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Going forward to the future

Naoko Nishioka

It's difficult to imagine our future.
I don't want to think about my future.

I have a progressive disease. For me, time passing means my body gets worse and it will be more difficult to control my body. Everyone gets difficulty controlling their own body by aging, but in my case, the speed of this is faster than a normal, healthy person. I use my wheelchair now for transportation.

We are forced to change our lives by the spread of COVID-19 now. I think more people have anxiety or difficulty imagining the future than pre COVID-19 era. This threat to which many people face might have different aspects from intractable disease from which only few people are suffering. However, I believe my experience can support someone. I record here my life where I was with anxiety and loneliness.

I was diagnosed with muscular dystrophy at age of 3. I was just told that I had muscle disease but I didn't know more information.

In my early teens, I wanted to know details of my disease and asked a lot to my parents and teachers. I wondered why I live. I didn't know anyone like me who had the same disease. I was alone. I got worried when I thought about my future.

When I was little, my parents chose not to tell the name of my disease. As this disease is progressive and if I knew it, I would get depressed. I was told my disease name at age of 18.

By my teens, I didn't have so much difficulty controlling my body. I needed handrails for steps but I could walk in my daily life.

I noticed the progressivity of my disease after being informed of my diagnosis. I became worried for the future. The threat of getting difficult to move always came to my mind. But vague fog which occurred

by not knowing my disease had been cleared. The situation doesn't change after knowing my diagnosis as intractable disease has no treatment. But my mind changed by noticing what I am facing or what I need to live with.

I don't need to give up what I can do now regardless of worry for the future. I decided to enjoy myself at this moment. Actually, troubles sometimes appear. Though I said "I want to challenge this.", the reply was "There's no one who tried this in the past so you can't try." It was hard to make a breakthrough. But it's exciting to think about what I can do now. Moreover, I get power when my thoughts are sympathized with by someone. Though when I can't do what I want to do, the thought of trying to do something or the situation I challenge will be made use of future development. For the future, I would like to accumulate my experience.

From my childhood, I had vague thoughts of working after graduating university. I was thinking that was the only way for me. It was difficult for me to use physical strength, but I thought I could work as an office worker. When I look back, I had only a narrow sight within a limited world. I narrowed my possibilities by myself. I had no dream for the future. Before thinking that I wanted to do something, I gave up as I didn't have physical strength. I approached my twenties while I was thinking about these kinds of things.

I became a university student and I reached the age of thinking about starting to work. Although when I might work at office, I realized so strongly that my limitation of walking or weakness of arms would be handicap. I came to know the system of employment for handicapped persons. There is a system in Japan for handicapped persons to work in accordance with their abilities. National and local entities, private enterprises and so on, all business bodies have the duty of "employing handicapped persons for a constant rate" by law. I searched and came to know I needed to get a "physical disability certificate" for using this system.

I got a "physical disability certificate". I tried to participate in job hunting with this. I searched the internet for companies which have employment systems for handicapped persons. I found a company

which has an office near my home and I applied for it. After interviews and a written examination, I got a job.

Though I talked about my disease in interviews, I worried how much I needed to talk about my disease to my boss or colleagues. When I was 22, I was using a cane when I walked, so anyone could understand I might have a handicap. But specific symptoms need to be described as words. It is difficult from my appearance to understand I have weakness of muscle. I need many words to describe to tell my disease accurately to be understood by others and to be given necessary consideration. My description at age of 22 is as below.

"I have muscular dystrophy and my power of muscle is weak. I need a cane for walking.

It's getting difficult to go up and down steps these days. I think I can continue to walk for 10 minutes, maybe. (I don't have confidence to say as this is up to my condition)

My hands are also weak and I can't carry heavy objects.

I need something to support my body when I stand up from sitting. It's easier for me to stand up from a high positioning chair. I can use western style toilet for now. (It is needed to squat in a low position to use Japanese style toilet.)

I don't know how much speed this disease progresses in the future. I have medical checks once a year. As there is no medicine for cure, I just have checkups. "

I don't know if this describes enough. I may remind myself, "Oh, I can't do that either. " It might not be needed to tell such details if I have no obstacles for work, but I'd like to tell accurately what I can't do. I felt difficulty having an appropriate distance with colleagues.

Though "getting tired and feeling fatigue" is one of the symptoms, other people may think I am just slacking off. It is hard to avoid overworking and take enough rest. I have most difficulty in my job to

judge how much I must do my best and it's hard to judge where is the additional plus alpha area.

When I entered my company, I was thinking "I may quit working after some years by reaching my limit of physical strength." I went to my office 5 days a week and worked full time. I drove by myself using a driving system controlled by hands. I began to think about using a power wheelchair as I had difficulty walking. There were problems such as how to open the doors, how to use a copy machine or how to serve at the employment cafeteria and so on. If I choose to quit using a wheelchair at my office for these problems, this means to give up working at my company. I wondered if I could work from my home. But in the 2000s, the telecommuting system could only be used by people with special circumstances such as childcare and long-term care. I was told by the HR staff that it would be difficult in my situation.

Three years have passed since I joined the company, and I gradually began to find pleasure in work, and I wanted to continue working if possible. I consulted with my boss and general affairs staff and began to use a wheelchair.

The burden on my body has decreased. However, I was also feeling eye lines from others to me. I was wondering how much consideration I should ask for.

Can I still continue to work? As I get older, I want to improve my skills, but as the disease progresses, my physical strength declines. I tended to notice that I couldn't do anything because of my disease. I didn't have a woman friend like me who was working with a progressive disease. I couldn't imagine how to continue working. I was just doing my best to do what was in front of me.

In 2008, at age of 28, I for the first time faced a woman who had the same disease as mine. This was an encounter via "NHK Disability Welfare Awards".

We talked about loneliness, anxiety and that "we don't want to think about our future." Our talk continued for a long time. We began to think that there might be people with situations same as us. We did raise an association for women patients of muscular disease. We

started communicating on the internet. There were encounters through blogs and so on, members came over 100 persons. I got connected with a woman who had muscular dystrophy, she was continuing to work with a wheelchair. She was a little older than me and worked with similar worries as me. While exchanging information, we thought about solutions to the problems together. I realized how encouraging it was to be able to talk to someone who is in a similar situation. I felt loneliness fading. "You are not alone" is the motto of our patient association. I also continue to hang this word on myself.

Though after I cleared one problem, a new problem appeared. This is the difficult point to go with progressive disease. I need to face problems continuously many times. While I face problems again and again, I realized that I can't pioneer my future just by worrying ambiguously. I need to discover the way to solve the problem by consulting my peers of patients' association or consultants of welfare and so on. Then I prepare for my future. I sometimes can't go through as I thought, but I learned the importance of cooperation instead of being worried alone. Though I don't have enough wisdom to solve problems by myself, we might discover solutions by working together, I

get worried when I can't image the future and I can't judge what to do. Some solutions sometimes appear after I go one step for trial. I'm often supported by my husband or personal assistants at home or when I'm going out. As support for commuting or support during work is dealt as activities for earning, costs of assistants are not the target of welfare. These costs need to be paid by myself or the employer. It is difficult to find assistants as resources are not enough. Time management is a difficult thing either. For these reasons, it's difficult for me to have support from assistants at my office. My company arranged the environment for me to work easier for me. I appreciate it.

It seems difficulties often appear if having intractable disease. However, hopes sometimes appear. One of them is the evolution of science and technology. Even people using wheelchairs can have

training to walk by wearing robot suits. In 2014, a training facility opened in my city. There are certain conditions for wearing a robot suit, such as height, weight, and no significant joint damage and so on. As I met those conditions, I started going to train. The electrodes are attached to the skin. The robot reads the weak signal (biopotential signal) leaking from the skin surface. And the robot suit assists walking according to my intention. The feeling that I could walk was so happy. Even after removing the robot suit, the movement of the legs improves a little. It doesn't mean that walking will improve dramatically, but I can't say anything about the pleasure of wearing the robot suit. I can do what I couldn't do by the robot suit. In 2016, insurance coverage was approved for eight diseases including muscular dystrophy, and some hospitals have begun to introduce them for rehabilitation. Until now, I continue to train regularly to walk with the robot suit. By taking a standing position with the help of a load-relief device, communicating my intentions to the robot suit, and walking. I am able to perform movements and improve blood flow. I want to continue as much as possible. The experience of "what I couldn't do can be done" made me think that the future may not always be difficult.

Another thing that changed my life was the rapid evolution of ICT (Information and Communication Technology). Web meetings have gradually become widespread in my company since the mid-2010s. Web meetings are online meetings with people in remote areas. Information such as video, audio, and materials can be shared on the spot with distant members via the internet. Until then, when it came to meetings, the mainstream was to gather in a meeting room. If you were in a remote place, you would either go out or use the video conferencing system installed in the meeting room. I can now have meetings at my own seat using a computer and a headset. Web meetings have become commonplace nowadays. Even though it is difficult for me to go out, it has become easier for me to work with people in remote areas. With the spread of Web meetings, restrictions on the venue have been reduced when holding meetings.

Following the enactment of the work-style reform bill in 2018 in Japan, the world has shifted toward establishing a work-life balance.

The government has come to support the introduction of telework (a flexible work style that makes effective use of time and place using ICT). The telework system has been expanded in my company as well. I found a new path to continue my work for as long as possible. I adopted telework several times a month. Even with telework, I can join meetings from home and communicate with my boss or colleagues via chat or voice calls as needed. I felt that I could work as if I were in the office.

As the burden of commuting gradually increased, I consulted with the people concerned and switched to work mainly by telework from the fall of 2019. The frequency of commuting and teleworking has been reversed, making it easier to maintain physical fitness. I identified issues during telework time and reviewed work procedures. I also improved the environment at home. For example, the work of handling documents was carried out collectively on the day working at my office. And when teleworking, the work was concentrated on the work that can be carried out only with a personal computer. As for the environment, I got a lot of stiff shoulders when using a laptop computer, so I installed a small stand on the desk to make it easier to adjust my line of sight. It's easy to switch on and off by moving the stand at lunch or after work. In addition, by preparing a wireless keyboard and keeping the distance between the screen and the keyboard, the burden of taking a typing posture has been reduced. A small mouse and a microphone speaker for meetings are also useful.

In March 2020, when I gradually became accustomed to new life, many employees of large companies were required to telework in order to prevent the spread of COVID-19. By limiting the number of people commuting to offices, the risk of infection has begun to be reduced. My colleagues also worked from home. I am currently working all the time at home. My experience of telework has sometimes helped my colleagues. I felt that I can support someone this time as my company emphasizes diversity. As teleworking progressed throughout the company, the work of handling documents was reviewed so that it could be carried out online. Restrictions on teleworking were reduced. In addition, it has become difficult for all to easily go out, and the word online has come to be heard here and there. It is becoming

possible to participate in events via online (seminars, live performances and so on). In the past I had given up participating because it was difficult to go out. I realized that there are cases where restrictions due to disabilities can be reduced by the changes of the social environment.

I'd like to continue working as much as possible. Since I turned 40 this year, there are 20 years until the retirement age of 60. I don't know how long I can continue, but I don't want to narrow down the possibilities by myself. I want to solve the problems each time at my best. I may get anxious sometime. It may be difficult to express my feelings. There's a time when I choose words, try to convey them, and stop. But I'm not alone. From my experience, I can think that there must be someone who can be with me.

I have possibilities to face anxiety in the future. But I want to say to myself "You are not alone." I want to say this to someone who face anxiety.

It's difficult to imagine our future.

There is a possibility of unimaginable progress in medical technologies or science in the future.

It is sometimes exciting to imagine the future.

Going forward to the future. I'd like to construct our future with you.

To the ones I have met before,

To the ones I'll come across in the future,

I appreciate that we can live our lives together.