you because you often use it . . ."

The mothers of other students were also busily sorting things out. Nobody seemed interested in me.

Whether that's good or bad . . .

"You should try and forget Higashi High School as soon as possible," Suzuki-sensei told me, "and become a student of Okayo (Aichi Prefectural Okazaki High School for the Physically Challenged.)"

So in order to 'forget as soon as possible', I removed my Higashi school badge and class badge and put them at the back of the drawer,

It's becoming really difficult now to move my legs forward. Holding desperately on to the handrail along the side of the corridor, I told myself "Don't be afraid, don't be afraid!" Tears came to my eyes as I thought, sadly, "I may perhaps . . ."

B-sensei's words flew over to me: "People are designed to be able to walk!"

I agree!

I empathize!

It's an unparalleled declaration of war!

"Climb Mt. Niitaka!" (the signal to start the attack on Pearl Harbor)

I fell over on the way to the classroom and started crying. A-sensei was just passing and asked me, "Are you sad?"

"I'm not sad," I replied, "just disappointed."

Why do people stand and walk on two legs? This is usually taken as a matter of course. The question came to me as I watched my friends walking briskly into the distance. Walking is really something . . .

I'm glad that I came here.

-Watching students playing baseball under the window . . .

-Watching students practicing sumo wrestling with the teachers . . .

But, getting accustomed to it is something else. I sometimes feel I'm in limbo. I've begun to accept the fact that I'm no longer a student of Higashi High. But I don't really feel that I'm a student of Okayo yet. If some stranger asked me, "Which school do you go to?", I wonder what I'd answer?

Emotional Turmoil

In the classroom, I said to A-sensei, "In my dream, when I stretched my back straight, I was able to walk briskly. You were pleased to see me doing that."

"Up to now," he said, "you've only had to think about your studies. But now you may be having a hard time with cleaning and other duties."

He then told me this:

"A child suffering from progressive muscular dystrophy wrote this poem:

God presented me with a handicap
Because He believed
I had the power to endure it

It somehow sounds like Hitler's words."

"Well," I replied, "I've actually had similar absurd thoughts, like 'I'm kind of mutation' or 'I'm only living here at the cost of many people.' And I've taken various viewpoints and thought many different things in order to comfort myself." After the rain, I could see a rainbow from the window. It formed a beautiful semicircle. I quickly climbed into my wheelchair to go outside.

"I envy someone who can ride in a wheelchair," said T-kun.

Hey, T-kun, I'll stick pins in your image!

I really wanted to say to him, "You're all right because you can walk." But I couldn't say it. The words might have ruined that beautiful rainbow.

Either Mom or Dad comes to collect me every Saturday. I stay at home overnight and then come back here on Sunday evening. I always have a fresh bruise somewhere on my body when I go home.

"Do you often fall over?" Mom asks me when she sees them.

"Well, because I'm so slow, I'm always pressed for time," I reply. "I ask the dormitory matron to wake me up at 4 a.m. and then I start studying. Otherwise I can't finish my daily duties . . . But the more I try to hurry, the stiffer my body gets, and I fall over."

With the motto "I must walk as much as I can!", I try not to use the wheelchair apart from when I go outside. But when I'm in a hurry or when I want to go to the library-which is located rather a long way away-I use it to save time.

I'll accept commuting to school in the wheelchair! (To be honest, when I ride in it, I tend to think, 'I'm done for. I can't walk any more.' And that makes me feel more miserable.)

I met the matron in the corridor.

"Good morning," I said.

"Oh, Aya," she replied, "are you going in your wheelchair? It's comfy, isn't it?"

It was so frustrating to hear her say that. I had a choking feeling and could hardly breathe.

What do you mean, 'comfy'? Do you think I like to ride in a wheelchair? No! What I want to do is walk. I'm very distressed that I can't walk. I suffer a lot from that fact! Do you think I ride in a wheelchair because I want to have an easy time?

I felt like pulling out my hair.

Mom's gray hairs are getting more conspicuous. Perhaps it's because my condition has taken a step backward.

Understanding The Disabled

Today we held a small Sports Day at school. The warm May sunshine felt so good. It was also Mother's Day and my younger sister's birthday. So it was a day for congratulations.

I rang Emi, my cousin who lives in Okazaki, to ask her to visit me. I wanted her to know how desperately I'm trying to live . . . Emi and I have been close since our childhood. We used to stay at each other's house during the summer or winter holidays and share the same futon. She looked so nice that nobody would have thought she was still a third grader at high school. She has big eyes with long eyelashes and she'd decorated her twisted hair with a gold hairpin. She was wearing a white blouse, a flared skirt, and red slip-on sandals with high heels. She came with Kaori, her younger sister, who is rather boyish and, in fact, is often mistaken for a boy.

There's a secret patch over clover in the corner of the playground. The three of us planted ourselves down and started to look for a four-leafed clover. I wanted to find one as a present for Mom.

"I wonder if we can really find one?" Said Emi.

I replied what had been in my mind for some time. "A four-leafed clover is just a deformed version of a normal three-leafed one, right? Why should something deformed be lucky?"

Emi thought about this a little, and then said, "Because it's unique."

Perhaps she's right. It's not so easy to find happiness. I suppose that's why we feel happy and say "Good thing we tried to find one!" when someone eventually does.

I fell over this morning and hurt myself. It made me cry. I have to become much stronger. I don't know whether it was because I was in hurry or just rushing. When I tried to move my legs forward, they wouldn't move, and so my body tumbled forward. I caught the handrail, but it didn't support me enough. Down I went with a thud.

When I was being carried on a stretcher along the corridor to the nurse's room, I caught a glimpse of the blue sky.

"Oh," I thought, "it's such a long time since I saw the blue sky lying on my back!"

And when I was lying on the bed in the nurse's room, I could see the sky through the windows again. The white clouds looked very beautiful as they drifted across the blue sky. Right, in the future, whenever I'm stuck, I'll look at the sky. In the Sukiyaki song, Kyu Sakamoto sang, "I look up as I walk along, so my tears won't fall . . ."

That's good, that's the spirit.

I slept well for about an hour. I felt much better, so I got up and went to the toilet (the Western-style one). In the toilet, it struck me that perhaps Auguste Rodin came up with the idea of creating *The Thinker* when he was sitting in a toilet.

I'm always defeated by the fact I move so slowly.

Yesterday, it was my turn to do library duty. I eventually got there after taking about 20 minutes using the corridor on the second floor. But there was nobody there. I was too late. Half crying, I borrowed *Wild Animals I Have Known* by Ernest Thompson Seton. I cried, even though I knew I could contact the dormitory using the interphone if I was shut in the library.

Today I got there at about 4 o'clock. The student on duty sent me away saying, "Please leave quickly! If you wanted to look for a book, you should have come earlier."

Resentment! I felt pitiful. I'm twice as slow as the others, so I don't have time to spare. It takes too much time to do ordinary things (e.g. washing). It's not a matter of lacking good ideas and intentions.

Today we went on an excursion to the zoo. I don't like zoos anymore.

-The sad face of an orangutan. (I've heard that orangutans are nervous animals that easily get neurotic.)

-A chimpanzee throwing stones.

-A pelican who can't even catch a fish

-A battered ostrich.

Looking at all those creatures I got tired and depressed.

I hate the duty roster system at the dormitory. But I suppose it can't be helped because without it group life couldn't operate . . . Because I'm slow, I'm always one or two steps behind everyone else for any activities we do together.

In order to cover up my slowness, I finished cleaning half the room before I went for the radio gymnastic exercises in the morning. But when I got back, the room leader suddenly said, "Aya, you can't clean the room, can you? So take care of the towels and disposal boxes in the toilet!" I was frustrated that I didn't argue back when she jumped to the conclusion that I couldn't do it.

'Forgive everything, bear the unbearable, endure the unendurable . . .' In some ways, the teachings of God distress me. It's that way of thinking that has made me weak.

If I could move my body faster, I'd have been happy to go and clean the toilet. But I couldn't clearly express my opinion. I left the room without saying anything (although I was thinking, "You rat!").

As soon as I went out, I felt bitter and I started crying., The matron was just passing and said, "Aya, you know you shouldn't cry while living in a community like this."

What can I do?

I went home. I cleaned the parakeet cage. When I was walking, I felt a slight pain in the inner side of my left hip joint. I sighed, thinking that now my important left leg is breaking down . . . I was horrified to see the unnatural movement of my left hand (the five fingers move individually when I open my hand or bend them). I also have a pain on the left side of my chest, in the joints of my arms, and in my right buttock. Perhaps I hit myself in the wrong place when I fell over. I should put a poultice on again.

My right leg and knee sting. Finally . . . In the bath, I stroke them, murmuring, "I banged my lower back and shoulders when I fell over. Poor body, damaged all over!"

From today, I'll try to walk for 10 minutes every day. Here I am challenging my self to see how far I can walk! At this rate, I won't be able to maintain a human elevation of 1.2 meters (the height of my eyes when I'm standing) when I'm in the third grade of high school.

I asked one of the students to show me photos of the third grade school excursion. I wonder if I'll be able to join the excursion next year.

In order to understand that I'm a disabled person:

1. Giving up. I must know my limitations and admit that I have a physical handicap. I'll make an effort from that starting point
2. Forgetting my healthy past self. I can run in my dream. According to Sigmund Freud's *The Interpretation of Dreams*, I have an incredibly strong desire (that's only a matter of course).

Tomorrow's the day for our student dance performance. I'm still lacking full awareness of being disabled, so I've been trying to dance beautifully. Actually, I think that spirit is wrong. I've practiced hard, but it hasn't gone very well.

As I was coming back today, feeling wrecked, the wheelchair motor at a low speed began to sound as if it was suffering as well.

"Am I so heavy? I'm sorry. Keep at it!"

I felt responsible for my weight of 35 kilograms.

Am I in high spirits today? No way. I'm just doing my duties because it can't be helped. I went to take part in the radio gymnastic exercises, had a meal, did some washing, took out the rubbish, attended the roll call . . .

The matron said "It's busy in the morning, isn't it?"

I wished I could have answered calmly, "I'll be busy the whole life." But my face just froze.

I think it's only when people are walking that they can really think of themselves as being human. For example, a company president thinks about ways of making more money while walking back and forth in front of his desk. And maybe that's why lovers often talk about their future while walking along together?

Suzuki-sensei's eyes
Remind me of an elephant's eyes;
A guardian deity in India,
An elephant knows everything.
I love those gentle eyes.

I was in a daydream in the classroom. All by myself . . . I remember being told off by my teacher for running along the corridor and rattling my desk when I was at elementary school! I remember a boy having his bottom spanked for jumping out into corridor through the classroom windows. I couldn't do a practical joke like that. I only watched with a smile on my face. I should have done things like that while I could.

Jumping out through the window . . . No one was there. It was quiet. There was a windows and there I was.

THUMP!

"What the hell are you doing? That's dangerous."

The nurse's room had to help me again. A-sensei referred me as "a girl with self-injurious behavior." It was painful, but I had the satisfaction of going out through the window even if I had to crawl.

I won't do it again.

I was hoping that the movements of my body would get a bit better as it got warmer. But in fact they're getting worse. I was hoping to enter the hospital during the summer holiday to benefit again from some new medicine, so I went to see.

Cold words . . . I can't enter the hospital during summer holiday because they won't have any new medicine . . . I felt that I even medical science had given up on me! It was like being pushed off a cliff. Now I'm filled with a sense of despair. It's as though I've been hit on the back of the head with a hammer...

17 Years Old - "I can't even sing anymore . . ."

For my birthday, Mom and Dad gave me five lovely notebooks and letter sets. Ako gave me a sand-glass. Hiroki gave me a bold-tipped ballpoint pen with four colors. He said I shouldn't cry any more that I'm 17. Kentaro gave me a book titled Shiroi hito, Kiiroi hito (White People, Yellow People) written by Shusaku Endo.

My Wishes on Becoming 17 Years Old

I want to go to a bookstore and a record shop. It's difficult even in my wheelchair. I can't move my hands the way I want to, and I often make mistakes operating it.

If I could go to a bookstore, I'd buy *Gone with the Wind* and *Anya Koro (A Dark Knight's Passing)* by Naoya Shiga.

If I could go to a record shop, I'd buy an LP of Paul Mauriat's music.

I tumbled in the bathroom. I couldn't stay balanced on tiptoe (I may no longer be able to do that) and I fell down on my bottom with a thud. I wasn't hurt but I was scared. Yes, I'm scared.

I wonder if my disease can heal naturally? I'm now 17. I wonder how many more years I'll have to fight against it until God forgives me . . . I can't imagine myself at the same age as Mom is now (42). I couldn't imagine becoming a second grader at Higashi High, and now I'm afraid I may not be able to live till I'm 42. But I want to still be alive at that age!

Homecoming

I felt so happy thinking about going home for my first summer holiday from this school that I couldn't get to sleep. I'm sorry I can't enter the hospital again because they can't get any new medicine. But I think my new medicine in the future will be in tablet form rather than injections. I was told that they're making an effort to produce it, so all I can do is give up and wait.

Just before lunchtime, an old man came to the house.

"I'm from Heiankaku Wedding Hall," he said. "Can I talk to your mother?"

"My mother and father are both out," replied my brother.

Five minutes later, we had a second visitor, a small middle-aged woman.

"I'm from Heiankaku . . ."

"Oh, your colleague came a few times ago," I shouted from upstairs.

"Is that your grandmother?" asked the woman.

My brother, who was at the door, burst out laughing.

"She spoke very slowly," the woman said, "so I assumed she was . . ."

Give me a break! Am I a 17 year-old grandmother . . . ?

At dinner, my sister told mom about this episode. I felt so miserable. It annoys me so much to be told I have a disability. It's clear I haven't really admitted yet that I'm disabled.

I helped Mom prepare dinner.

She said to me, "Could you mix the Chinese chives and meat to make some gyoza dumplings?"

Ugh! Making gyoza dumplings? Involuntarily, I made a face. (I hate gyoza.) Still, it was all right, because the main course was chirashi zushi (a kind of sushi with the ingredients chopped and scattered over a bed of vinegar rice) . . .

As I was breaking four eggs and putting them in the pan to make some scrambled eggs, I suddenly thought about I-sensei. When she wanted to cook some rice in the morning, she would wake up and switch on the rice cooker instead of using the timer. I admired her because she didn't rely on machines. When we were making breakfast at school camp, she noticed I was coughing (I'd choked on some tea). She came over and stroked my back. She was a very gentle teacher . . .

When I was cooling the rice for the sushi using an electric fan, I put the pot between my legs and got burn marks about two centimeters long inside both thighs. I thought they looked rather beautiful-a slightly reddish color.

The members of Tanpopo no Kai (the group of handicapped people) work during the day and then get together in the evening to produce a mimeographed copy of their magazine called Chikasui (Underground Water). When I rang the group and told them I was staying at home for summer holiday, they invited me to join them.

"Mom is it only bad girls who go out in the evening?"

"Well, I suppose it's all right as long as you're with good people," she replied. "But isn't it a bit dangerous to go out in the dark?"

At 8 pm., Yamaguchi-san arrived in a car to pick me up.

Before I went out, I said to Dad "I'll be back soon."

He was lying on the sofa in the Japanese room watching television. He had had a drink with his dinner and his face was rather red. "Aya," he replied, "I'm rather worried about you going out in the evening. In the future I think you should only go out in the daytime."

I was so pleased to hear him say that. Actually it was a bit of surprise to hear advice from Dad. He doesn't usually interfere with his children. He puts on airs, but he's really a shy person. I prefer him when he's a bit drunk to he's sober.

Falling Over

In the past, when I wanted to hurry, I could. Now, even if I want to hurry, I can't. I'm afraid that in the future I may even lose all sense of hurry. Oh God, why did you give me this burden? No, I suppose everyone has some kind of burden. But why is it only me that has to be miserable?

The way I fell over today was really pathetic. When I take a bath, either Mom or Ako helps me take off my clothes in the changing room outside the bathroom. They run some hot water on the floor of the bathroom to warm it for me. Then I crawl across the tiles to get to the bathtub. Today, when I was trying to grab the edge of the bathtub so that I could get into a half-sitting posture, I fell on my bottom. I was unlucky because there was a plastic soap dish right under me. It broke into pieces and fragments got stuck in my buttocks. I cried out in a loud voice.

"What happened?" cried Mom as she flew into the bathroom.

She was very surprised to see a red river of blood mixed with the hot water. She placed a towel firmly on my bottom and then poured a lot of hot water over the parts of me that were still dry. Then Mom and Ako held me. They quickly dried off my body and got me into my pajamas. Then Mom covered all the cuts on my buttocks with gauze patches.

"With cuts like that," she said, "I think we'd better go to the hospital."

It turned out to be a serious matter. I had to have two stitches at the hospital and didn't get back home till around 9 o'clock. I was so tired.

It was a sudden accident, but I realize what was happening at the time. There was no real reason for me to stumble and fall over, or for my hands to slip. I wonder why a nerve can stop functioning momentarily. I felt sorry toward Mom for what I'd done.

While Mom was busy sorting out my many types of medicine to divide them into doses, I just lay in bed. I had a slight stomachache.

But whatever your excuse was, Aya, your attitude was wrong.

Partly because I was tortured by my conscience, I felt like reading *Okasan 2 (Mother 2)*, a collection of poems by Hachiro Sato. My hand reached out toward the bookshelf.

Asking My Self Some Questions

The summer holiday will soon be over. The only thing I've completed successfully during the holiday was looking after the parakeets. They come out on to my hands or shoulders and wait while their cage is cleaned. I give them some new water and feed, then I put them back through the small door into the cage one by one. They're so cute, They sometimes peck me, but it's not painful. I'm sure they're saying "Thank you" and I say, "You're welcome. I'm happy as long as you are happy." The whole thing takes about an hour as I talk to them. I get sweaty doing it, because I have to close all the windows so that they can't fly away . . .

Self-Reflection (Q&A)

"Aya, why don't you study much?"

-"I don't know"

"Don't you feel sorry for your parents who work so hard?"

-"Yes, I do. But I can't study"

"You're spoiled, you know! Look at the outside world. There are many people out there who are trying very hard on their own. In fact, one year ago, you were . . ."

-"Don't say any more! After Motoko-sensei told me that life is not all study, I began getting lost."

So, after all, I have to face the end of the summer holiday without having done anything much at all. I'm scared about starting the new term!

I'm the one who's most aware of the changes (for the worse) in my condition. However, I don't know if they're getting only temporary or they mean I'm gradually getting worse.

I explained the changes to Dr. Yamamoto:

1. The movement of my hip joints is bad. They still move back and forth to a certain extent, but they will hardly open to the left or right. (I can't move my legs like a crab). And because my Achilles tendon is hard, it interferes with my efforts to move my legs forward.
2. It's getting difficult for me to pronounce the ba and ma columns of the kana syllabary.

Dr. Yamamoto encouraged me by saying that these things will get better, depending on how much I practice. She added that she'd give me some white tables to help soften my tendons.

I wanted to ask the truth about my disease, but of course I'm scared to know. I don't have to know that. It'll be all right as long as I can live know as well as I can.

"Aya," said Mom in a spirited way as we were going home in the car, "you changed to Okayo because you couldn't continue your life at Higashi High School. You're quite a serious case even there. You may be feeling you're not accepted at Okayo, either, and gradually start shrinking with fear. But don't worry. You received the gift of life. And you'll always have a place to live. If you have to spend your life at home, we'll refurbish your room for you so that it's nice and warm and bright with lots of sunshine."

I think Mom wanted to cheer me up because I was looking so miserable.

"It's not like that, Mom, I'm only thinking about how I should live today. I'm not looking for an easy place to live."

That's what I was shouting in my heart.

I went to the washroom to wash my crying face and looked at myself in the mirror.

"What a lifeless face I have!"

I remember saying to my sister in a cool kind of way that I could find some charm in my face even though it was ugly. But I couldn't say that with the face I have now. The few facial expressions I have left include crying, grinning, a serious look, and a sulky face. I can't keep up a vivid and bright expression even for an hour.

I can't even sing any more. The muscles around my mouth have a kind of tic. And because of the decrease in the strength of my abdominal muscles, I can only whisper like a mosquito.

I've been talking the white tablets every day for one week now. My talking tempo has speeded up a bit and it's become easier to swallow food. The tension in my right leg has been eased slightly. However, I still have difficulty moving my legs forward and they're still painful.

Autumnal Events

The School Festival

Mom and my sisters came. Mom said she was in tears watching I-sensei dance on the stage.

"How come?" I asked.

"Maybe it was because she looked like she was trying so hard. At an ordinary high school, only the students perform, don't they? I was moved by a teacher performing earnestly together with the students. I think that's why my tears welled up. And there was also that boy who played monkey and walked around like someone suffering from cerebral palsy. But in fact he can't help but walk like that. Maybe because it was a perfect role for him, everyone laughed. That made me cry even more."

It struck me then that I inherited my crybaby side from Mom.

"But Mom," I replied, "around April, when I saw S-chan falling over and laughing, I thought she was superhuman. I wondered if I could ever become that strong. But these days even I can laugh when I fall over. I think everyone laughed when they saw that boy's monkey costume rather than that at the way he walked.

The Undokai Athletic Meet

I never imagined a school for the handicapped would have an athletic meet. I was wondering how the students could possibly all parade around if they couldn't walk . . . (I totally forgot that some people can walk, and there are also wheelchairs.) There was a real sense of fulfillment in completing something by helping and cooperating with each other and by contributing things that were lacking.

The students in serious condition produced a creative dance performance themselves. When it was time for the autumn leaves to fall, stupid me got the wrong group and dropped them! However, I was dancing as hard as I could, just like a butterfly (at least in my heart . . .)

Because we were all serious cases, I thought it would be impossible to present a beautiful performance. But I was surprised when I watched the video in the library. What a beautiful show we put on! We can do it if we try.

One strong impression that remains was glancing up and seeing the fresh blue of the sky while I was dancing.

I think the biggest difference between this and the athletic meet I had at Higashi High is that I have changed from being an outsider to being someone who's involved. And I've changed my mind: now I realize that if I try hard enough I can do some of the things I thought I could never possibly do because of my serious condition.

The teachers encouraged me. They said things like, "Aya, you can do it if you try! The performance will be great," and "The dance warmed up thanks to you dropping the leaves!"

Dr. Yamamoto said a similar thing: "Little Aya, I think something in your mind has started changing because you're now aware that you're someone who's involved."

Suzuki-sensei came back from his long-term study and training course. He told me what he had studied while staying with children who have severe physical handicaps.

"Some are 10 years old, but their mental age is still the same as a one-year-old baby, so they won't respond to anything. They'll put anything in their mouth, even a stone or a lump of mud . . . Looking at those children; I realized there must be some kind of guidance suitable for babies. The point is we have to make endless efforts and have good techniques to give the appropriate guidance to each individual. Everyone's trying hard-those with a severe physical handicap, the teachers who guide them, and you and me, Aya. So, let's keep at it, shall we?"

Listening to his words, I felt rather ashamed and ungrateful. Up to now, I thought that I wouldn't be in so much pain if my intelligence's proportion to the inconvenience of my body . . .

When I was an elementary school student, I wanted to become a doctor. When I was a junior high school student, I thought of going to a university with a welfare faculty. Then when I was a student at Higashi High, I started thinking it would be nice to go on to a literature faculty. But even though I have changed my mind a lot, I have consistently had the feeling that I want to do some kind of work that is useful to other people.

I don't have any specific goals right now, but I wonder if I could provide meals or something like that for children who can't move? I'd like to help them understand the warmth of people by holding their hands. I wonder if I can at least be some use to someone?

A long time ago, Atchan said to me, "It might have been better if I wasn't born." I was so amazed to hear that. It was a comforting surprise because it blew away all the disgusting things that were deposited at the bottom of my heart along with many sighs. I had thought the same thing many times. But knowing that a child who can't even move doesn't have the chance to think that, I couldn't help feeling really sorry.

I can no longer return to my past. My mind and body are exhausted like a piece of old cotton cloth. Please help me, teachers!

I was tired out from crying, but I managed to answer a calculation table for commercial bookkeeping. My answer matched perfectly! I'm so happy. But it took me well over 55 minutes-that's not so good.

The Year End

I wrote my New Year's cards. I only knew a few of the postal codes-including 440 (for Toyohashi City) and two or three others. I came across various codes this year, partly because I got to know my teachers and friends at Tokayo. Japan is a huge country.

Everyone's busy doing the year-end cleaning, rice-cake making and shopping. What should I do?

"Aya, you're in good condition, aren't you?" Said Mom.

"Can you wipe the floor?"

"Sure"

Mom squeezed the wet rags for me and then placed them on the floor a certain distance apart.

I'm losing my excitement about the New Year. Why can't I feel refreshed and think about some New Year's resolutions? I cried out loud, feeling that I've gotten stuck somehow. My stock keeps falling.

A teacher at Higashi High once said, "What's important for solving a problem about modern Japanese is to grasp what the question is asking and follow it with an open mind. To become open-minded, you

shouldn't have any preconceptions. For that purpose, you must read a lot of books. The more you read, the less you will have preconceptions."

Yes, I will read a lot of books and associate with the many characters in them. I've just realized that consideration for others and their feelings is also fostered through reading. From time to time, I stop talking when I decide I can't be understood however much I try. Too many times I've regretted that later, thinking that I should have done something different. That's why I keep getting depressed.

I decided to write my first calligraphy of the year. I took out a new thin writing brush and rubbed down an ink stick. It's difficult to do calligraphy without a model. Life without a mode is even more difficult.

After practicing for a while, I wrote a good copy: the character sunao (meek).

A Speech Disorder

I'm having difficulty pronouncing the ma, wa and ba columns of the kana syllabary, and also the syllable n. During the chemistry class, I was called on to reply. I knew the answer was mainasu (minus) but I couldn't pronounce it. My mouth can form the correct shape, but I can't utter a sound. Only air comes out. That's why I can't make myself understood.

These days, I often talk to myself. Up to now, I didn't like doing that because I thought it made me sound stupid, but I think I'll try more now. It's good for practice for my mouth. Whether there's anyone else there or not, I'm speaking . . .

I thought of running as a candidate for the position of Secretary of the Student Council. I entered the same race when I was in the fifth grade at elementary school. There'll be a public debate between the candidates, so I must do some speech training. Ah, there are so many things to do, including training and studying. I'm up to my neck in it. Good grief!

I remember having a big fight with one of my classmates during those elementary school days. One day, I went for a walk to the square with my dog Kuma. My classmate was there with her elder brother and their dog. The fight started because she set her dog on Kuma.

"Why did you do that?" I asked her.

"Because my brother told me to do it," she replied.

I got really mad and said, "So would you commit murder without a second thought if your brother told you to do it? He isn't always right, is he?" (It's the kind of logic I learned from Mom.)

But she wouldn't stop her dog. Then a big fight between us humans broke out. It was so fierce! It was so intense! I didn't stop even when my head was pushed into a ditch. My younger brother and sister backed me up.

Yes, with such power and such a sense of justice, Aya should definitely run for a position on the Student Council.

My speech disorder is becoming more conspicuous. When it comes to conversation, both parties now need lots of time and patience. I can't say, "Er, excuse me . . ." while trying to pass someone. I can't have a proper conversation unless both the person I'm trying to talk to and I prepare ourselves for listening and talking. I can't even express moments of pleasure by saying things like "The sky is beautiful. The clouds look like ice cream."

I get very frustrated.

I get annoyed.

I feel miserable.

I feel sad.

And, in the end, tears fall from my eyes.

Frustration

One of the teachers stopped me today and said, "Aya, are you feeling frustrated?"

I went speechless. I suppose they must have concluded that from my questions, my essays, my drawings, etc. But damn it! How could they dismiss what's inside my heart simply as frustration?

From having a healthy body, I've turned into a disabled person and my life has greatly changed because of that. What's more, my disease is still advancing. Now I'm fighting against myself. I can't have any sense of satisfaction while I'm fighting. As I go through all this worrying I know everything won't be solved by asking someone to listen to me, but I just want them to try and understand how I feel, and support me, even if only a little. That's why I consult Suzuki-sensei, showing him my notebook that includes all my thoughts and worries. Other teachers tell me that I should try to digest them inside my self. But I can't stand or even move because the load on my shoulders is too heavy.

"Do I look like a girl representing Frustration Incarnate?" I asked Mom.

"Everyone suffers from frustration," she answered. "It's better to be brave and say whatever you think on the spot. If you worry too much later about what was said to you, or the things that you did, they'll think you're always concerned about something!"

I know I don't respond quickly. I sometimes don't even admit to my self that I'm disabled. I'm in the depths of despair. But, strangely, I don't feel like dying, because I feel a time of fun will come some day in the future . . .

Jesus Christ said that living in this world is a divine test. Did he mean that while you're leaving you should be looking at yourself after death . . . ? I must read the Bible.

Meals

I can no longer use chopsticks very well. My right thumb doesn't stretch enough and the other fingers get stiff and won't move, so I can't hold things between my chopsticks. The way I eat now has evolved naturally. I've mastered my own way of eating.

The menu for this evening included rice, fried prawns, macaroni salad and soup. First of all, I threw the macaroni salad on to the rice. I do that with all the fine, small stuff. I can manage to hold a fried prawn because it's big, but I'm not particularly good with noodles (although I love udon).

I have to be careful about swallowing. I often choke, so I have to transport the food with good timing, move my mouth in a certain rhythm, hold my breath, and then swallow.

Chika, my classmate, can't use her left hand well, so she brings her mouth close to the container to eat. Teru-chan puts everything, such as the rice, the side dishes, and the ingredients of the miso soup on to her plate to eat them. I'm somewhere in between them. I can use my left hand, so I can hold a bowl. That means I can pretend to look like an ordinary person.

A long time ago, I read a book written by Kenji Suzuki, the TV announcer. In it he said that when two handicapped persons meet an 'arranged marriage' meeting, the first thing they should do is reveal their weaknesses. Is my way of eating a weakness?

"Am I conspicuous because I'm so slow?" I asked the head matron.

"Rather than saying that," she answered, "I feel sorry for you."

It was a rather shocking remark.

I feel sorry that again at Okayo I have to have other people doing everything for me. Handicapped people are classified into two categories: serious cases and light cases. I'm classified as a serious case.

March

Congratulations to Ako and Hiroki for graduating from junior high school. Now you have to face the high school entrance exams. Good luck!

Feeling like going out into the fields
To pick the fertile horsetail shoots.
The spring rain silently drizzles down.
This spring brings only loneliness.

I'm really concerned about my future. I've already turned my back on my life without being aware of it. What's happened to my hopes for the future? I can no longer think seriously about what I want to be in the future. Let it be. The waves of my fate have washed me away. I don't even know what kind of occupations left for me.

"There'll be another year," says Mom.

"I only have one year," I think.

I don't know how to bridge this gap in our way of thinking anymore.

The students who come to school every day from Aoi Tori Gakuen Medical Welfare Center - and those who have been living in the dormitory since they were young - are different to me. They don't have any hesitations and they seem to live their lives very smoothly.

"We don't mind a cheat, but at least be punctual!"

Because I'm always slow and late, R-sensei and the head matron tell me the same thing. But take the cleaning, for example: I'm slow, but I still want to do the cleaning properly. I can't cheat like that . . .

Matron I is very kind. She envelops me in a mother-like love. I like her very much because she makes me feel relaxed. She says she can't sleep well at night, so I think I'll give her a stuffed animal. Matron Y is the one who always hurries me along, repeating that I'm slow. But she watched me quietly the other day for about 10 minutes when I was crossing the 3-meter-wide corridor at the dormitory. Their kindness differs in quality.

I overheard mom talking to one of the matrons:

"I'll take Aya with me when I die."

I didn't know she was thinking that deeply. I realized that was a mother's love.

I forgot to push button to start charging the Machine (my electric wheelchair), so it ceased to be a machine. I was in trouble. I pushed it up the slope with all my energy. I had a pain around my lower back. I took a brief break on the connecting corridor on the second floor. I could see something small moving on the hillside when I looked down at the ground. It was a puppy. It looked lonely.

Just then a teacher passed by. "Ah, dogs like nice scenery, too!"

It struck me then that the feelings you have toward something that doesn't speak vary depending on the person or your mood at that time.

What should I do after graduation? In the past two years, my disease has become much worse. mom says I should concentrate on getting thorough treatment by consulting Dr. Yamamoto. It's no longer a matter of

whether I can motivate myself or not. It's not a time for expecting encouragement, either. I just have to carry on.

I put my feet under the kotatsu heated table and ate some snacks. Ako had left for me. "Keep it up, Aya!" she said to me.

Recently I've been feeling something strange. Sometimes my vision gets blurry and my brain starts to reel. The shape of my right foot has also changed. The joint of my big toe is protruding and the other toes are kind of flat. I feel disgusted thinking that this is my foot. Now I'm 149 centimeters tall and weigh 36 kilograms. I hope my foot won't lose the strength to support my body.

Do you hear me, ugly foot?

"I'm getting worse and I can't walk any more," I said to matron G when she was helping me change my wheel-chair. "There was a time when my disease was at a mild stage and I could walk. In that state, I could have taken care of the others at the dormitory. But I came here after I'd become quite helpless, and now other people have to help me. I really feel sorry about that . . ."

Toward the end, it was difficult to get the words out properly, but I managed not to cry.

Mom was crying.

"It was your fate that you got ill, and it was also our fate as parents to have a child like you. Aya, I'm sure you are having a hard time, but we're having an even harder time. So don't get sloppy about trivial things. You must live strongly!"

When I was going back to the dormitory to change my clothes and get ready for the PE lesson, some phlegm got stuck in my throat. I almost choked to death. I can't get any abdominal pressure and I don't have much lung capacity, so I couldn't get rid of it. It was very painful. I definitely feel I'll die one day because of some trifling little thing like that.

A Third Grade High School Student

Thinking that my boarding school life will soon be coming to an end, I poked my nose into the Executive Committee to excess this year. I also worked hard for the Christmas party, eager to entertain everyone. I was so busy. But I was satisfied with myself this year because I did various activities for the sake of other people.

"I won't let little things defeat me," said Mom, "so, Aya, you, too, will have to hang on for a prolonged war."

I was ashamed of myself for only thinking of the present. Spring will soon be over, as I put my hand out of the car window to catch the flower petals fluttering around, I could feel Mom's deep love. That gave me some peace of mind.

I'm more scared when I get up in the morning than when I go to sleep on my own. It takes me about an hour to fold up my futon and put on my uniform, another half an hour to go to the toilet, and then 40

minutes to eat breakfast. When my body isn't moving smoothly, it takes even longer. I don't even have time to look up at someone's face and say, 'Good morning.' I tend to look down all the time. This morning, I fell over again and got a nasty bang on my chin. I checked to see if it was bleeding. It wasn't, so I felt relieved. But I know that in several days I'll start feeling some pain, with bruises on my shoulders and arms.

I lost my center of balance in the bathtub and sank down bubbling into the water. Strangely, I didn't feel I might die. However, I saw a transparent world. I guess Heaven is like that . . .

I put my hand on my chest.
I can feel my heart beating.
My heart is working.
I'm pleased. I'm still alive!

The gums above my right front teeth are swollen. The nerves have died again.

I went with the disabled group on an overnight trip. Many volunteers came along to look after us. Like a three-year-old infant in the rebellious phase, I had to keep saying, "I can do this by myself so I'll do it!" That stung my conscience. Etsuyo eats her food lying down. A girl who was passing by looked at her with a funny expression on her face. I'm glad I can eat sitting up. I began to think that we disabled people are all the same really, although our disabilities take different forms.

Rika, my four-year-old sister, was with us. She said a cruel thing:

"You aren't beautiful, Aya, you know, because you wobble."

I spouted out my tea involuntarily when I heard that. Young children are cruel because they say things in a straightforward way without considering whether someone may be hurt by what they say.

The School Excursion

I was thinking it would be very difficult for me to go on the school excursion. But it seems I can go after all. Mom will come with me and Dad will look after the house.

A Record of My Impressions
Pigeons and me: Hiroshima Peace Memorial Park

"Po-po-po" and "Kuru-kuru" the pigeons were cooing. At first they didn't come close to me (I think they were afraid of the wheelchair.) But when I held out some bird food, they came and perched on my shoulders, my arms, and my head. It struck me that both the pigeons and the people who dropped the bomb were very calculating types.

I went round the Peace Memorial Museum a few minutes ago. It was dark inside. Only the exhibits are brightly lit, so it's filled with a weird and heavy kind of atmosphere. There's a model on display showing the time of the bombing. A mother and a child in tattered clothes were escaping from something holding hands. All around them was red with fire. It was the same color as the blood plasma which oozes out after I fall over and cut myself.

"It's revolting!" Mom muttered behind me. She turned her face aside and said, "I shouldn't say that, should I? I should say 'I feel sorry for them, because they didn't want to be like that.'"

I didn't think it was revolting. That was not everything about the bombing. That was not everything about the war. A simple child like me, who doesn't know anything about war, was pretending to be tough like that.

On display were the cranes folded by Sadako, who died of A-bomb sickness. They were made using a kind of transparent red wax paper.

I don't want to die! I want to live!

I felt as if I could hear Sadako's cries. But, what kind of disease is A-bomb sickness? There are people who still suffer from it after 35 years, so is it hereditary disease? I asked Mom, but she didn't know exactly.

There was a stuffed horse with keloids, tiles burned by heat rays, 1.8 liter sake bottles melted into limp shapes, some scorched black rice in an aluminum lunchbox, battered clothes people wore during the War, etc.

The reality of it all puts a merciless pressure on you. We didn't experience the War. But we can't turn away and pretend we don't know anything about it. Whether we like it or not, we have to admit that many people were killed by the bombing in Hiroshima, Japan. I think the best memorial for those who died is to vow that we will never let such a tragedy happen again.

After a while, I realized there were some elementary school children from Hiroshima inside the Museum. There were looking at the exhibits and me in my wheelchair with the same expression, as if they were looking at something horrible. I thought I shouldn't be concerned about other people's eyes.

"Perhaps a wheelchair and a wheelchair rider are unusual things to them."

Thinking like that, I could concentrate on the exhibits.

Suzuki-sensei called us and we went downstairs. I felt relieved to escape from the uncomfortable eyes and the heavy atmosphere.

Outside it had started drizzling. Mom tried to put a raincoat on me as I sat in my wheelchair. I tried to stop her, saying, "That's not cool." But nobody was saying anything, so I reluctantly did what she said. She placed a towel on my head as well.

The fresh greenery in the park was nice. The trees were all wet from the rain. They were shining under the cloudy sky. The fresh yellow-green leaves of the camphor trees looked beautiful against their black trunks. I wanted to sketch them.

We went deeper into the green trees and came to the Peace Bell. The rounded roof supported by four pillars represents the Universe. The dying lotus leaves in the pond surrounding the bell also seem to have a history.

"Anyone who wants to ring the bell, come over here," said one of the teachers.

I glanced over. Terada-san and Kasuya-kun rang it.

DONG . . . DONG . . .

The sound faded away into the distance with a lingering resonance.

"I'm listening to the sound of this bell wishing for 'peace' so I should do whatever I can, even though I won't ring the bell."

Thinking like that I closed my eyes and prayed.

Because of the rain, the water in the Ohta River was the color of earth. After the bomb was dropped, it was filled with wounded people. They were crying, "It's so hot, so hot!" Imagining the scene in my head was scarier than looking at the exhibits in the museum.

The pigeons came and perched on my shoulders and arms one after another. Their feet were soft and warm. They flocked around me pecking at the feed I was holding. There were loads of them. They're feral pigeons, so they're not particularly beautiful. I found one with bad legs. It was walking even though it was disabled one. I obstinately tried to feed only the disabled one. But I couldn't do it very well. There are so many pigeons in the park, I suppose it's only seriously disabled and couldn't walk, like me, perhaps it couldn't live. It struck me that I should be grateful that I was born as a person and can therefore stay alive.

Am I wishing for 'peace' because I'm person who can only live in a 'peaceful' world? That's a rather shameful wish.

After a while, I also felt like giving a piece of bird food to the other pigeons, not just to the one with bad legs. As I looked at the pigeons with their tottering steps picking up the feed, I thought about the sense of 'welfare' that we have in our human world.

18 Years Old – Having Understood The Truth

I had rather a big shock today. Here's the conversation I had with four-year-old Rika:

"Aya, I want to be wobbly like you."

"But then you couldn't walk or run, and you'd find it boring," I replied, as cool as a cucumber. "We've had enough of this problem with me."

"All right, I don't want it, then," she said immediately.

This happened in the entrance hall. Mom was some-where in the house. I wonder what she thought when she overheard us?

Final High School Summer Holiday

I took a bath in the morning (to make my body more supple). Mom was busily moving around saying how hot it was. I felt sorry for her because I didn't feel hot at all, so I worked on math calculations until I was sweating.

After lunch, I got a toothache. I took advantage of being at home to cry.

"How old are you?" said my brother. That's a favorite remark of his. He put some ice in a plastic bag for me. That cooled my cheek and I slept for two hours feeling comfortable.

When Mom came home, she applied some Shin Konjisui painkiller to my tooth. Then I played gomoku with my brother. He beat me, 8 games to 2. Ako comes home late because of her part-time work. At my request, we had cold tofu and sashimi for dinner.

In the evening, I fell down again. As I was standing up to switch off the bedroom light, I fell down . . . SLAP-BANG. I made a terrible noise and Mom came flying in.

"What happened? Aya, you have to use your brain and build on the things you've learned up to now. If you keep falling down like this, I won't even be able to go out to work with an easy mind."

As she was saying this, she attached a long string to the chain hanging from the light. I must be more careful about what I do late at night.

I cleaned my room enthusiastically, thinking "Today's the day!" I was moving around on my knees, so the vacuum cleaner didn't suck up the dust very well. But I worked desperately at it. I felt so good afterwards.

Keiko came to visit me.

Like Aquatic plants
Floating on a pond,
Talking with my friend,
Just looking at each other,
About our innermost feelings.
My friend with her sparkling eyes
Tells me about her dreams.

Keiko talked a long about her future dreams. I felt this was how we would become adults.

Tomorrow's the day for me to enter the hospital again.

Second Hospital Stay (Nagoya Health University Hospital)

This time, the main tasks will be checking the progress of my disease, having injections of a new medicine, and undergoing rehabilitation. The difference from the previous stay is that I've been asked not to go out alone (because of the danger of falling down).

When I went to the toilet, I glanced outside over the window-sill. I felt depressed when I saw the gray walls and black buildings.

"Why do you look so tired?" asked the nurse who was accompanying me.

My nystagmus (involuntary movement of the eyeballs to left and right) is becoming more conspicuous these days. I had an eye check in the room for brain wave tests. The doctor there has a bad leg, too. It struck me that I could work if only I had at least one part of my body that functioned properly.

"Why are you putting that cream on?" I asked.

"Because you're having checkup," the doctor replied.

That answer struck me as a bit off the mark. I wonder if he responds like that to ordinary people. Perhaps I look stupid because I have both a physical handicap and a speech disorder.

Dr. Yamamoto took me to Nagoya University Hospital in her car to carry out further tests. If I suddenly look right gazing forward, the red ball I can see gets blurred, divided into two parts. This time I tried looking left all of a sudden. The degree of blur was less on the left. As I thought, the disorder of my right motor nerves is progressing more. In the car, I told Dr. Yamamoto that after the injection I don't feel sick like I used to and I was wondering if that meant the new medicine was no longer working on me. I also told her that although my Achilles tendon seemed to have softened, my speech disorder was getting worse.

"As for the speech disorder," she said, "the best thing is to finish saying what you want to right up to the end, even though you may find it difficult to pronounce all the words. Ideally, people will get accustomed the way you speak."

Training

1. Using a pair of crutches. (I almost fell over because I haven't got much strength in my right hand).
2. Practicing standing up from a chair.
3. Though I was told I wouldn't be able to walk unless I could kneel, I felt dizzy and couldn't do it well.
4. Handiwork: knitting, making things, etc.

The 20th day in hospital.

I had the second round of tests on my functions.

"There are no big changes," they told me.

I was shocked!

"But you haven't gotten any worse," they added.

That's no good! I have to get better-even if only a little.

I went to the Rehabilitation Room. There were many physically handicapped adults in there, but not many children. There was a man who was paralyzed on one side as a result of a stroke. As he watched me gritting my teeth as I tried to kneel on a mat, he was wiping his tears away. With my eyes, I told him, "Look, I really can't afford to cry now. I'm in so much pain, I want to cry, but I'll save that until I can walk. You should keep at it too, OK?"

I feel uneasy and anxious about how much effort I'll have to make in order to be able to walk. When I returned to my room, I held some knitting needles-though rather than saying 'held', it would be more accurate to say 'grabbed.' Once I've grabbed them, I can't let them go again; my body gets stiff and I can't open my hand or clench my fist. It takes me up to 30 minutes to knit just one row.

I think I'll practice the kindergarten song Musunde, hiraite (Clench your fists, open them . . .), keeping it secret from the other patients in my room.

Whenever the hospital director or the doctor in charge comes round, a lot of young interns follow them. Their conversation makes me feel sad:

Item 1. The computer route inside my cerebellum is broken, so the movements which ordinary people can do involuntarily are only possible after the instructions have been fed back once to my cerebrum.

Item 2. My occasional grinning is pathological.

The interns listen seriously to the director or the doctor in charge, but I feel rather bitter. It's not nice to have yourself talked about like that. I like the interns because it's fun when we talk about books or friends, but they become different during those visits when they peer at me with curiosity. However, they can't become good doctors unless they study hard, so I guess it can't be helped . . .

I can move busily around the hospital thanks to the splendid service of my wheelchair - when I go for rehabilitation, various tests, and treatment on my teeth. I've made friends with a lot of patients and nurses. K-san made some rice balls for me. The middle-aged man who gave me a melon invites me in the

evening to watch TV with him. One intern nurse brought me an ice cream. The middle-aged woman in Room 800 arranged some flowers in a vase for me. I read a nursery tale with Mami-chan. I feel like they're all my relatives. When one middle-aged man was leaving hospital, he said to me, with tears in his eyes, "Aya, do your best till the last minute!" I really have a chance to meet a great variety of people. Everyone says "You're a good girl, Aya. I admire you." (But I feel embarrassed because I don't think I'm a 'good girl' at all.) I've only been here for a short period, but I'll never forget you all.

Graduation

As graduation day approaches, the topics in all the classes have focused on attitudes toward entering society with a handicap and possible places of employment. When I entered Higashi High, I studied with the goal of going on to a university. When I was a second grader at Okayo, I could still walk and thought I could find employment. But everything became impossible when I became a third grade student.

**-kun = ## Company

**-san = a vocational training school

Aya-Kito = staying at home . . .

That's the route fixed for me.

For the last two years, I've been taught to 'acknowledge being disabled and start from there.' I've had to suffer and fight a great deal. Every time some bright light came into my life, I had to experience a burst of heavy rain or a typhoon . . . followed by more fine days. I've reached graduation always carrying a feeling of instability. How much longer will I have to suffer and fight until I can find my life? I wonder if the disease gnawing away at my body will refuse to release me from agony until I die - as if it doesn't know the destination?

I wanted to be useful to society in some way, making the best use of the knowledge I've acquired from twelve years of school life and all the things I've learned from my teachers and friends. However small and weak my power might be, I'd have been so pleased to give something. I wanted to do something out of gratitude for all the kindness I've received from everyone. One thing I can dedicate to society is my body, for the sake of medical advance: I can ask for all my usable organs, such as kidneys and corneas, to be distributed to sick people . . .

Maybe that's all I can do?

At Home

I had a feeling of nostalgia as I unpacked all the belongings I used during my boarding school life. Now I feel like an old woman. Mom and Dad go out to work and my brothers and sisters are spending their regular lives, commuting to school and nursery school. If I'm the only one in the family leading an undisciplined life, I'll become a burden to them, so I should at least try to lead a planned life:

1. I'll address people properly: "Thank you," "Good morning," etc.
2. I'll try to speak words sharply and clearly.
3. I'll try to become a considerate grown-up.
4. Training. I'll gain some strength and help with the housework.
5. I'll find something to live for. I don't want to die while I still have things I must do.
6. I'll try to stick to the family routine (times for meals, baths, etc.)

Damn! Damn! I bang my head against pillow.

Everyday between 8 a.m. and 5 p.m., I stay here by my self. I'm unbearably lonely. I write my diary or some letters, I watch the TV program Tetsuko no heya (Tetsuko's Room), and I have some lunch. Then I wipe the floor, partly as a form of training. I'm leading a life which is free, but, in fact, it cannot freely be controlled.

I feel relieved when we all have dinner together, But then I feel lonely again when I go to bed, thinking that tomorrow will be just the same as today. Just as I was feeling like that, I toppled forward, even though I was in a sitting position. I broke the crown on my toot that I'd bothered to have put in.

"Aya, your voice has been getting smaller recently," Mom said to me. "Your lung capacity's decreasing, so I think you should train to speak out more. Why don't you sing loudly during the daytime? Nobody will laugh at you. And when you ask everyone to come together, call us so loudly we'll all be surprised! Why don;t you practice a bit now?"

I sat on the floor with my back straight and cried out, "Hey!" My pitch was very high and we both burst out laughing. I tried again : "Hey!" My brothers and sisters came running downstairs, all shouting, "What's going on?"

I did it!

"From now on," Mom explained, "Aya will shout 'Hey!' whenever we want everyone to come together for something. Well, now you're all here, how about some dessert?"

We all laughed at the humorous way Mom spoke and then we ate some bananas.

Third Stay in The Hospital

"I'll rely on Dr. Yamamoto."

I want to get my body repaired at the hospital. I can only live properly if I have good health . . . I wonder if I can be sure - somehow or other - of being able to do at least my own things when I reach 20? Doctor, please help me! I'm trying to encourage myself by saying that I don't have time to be wimpy. But I can't stop my disease from progressing, however much I try . . .

"You're not a student this time," said Dr. Yamamoto, "so you can take your time and stay at the hospital until you get better. Then you must do your best to stay alive. As long you're alive, I'm sure some good medicine will be developed. Up to now, neurology in Japan has lagged behind other countries, but recently it's been advancing at an incredible speed. Leukemia was a fatal disease up until a few years ago, but today some people are cured. Little Aya, I'm studying hard with the hope of being able to cure patients like you."

I couldn't stop crying. But today they were tears of hapiness.

"Thank you, Dr. Yamamoto. You haven't given up on me. I was so worried you mnight give up on me because I haven't recovered, even though I've stayed in the hospital twice and used the new medicine." I nodded my head strongly in assent. I couldn't speak properly. My face was steaked with tears.

Mom had her back to me. Her shoulders were shaking.

I feel so happy and so grateful for having been able to meet Dr. Yamamoto. Whenever I'm weak physically and mentally and feeling deeply discouraged, she comes to my rescue. Even when she has many patients waiting in the Outpatients' Department, she listens to me carefully without taking any lunch. She gives me hope. She gives me light. Her words-"As long as I'm a doctor, I won't turn my back on you"-were so reassuring!

Already three months have passed since my graduation. I received a letter from one of my classmates. She had found a job working at a company. She told me she was getting used to being there and was trying hard. As for me, after three months, I'm leading a hospital life again-in order to start over by repairing the damage to my body . . .

I started off my day by singing Bata ga saita (The Roses are Blossoming) in the toilet. I played the harmonica to increase my lung capacity. It had a very nice sound. It sounded as if it was blowing everything away-including all the bad things and death. I'll play it again without worrying about upsetting the neighbors.

On the way to Rehabilitation, I dropped by the toilet. As I was trying to sit down, I felt heavily on my buttocks into the toilet bowl and wet the back of my sweat pants. I didn't have time to change, so I went straight to rehabilitation. When I was doing my walking training, Y-sensei took hold of the rubber part at the back of my sweatpants. Discovering it was wet, he went away and left me as I was. Aya was left all alone at the parallel bars! Regarding it as 'independent training', I put a protector on my right foot to keep my ankle at 90 degrees, put some urethane between fingers, and started walking. I held firmly on to the parallel bars, Toodle, toddle . . .

Y-sensei watched me. "Put your legs forward a little more quickly," he told me.

I wanted to say, "It's awkward, you know, because my legs, the upper part of my body, and my hips won't moving forward together. If I get tense trying to do something about it, my legs get left behind and that's why I fall over." But I was rather diffident because I felt uncomfortable about my sweatpants. I said nothing and tried to do it many times by myself.

The Mirror

I had my hair cut today. But I didn't want to look in the mirror. I don't like looking at myself with a demure expression. As for my complacent smile and the face with my eyes shut tight that I always show to other people, they're not worth looking at. However, there's a big wall-mirror in the Rehabilitation Room. O-sensei said I should look at myself in it to correct what's wrong with my posture. In my head, I have an image of myself as an ordinary healthy girl. But I didn't look so beautiful in the mirror. My backbone's bent and the upper part of my body leans forward. There's nothing I can do but admit that facts are facts. However much I try, I still can't completely throw away the hope that I can escape my disability. I want to acquire at least one fact-that thanks to my strict rehabilitation. I've become able to do something I couldn't do before.

I took on the challenge of conquering my body with willpower. But I failed. My face went white and I felt sick. I gave up. I realized that I was digging my own grave.

"Be careful not to overdo it."

I fell over today in the toilet and hit my head badly. There was no bump, but I had terrible headache. I thought I was dying.

There was a flash of lightning outside and we started hearing thunder. I went to the public phone in the corridor in my wheelchair and rang home. Mom answered.

“Aya, I’m looking forward to Sunday,” she said. “We only have three days to go. What do you want me to bring? I’ll do your washing for you. Can you hear thunder there?”

“Hmm, yeah,” I answered coolly.

“Now I could die”, I thought.

A theft

I do my washing myself once a week, today, as usual, I put my dirty clothes in a canvas bag and my purse in the back pocket of the wheelchair. Then off I went. I took the elevator from the eighth floor to the first floor I read a book in the lobby while I was waiting for my turn.

A middle-aged woman called me.

"Right, it's my turn," I thought. I put my hand in the pocket to get my purse. It wasn't there! I checked several times, but I couldn't find it. I was sure I had put it there. I was very upset.

"What's the matter?" asked a man who was also waiting.

"I seem to have forgotten my purse, so please go ahead before me," I said and left.

I never expected that kind of thing to happen, so I didn't bother to keep an eye on the back of my wheelchair. I lost ¥400 and my purse. I'm sorry, Mom.

Suzuki-sensei and Tsuzuki-sensei from the school for the handicapped came to visit me. It's four months since I graduated. I was pleased to see that they haven't changed at all.

"Please lie on my bed," I said.

"Well, I don't really like lying on a hospital bed. Do I look tired?"

"No, but if your body odor is on my futon. I'll feel secure and sleep well!"

There were both at a loss as to what to say. They had an indescribable expression on their faces!

Ako visited me. I went out with her in the wheelchair. The sun shone so strongly I could hardly open my eyes. I want my skin to be darker. I'm too white.

Wonders will never cease! The tsukutsukuboshi cicadas (Meimuna Opealifera) were already buzzing. Wait a minute, summer's disappearing!

Ako seems to be suffering a lot because she lacks motivation. Perhaps she can't find what she's looking for. I can understand how she feels, but I'm a bit worried about her. On the spiritual plane, she's more independent than me. It seems that I'm the one who has the last ability to become independent of our parents.

The middle-aged owner of an electric appliances store who had had a stroke bought me a hime-yuri star lily at the flower shop on the 1st floor of the hospital. He can only use one hand, so he passed his purse to the woman at the shop and asked her to take 250 yen from it. Then he gave me the flower saying, "Let's hope it blooms!" His gentle face looked radiant.

Like a mother kissing her baby's cheek,
I kiss the bud of the lily
That's just about to bloom,
Wishing it to be gentle and charming.

A Pronouncement

- * I've gained some strength since the start of my hospital stay.
- * I can now make two return journeys holding on to the parallel bars, but it's still impossible to do practical walking while holding onto something.
- * Regarding my speech, people often have to ask me to repeat myself. I was hoping to use writing as only the final tool of communication, but I have had to use it a few times.
- * My meals have been changed from ordinary food to chopped stuff.

Today was my last day in the hospital. I did my final washing at the risk of my life. I got up at 4:30 and went down to the room. There was nobody there. It was lucky I could use the machine right away. But when I had to move the washing from the spin drum to the drier, I couldn't do it unless I was in a standing position. Normally someone helps me.

"Mom, help me!" I shouted in my heart, but there was nothing I could do. I realized I will have to face this kind of thing many times in the future.

"Your disease won't get any better, Little Aya," Dr. Yamamoto told me, "and it could get worse. But in order to slow down its progress, you must train yourself to stimulate your brain."

That was a very tough and painful thing to hear. But thanks for telling me the truth, anyway. How should I live in the future? The choice of paths I can take has been narrowed down. It seems very demanding. But I'm determined to live my life facing forward, even if I have to crawl. I shouldn't shrink from it.

Dr. Yamamoto also kindly said, "Don't let a cold develop. Please ring the hospital immediately if you have trouble breathing or have a temperature. Keep stretching your Achilles tendon and do lots of deep breathing exercises. I hope you'll keep moving around as much as you can."

Thank you Dr. Yamamoto, all the nurses, and the other patients. I think I may need your support again some day. I hope you'll look after me then in the same way.

19 Years Old – "I May Not Last Much Longer . . ."

Ako gave me a shirt to congratulate me on leaving the hospital.

I was determined to keep at it again today, but all I did was eat, brush my teeth, go to the toilet, and sleep. That's how the day went by.

I had my hair cut in the evening. It was trimmed short and prickly. I can't take care of it myself, so who cares whether I have curls or not? Thinking carefully, I understand Mom's consideration very well; she said that the time needed for combing should be reduced. When I looked in the mirror, I realized I now have the same hairstyle as Dr. Yamamoto.

Solitude

If I recover from my disease, if I become able to walk like I used to, if I become able to talk without feeling any inconvenience, if I become able to eat using chopsticks well . . .

Thinking like that is only a dream. I shouldn't let thoughts like that into my head.

As a disabled person, I'll have to live my whole life bearing the burden on my shoulders. But I'll fight against it, even if I'm in pain . . . That's how I've made up my mind to think . . .

Since Dr. Yamamoto told me my disease won't get better, I have prepared myself to burn to the full and then disappear all at once, hoping for a short life.

Mom, I'm sorry that I've made you worry so much and that I can't repay you at all. My brothers and sisters, please forgive me: not only could I not do anything worthy of an elder sister, but I've also taken away your mother's attention.

I know I'll be thrashing around for a several months to come. That's my life.

Oh, what on earth should I do?

I've moved from the upstairs room I've been using for a long time to the 6-mat Japanese room downstairs on the 1st floor. It's closer to the kitchen, the bath, and the toilet. It also faces the corridor the family passes along most. If the large windows is opened, I can see the garden, and Kuro, our dog, is always there looking at me.

Kuro had four puppies! They can't see anything yet, but they're good at finding their mother's nipples. Kuro looks great as a mother. And this morning, the buds of the lilies opened. I'll name the female puppy Lily!

Love

In the evening, I received a camera seminar. My brother came to my room with his chemistry homework and his new camera. I guess he stayed with me because he thought I might be feeling lonely by myself. What a kind boy he is!

For more than two hours, he happily explained to me all about his camera. Then he went back to his room without doing any homework.

"Tomorrow," he said, "I'll get up at five o'clock and remove any sharp stones from the playground for the puppies."

But surely he'll have to do his homework, won't he? Kuro's puppies, I don't think he'll have time to remove the stones from your playground. Sorry about that.

I feel loved in the warmth of my home. But I can't express my love to everyone. I can't speak and I can't make any actions to express it . . . The best I can do is smile in response to their love.

- *I should go to bed early and get up early.
- *I should brush my teeth quickly.
- *I should not be late for meals.
- *I should do my training every day without forgetting.
- *And I will make an effort to respond to everyone's love.

Self Training

- Standing up 10 times
- Raising bottom 10 times
- Rolling and sitting up 10 times, leaning to right and left
- Raising arms for 5 minutes
- Standing up holding onto something for 5 minutes
- Breathing in and out deeply 3 times, blowing my harmonica, and again breathing in and out deeply 3 times (When I blow the harmonica, I can get a good sound if I pinch my nose so that my breath doesn't leak out)
- Knitting and making kimekomi quilt balls to train my hands
- Reciting picture books to improve my speech . . .

Late Autumn

Suddenly I noticed the cicadas have stopped singing. They've passed the baton on to the bell crickets. It's getting chilly both in the morning and evening. I can't help feeling that my stamina and my energy are both deteriorating.

Is it all right for me to stay alive?

If you die, you won't leave anything behind.

Love-what a sad person I am relying only on that! Mom, is it really all right for an ugly person like me to be living in this world? Mom, I'm sure you can find something shining brightly in me. Teach me. Guide me.

Looking at the canna reeds
Bloomin in the garden,
I miss you

Early this morning, I was woken up by the yelping of the puppies as they played with each other. The early morning sunlight was streaming in through the window. Lying in my futon, I watched them for a while. They've really grown up quickly. They were only yelping until recently, but now they can also growl like mature dogs. That could also be said about me . . .

I smiled a bitter smile when I thought that.

I want to go to a florist to buy a pink rose.

I want to go to a cake shop; I'll decide when I look through the window whether I want a cream puff or a shortcake.

I want to go to the liquor store; I'll say to the chunky middle-aged man with the reddish face, "Can I have a bottle of Akadama Honey Wine?" I want to give it to my brother.

My wish has come true: I was presented with a copy of Totto-chan written by Tetsuko Kuroyanagi. But leaving the enjoyment of that till later, I started on my kimekomi craft work. I have to cut the kimono cloth into several pieces of the same shape. Then I paste them on to a round wooden ball with glue. I can't use a pair of scissors well, and it's also difficult for me to fix the cloth with pins, so I only make slow progress. I'm really serious when I cut the cloth because I won't be able to complete it properly if I get the measurements wrong.

As I was about to go to sleep at night, I heard the door being knocked. (I remember a scene like this in a book written by Shinichi Hoshi.) As I said, "Come in!" The door opened quietly and in came a young little girl . . . Yes, it was Rika.

"Aya, I have something to talk about," she said in an unusually serious manner. "Tomorrow I'm going to nursery school. I won't be able at home, so you'll have to be a good girl, all right? Don't fall over. We'll play together when I come home, all right?"

That made me cry.

I think you inwardly digest your mother's affection and it is changed into love towards other people.

When I gave peanuts to the birds, they ate them happily. But as soon as I opened the wire netting over the entrance to clean their cage, the birds suddenly flew out and disappeared. They could only fly away like that because they didn't know that they may not be able to live in the wild and that there are scary enemies out there. Please come back when you realize that . . .

Feeling sad, I wrote some letters to my teachers and friends.

"Please buy me a spiral-bound notebook like sketchbook," I asked Mom "I don't feel like writing my diary in an ordinary close-ruled notebook."

"What?" she replied. "Aren't you being a bit selfish saying you can only write your diary depending on your mood. It might be different story when your condition is bad, but right now you should think that you must write something anyway."

I learned something else from Mom's way of life. She was right. If she said, "I can't get into the mood for preparing dinner," I'd starve.

Rika visited me when I was lying down - I was coming down with a cold. She sat beside my pillow and started drawing a picture of rabbits on the pillow cover using a marker pen - a big rabbit and a small rabbit standing next to each other. She also drew three or four circles between them. I think she intended them to be flowers.

"Aya," she said, "I thought you might be lonely sleeping alone during the night. So please make these your friends."

Her tenderness again made me cry.

I read an article in today's morning paper about a disabled person in an electric wheelchair who has done a correspondence course for twenty years so that he could acquire a clock repair qualification.

I don't develop anything. My body has stopped its emotional growth.

I wonder if there's any kind of job I could do? (My brother says there isn't, and I half agree with him.) But I don't think everything is impossible.

All I can do right now is write and do kimekomi craftwork. Even if I can't have a job, I can at least help Mom by wiping the floor, folding up the washing, etc.

Today I was intending to make some more kimekomi quilt balls, but I ended up playing with my sister instead. During that time, Mom cleaned my room.

"Leaving the dirty stuff as it is - that's what animals do," she said.

I really appreciated what she did. All the hairs stuck in the carpet (over the tatami mats) had beautifully disappeared. But it became a bit too clean - I couldn't feel relaxed.

I wanted to know how Mom felt when she was cleaning my room. She had to spend half her day looking after her troublesome child . . .

"Poor Aya!" said Ako.

"What's fun for you, Ako?" I asked.

"What's fun for you, Aya?" she replied.

"Nothing," I answered.

"Poor Aya!" she said.

Today I was training on the mezzanine floor. I practiced holding the rocking chair and letting go with both hands.

I wasn't very stable and I could only stand for about five minutes, but that's how I'm trying. Yet why can't I do it better?

My brother also said, "Poor Aya!" It was already dark outside and the bright TV screen was reflecting dimly white on his face.

I want to go somewhere spacious.

I don't like being cramped any more.

I feel so much pressure.

I can't go out because it's cold outside.

I keep thinking about death, so I'm scared.

I can't move . . . I'm beaten.

I want to live!

I can't move, I can't make money, I can't do anything useful to other people.

But I want to live.

I want to be understood . . .

Rika spread some jam thickly on a piece of bread. It dribbled onto the floor while she was eating. "What a waste!" I thought. But Mom just wiped out the jam, saying, "Too bad!" Where does this difference in attitude come from?

When I failed trying to stand up from the chair, I squashed the orange in my pocket. Feeling like Mom, I was able to think, "Too bad!"

Cruel Words

At last I've been 'referred to.'

Mom and I had gone to the hospital for an examination. I almost fell over into the toilet and Mom was supporting me. I was desperately holding onto her.

Beside me, a woman in her 30s wearing clothes with a red check pattern whispered to her little boy: "Unless you're good, you'll become like her."

Her comment made me feel very sad and miserable.

Mom cheered me up by saying, "Well, if she raises her child by saying things like that, when she grows older and has troubles with her own body, she may realize her teaching was wrong and the fact that she wasn't a good mother has come back to haunt her."

I guess I'll have to face this kind of incident more frequently in the future. When young children encounter someone different from themselves, they get interested and stare. It can't be helped. But it was the first time I've been treated by an adult as raw material for child discipline. That was rough on me.

My family reckoned I must feel lonely being all by myself during the day, so they got me a cat. It's quickly become attached to me. It comes into my futon or inside the kotatsu with me. And it sits on my knees. It's very cute. When Rika holds it, she hugs it tightly; it doesn't like that and tries to escapes from her. Then she pulls its tail and tries to put it on her own knees, no matter how much effort it takes. It refuses more and more. Then Rika gets angry. In the end, she hits it. I tell her off, saying she shouldn't hit it. I tell her off, saying she shouldn't hit it. Rika glares at me and then starts hitting me.

"Don't you dare!" I say, pretending to be angry with her.

Rika jeers at me, saying, "Aya's angry, Aya's angry!"

"If you say so."

I told Mom.

I'm 19 years and 5 months old; Rika is 5 years and 7 months old.

I'm living the life of an old woman: no youth, no energy to live, nothing to live for, no goals to work toward . . . All I have is my deteriorating body. Why do I have to be alive? On the contrary, I want to live. The only things I enjoy are eating, reading and writing. I wonder what other 19-years-old enjoy?

When I had my last medical examination, I was told to enter the hospital again after the New Year. I'm scared because I'm only getting worse and there's no sign of recovery. When I think about that, I can't help crying. Thrashing about in the darkness . . . Is that my life? Damn! Showing my defiance, saying "What's wrong with being 19 years old?" or "What's wrong with being 20 y ears old?" won't lead anywhere.

When I cry everyone gets depressed. When I cry, I get stuffed-up nose and a headache and I feel tired. So why do I cry? I have nothing to aim to finish-neither a job nor a hobby. Unable to love anyone or stand on my own . . . I'm wailing.

I look at my tear-filled face in the mirror.

Aya, why do you cry?

I had instant ramen noodles for lunch today - -known for the slogan 'Just add hot water and it's ready in three minutes.' Because I can't sip soup well, I choke easily. It's very painful, you know. If I choked and couldn't breathe when nobody was with me, it could be fatal.

Chika-chan, my senior at boarding school, had polio. She drooled a lot, but she could drink tea from a teacup. Ikeguchi-kun used a straw. Why can't I drink without dripping? Maybe it's because the muscles I

use to swallow has weakened. Today I concentrated on my mouth. Like drinking sake from a small cup, I tried to sip it little by little. I didn't choke, so I was happy.

There's another thing I felt happy about. Up to now, I couldn't do something that to most people is a matter of course. It's embarrassing to write this, but because I often couldn't get to the toilet in time, I had to keep changing my underwear. I realized the cause of the problem: I only started moving after nature called, but I couldn't move fast enough. So I decided I should go to the toilet regularly at fixed times. And it worked! - now I can manage without any accidents! I'm so happy, I want to tell someone. But it's not the kind of thing you can tell to everyone, so I'm secretly enjoying my success.

Class Reunion

Five teachers from the boarding school, as well as 17 students and their parents, gathered at the restaurant called Inaka. I was happy to see everyone looking well. Before the dishes were served, everyone stood on the veranda chatting in the warm sunlight. I was the only one sitting.

Suzuki-sensei came over and sat down cross-legged beside me. Our eye level became the same. He gave me a handkerchief, saying it was a souvenir from Singapore. As usual his eyes were gentle like those of an elephant. Yo-chan gave me a book she'd bought using the wages from her job - Cherry-chan to Einstein boy (Cherry and the Young Einstein) by Teruko Ohashi. We ate to our hearts' content and laughed happily.

"It's been a while since we ate a full-course Japanese meal and saw everyone, isn't it?" Mom said later. "We can enjoy a lot of good things if we're alive, can't we?"

"Yes, we can," I answered.

If someone only says one or two words a day, can you say that they are really leading a life as a member of society? . . . I'm becoming that kind of person.

If someone can't do anything by themselves, and has to have other people look after them in order to live, can you say they are leading a social life? . . . I'm that person.

I want to be useful to other people. --> I will at least try to do my own things so that I won't disturb other people. --> I can't live unless I have someone to look after me. --> I'll become a greater burden on other people . . .

That's the story of my life!

It's snowing. Even with the electric heater on full (oil heaters irritate my throat, so only in my room there's an electric heater) and warming my self in the kotatsu, I feel chilled to the bone.

I started reading Hashi no nai kawa (The River with No Bridge) by Sue Sumii at the New Year. I finished five volumes at a stretch. I easily get totally absorbed. It's a bad habit. I even skipped training to read it. The air was cold when I went out into the corridor. I felt a chill. I put on a short padded jacket in an attempt to avoid getting a cold. But I sensed danger because my body's so stiff. I've decided to eat my meals in my room while it's cold. I feel lonely when someone brings me my food and I eat it all on my own, but sometimes my brothers and sisters come and eat with me.

To tell the truth, I don't like sleeping and eating in the same place.

A Traffic Accident

ALL RIGHT, ALL RIGHT . . . Ako was injured and entered hospital. On her way home on her bicycle, she was hit by a car that didn't stop where it was supposed to. She was taken to hospital by ambulance. Will she be all right? I don't know what to do. I can only pray for her . . .

Mom came back from the hospital. Ako has broken two bones in her right leg. She'll have to have an operation once the swelling goes down. Mom said Ako was crying as she did her best to endure the pain, and kept saying, "Mom, I'm sorry about this."

"It was a good thing that she didn't hurt her head. I was really relieved," Mom said quietly. She looked smaller somehow or other.

"Please take me to see her," I said.

"I'll take you when her operation's over and she starts smiling," Mom replied. "If you start crying, it may make her injury hurt more. So you'll have to wait for a while."

Oh I feel like flying to Ako and saying, "Ako-chan, hang in there!"

My brother dropped by the hospital on his way back from school, but he didn't tell me how she was. Is she that seriously hurt? I really want to eat some sweetened adzuki beans, but I'll be patient until Ako gets better. Hang in there, Ako-chan!

Is Mom all right? She doesn't seem to be sleeping much.

"Mom, I'm anxious about Ako, but I can't do anything," I said.

"Please don't fall over and hurt your self," she replied.

"That's the best thing you can do to help."

It seemed to me a rather passive way to help, but I nodded. Then I said, "Yes, I can see that. I know I won't be able to see Ako until I stop crying. But I'll try hard not to cry, so please take me to see her."

Rika suddenly said, "Ah, I want to die!"

I go serious just hearing the word 'die'. Even when I threatened her by saying "It'll hurt you know," she said,

"That's OK." When I said, in haste, "You won't be able to go on any picnics," she finally said, "I don't like the sound of that. I won't die then."

She wasn't seriously saying that, of course, but I was kind of seriously trying to stop her.

A breeze is blowing-you can feel the arrival of spring. Even the grass shoots are growing rapidly. I can't scratch my left Achilles tendon very well, and it's difficult to sit-maybe because I didn't do much exercise during the cold das. I've also developed a phobia about going to the toilet. I often get stiff shoulders and

feel uncomfortable because I don't sweat, even when it's hot. My tongue's movement's poor and I can't even lick a soft ice cream. I guess that's part of the reason I'm having difficulty speaking.

Yamaguchi-san's brother brought a new car. He invited me out for a drive. That was really unexpected!

It was a beautiful spring day. The shepherd's purses, Chinese milk vetch, dandelions, and early clovers were all beautiful. I wanted to make a ring of flowers, but I couldn't do it by myself. I felt embarrassed to ask a man, so I didn't. I found one clover which was sticking out over a ditch. Worried it might fall in, I peered over at it. But it was all right because it had a big root. I felt it must be strong as long as it has that support.

We dropped by Yamaguchi-san's house on the way back. He played his electric guitar. It was a very powerful sound. He said he's deeply into guitar-playing now. He wants to have more equipment, but, he said, "The money comes first, and everything else follows."

In my case, "A sound body comes first, and everything else follows."

That's more difficult than money.

"Mom, I Can't Walk Any More."

A baby sits when it's around eight months old, crawls when it's ten months old, and walks when it's over one year old. I used to walk, then I gradually went back to crawling, and now I'm sitting most of the time! I'm degenerating. And some day, I suppose, I'll be bedridden . . .

Is it only a matter of me being patient? One year ago, I could stand, I could talk and I could laugh. Now, I can't walk, however much I try, however much I grit my teeth and try to hold on with a frown.

'Mom, I can't walk anymore,' I wrote on a piece of paper, restraining my tears. 'I can't stand even if I hold on to something.'

I opened the door slightly and gave it to her. I closed the door again quickly because I didn't want her to see my face, and I knew it would be painful to see Mom's face.

I crawled three meters to the toilet. The corridor was chilly. The soles of my feet are soft like a normal palm of the hand. But my palms and knees are hard like a normal sole of the foot. Crawling's not a nice thing to do, but it can't be helped. It's the only way I can move around . . .

I felt somebody behind me. I stopped and looked back . . . There was Mom crawling behind me, without saying anything . . . Her tears were falling to the floor . . . All my suppressed emotions suddenly burst out and I started crying.

Mom held me tightly and let me cry as I wished. Her knees were soaking wet with my tears, and her tears wet my hair.

"Aya, we're sad, but we'll keep going, OK? I am with you. Now, let's go back to your room before your bottom gets cold. I'm strong enough to carry you on my back. Even if we have an earthquake or a fire, I'll help you first. Don't worry and sleep tight. There's no need to think about unnecessary things."

Then she carried me back to my room in her arms.

I've become a person who can do nothing but weep and whimper. The lump of an inferiority complex is growing inside my brain. I think it's a product of being disabled. But I'm still alive. I'm continuing to breathe in order to live - because I can't die, and nothing can be done about me. That's a dreadful way to say it. When I cry, I get wrinkles on my eyebrows and my face becomes ugly. To improve my face when I look in the mirror, I try to grin even though there's nothing funny.

Let's Live

I want to inhale the blue sky with all my might;
A refreshing cool mint breeze will gently caress my cheeks.
Scattered white clouds reflected in your clear crystal eyes.
I've been dreaming of this wonderful moment . . .

I want to jump up toward the blue sky with all my might;
A robe of cobalt blue feathers will gently envelop me.
Without thinking I am ugly,
Earnestly believing that I may be useful somewhere.

Where do you think I should go?
Always crying by myself,
My notebook is my friend;
Answers it cannot give me,
But my spirit is lifted when I write.

I am asking for a helping hand,
But I can neither reach out nor touch;
My voice only echoes, yelping into darkness.
Evolution from monkey to human took an incredibly long time,
But degeneration is so fast . . .

I dislike being alone during the daytime. Afraid I may no longer be able to talk; I read picture books aloud and do vocal exercises. Today I did deep breathing give times and stretched my neck ten times.

Mom says that I shouldn't try to do too much even when I'm on my own. She thinks it's dangerous. She's always worried until she comes home and sees me. Although those words would make my life even more passive, I can see they're reasonable because in fact I do fall over - my lips get swollen and I break my teeth.

Worried about me being alone, Jun-chan and her mother sometimes come to see me. The middle aged woman from next door also pops in to see what's happening. But my heart's not satisfied. It's very hard to live through each day without any purpose. I can only think about odds and ends in my head, but I can't do anything. How long will this life go on? . . . Mom, I'm in pain. Please help me . . .

Now that it's also dangerous for me to take a bath on my own, either Mom or Ako comes in with me, wearing shorts. Ako washes my hair and my back. I can't raise my right arm any more. It seems my shoulder joints have stiffened up.

Message to Dr. Yamamoto

You said "Vakye what's left rather than what's lost."

The light will shine some day, and the green buds will appear . . .

Have hope, look toward the future, and stand up, keep going don't give up . . .

Those are the passwords!

"Nothing will come back even if you grieve over it," said the doctor I trust. "Develop what's left more than what's lost."

I'll try to keep going.

I swear I won't get depressed . . .

It's started to rain.

I envy the changeable nature of the weather . . .

But people can't live being so changeable, can they?

-The contents are irresponsible

-My mind's sloppy

-My writing's shaky

Nothing's any good, you idiot!

So what would you say is left for me?

I had a dream that my family went on a trip to a place that you couldn't go to in a wheelchair.

"Have a nice time," I could say with a smile. "I'll be waiting for you here at home."

I think things like that may become more frequent. I want to be ready for when they become reality.

Limits

People often say that the beginning of the rainy season is a bad time for sick people. And in my case I'm getting worse and worse as if I'm falling down the stairs.

-I have diarrhea, my body feels dull. Dehydrated?

-My hips are unsteady.

-It's difficult to swallow.

-I fall over and my lips bleed.

-It's difficult to read characters and see other objects. Everything is out of focus.

I was contacted about the festival they're holding at the boarding school, but I don't have any energy at all to go.

My disease has developed too far.

The days when I don't write at all have been increasing.

I can't use a ballpoint pen well . . . I want to think it's because I haven't been writing much.

I may not last much longer . . .

20 Years Old – "I don't want to be beaten . . ."

A Fall in The Toilet

Mom brought back some cakes, but I didn't have the energy to eat them. I've been lying down almost all day.

Thinking that was not so good, I tried doing some sit-ups on my futon. I could only manage one.

The summer holiday's starting tomorrow. Mom's telling my brothers and sisters to discuss what they will do so that they won't all go out at the same time. That's reassuring. I'm sorry to be such a burden. I'll make an effort to get better, so please forgive me.

When I go to the toilet, either Mom or Ako comes with me. They help me to pull down my pants and sit on the toilet. Then they wait for me outside. One day, I swayed to one side and fell down with a thud. I don't know how it was cut, but my finger was bleeding. I lost consciousness.

The next thing I knew, I was in bed. I could see the blurred faces of Mom, my sisters and my brothers. Then again I fell into sleep. I could vaguely hear Mom's voice somewhere in the distance saying, "You were just unsteady because your blood pressure was low. Don't worry about it and sleep well."

A stable iron toilet seat weighing more than seven kilos has been installed. The family chose it at the shop selling special equipment for the disabled in Nagoya. At the same time, they got a bead mat for me (to help avoid bedsores) and a sheet to prevent the mattress getting dirty.

Also a small desk with short legs (with writing tools, notebooks, letter paper, and so on) was put within my reach. On top of it there's a bell which produces a loud sound when it's rung.

Now I spend most of the day sleeping. I'm scared of food going down my respiratory tract by mistake because I can't swallow well, so I can only eat a small amount three times a day. I eat so slowly that lunchtime comes round just one hour after breakfast.

My whole day is taken up by eating, sleeping and evacuating. What's more, someone has to help me do all those . . .

I think my life has finally reached the point where it's just one step before it will impossible to stay at home.

I've decided to stop thinking on and on about my disease.

Looking for a hospital

Today, Mom and I went to Nagoya Health University Hospital. I lay on the passenger seat with the back lowered.

I mostly dozed till we arrived at the hospital.

"I'll push them to let you stay here," said Mom, "so don't worry. I know the heat's bothering you, but you'll just have to be patient till the weather gets cooler. Aya you have a lot of fight left in you. I'm sure you'll get better."

But I felt that this time I might not last: I have neither the stamina nor the motivation. I don't even have the strength to think, so I couldn't possibly put up a fight. I don't want to be beaten by my disease, but the demon of ill-health is too strong.

As I lay on the ward trolley, Mom was negotiating with an outpatient nurse, trying to keep me from overhearing:

"We can't possibly wait in the waiting room as long as we usually have to. She's so weak. Please treat her as an emergency patient and give her a medical examination quickly. If the other patients are unhappy about it, I'll gladly explain her condition to each one of them and ask for their approval."

The nurse disappeared inside the consultation area, saying "I'll ask Dr. Yamamoto." Moments later, Dr. Yamamoto herself appeared. She took hold of my hand and said, "Ah, long time no see, Little Aya. I've been waiting for you."

Oh, this will keep me going . . .

It would be a pity to die now . . .

If only I could write again, I wouldn't have anything to regret . . .

Saved by Dr. Yamamoto yet again . . .

Tears filled my eyes. Mom was crying, too.

After the consultation, Dr. Yamamoto said she would introduce us to Akita Hospital in Chiryu City where she goes twice a month for medical examinations.

I felt relieved when she said, "Little Aya, I think you should enter the hospital as soon as things have been prepared for you. Please wait just a little. I want you to be where I can keep an eye on you."

My upper lip was bent when I fell over, and now it won't meet with my lower lip. I handed the doctor a memo that

I'd written at home:

'It's difficult for me to swallow, so please give me some medicine to relieve the tension in my throat.'

After the examination, Mom drove me home. I vibrated in the car for two hours.

"You have to gain stamina," Mom said. "Tell us anything - anything you want to eat or anything you may be able to eat. Do you want something now?"

"Yes, I'd like you to bake me a cake," I answered.

"Uh-oh," replied Mom. "Ako's better at baking cakes than I am. Ako, Aya would like you to bake her a cake!"

"Then I'll make you one first thing in the morning," said Ako, all smiles. "Please look forward to that."

I was exhausted and went to bed immediately.

Mom visited Akita Hospital by herself. Before she left, she told me that she'd check what kind of hospital it was and talk with the doctors in detail. She also told my sister to ask me what I would need, sort out some things for me, and put them in a box.

Hospital admission and a caregiver

I've finally entered Akita Hospital. I was feeling nervous because I'm not familiar with it.

A little old lady came to look after me.

"I'm Aya," I said in a small voice. "Nice to meet you."

Mom explained to her in detail about my condition, what I couldn't do, and so on. But it's really difficult to get her to fully understand.

My speech disorder's getting worse, so I asked Mom to buy a magic blackboard. I probably say some words that other people can't understand.

The movement of my tongue's bad, so the food overflows my mouth. My way of eating looks filthy. It's a pitiful sight.

I feel miserable for being unable to communicate well.

I'm the one who should take the most sensible attitude. But I don't feel very confident . . .

Mom, what am I living for?

I felt dizzy. I had a tearful face. But I closed my eyes and stayed still.

There's a pigeon's nest on the branch of the tree outside the window. A chick is growing up in it. I'm happy about that.

My little old lady helped me get into my wheelchair and took me to Building #1. Then what? I used the Western-style toilet to relieve myself.

During rehabilitation, I tend to close my eyes when I stand holding the bar. I can't easily open them again. I know I shouldn't be scared, but my body gets stiff because I feel I might fall over.

I should properly grasp the things I can do now and put them into practice. Then I won't have to suffer so much mental agony that I can't get to sleep at night . . .

I can't convey my desires quickly, so I sometimes can't get to the toilet in time. Mom suggested that I should use a urinary drainage bag during the night. The reason for that is that the caregiver gets tired if her sleep is disturbed.

I started crying, saying, "I don't like that idea because I know when I want to urinate. I'll try to tell you in plenty of time, so please don't do that."

"All right, all right," said the little old lady gently. "Don't cry. You won't have to have one."

That made me cry even more.

In the morning , I met the Hospital Director in the corridor.

"Good morning, Little Aya. How are you doing?"

I smiled and tried to say "O-HA-YO" (Good morning) with pouted lips. By the time I got it out, he was already a long way down the corridor. He must be very busy.

My tearful face is taking root - that's no good.

At night, my arms and legs got tense and stiff. The little old lady got up and gave me a massage.

Because I couldn't easily express myself, I lost my temper and cried. I'm the one who should be blamed for not being able to communicate well. There was no reason for me to get angry with the little old lady. I'm sorry.

It's nice weather today. I want to stand up. I want to talk.

My little old lady praised me, saying, "Your handwriting's a bit better. You're eating a little quicker now, too, and you're not dropping your food."

I feel there's something to live for if I improve even a little, and I get more relaxed. I must live considering how other people feel. I made a promise to Dr. Yamamoto that I'll try to be able to ride in my wheelchair by myself by the next time I see her.

I saw the blue sky. It's been a long time. It was so transparent, I felt I could be sucked up into it.

My pronunciation of the 'na' and 'da' columns is not very clear. It's also hard for me to say the 'ka', 'sa', 'ta' and 'ha' columns. I wonder how many words there are left that I can actually say? I'll have to overcome this somehow or other.

Gather up your fighting spirit or the disease will defeat you!

My little old lady bought me an 'okonomiyaki' savory pancake for lunch. We had half each. I also had some 'o-shiruko' adzuki bean porridge with rice-flour dumplings.

I was running a fever and had no energy to talk. I felt very heavy. I lay in bed all day. My little old lady looked into my face with a worried expression on her face.

Aunt Kasumi took me to the coffee shop inside the hospital. She helped me drink lemon soda with a spoon, one spoonful at a time. I had given up on the coffee shop, thinking I'd never be able to go there as long as I lived, so that made me so happy.

My little old lady's hands are rough and cracked now. They look so painful. It's because she has to keep on washing my nappies due to my failures during the night. I'm sorry.

The Chunichi Dragons won the baseball league pennant! For some reason, we had a bonus of sweet red bean rice and a cup-steamed egg custard for dinner. I wonder if the Hospital Director or the head chef is a Chunichi fan?

I wanted to stand up, but when I tried, I swayed like a swing and almost fell over. I was scared. My little old lady helped me.

In the morning, I nearly choked. I was scared again. Unless I take care eating things - however tasty they may be - it could prove fatal.

When my little old lady took me to the toilet, we saw a vase full to overflowing with beautiful cosmos flowers.

We winked at each other and stole one bud. We put it in the vase in our room.

"Little Aya, you're depending on your caregiver too much," Dr Yamamoto scolded me. "You must find what you can do by yourself and do it."

I was happily thinking I was OK if I simply stayed out of bed for a long time, but I was wrong. Starting today, I'll practice fastening my buttons.

I could walk! Leaning on my little old lady, I asked her to take me to the park. I wanted to play with some dirt; I felt like putting the soles of my feet on the soil. I asked her to put my feet down softly on the ground from the footrest of the wheelchair. The soil was so comfortably cool!

I desperately practiced fastening my buttons and rolling over and standing on my knees for rehabilitation. My little old lady was impressed with what I was doing and helped me. She also bought me a pair of sweatpants and a jacket. I must keep at it more . . .

I want to go home over the New Year. I wonder if I can make myself understood. I'm worried about how I can communicate with everyone if they can't understand what I'm saying. But I still want to go home.

The bud of the cosmos has opened.

My little old lady cried while she was watching me training. "You did a good job!" she said.

"Why don't you watch Aya once?" she said to Mom one day. "She's working very hard, you know."

But Mom replied, "It hurts me too much to watch her." Then she said to me, "Aya, you've done very well. We want you to come home for the New Year."

I moved my bowels carelessly.

"I'm so sorry," I said to my little old lady.

"Oh, helping you is my duty," she replied. "It can't be helped."

Still, I didn't know how to feel.

I had some ham for lunch. I hadn't tasted ham for a long time. It reminded me of the past.

I wonder how I can show my gratitude to my little old lady? I can't buy her anything because I don't have any money. It will be nice if I get better soon and can look after her. Please wait till then!

Striving to live for the present

In another ten years . . . I'm too scared to think about that.

I have no choice but to live today as earnestly as I can.

Living is all I can do now.

I'm young but I can't move . . .

Dilemma and impatience.

But I'm a patient, so I have to focus on recuperation.

You, one person,

Advise me not to write too much.

Appreciating that,

I put my hands together in thanks.

Thinking on my sickbed . . .

(At this point Aya's handwriting becomes illegible.)

I understand that menstruation - the indication that you're a real woman - stopped if you grew weak from illness. I also thought that it was a sign of recovery if it started again after six months.

Glancing up from my sickroom,

I saw the blue sky;

It gave me a ray of hope.

A - RI - GA - TO

I can't lead my life without my little old lady or without depending on someone - for everything, including turning over in bed, dealing with my bowel functions, putting on my clothes, taking off my clothes, eating, sitting up . . . Mom has to work and look after my brothers and sisters. She's not just a mother to me. My little old lady is spending her life only for me. She cooks noodles and 'mochi' rice-cakes (my favorites) for me.

She encourages me to eat more - even if just a little - and get better as soon as possible so that I can go home. Her daughter-in-law sometimes brings in dishes she has cooked herself and serves me. Her grandchildren come and take my photo. Her whole family really looks after me.

I can hardly talk. All I can say is "A-RI-GA-TO" (Thank you). But I want to convey my happy feelings to them using lots more words.

Each person has unspeakable distress.
When I remember the past,
Annoyingly, I cry;
The reality of today
Is too cruel, too severe,
And doesn't even offer me a dream;
Imagining the future
Brings me yet another kind of tears.

21 Years Old – "For as long as she is alive"

by Shioka Kito (Aya's Mother)

"Mrs. Kito, please come over here quickly!"

I received the call from the hospital at my workspace. In a panic I rushed to the hospital as fast as I could;

I can hardly remember how I did it.

I pushed my way through the doctor and the crowd of nurses who were gathered around Aya's bed . . .

"What's the matter?" I cried out.

Aya was breathing as if she had hiccups, but she smiled when she saw me.

I hugged her at once, thinking, "Thank God, she's alive!"

The doctor told me that a patient in the same room had noticed that Aya was in agony because she couldn't get rid of some phlegm stuck in her throat. The patient told a nurse. They administered emergency treatment and her life was saved.

Due to a variety of minor things, such as developing a fever and faulty swallowing. Aya's condition has gradually deteriorated. It's just as if she's going down stairs one at a time.

Starting around that time, her writing became very distorted and almost illegible. However, her spirit of wanting to write in order to live didn't decline at all; she continued writing in her sketchbook holding a felt-tip pen with all the strength she could muster in a hand which wouldn't move as she wished.

Today, she can't even do that. However, I am sure that she is still writing in her heart, while desperately fighting against the demon of ill-health.

"Can I . . . get married?"

by Hiroko Yamamoto

Introduction

I had a call from Aya's mother one Wednesday afternoon in late September. It was around the time of day when the outpatients waiting to be examined and those who were undergoing an examination were all beginning to get a little tired of having to spend such a long time in the hospital. She told me she was preparing to publish Aya's diary, which had been written over a long period. She wanted to ask me, as her doctor, about the disease Aya had suffered from and also about my association with her.

While advising Aya to keep her notes in a diary and organize them into a book, I was concerned about the fact that there wasn't much I could do to help her. So I was relieved and very pleased to hear that publication was getting under way. Aya is no longer able to get up by herself and is now bedridden. She has to rely on someone to help her eat and do everything for her.

Her mother said she wanted to complete the book as quickly as possible for the sake of such a daughter. I felt a lump in my throat when I heard her mother's way of talking. I granted her request. At the same time, I thought that looking back would be a good chance for me to put everything together; my encounter with Aya was also deeply connected with my own growth as a doctor.

You may find what I have to say about Aya's incurable disease - spinocerebellar degeneration - a little difficult to follow. But I hope you will read it carefully because it is important to understand her way of live.

What is spinocerebellar degeneration?

A human brain has about 14 billion nerve cells, supported by more than ten times that number of cells. The nerve cells are classified into many groups. Some function when you are exercising and others work when you are observing, hearing, or feeling something. As long as a person is alive, many groups of nerve cells are working.

The nerve cells inside the cerebellum in the brain, the brain stem, and the spinal cord are required for the body to maintain balance reflexively, and to achieve quick and smooth movements. Spinocerebellar degeneration is a disease in which those nerve cells gradually change and then finally disappear. We haven't yet discovered why they behave like that. According to nationwide statistics there are just over 1000 patients suffering from the disease in Japan. However, it is said that the real number of patients is two or three times that figure.

The most frequent symptom of the disease at the early stage is when you feel your body is swaying. At first you may think it's because you are tired or have anemia. But it gradually develops to the stage where you can't walk straight. People may start asking if you're drunk. Other early symptoms can include: dimmed vision, double vision, or things appearing to shake; difficulty in speaking because you can't get your tongue around certain sounds; difficulty urinating and the sensation of residual urine even after you've been to the toilet; feeling faint when you stand up because your blood pressure suddenly drops; etc.

How the disease progresses

The swaying increases and you need some kind of support when you are walking. If it gets much worse, you cannot stand by yourself with your legs together. Pronunciation gradually becomes unclear and your speaking rhythm deteriorates, so people cannot understand what you are saying. The movements of your hands and fingers can't be controlled as you wish. That means you have difficulty writing and nobody can read what you write. You can't use chopsticks when eating, and you can't carry food properly to your mouth, even with a spoon. And even if someone helps you to eat, it takes time to swallow, and you may sometimes choke and spray grains of boiled rice everywhere.

These symptoms progress little by little until you finally become bedridden. Then there are various dangers: bedsores can get infected; you may develop pneumonia because food gets into the trachea due to the failure of swallowing; urine is left in the bladder, and an increase of bacilli leads to cystitis or pyelitis. As a result of all or some of these symptoms a patient usually dies in five to ten years.

Is there no remedy?

Today there is no remedy available. The cause of the disease is still unknown, so we are groping in the dark regarding proper treatment. There is a medicine that can temporarily prevent the disease from advancing or slightly slow down the speed of its advance. It has been drawing a lot of attention, but it hasn't been used for very long and we need to take a long-term view of its efficacy.

But thanks to the remarkable advances in genetic engineering in recent years, it is surely only a question of time before it will be possible to determine the chromosome in which there is a gene that causes the disease - if the disease is hereditary. Then it may be possible to replace that gene with a healthy gene. I sincerely hope that the sad voices of the spinocerebellar degeneration patients and their families will be fully added to the debate over the rights and wrongs of gene manipulation.

But that is for the future. The most effective guidance for the time being is for patients to continue exercising and training. They must try to maintain the strength of the muscles in their whole body and look after themselves as well as they can.

How do you explain about the disease to patients?

It is not difficult for medical specialists to diagnose the disease. However, they tend to agonize over how they should explain it to the patients and their families. Some doctors prefer not to tell the patients that there is no chance of them getting better. Instead, they encourage their patients with words like, "Don't worry, you will be cured." However, they know that the patient's condition will gradually get worse, and it's impossible for them to recover. They may explain this to the patient's family to a certain degree. Other doctors give up in despair and all they do is tell the patients and their families that it's a very serious disease for which there is no cure.

What I say to patients is this: "It is very difficult to cure this disease. There is also the possibility it will slowly get worse. However, today various types of remedy are being developed." Then I explain in detail how many more years the patient will probably be able to walk, and how long they will be able to sit and move their hands and legs.

Patients and their families tend to be temporarily shocked by the news. But they soon recover their normal spirit and start planning their new life and how to spend their social life while coping with the

disease. Some patients, however, visit various hospitals hoping to get more reassuring words about a cure. They never come back to me as outpatients. That discourages me, because I start worrying I couldn't make myself understood properly. I have to conclude that to begin with we didn't have a good rapport. I guess those patients and their families who stay with me have thoughts similar to mine as their doctor. Little Aya Kito (referring to a grown woman like this may sound strange, but to me she is still 'Little Aya') and her mother were among them.

First meeting with Little Aya

I had just returned from a three-year stay in the United States. I was working in the 4th Study Room of the 1st Department of Internal Medicine at Nagoya University Hospital (now the Department of Neurology) with Professor Itsuro Sofue. I was helping to analyze nationwide data on sinocerebellar degeneration. I also wrote the professor's findings about the outpatients in their case records. One Monday, a junior high school girl with a short bob was brought to the examination room by her mother. In recent years, the number of specialists who examine nervous diseases in pediatric departments has increased.

So it was unusual for a child to come for a consultation at the Department of Neurology. I learned later that Aya's mother was a nurse working for a health center in Toyohashi. She had discovered that the professor was the leader of 'the research team on sinocerebellar degeneration, a disease specified by the Ministry of Health and Welfare.' That explained why Aya had bothered to come all the way to our Department of Internal Medicine as an outpatient. It had been her mother's decision.

On the medical chart of the girl who sat in the middle of that bright consulting room in the early afternoon was written 'Aya Kito, 14 years old.' Her small round face with eyes wide open gave the impression that she was a bright girl. Her eyes looked worried as she glanced in turns at the professor and her mother as they talked.

After the first examination, the professor diagnosed spinocerebellar degeneration. He explained to Aya's mother about the disease. He gave instructions on how to get a CT scan for Aya to check the inside of her brain, a center of gravity oscillation test, and an eyeball motion test. Those tests would provide a better analysis of the symptoms. He asked Aya to come back as an outpatient about once a month to check her condition.

I was impressed with the positive attitude of both Aya and her mother despite the great anxiety pressing down on them. I felt a strong affinity with them. Soon I came to have my own outpatients in a different consulting room, so I no longer had the chance of seeing Aya being examined. But we often went to the hospital on the same day and met each other in the corridor.

Aya's mother grasped the progress of the disease very well. She sometimes told me in a sad voice that Aya's swaying was increasing and she had stumbled, or that her writing had become more disordered. Sometimes she also reported happily that Aya was doing well at school, was getting good grades, and had had an internal school report praising her good attitude, so she could enter a public high school. She also told me Aya had passed the 3rd level of the Practical English Proficiency Test. I kind of championed Aya who was doing her best to fight against her disease. "The third level of the Practical English Proficiency Test is quite difficult, you know,"

I said proudly to my colleagues, as if she was my own daughter.

One day, around the time when the cherry blossoms in Tsurumai Park were budding and the light pink petals were started to emerge, Aya's smiling face appeared round the corner of the curtain of my consulting room.

"Dr. Yamamoto," she said, "I passed the entrance exam!"

As I replied "Congratulations and good luck!", I couldn't help wishing that her disease would at least not develop too far before her high school graduation. That also encouraged me to press on with my research on a possible remedy that was being developed.

The high school that Aya entered was located in Toyohashi in Aichi Prefecture. It was oriented toward preparation for university entrance examinations. Her lively high school life began. But soon Aya's balance worsened. She could no longer commute to school on a crowded bus every morning. Even though her mother was busy as a nurse, she took Aya to school by car every day. Aya sometimes fell over in her school days and came to the Outpatients' Department with cuts on her knees or a lump on her forehead. Her mother's face darkened momentarily as she told me that Aya's scores at school seemed to be getting worse little by little.

But immediately after that she smiled cheerfully and said, "But because her writing is so slow during tests, she runs out of time. So it can't be helped, can it?"

In fact, Aya couldn't take notes properly. She also had to change classrooms for different lessons, and was always late for classes because her movements were so slow. Her high school apparently regarded that as a big problem. However, her classmates helped her a lot, carrying her textbooks or holding her hand when they saw her desperately trying to walk. I can imagine how grateful she was, but also how frustrated she must have felt about her disabled body. However, she was always smiling and her big eyes were active in her face as it gradually went thinner and smaller.

It was decided she should enter the hospital during her summer holiday in order to try out the new medicine.

Little Aya's admission to the hospital

Aya stayed in Ward 4A at Nagoya University Hospital. She was very popular with the nurses. Although she was a high school student, her childlike face gave her an angelic look. She obediently followed everyone's instructions, hoping to get better, even if only a little. She planned and practiced various exercises for her hands and legs. It was impossible not to be fond of her. The new remedy had a slight effect, but it didn't reduce her daily inconveniences. The nurses complained to me, saying "Dr. Yamamoto, Little Aya is working so hard. Why can't you do something to help her?" I felt a loss. Around that time, word was going around that the professor at the hospital was an authority on spinocerebellar degeneration. Many patients came to our hospital from all over the country. Aya and U-kun, a boy one year younger than her, were young and cheerful patients. But some of the patients were bedridden, only getting up to go to the toilet in a wheelchair. Sharp-eyed Aya mentioned the names of the seriously ill patients to me and asked, "Will I be like them soon?"

I knew Aya had various dreams for her future. During my rounds, she would carefully check my reactions as she told me about them. I had begun feeling that it was about time to tell her properly about her disease.

So I answered, "It will be a long time from now, Little Aya, but yes, you'll be like that eventually."

I explained to her in detail what would happen to her as time passed: her swaying would gradually increase; eventually, it would be difficult to walk; her speech would become unclear and would not be understood; and writing and using her hands for any kind of handiwork would become difficult.

For several days after that, she was very depressed. But soon she started asking me positive questions again: "Dr. Yamamoto how much longer will I be able to walk?" or "Do you think I could manage this kind of work?" I felt sorry for her, but I thought it was good that I had explained everything.

In fact, after that, our mental bond became stronger. We could talk openly about the very serious symptoms of the disease, and knowing in advance what would come next made it easier to decide what to do next.

Her stay at the hospital that time couldn't do much to improve her condition. However, I believe she left the hospital understanding what was most important for the long life under medical treatment that she would have to face.

Changing to a school for the handicapped

Aya's high school requested that she leave the school because she was causing trouble for the whole class. It was just what we had feared would happen. Bitterly disappointed, Aya's mother told me that her classmates were helping her go up and down the stairs when she moved to another classroom and saying, "It's no trouble, Aya!" We'll help you in the same way in the future."

I felt brighter when I heard that her classmates were supporting her.

Her mother told me that she was going to ask the school to let her daughter stay.

"If the teachers have any questions about Little Aya's disease," I said to her, "I'll be happy to explain. Or I could go with you to the school."

But her mother replied that she would prefer to go by herself. She went to the school many times, despite her busy work schedule, and made a strong appeal to the school authorities for Aya to stay there. In the end, however, it was decided that Aya would move to a school for the handicapped. The grounds of that school are designed so that the students can freely move around in wheelchairs. It also has a rehabilitation facility where they can study while having treatment. But I think it was a big shock for Aya's mother who, supported by many of Aya's classmates, had been fighting against the move. When she told me in a sad voice that Aya was going to move, I felt a lump in my throat.

I suppose that the high school administrators did not know how to deal with Aya. Their conclusion was that if there was a school designed for children like her, why shouldn't Aya go there? But I wonder if causing trouble was the only effect Aya had on the school. From what I heard, the desire to care for a disabled friend was emerging very naturally among her classmates. They could learn a lot from the serious attitude of a friend who was trying so hard to live. I was very disappointed with those evolved in her education.

They didn't even inquire about her disease. They just did things by the book. Today, the issue of bullying is talked about a great deal, but I believe there was no hint of a dark shadow over Aya's classmates. Much later, when Aya entered the hospital again, I remember her saying to me happily, "Please give me permission to go out because I'm going to meet my high school friends."

Hospital life at Nagoya Health University Hospital

In April, 1980, I finished my doctoral thesis at Nagoya University. I moved to take up a new post at Nagoya Health University Hospital - now called Fujita Health University Hospital - in Toyoake, Aichi Prefecture.

By then Aya required the use of an electric wheelchair, and she could only travel to the hospital by car. Because Toyoake was closer to her home than Nagoya, she moved to the same hospital where I was now posted.

As I examined Aya in the consulting room at the new hospital, I compared her condition to the day when I had first met her in Nagoya. Her cheeks had been much fuller then, and I had been able to understand what she said much better. Even though she had claimed she was swaying, she was walking quite normally to other person's eyes . . . After just five years, however, she needed someone to push her around in a wheelchair, she couldn't utter words quickly even though she tried hard, she could only speak by twisting and stretching her thin neck, and her way of speaking was hard to understand for someone not accustomed to it . . . I was shocked by her deterioration.

After leaving the school for the handicapped, Aya stayed at home while the other members of her family were out at work or school. She had lunch on her own and looked after herself. Her mother was worried about possible accidents while the others were out; Aya often fell over inside the house even if she was holding on to something. In fact, every time she came to the Outpatients' Department, she had injuries from falls which had caused internal bleeding on her face, arms and legs. There were more of them than before and they were becoming more serious.

She entered the internal medicine ward on the eighth floor of Building #2 of the hospital in order to have treatment and rehabilitation for the second time. She was the first spinocerebellar degeneration patient in that ward.

There were seven or eight other patients there that I was in charge of, plus some others, all with heart or blood disorders. Many of the nurses were young and some of them were younger than Aya. I had gotten into the habit of calling her 'Little Aya'. It sounded funny to hear the nurses who were younger than her calling her 'Little Aya' as well. But it shows the affection everyone had for her.

Aya operated her wheelchair herself. She washed her face using her disabled hands, went to the toilet, and cleaned the table for meals. She went for rehabilitation without fail, and read books sitting on a chair or on her bed during the daytime. She got interested in handicrafts and the origami that the other patients in her ward were teaching each other. But she was distressed at not being able to do as she wanted. The head nurse was touched when she quietly watched her at those times.

More than anyone else in the same part of the hospital, it was the older patients who were moved by Aya. They were paralyzed on one side because they had had strokes - their blood vessels had suddenly become restricted or broken. They couldn't move their hands and legs as they wished. They got very annoyed and sometimes skipped rehabilitation sessions. Some of them had almost lost their desire not only for exercising but for life itself. However, when they saw the serious efforts made by Aya, who could have been their granddaughter, they were encouraged to do their own training again. They started bending and stretching their arms and legs on their beds.

Both their families and the nurses were pleased. As their doctor, I couldn't ask for more. I had explained the benefits of rehabilitation over and over every time I made a round of visits. I had tried to say various

things to motivate them. But I realized that what I said had less effect than the way Aya looked as she pushed herself as hard as she could in her wheelchair.

"Can I . . . get married?"

The examination and treatment of patients is not the only role of a university hospital. It also has to carry out research and educate medical students, teaching them how to become good doctors. After studying about diseases in a general way, the students are divided into small groups of six or seven. They make a round of visits to a different department every one or two weeks to examine the patients. They read the relevant textbooks and receive guidance from the doctor in charge of the patients. This is the curriculum called 'porikuri' (polyclinic). Two groups often have to remain in the hospital at night, and sometimes even sleep over in the special 'porikuri' rooms: the students of the surgery-oriented departments, who have to observe operations, and those of the obstetrics department, who also have to attend the birth of babies. I feel sorry for the patients who cooperate in this curriculum, but I always ask them because I think it is an important way to foster good doctors. The patients all kindly agree. When the visits are repeated, patients get used to them. They even acquire better knowledge by glancing at the textbooks carried by the students and listening to what the doctor explains to them. Reversing roles, the patients sometimes even teach things to the students in the next group that comes around - which is no laughing matter.

Aya was in the same age group as the students. I was a little concerned about her state of mind, but I wanted the students to get some understanding of her disease. I made up my mind to ask for her cooperation.

She nodded with a wet little smile.

Three students, two young men and a young woman were responsible for Aya. They carefully examined her and studied hard about her disease. Though their visits finished after one week, one of the men sometimes went to see Aya in the evening while he was studying in a different department. He was blessed with good health and came from the kind of family in which it was only natural to study medicine. I could imagine he was shocked to learn about Aya's circumstances: entering a high school aiming at university study, and then having to move to a school for the handicapped because of her disease. And he knew that the disease was 'slow but progressive.' I was pleased to hear that he found time to visit Aya not just because of his interest in the disease but because of his kindness. It suggested to me he would make a good doctor.

One day, I was walking along the corridor after finishing my round of ward visits. Aya suddenly came out of her ward in her wheelchair, just as if she had been waiting for me. She stopped beside a fire hydrant on the dimly-lit wall and asked me a question out of the blue:

"Dr. Yamamoto, can I . . . get married?"

I automatically answered, "No, Little Aya, you can't."

Then I thought for a moment. Why had she asked that question? Maybe there was someone she liked . . . could it be that medical student who had been visiting her? Thinking I should listen to her carefully, I crouched down and looked into her face as she sat there in her wheelchair. I was shocked to see the look of surprise in her eyes. She had clearly been startled by my firm reply.

Aya was in a state where she had to struggle even over small things, and she knew that her disease was gradually getting worse. I had assumed that she would never even think about marriage in general, let alone think about whether she could get married or not.

Now I realized, however, that reality was different: she had become taller, her breasts had developed, and she was having her period regularly. It always bothered her because it made her sway more. I'd watched Aya grow from a young girl into a woman. So why did I assume that she would never think about getting married and having a family? I felt ashamed of myself. I had decided on that dogmatically. Even though we had been deeply associated with each other for so long, I hadn't fully understood her.

That made me reflect on my conduct. It was the biggest shock that I had ever had from one of my patients.

I will never forget Aya's large, shivering eyes and surprised expression at that moment.

I suppose my answer had caught her off her guard.

"Why can't I?" she asked. "Is it because my children would have the same disease?"

"Well, you need someone to get married to," I answered as cheerfully as possible. "First of all, you'll have to find someone who fully understands your condition and will agree to marry you. Do you have anyone in mind?"

It was a very cruel answer. But I didn't want to give her a vague reply that would encourage her to cherish an illusion that would soon be dashed.

I was moved to tears as she shook her head and said, "No."

I don't know which came first - her face becoming hazy because of my tears or her eyes filling with tears. For a while, I couldn't move.

For several days after this incident, I could still hear her voice asking, "Dr. Yamamoto, can I . . . get married?"

The student who had visited her from time to time gradually stopped going to see her. I suppose he got too busy. Perhaps partly because of that, Aya committed herself to rehabilitation as if nothing in particular had happened. And she seemed cheerful in her ward.

Around the end of her stay in the hospital, Aya began to suffer from orthostatic hypotension. She would get a headache and feel nausea whenever she got up. Then one of the patients in the same room died suddenly. That made Aya's anxiety about dying stronger. She spent several days looking very depressed. Again I explained to her what would happen to her as the disease progressed, but I said it was a long time before she would have to face death herself. She nodded. Little by little, she became cheerful again. However, she started needing other people to look after her. She moved to a hospital that permitted a caregiver to stay with her. I sometimes go there to see patients in my special field. Later she moved to a hospital closer to her home in Toyohashi.

Although I haven't seen her mother for more than two years, she keeps me updated on Aya's condition. She consults me and a young doctor from my university who has been sent to the hospital where Aya is staying now. So I have a good grasp of how she is doing. I hear she is loved by everyone wherever she goes, and her caregiver looks after her with warmth and compassion.

Whenever my patients with this disease start getting discouraged, I encourage them by talking about Aya. Recently, I've been thinking that in fact I am the one who has been encouraged by her most of all.

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Afterword

by Shioka Kito (Aya's mother)

When we went to Nagoya University Hospital for a consultation, the doctor told us the name of Aya's disease.

He explained to us how her physical abilities would gradually be lost as the disease progressed and that there was no cure. Like any parent, I prayed that at least my child would turn out to be an exception, that the progress of the disease would stop where it was, and that some kind of miracle would happen.

My daughter believed absolutely that she would be cured. I was very confused and I found it hard to come to terms with the situation. As her parents, how should we look after her? I realized that we would have to face our future firmly, walking together with her and supporting her as a solid pillar.

Some people who acquire a partial disability, such as the loss of an arm or a leg, can use their other healthy parts to compensate. But in the case of spinocerebellar degeneration, the patient's whole body loses its locomotive power. All the large motor functions, such as sitting and walking, are gradually lost; so, too, are the fine motor functions, such as writing and using chopsticks. The whole process requires a long battle against the handicap. And the tactics have to change according to the patient's condition.

Constantly threatened by the progress of her disease and under the pressure of anxiety and fear, Aya refused to accept the inevitable or to give up. She continued to make an effort. But finally she became bedridden.

Today she can hardly speak and cannot even wipe away her tears. I wonder what on earth how she thinks about herself inside her clear brain? But there is no way to understand that now. She has been deprived of the ability even to express her feelings.

In the sixth year of her illness, when she became unable to cope with daily life by herself, she wrote "What am I living for?" in her notebook (page 162). She asked me the same question. She had tried so hard to keep going and had fought as hard as she could. But the end result was that her life was moving ever further away from the life she wanted to live. She seemed to be reproaching herself, saying "My life is worthless," "I have nothing to live for," and "I'm just a burden."

She never did or said anything to criticize others, such as "Why is it only me who has become like this?" or "I wish you had never had me." That made it all the more difficult for me to answer her.

The major events in her life - such as the outbreak of her illness, her move from Toyohashi Higashi High School to Aichi Prefectural Okazaki High School for the Physically Challenged, her graduation, when she became unable to walk, and finding a caregiver - were always obstructed in some way. That made Aya depressed.

We groped along digging in a pitch-dark tunnel together as we tried to heal her bloody, damaged body. But then we found we had to face another obstacle. We have come this far, somehow or other, hoping to find a brighter path where we could say: "Oh, this is what we've been looking for!" But the reality of the terminal station we have now reached has turned out to be too cruel.

I cried together with Aya when she cried. I joined her in her sadness as I helped her to get up whenever she fell over. And when she became unable to move and had to crawl along the cold corridor, I followed behind her, crawling at the same pace.

I couldn't take the commendable attitude of never showing my tears in front of the children. Because I understood Aya's agony and pain very well, I thought that was only a natural way to show myself as a mother.

But from the position of being a grown-up and a parent, I didn't differentiate her from her healthy brothers and sisters.

Regarding the words 'It can't be helped because she's ill,' I often insisted she should carry out things properly except those that were really impossible for a disabled person. The difference from the others was only that she had an extra burden on her shoulders due to her illness. And I had to share that burden. Aya said that because of that burden her life had gone off the rails. But I bought her various books about other people's battles against disease. I made her read them, telling her that this was her life, too. I didn't want her to become narrow-minded, thinking that she was the only unhappy person in the world.

I tried to encourage her by saying, "Aya, you've tried as hard as you could with everything and that really surprises everyone. I think you've been leading a much more decent life than your mother, who has been living very nonchalantly without any physical defects. That's why you have friends who still visit you and say there are a lot of things they can learn from you. That's wonderful!"

I decided to make these words to reply to her question, "What am I living for?" I started to organize her notebooks which spell out the way she has lived through her life of bitter struggle. Hoping to produce a book that would provide Aya with some comfort and give her something to live for, I consulted Dr. Hiroko Yamamoto, Assistant Professor of Fujita Health University. She kindly agreed to cooperate. Aya herself says, "I haven't lead a decent life that I can tell other people about. I'm embarrassed because I always cry. It's been a life full of regrets, constantly telling myself I should have done lots of things."

Aya's brothers and sisters

Aya's brothers and her sister Ako were junior high school students when it was decided that Aya would move to a school for the physically handicapped.

"There's no hope of Aya recovering from her illness," I told them. "It will only get worse. In a few years, I think her condition will be such that we won't be able to take our eyes off her. But I will look after her mostly, so I hope you will plan your futures firmly and take care of your own health."

They listened to me quietly and seriously.

Ako, who is just one year younger than Aya, was proud of her hair which reached down to her shoulders. But suddenly she had cut it short a few days later.

"Why did you do that?" I asked her.

"Well," she replied, "I just wanted to change my image."

Observing how her behavior gradually changed after that, I felt that she had decided on her own way of living or had resolved to do something.

When she shared a room with Aya, they often argued. There seemed to be a sense of rivalry between them over everything. That made me worry. I couldn't understand why they couldn't get along better. But

now that Aya has become bedridden after her life in a wheelchair, Ako is acting like her elder sister. She has become her main advisor and gives her a great deal of mental support.

Unlike Aya, she was able to graduate from Higashi High School. Now she is studying at Aichi Prefectural College of Nursing & Health. She is hoping to work beside Aya in the future.

The elder of Aya's two brothers has grown up as a man who doesn't play any role directly connected with Aya.

But he calls from time to time and says, "Are you all right, Mom? Don't strain yourself."

I say, "Why don't you go and see your sister? That would make her happy."

But he only replies, "Well, I will some time . . . Please tell her I'm doing fine and she should keep at it." It may be partly because he, too, felt a strong surge of emotion when he see Aya crying the last time he went to see her.

He has been working as a policeman in Mie Prefecture for almost two years now. He expressed his sympathy for his sister by quietly leaving his postal savings book - in which he had saved money little by little - saying, "Please use this for Aya."

How will Aya's brothers and sisters get along with their ailing sister when they grow up? Looking back, I realize that apart from being unable to do enough for Aya, I have rather neglected our other children. I sometimes hear about families in which people ignore their brothers and sisters. That kind of thing worries me as I get older.

I have never said that they should plan to help with Aya's care in the future. But it seems that they are naturally tightening their bonds to look after themselves after I go. That makes me feel very happy.

Medical treatment

At the first hospital, patients like Aya with a disease of the cerebellum, which controls the body's motor functions, were treated in the Neurology Department. In the early stage of her illness, we felt a sense of security because it was part of Nagoya University Hospital. We commuted a long way feeling relaxed, without ever regarding it as a hassle. But, as Aya's disease progressed, she became unable to move around on her own.

For various reasons, the hospital refuses to allow her to stay.

The more serious a patient's illness gets, the better is it for them to stay and receive treatment at a hospital with a comprehensive medical system and facilities. But the present medical system doesn't allow that. Hospitals like that have a policy of providing 24-hour care, so personal caregivers are not permitted to stay there. But how far is 'nursing' care provided by the hospital? Who is responsible for the part outside the 'medical' care? There is now other way but for the family to commute every day to compensate for that. If you can't do that, the patient cannot remain at the hospital and must move to a private hospital. However, there are not many places available for special diseases like Aya's.

Thanks to an introduction from Dr. Yamamoto, Aya was treated for two years at Akita Hospital in Chiryu City.

This was located a long way from our home, so her contact with the family was greatly reduced. Going to see her once a week was the best we could do, and we had to rely on a caregiver to look after her on the other days.

There seemed to be no end in sight for her life in the hospital. We wanted to bring her closer to us, so we started looking for a suitable hospital in Toyohashi. First we made telephone inquiries to various hospitals. When we found one that we felt might accept her, we visited it and explained the details of her case. We were moved from hospital to hospital. Then she spent around one year at N. hospital in Toyohashi.

I knew there was nothing to worry about as long as they clearly understood Aya's condition. But, to be honest, as her mother I worried a lot every time she moved to a new hospital. Would she be all right? If she got phlegm stuck in her throat or her body went stiff, she might suffocate and die. I wondered if they could provide the appropriate emergency treatment if that happened. Luckily, the woman doctor in charge of Aya had been taught by Dr. Yamamoto. I felt relieved when I heard the two doctors sometimes met each other at the university hospital.

In June this year, she moved to Koseikai Hospital in Toyohashi for the third time. She is still there today. At the beginning, she could hardly eat due to the stiffness of her body. It may have been the result of the tension and fatigue caused by moving from hospital to hospital.

"Next time you become unable to breathe properly," a doctor in the Department of Surgery told her, "we'll give you a tracheotomy." He also kindly explained to Aya by writing in her notebook. He wrote: "You'll be all right. Don't worry. If you get better, we'll immediately close it up again." I have been reassured by the efficient cooperation between the Departments of Internal Medicine and Surgery and help from the rehabilitation doctors.

I can only visit Aya in the evening on weekdays or on Sundays, so I can't meet with her doctor. But a nurse always informs me of the day when her doctor will be on duty. I can contact the doctor to discuss any worries we have and Aya's questions that she has written in her notebook. The doctor makes every effort to answer our questions. I trust him, I thank him and I respect him. He provides Aya with peace of mind and Aya smiles. Aya loves taking a bath. Receiving the news that she will soon get the chance to take one gives her something to look forward to.

Caregivers

One of the worries that Aya and I had was the problem of finding a caregiver. It would easily be solved if I stopped working and looked after her. But my husband and I had financial problems: we had to raise our other children; and we had taken out a mortgage on the new house assuming that we would both be working.

I couldn't afford to give up my job.

There was no alternative but to find a caregiver. Aya is a patient with a very serious illness. She can't look after her everyday life at all and her speech is difficult to understand. She can only communicate by pointing at a board of Japanese syllables, and her fingers move very slowly. She has to drag her finger across the board until she eventually reaches the syllable she wants. It takes a lot of patience to wait for her to spell out a message. Eating a meal takes her at least two hours. So looking after Aya demands a great deal of effort.

The first caregiver we found was a 70-year-old woman. She treated Aya tenderly, as if she was her own granddaughter. Aya could communicate better with her than she could with me. Just by watching the movement of Aya's mouth, she would say, "Yes, yes, I understand." I was the one who had to ask, "What did she just say?" Watching her looking after Aya so efficiently, I was very grateful that we had found such a good person and also for her valuable work.

But we had a hard time after Aya was moved to N. hospital in Toyohashi. I can't remember how many times we had to change caregivers that year. When I ask one who had stayed with her for a longish period, "Aren't you having a hard time with Aya?", she replied, "If I gave up at this level, I wouldn't be fulfilling my duties." But another caregiver who kept saying, "I'm having a really hard time; it's so hard and hopeless," didn't stay long.

The problem was the timing of a replacement. The Chairman of the Association of Caregivers had told us that the family must look after the patient until the next caregiver is found. I would suddenly get a call from the association at my workspace. We were in a disadvantageous position because Aya was difficult to care for and it was certain that some caregivers would soon get tired and give up. But what could we do?

I offered to stay overnight once or twice a month instead to let the caregiver take a rest. That was the best I could do. I often went to the hospital with some reluctance, wondering if the caregiver would say that she wanted to leave. When I asked the hospital for their cooperation in asking the association to find a replacement, they said there was nothing they could do if the association said there was no one available. All they could do was ring them to ask for a caregiver the first time.

Dr. T. called me and said, "Mrs. Kito, you won't find a good caregiver like that anywhere else, you know. You should cooperate with her as much as you can so that she will stay for a long time. Aya is a difficult patient, so no one else would want to come and look after her."

That sounded to me like a kind of threat. How could he say words like that - which would drive a weak person into an awkward position - at the same time as he was saying the hospital had nothing to do with the association? Not only did the hospital never say, "Let's think about this issue together," it was even refusing to help us. That suggested he was in no position to meddle in our affairs.

I went to the association several times to explain the situation and ask for their understanding. I don't know whether it really had a labor shortage or it was just that nobody wanted to help Aya because the rumor was going around that she was a difficult case. But I didn't want my child, who had no hope of getting better, to have to worry about anything apart from her disease.

I started looking for a different hospital. I rang Koseikai Hospital at my last hope and had an interview with the general manager. I explained in detail Aya's condition, why we wanted to change hospitals, our family situation, etc. The hospital accepted her immediately. The general manager efficiently arranged a room for her and contacted the H. Association of Caregivers (different from the previous one). My eyes filled with tears of relief and gratitude.

A patient's treatment is always the first consideration, but each patient's background situation is different, and that can disturb their recovery. It's a matter of course that the patient's family should do their best to stand on their own feet without totally relying on other people. But those who are involved in providing medical services have their own position, and they should also put their energy into supporting the patients and their families, aiming for each patient's return to society. It's not an exaggeration to say that after all Aya was able to enter a hospital that had that kind of policy and she could concentrate on receiving medical treatment.

I also realized that the personality of the caregiver who shares the patient's life around the clock can have a great effect on the patient.

One day, for the first time, Aya complained about a caregiver: "Mom, this caregiver's threatening me . . . She keeps saying she'll leave me alone . . . I get hungry during the night because she lets me only eat two or three mouthfuls of food . . . She says my disease can't be cured, anyway."

It took Aya a long time to tell me these things, desperately moving her stiff fingers over the syllable board.

That caregiver had never showed that kind of attitude to me when I met her at the hospital. But I had been wondering why Aya's stiffness had suddenly become worse and why she seemed to be losing her energy day by day.

It had reached the point where she had to have nasal feeding (by inserting a tube into the esophagus through the nose). We knew Aya couldn't hope for longevity. We knew we may lose the fight against the progress of her disease. But that didn't mean Aya had to endure a bed of thorns every day.

I mustered up the courage to say to the nurse, "Aya is not a girl who says anything willful or demands too much. She's a tenderhearted girl with delicate feelings. She apologizes when she has to wake the caregiver up during the night. Please understand that for her to complain like this means that the situation must have gone beyond what she can endure."

Several days later, the caregiver was replaced with a younger woman. Aya was rather tense for two or three days because she couldn't get used to the new situation, but her stiffness almost disappeared. Eating still takes a long time, but the new caregiver says to her, "Aya, eating is your job, you know!" Helped to eat by the caregiver, Aya's cheeks have filled out again. The caregiver also sometimes does her make-up for her, which provides a lot of satisfaction to her feminine sensibility.

The same caregiver continues to look after Aya today. She provides variety and joy to Aya's daily life by helping her to sit on the bed and ride in a wheelchair. A lot of laughter can now be heard coming from her room.

A hospital is really only a temporary kind of home, but it's where Aya now has to live permanently. I think she regards her caregiver, who shares that life with her, as a substitute mother or a member of the family.

I can see it in her happy smile when the caregiver returns after she has been out on some business for a few hours.

This life of suffering, in which no flowers are about to bloom and Aya is unable to enjoy as much happiness as everyone else, will continue. But I pray that even the small pleasures she can experience now will last at least one more day under the warm protection given her by the doctors, the hospital staff, and her caregiver.

Since the idea of publishing Aya's diary was reported in a newspaper, she has been encouraged by many people.

She has been contacted by her former teachers and visited by Okamoto-sensei. She has had the chance to meet her old friends again. Many days of joy have returned. I can only say how really grateful I am to everyone.

January 1986

Postscript

by Shioka Kito (Aya's mother)

25 years and 10 month . . . Aya's short life eventually came to an end.

She suddenly fell into a coma and stopped breathing. Even at that critical moment, her heart continued to beat desperately, as if it was crying out, "I'm hanging in! I won't give up!"

Although an artificial respirator was being used to keep her alive, her face bore a calm expression, as if she was sleeping comfortably. I wanted her to open her eyes wide and smile at us. I wanted us to talk together with our eyes, even for just one more time.

"Aya, please look at me! Can you feel Mom's warmth?"

Even though we knew there was no hope, we've managed to overcome so many hardships in the past . . . It seems too cruel to end like this . . . It's so sad! . . . If you're leaving us soon, Aya, you should say goodbye to us . . . Aya, can you understand what I'm saying?

But she did not respond to our words or our touch.

Your sisters, your brothers and Dad and I are all here. But we can only watch you. There's nothing we can do to help you . . . If only we could relieve you of even a little of your pain . . . Our bodies are twisted with sadness . . .

Aya's blood pressure started going down. Her heartbeat got slower as if its energy was fading away. I was trying to tell myself that the time was approaching to part from Aya in this world. I was wondering what kind of state she would want to be in when she ended her life.

We switched on her favorite radio cassette deck beside her pillow.

It was around midnight.

Surrounded by her parents, her sisters and her brothers, listening to classical music with the volume turned down so that it wouldn't disturb anyone in the other rooms . . .

The ripple mark on the electrocardiogram suddenly became a straight line.

I remembered the words Aya had said before her condition deteriorated:

"It would be so nice to fade away like falling asleep on a beautiful carpet of flowers listening to my favorite music."

Aya passed away at 00:55 on May 23rd, 1988.

Message from the Publisher

As Aya's condition worsened, her diary entries became virtually illegible. Shioka Kito, her mother, transcribed them in order to put this book together. During the editing process, many people cooperated with us and gave us tremendous encouragement. We are really grateful to them all for their kindness. Aya passed away quietly while surrounded by her family at 00:55 on May 23rd, 1988. Although she was unable to speak, just before departing this world she strongly uttered the sound 'a,' the first syllable of 'arigato' (Thank you).

Please send any thoughts you may have after reading this book to our editorial section.

Thank you very much.

FA Publishing Company

Translators' Note

This book was first published in Japanese in 1986. The translation is based on the revised edition, to which a postscript by Aya's mother was added. Most of the original diary dates were excluded during editing, so we have added the years for each chapter to give some idea of the passage of time.

To express familiarity or respect, the Japanese often add suffixes to names. Aya used many in her diary. Where it seemed appropriate, we decided to retain them in the translation. For example, Aya refers to most of her girlfriends by adding the suffix '-chan' to the first letter of their given name ('A-chan') or the first Japanese syllable ('Satchan'). In the few places where she uses the full given name, we have removed the suffix ('Emi').

With boys, she usually adds the suffix '-kun' ('T-kun').

The common Japanese suffix '-san', which is generally used for adults, is somewhat vague because it can refer to both sexes, rather like 'Dr.' in English. In some cases, it is not clear whether Aya was referring to a man or a woman (and in a few cases, students), so we decided to retain it. The same is true of the polite suffix '-sensei', which basically means 'teacher' but is also used for doctors and other people of authority. Aya generally referred to her school teachers by adding '-sensei' to their surname ('Inamoto-sensei') or to the first letter of their surname ('I-sensei'). In one case, she used the full given name of a female teacher ('Motoko-sensei'). Aya also used '-sensei' to refer to her doctors, but it seemed more sensible in English to translate that as 'Dr.' to distinguish them from her teachers.

In the case of her first caregiver, Aya referred to her by name; she affectionately used the term for an elderly lady, 'Obachan', which literally means 'granny.' We decided to translate this as 'little old lady'. Aya also used the suffix '-obachan', which is used for middle-aged-woman.

Another cause of translation problems is the Japanese convention of referring to siblings by their age relative to the speaker rather than by using their name. For example, 'imoto' means 'younger sister' and 'ototo' means 'younger brother,' and you can refer to your elder sister as 'one-san' or 'ne-chan'. This convention is not used so much in English, especially when talking directly to one of your siblings. In written Japanese, it is often easier to write the one character for 'imoto', for example, than writing out your sister's name. This is somewhat confusing in Aya's case because she had two younger sisters and two younger brothers, and it is not always clear which one she was referring to. In a few diary entries she does use her sisters' names, but neither Aya nor her mother ever refer to her two brothers by name. As far as

possible, we have determined which brother or sister was being referred to and followed the English convention of using their names.

When Dr. Yamamoto first met the 14-year-old Aya, she called her 'Aya-chan.' To suggest the affection inherent in that form of address, which her doctors and nurses continued to use even when Aya was in her twenties, we decided to translate it as 'Little Aya.'

The text includes expressions in Aya's local Aichi Prefecture dialect, but we have not attempted to duplicate them in English.

Yoko Toyozaki
Stuart Varnam-Atkin
2007