

## **The 52<sup>nd</sup> NHK Welfare Award-Winning**

**“Hazy Moonlight” : Writing a song with Yu san**

**Kumiko Takagi**

Since childhood, I have been interested in “words and languages,” which convey thoughts and feelings. I have worked and have been involved in volunteer work mainly in the language-related field as a translator and interpreter. As time passed, I found myself hoping to help challenged people who have difficulties in expressing their emotions and thoughts through speech or body language.

One day, I happened to hear about the AJU Independent Living Center established to create a welfare community, where even if you are severely impaired, you can live happily with local people. Knowing that the center opens its door to visitors and those who are interested, I visited it in the hope of learning different things through volunteer work to support those who live there.

“You don’t have to do anything specific. Do whatever you think is good for the residents.”

That was all I was told at the center on my very first day. In the beginning, sometimes I went walking with clients, pushing their wheelchairs, and sometimes, I went shopping with clients who were impaired verbally or physically to help them choose what they wanted by asking them many questions. At other times I played seasonal songs as the background music on the piano in the lobby, which led to the chance to play a duet with one of the clients.

### **Encounter with Yu san**

After around half a year had passed since I began to work as a supporter at the center, a staff member said to me, “An ALS (Amyotrophic Lateral Sclerosis) patient is going to stay in the independent living experience room as a trial. Would you like to work as her caregiver?” I was told that it was getting harder for her to speak as the disease progressed, yet she could express her intentions by pointing her finger on a small Japanese alphabet board and that it would be all right if I did whatever she wanted me to do. That was April of 2014.

“I would love to,” I replied immediately, thinking it was a great opportunity. As I

thought I should learn about ALS beforehand, I did some research on ALS. Everything I read was grim: “All people with ALS experience progressive muscle weakness that leaves its patients bedridden, followed by fatal respiratory paralysis to death.”

“Sensory nerves are not affected.” “The cause and cure of ALS is not yet known and there is no treatment available.” I wondered how the woman I was going to meet, was feeling every day and how I should treat her. Though I took the task without thinking so much, I started feeling the weight of that decision. However, I was also looking forward to meeting her. With mixed feelings, I went to meet her.

When I visited the private room I was told to go to and introduced myself, the woman in the wheel chair nodded with a gentle smile. I had heard how old she was, but she looked much younger than her age and she was beautiful. I asked how I should address her. She pointed at a hand-made A5-size Japanese alphabet board with her knuckle of middle finger of her left hand.

“Call me by my first name, Yu”, she said.

All right, Yu san.

“Then, call me by my first name, Kumiko.”

It was an unforgettable encounter.

We hit it off with each other so immediately that I don't remember what we started talking about. We talked and talked endlessly. Yu san used the board and I used my voice. Her barrage of jokes kept me laughing. In turn, I shared my embarrassing stories. I had heard that she could hardly make a sound, but she laughed at my stories, which made me happy.

Then suddenly I remembered that I was there to do something to help her as a caregiver, so I asked her what she wanted me to do, such as go shopping or clean her room. Yu san pointed on the board, looking at me seriously.

“I would like to continue chatting like this. This is really fun. I haven't chatted and laughed this much for a while, maybe for years.”

The fact that she hadn't had a chat for years shocked me. Having a chat with friends, which is not unusual at all to me, is something special to Yu san.

Then Yu san told me her story little by little. She told me about how strange her body felt at first, about the time she was diagnosed with ALS, and about learning what would happen to her, about the progressive symptoms, about her family taking care of her, and

about her friends gradually leaving her.

Before I knew it, it was nine in the evening. From the starting time, three in the afternoon, we had sat in that room talking nonstop. The six hours went by surprisingly fast.

### **Promise on a viewing deck**

After the trial period, when it was time for Yu san to go back home, I took her to Nagoya Station. As she said she had time to spare before her train, we went up to a viewing deck located on a skyscraper in front of the station on a whim.

While we were taking in the view of the city that spread below and mountains in the distance, Yu san talked about a lot of things. Her parents, her caregivers, were getting older and their strength was waning, which increased the risk of hurting either themselves or Yu san while taking care of her. She was blaming herself for burdening her family, too. That was the reason why she wanted to try to live an independent life with official support and professional advice and she underwent the living experience program.

“We are a very close family, but I have brought trouble to my family because of this awful disease.”

I was at a loss for words. For a while we were just looking at the view in front of us silently. Yu san pointed to the board one more time.

“But, Kumiko san, I will live. I will survive. I won’t give in.”

Yu san looked dignified and steadfast, her strong will showing on her face. It was I that almost started crying, saying, “Yes, you’re right. Live! I will support you!”

### **Wavering Heart**

After that, Yu san started leading an independent life at a share house. We had exchanged contact information, so we started to e-mail each other. I introduced Yu san to my colleagues of an ICT volunteer team, and I took her to meet my friends.

“I am glad that I have a lot of opportunities to go out and meet people and I can ask people about my disability. Everyone is really nice”.

But cruelly, her disease is progressing steadily.

Once, I asked her, “Excuse me for asking, but do you feel something changing or getting worse day by day?”

“Yes, I do. I heard that my disease is progressing slowly, but I feel that, though it’s hardly a detectable change, little by little my movement is becoming more limited. I am almost crushed with fears that tomorrow I will not be able to do what I can do today,” Yu san replied.

While gradually losing physical function, the independent life requires me to decide everything by myself and give helpers proper instructions. A lot of troublesome things lie heavily on me, like thinking about my living environment or negotiations in bureaucratic procedures. It is more frustrating than anything else that I cannot express what I am thinking. Therefore contrary to my intention, the things are decided without my consent, leaving me stranded and frustrated.

While I am determined not to yield to my disease, the progressive illness, fear of death, a sense of isolation and hopelessness gnaws at me.

One day, after we had known each other for two years, Yu san said,

“I was almost crushed with stress. Even though I keep trying my best, yesterday, after a long time, I burst out in tears. I didn’t know what to do and lost control of my feelings. But I can no longer wipe my tears by myself.”

I didn’t quite know what to say and asked a banal question,

“You cannot sleep well at night, can you?”

“No, I can’t. Once I wake up after a short sleep, thinking about a lot of things keeps me from going back to sleep. I just lie there staring at the dim light coming through the curtains.

“You are wavering, aren’t you?”

“I really am. And my mind is unsettled. Yet the next day, a helper visits to assist me as usual, hectic time flies and another day comes again. Some of them make small talk about themselves. Everyone has stories to tell and is wavering about what to do”.

“Yes, that’s what humans do.”

“Yes, each of us. Still I can’t help but ask myself why only I got this disease”.

“I know.”

“It is no use thinking about it, but ...”

“I know.”

It was a shame that I could only repeat, “I know.”

### **Let’s write a song together**

She is always trying to be cheerful and pretend to be okay. I thought I understood her heartache. However, the feelings she poured out that time gave me a lump in my throat. Then I wondered if I might be able to do something for her. There had to be something I could do to encourage her, something to excite her, though she said only listening to her soothed her soul. This is why I decided we should write a song together.

There was an event that gave me the idea.

In 2012, my friends and I visited a special support school in Natori City in Miyagi Prefecture, which was seriously damaged in the 2011 earthquake and tsunami, to present hand crocheted hats made by American supporters. This brought me to found a small organization where we support and have contact with the people in the tsunami-hit area. In 2014, I accompanied the supporters on a visit to the city when they brought additional crocheted hats to Japan.

During our stay, a man in the disaster area told me that his dear friends were killed in the tsunami, that he had been suffering from survivor guilt, and that even so he needed to move on somehow and struggle to his feet, thinking about the time he could never get back. Listening to his story was the only thing that I could do at that time. But soon afterward, meeting people who had moved forward past their difficulties, I found that even though the city was destroyed by the natural disaster, it is true that the people had lived, lived, live and will live there. The spirits of their deceased beloved ones are always with them and protect them. I wanted these messages to spread in some way.

Then, I came up with an idea of writing a song. I wrote the song lyrics using the words of the people in the disaster area, the messages of the American supporters, and what my friends and I felt through the activities. Though I play the piano, I have only a superficial knowledge of music. I don’t know why, but a simple melody came to my mind

automatically.

The singer-songwriter Chiaki Arisaka, whom I encountered by chance, sang the song “When I Think of You” in a concert. We felt connected with each other because she herself experienced the 1995 Hanshin-Awaji Earthquake and has performed supportive activities since the disaster occurred.

Sharing the song enabled us to relate to the people we met in the stricken area. Quite a few people who found universal messages in the song said that they also would like to sing the song. Some of my friends were so kind as to translate the Japanese lyrics into English, Chinese, Korean or Vietnamese. We found joy and pleasure in meeting new people through the song and deepening the relationship with them. I hoped to share this joy and pleasure with Yu san.

Even though she always says, “I want to be understood. I want people to know about the disease,” writing a song and putting it out means that she exposes herself.

Can she approve of the idea of writing a song together? I was debating whether to ask her or not, but I mentioned it to her.

### **The first verse**

There was nothing to worry about. Yu san was delighted to hear that and said, “I am happy to hear that. I didn’t want to wait for death to come without doing anything. I like the song ‘When I Think of You.’ I also have many things I want to say. If I could deliver my messages to those who don’t know about ALS, I would never be happier. Thank you so much. I’ll give it a try.”

Then, it was time to begin. Immediately, we started to write a song. Each word she delivered touched me emotionally. As her casual remarks always strike home with me, what I should do is to set melodies to words to create the synergy with the words. Intentionally, we avoided specific terms such as ALS and those directly associated with the disease.

Reading the phrases she wrote for the lyrics, tunes came to my mind naturally. The melodies were as simple as the former song, but Yu san said they were beautiful. After we changed some words and the word order, the first verse and the tune were finished

almost at the same time.

*I have chosen the way to go  
I have taken all what befell me, though  
Way too many burdens fall on me  
At a crossroads I stop and freeze*

*Way too many struggles overwhelm me everywhere  
Though I know it will take me nowhere  
“Why me? Why only me?” sighing in pain  
“Tell me why?” asking in vain.*

*Back and forth my mind goes, my heart is wavering  
The hazy moon in the water’s shivering  
Cry and cry, cry deeply, cry until I fall asleep  
Under the silver moonlight*

I sang the song for her. She said, “This is good, really good. It accurately describes my feelings and makes me cry,” which made me happy, too.

We were beside ourselves with the joy of would-be musicians.

But when I showed the song to my friends of the support organization, who were ready to translate the song into various languages and looking forward to the completion of the song, one of them only said, “Sorry, but it is too painful.”

“What?”

“This is depressing,” said the other friend.

“The lyrics are the essence of Yu san’s feelings. The fact is far harder than this.”

“I know, but ...”

“But what?”

“Something is missing. Something like consolation. I mean, it’s a song. It conveys her emotional pain, but please don’t be satisfied there. Why don’t you put some consolation even if it is not true?”

“Even if it is not true? That’s impossible.”

I was totally upset, but Yu san calmly listened to what they said.

“I understand how they feel. It is intolerable pain. Occasionally, some listen to me, but it makes them feel depressed, doesn't it? Then they leave me gradually. This is the reason why I hesitate to tell people my story recently. I don't want them to feel depressed, and it's impossible to make myself completely understood after all.”

I knew it was Yu san that was suffering most, but I didn't know what to say. She continued,

“It was better to hear their true feeling about the lyrics. A song is a work of art, so it needs something more than pain and sadness, something which makes you go forward even in hard time. Though I don't know what to do and I feel I will not be able to stand this pain anymore, I won't abandon the hope of the development of an ALS drug. Even though all hope is gone and I cannot have control of my body anymore, I will never give up. I will live. I will stay alive.”

“I know.” I thought, “Who is encouraging whom?”

“But,” she went on, “I will not change the lyrics even though they are said to be too depressing. They reflect the crying in my heart.”

“I know. No matter what anyone says, I will never change the first verse.”

“All right. The first verse should be left as it is. Let's move on to the second verse.”

### **Looking in the same direction**

We started the second verse, depicting the feelings Yu san poured out. I especially liked the phrases in which she expressed the instant lift given to her by her helpers' small kindness or strangers' consideration for her when she was feeling alone.

Without actual conversation, a little empathy toward others encourages you to move forward. I thought this was a good phrase. A question popped up in my mind.

“Each phrase of yours is very touching. Have you written poetry or something?”

“It's not really a hobby or anything, but I have always liked writing poems and things.”

“I see. Then working on writing a song is just your thing, though I brought up the idea on a whim.”

“Kumiko, you know what? I really appreciate it. Writing a song enabled me to confirm calmly my various feelings which were bottled up and close to blowing up inside



me. I felt so depressed that I really didn't know what to do."

I said to her,

"I was glad to write the song with you. What I thought first was only that it would be a chance for you to vent your frustration. I just wanted to face you and understand your feelings.

But gradually I began to feel differently about making the song. I thought Yu san's words echo the pain that I and others experience in our daily lives to a greater or lesser extent. I started to write a song with Yu san because I thought it would be good for her. At first, it was one-directional, where I listened to her feelings. Naturally it turned into a give and take, finding words to describe each other's feelings. It was as if we were weaving words into the lyrics. Then at last, it was as if Yu san and I were side by side conveying messages toward someone struggling similarly in a tough situation. Noticing that finally, both of us were very glad to have created the song together.

### **The birth of the song "Hazy Moonlight"**

Finally, the song was completed last September.

### **The second verse**

*Shattering the armor I'm clad in,  
At the crossing, crowds are coming and going  
Over the cracked mask, tears are streaming down  
I left them falling slowly down*

*I don't know how to dry my tears away  
Biting my lip, I can no longer take my way  
Then I notice someone looking at me tenderly  
Without saying a word to me*

*As we felt the same pain, some time ago  
For a moment, ephemeral feelings echo  
Soon we take our eyes off each other before long  
And go back the way to where we belong*

*Around, around, my mind's going around,  
Restless time is flowing along.  
I'm not alone, will never be. Somewhere, someone and I  
Are looking up at the same night sky*

## **Ending**

*Waxing moon, waning moon, and back to new again  
After night, another day comes again  
Lying in pain, I believe a new day will come soon  
I will try a little more wishing on the moon*

*La la la ...  
I try a little more, wishing on the moon  
Following silver hazy moonlight*

We named the title of the song “Hazy Moonlight.” We decided on it, thinking of the dim light Yu san was watching when she couldn’t sleep at night. The light is not bright enough to show the course, but it is pouring on her as if it was watching over her fondly and quietly.

As an experiment, we employed VOCALOID (a singing synthesis software) voice to post the song online. We wanted the message from Yu san, whose voice was almost lost, to be conveyed intactly to the audience without the personal feelings and emotions of a singer. After posting the song, there were pros and cons about the voice, but I think many of them understood our intentions.

Two months after the completion of “Hazy Moonlight,” in September, Chiaki Arisaka sang this song, at our request, at another concert held by the support organization. Arisaka’s voice, which Yu san loves, delivered Yu san’s feelings to the full house.

I actually had asked Yu san to make a brief talk about the song after the song was sung. Yu san spoke every word slowly and carefully in what remained of her voice, and then her helper echoed her words. Some in the audience wiped away tears as they listened.

Yu san, with her makeup carefully done and hair done prettily, looked very beautiful, full of confidence and absolutely radiant.

### **After that**

It has been around one year since we made “Hazy Moonlight.” We are still receiving a lot of messages from the people who listened to the song. “It was very moving.” “I learned about ALS for the first time.” “Yu san is amazing. She is trying hard dauntlessly in spite of such difficulties.” We deeply appreciated those messages.

Yu san continues to fight against ALS.

“Kumiko, ‘Hazy Moonlight’ is wonderful, isn’t it? In spite of it being my own song, it touches my heart. I feel accepted not only as a patient but also as a person by making the song. I really appreciate the people connecting through the song. It’s good not to be alone, isn’t it?”

Translator: Yuko Komada