

"Sorry...I couldn't give birth to a healthy child"

What were her husband's words that supported her? Living with a Daughter with Down syndrome

Interview and text by Midori Tanioka

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"The other day, my seven-year-old son said to me as if it were the obvious thing to say, 'I'm so glad Aiko has Down syndrome'. I asked him why he thought so. He replied, "Because Aiko is sooo cute, she's like a baby all the time". If I were asked, "Are you glad Aiko has Down syndrome?" I might not be able to immediately answer 'I'm glad!' but I can say that I am glad that Aiko is Aiko. That feeling is certain.

3 a.m. on November 29, 2019.

Eri Ara, 38, still clearly remembers the scene when her new-born baby, Aiko, was loaded into an ambulance. The ambulance arrived and Aiko and the doctor got into the ambulance. When the door closed, the sirens sounded. It was snowing that day, and the roads were beginning to be covered with a light dusting of snow.

"At the time, I didn't think it was going to be a big deal", Eri recalls as she gazed lovingly at the smiling face of Aiko (1 year old). I saw the ambulance off with the thought that I would see her tomorrow. My heart aches looking back on it now."

The next day, Aiko was reunited with her parents in the heavily guarded NICU (Neonatal Intensive Care Unit), where she had an IV in one hand, a tube for oxygen in her nose, and an EKG attached.

"She has three holes in her heart and may have a chromosomal abnormality."

What if you were suddenly told that your child might have Down syndrome?

Eri says, "Like many parents, I went through a period of darkness." But now, when Eri posts a photo of Aiko's dazzling smile on Instagram, she always adds the following hashtag: "#theluckyfew".

This is the story of Eri and Aiko's one year and eight months together. But at the same time, it is not just the story of them.

It is a story that is relevant to the families of the approximately 2,200 children born with Down syndrome each year (approximately 6 children born each day), and those of us who live in the same society as these children.

Room 221, my child born at 2,355 grams

A beautiful farm stretches across the hills of Yoichi Town in Hokkaido. This year marks the 12th summer since Eri and her husband, Masahito, started their vineyard together in their 20s.

Eri, who puts her heart and soul into growing grapes every year, has two children. They are Joichiro (7) and Aiko (1). Aiko will turn 2 years old in November this year.

—*How was your pregnancy with Aiko?*

Eri: During my pregnancy check-ups I was always told that everything was going well and that I was doing well. I had morning sickness, but I continued to work at the vineyard as long as I could.

—*Do you remember the day you gave birth?*

Yes. It was in the middle of the night at the end of November, one month earlier than the due date. I suddenly had pain in my stomach and started bleeding a little. I went to the hospital around 6:00 a.m. because I thought I might be in labour. Seeing as I would soon be 36 weeks they decided to give me an IV drip.

Once the contractions subsided I was told, "Your baby will be born tomorrow once the IV drip is removed". Finally, tomorrow! I was so excited that although I was about to go to bed, the intervals between contractions became shorter and shorter. They soon became only 10 minutes apart and within the hour Aiko was born.

—*It all happened so fast!*

Yes, it happened very quickly. I still remember the midwife rushing into the hospital room from home, taking off her jacket, and dashing into the room. The nurse shouted, "Here!!" and the midwife replied, "Wait a minute! Oh no! I'm going to have to put gloves on first!" (laughs).

So, Aiko was born not on the delivery table, but in the hospital room bed at 23:03 p.m. (room 221) on November 28, weighing 2,355 grams.

—*Do you remember the new-born Aiko?*

Yes. After the umbilical cord was cut, there was no place to put Aiko because it was a hospital room. The midwife told me, "Mom, hold your baby for a minute". I held her in the same position in which I had given birth on the bed, with her upper body slightly raised.

I still clearly remember how small my baby was and how warm and fuzzy it felt.

"Her breathing isn't steady." Aiko was rushed to the hospital by ambulance in the snow.

—*Please tell us what happened after that.*

I gave birth in the hospital room, so had to move to the treatment room afterwards. After Aiko and I finished our treatments the nurse said, "Please rest for the rest of today."

I think it was about three hours later, when I was sleeping in the hospital room, when the doctor rushed in and said, "Mrs. Ara, we are going to take your baby to a bigger hospital. I'll ride in the ambulance with her. You will be able to see her tomorrow."

While we were waiting for the ambulance, the nurse said, "Do you want to see your baby?" That's when I took a picture.

That picture brings back so many memories. Aiko was then in the NICU with tubes filled with oxygen and IV drips... her face was swollen and she looked like a different person to this picture. That lovely picture I took became my salvation for a while.

—*Did the doctor explain Aiko's condition to you before he got in the ambulance?*

Their explanation was, "Her oxygen levels did not go up and she seemed to be having difficulty breathing". The doctor added, "It may be that she has a heart problem."

Looking back, I think that the nurses, midwives, and doctors must have realized that Aiko had Down syndrome. In many cases medical professionals notice simply by holding a baby or by the feel of their skin.

As the ambulance drove away, the nurse asked, "Are you okay?" and hugged me on the shoulder. But I didn't take it too seriously at the time because I thought, "It will be fine, I'll see her tomorrow."

It was snowing that day and there was a light dusting of snow on the road. I still remember the scene clearly.

Notification of Down's syndrome. The day I held my son's hand and burst into tears

—*Did you go to see Aiko the day after she was taken to the hospital by the ambulance?*

Yes, I did. The nurse at the maternity hospital gave me painkillers and told me to take some with me. My husband, son, and I were driven to a large hospital in Sapporo that had a neonatal intensive care unit (NICU) to see her.

The NICU we were taken to was a special place that was heavily guarded. I went in alone at first. I had to leave all my belongings with them and disinfect it several times. The place, with its echoing EKG, was just as I had seen it in TV dramas. I could hardly believe it was real. It was only then that I realized how big Aiko's condition might be.

—*Do you remember Aiko's condition in the NICU?*

Aiko had an IV drip in both hands, a tube through her nose to secure her breathing, an EKG... She was covered with tubes. She was laid on a special bed to keep her body cool...

It was such a change from the lovely figure I saw yesterday that I wondered, "What's going on?"

I asked the nearby nurse, "What's wrong with her?" But she only replied to say that the doctor will explain later.

I didn't know my child's condition but yet had to explain about the NICU and sign various consent forms... I was flooded with various feelings as I looked at Aiko. I remember that I couldn't comprehend the situation well and burst into tears.

—*It must have been hard to have such an event happen so soon after the birth. What did the doctor explain to you?*

The doctor explained the situation to me in another room. He said, "There are three holes in Aiko's heart. Some of her characteristics match so I would like her to have a chromosome test". I was confused about what he was saying. The doctor then said, "Have you ever heard of Down's syndrome?" At that moment, I immediately understood that Aiko had Down syndrome.

I was with my son, so I acted stout first.

But later, the cardiologist showed me a drawing of her heart. He explained, "There are three holes here, here, and here, and the blood flow is like this. In the worst case scenario it could cause heart failure".

I tried not to cry, but as I held my son's hand, I couldn't stop myself. I remember that my son, who was 6 years old at the time, asked, "Mom, why are you crying?"

—*Do you remember what you and your husband, Masahito talked about?*

We didn't have much time to talk because we were with our son. But I remember when we were in the waiting room we exchanged a few short words, like "We never expected that we are going to raise a child with a disability", etc.

—*How did you feel after returning to the maternity hospital from Sapporo?*

We went back to the maternity hospital with my husband and son and stayed in the hospital room for a little while. I remember I was trying not to cry anymore in front of my son and trying my best to look healthy.

Once my husband and son returned home, an experienced nurse asked me gently, "Are you okay?". At that moment, everything I had been trying to hold back broke down. I couldn't stop the tears from flowing one after another.

The nurse didn't give me any advice; she just silently listened to me.

I didn't even know what I was sad about that day. I took a shower and felt a little calmer, but my tears would spontaneously flow again. I cried and cried and cried. I kept crying so much that I thought I was going to lose my eyes.

—*What was your emotional state like while you were in the hospital?*

Looking back on it now, it was a time of darkness. I don't think there was a more difficult time than that time. I would search for Down syndrome on my smartphone to find out its characteristics. I would then feel depressed and look for other possibilities.

Children with Down syndrome often have a single palmar crease on their hands. I had a 5-second video of me holding Aiko in my arms, and when I looked back at it in slow motion I saw that Aiko had a single palmar crease. I realized then that she had Down syndrome.

Even though I was becoming more and more convinced that it might be Down syndrome, Aiko was not with me and I could not do anything on my own.

And yet, at the maternity hospital, a celebratory meal was served to me and the cleaning staff said their congratulations. The gap between the happy mood of the maternity hospital and my current situation was really painful.

—*How did you receive the information about Down syndrome on your smartphone?*

When I saw the phrases "slow growth" and "often has complications", I didn't see Down syndrome in a positive light. I was just worried about what kind of parenting I would have to do.

Down syndrome comes with some facial features and I wondered if Aiko would ever resemble me. I also wondered if she would be able to exercise, or if she would be able to get married, or have children... I was always thinking like that.

Looking back now, I think I was too ignorant back then. I only knew about Down syndrome through images.

Even though they have Down syndrome, they of course all have different facial features and look like their parents. They can wear cute clothes, go shopping... they can of course talk, go to school, and get a job. They can become artists, models... Some also get married.

But at that time, I couldn't see anything positive and felt like I was in a long tunnel.

"I'm sorry I couldn't give you a healthy baby..." What were her husband's words that supported her?

—*Did anything happen that made you see a way out of that tunnel?*

The time at the maternity hospital was nothing but pain, and the doctor, who understood the situation, asked me, "Do you want to leave early?" I was discharged on the third day.

I remember I sent a message to my husband on my last night in the hospital saying, "I'm sorry I couldn't give you a healthy baby."

—*What was your husband's reply?*

My husband replied, "Aiko is alive and well."

I went to see Aiko the day she was discharged from hospital, and when I saw her, I thought to myself, "Yes, Aiko is alive." She's hooked up to a lot of tubes, but she's doing her best to stay alive.

I took a lot of pictures that day, and finally was able to show my son many pictures of Aiko.

—*Did you start to see the end of the tunnel little by little?*

Of course, it took time. I had two weeks to wait for the test results, so I spent some time at home in agony until then. There was a time when I tried to drive to see Aiko despite my postpartum body, but my husband stopped me and I turned back, crying a lot.

It was only when I went to see Aiko on the ninth day postpartum that I thought, "I might be okay."

When I saw Aiko sleeping wrapped in warm blankets and a number of tubes reduced, I thought, "What a lovely child." I stopped looking for the characteristics of Down syndrome and just looked at her with love. I was kind of relieved to find myself looking at Aiko and saying, "She's so cute, she's so cute."

That day I gave Aiko my breast for the first time.

I remember vividly the room temperature and smell of the GCU (new-born recovery room), the beeping sounds of the machines, and the music box as I breastfed her. I remember everything vividly. I am sure that I will never forget that day as it was the day I thought, "It's going to be all right".

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Editor's note

When I started researching Down syndrome for my interview with Eri, I realized I was too ignorant about Down syndrome. I had never imagined how a baby with Down syndrome would grow up, learn, and go out into the world, or what kind of life course he or she might have.

The incidence of Down syndrome is said to be about 1 in 700, and it is actually a very familiar disorder. Many people are probably afraid of it because they do not know about it, even though it is very familiar to them, and it is perhaps natural that many people have a negative impression of Down syndrome, which is often discussed in combination with prenatal diagnosis.

We also came to understand that this image is the cause of suffering for many parents of children with Down syndrome, including Eri. Modern medicine can force us to make life choices in a very short period of time.

However, perhaps our understanding of Down syndrome is not advanced enough to allow us to make such an important choice.

This interview is Eri's story. But at the same time, it is a story that we all need to know.

Interview and text by Midori Tanioka;

Photo by Koichi Tanioka

In the next issue, I will hear her feelings and reactions when she told her parents and her eldest son that Aiko had Down syndrome, her child-rearing days with Aiko's smile at the centre of the family, and her thoughts on prenatal check-ups.