

Death with dignity

Satoko Murate

— Part 1 Grandmother —

“Good morning, Hanako-san!”

Responding to my bright voice, grandmother opened her eyes slightly for an instant, and then closed them again and fell asleep. I linked the nasal gastric tube from her nose to the pack of nutritious liquid. A drop of thick white liquid started to trickle down. For more than five years, she had been bedridden and almost in a comma.

Hanako-san was a large woman for her generation and very courageous and she had a strong-minded character. There was an episode when she turned the burglar away at midnight, scolding him harshly. After the police arrested him, the burglar told the policeman that he had never seen such a powerful woman in his life. As my mother died young, she raised my sister and me. She was very strict with us.

“Study hard! Study Hard!”

That was one of her sayings. She wanted us to carve out our future for ourselves with our own wisdom and perseverance. She was a “Godmother” to our family.

When she was 90 years old, Hanako-san had a stroke and suddenly became unable to swallow due to a deterioration of consciousness. We faced the pressing question of how to feed her. There were three alternatives. The first one was a gastric fistula, which provides liquid nutrition directly to the stomach through a catheter. It is relatively easy to manage, but it needs an operation to fix the catheter to the stomach wall. The second alternative was nasal feeding, which provides nutritious liquid through a nasal tube. It did not require surgery and was easy to put on and remove, but patients always feel uncomfortable with a tube through their nose. The third one was doing nothing and leaving things as they were, which meant she would die soon.

When she was in good health, Hanako-san was interested in “death with

dignity” and wrote down “a living will” saying that “I want to die peacefully without unnecessary treatment.” She was no longer able to decide anything by herself. I remembered the day when my father (Hanako-san’s son) and my aunt (Hanako-san’s daughter) had a fierce quarrel about her terminal treatment.

“I oppose both gastric fistula and nasal feeding!” my aunt adamantly said. As a pure naturalist, she believed that we should let Hanako-san go without any treatment.

“It is against her living will, and it is a pity for her!”

My father, who was a doctor, claimed that neither gastric fistula nor nasal feeding was an unnecessary treatment but both were standard procedures.

“If we do nothing, she will die in a few days,” he said.

“She is already 90 years old. It is enough. Let’s her go!” my aunt insisted.

“You say these treatments are not natural, but I think it is more unnatural if we do not provide any treatment. If Hanako-san does not have a vital force, she will die without responding to any treatment. It is up to her, and it is more natural.” my father replied.

As for me, I wanted Hanako-san to live as long as she could. I thought I could not endure watching her dying without feeding. Because in the end, it would be a death from hunger. Although I could understand what my aunt says, I could not agree with her emotionally at that time.

In the end, we chose the nasal feeding for Hanako-san. No one could overturn my father’s professional wisdom. He said the operation for gastric fistula would be too hard for my grandmother. And he also could not choose the third option, which was to let her die without any treatment.

My father started Hanako-san’s nasal feeding. It was, however, not a silver bullet. She was suffering from severe diarrhea, and she had to wear gloves to prevent herself from pulling out the tube from her nose. It seemed to be cruel for her. Gradually I became skeptical about our choice.

Then suddenly, too suddenly, my father died, leaving his mother behind. Amid the terrible confusion, it became my mission to take care of Hanako-san.

While continuing her nasal feeding, I was always thinking about what it meant for her life. What is the purpose of her life? Is she delighted to live a bedridden life?

After seven years of bedridden life, Hanako-san finally passed away. After her funeral, I read her living will again and again, and spoke to her photo.

“Did you die with dignity, Hanako-san?” But she said nothing.

— Part 2 Granddaughter —

When my daughter-in-law returned from her pregnancy checkup, she told me that something wrong was happening with her baby’s heart and she would have to have a Cesarean. Over the phone, she was weeping, and I felt as if I fell into the bottomless pit.

“Don’t worry! We will work together to bring up the baby and do our best!” Contrary to my positive words, I thought the future of our family would completely change by having a physically disabled child.

Two months after, the baby girl was born by Cesarean section. Her mother named her “Nao” (a combination of kanji character meaning “seven” and “live”), hoping that she could live as long as possible. Nao was a beautiful baby with bright eyes and a shapely nose. As the first granddaughter, Nao became one of the precious members of our family.

Nao had a fatal defect in her heart. Her left ventricle that pumps the blood around the body did not work well. Her doctor said that Nao would have to undergo a big surgery when she became one month old. It would be a challenging operation with a success rate of 13 %. Then after one year, she would have the second operation, and lastly, she would have to undergo the third operation when she became three years old. Even if she could survive these three operations, she would neither be able to walk fast nor have her own child in her life. It was a hard pronouncement for us.

Nao survived the first surgery. It was a big operation that took 12 hours.

During her surgery, I was restless and sitting in front of our family Buddhist altar all day long.

“Please, please save Nao’s life.”

Miraculously, she survived. When I heard that her surgery succeeded, I was so relieved that I sank to the floor. I thought Nao had a strong vital force.

Two months after her surgery, I had an opportunity to hold her in my arms for the first time. When I met Nao at the neonatal intensive care unit, I could not hold back my tears. With a tube of oxygen in her nose, a long installation on her foot, and scars from her major operation on her chest, she was lying in the baby bed. I cautiously held her in my arms. She gazed at me, and her sparkling black eyes spoke to my heart. I felt her strong will to live in her eyes.

Three months after her operation, Nao was allowed to leave the hospital and go back to her home. Her parents, brother, and grandparents, all her family welcomed her. Everyone was so delighted and enjoyed the life with Nao. I bought a present, the first present for her, a small stuffed caterpillar. I bent its funny face to her, saying, “Hello!” A caterpillar bobbed his head to her, saying, “Hello, again!” She smiled, stretching her tiny arm to try to grab it.

However, after only two weeks staying in her home, her condition took a sudden turn for the worse. She was unable to discharge her urine due to heart failure. She entered the hospital again and fell into a critical condition.

“There is no way to save Nao-chan’s life except a heart transplant.” her doctor said.

He explained the details. If Nao undergoes heart transplant surgery, she will have to wait for a donor with the help of a ventricular assist device. And once the ventricular assist machine is attached to her body, it will never be removed again, because it is regarded as a kind of homicide under the Medical Care Act. As a result, Nao will have to live bedridden with the machine for several years or many years until the donor appears. The doctor pressed us for the answer whether we will choose the heart transplant or not.

A family conference was held. We gathered and discussed what to do. In the end, all of us were of the same opinion. No one wanted the heart transplant

surgery, which cost a huge amount of money and took a lot of time, and above all, everyone did not want her to feel pain any longer.

One week after we made our decision, Nao passed away. Her little coffin was filled with a lot of flowers. I put the caterpillar toy in her coffin and asked her, "Was it a good decision for you, or wasn't it?"

Her face was so peaceful as if she were sleeping.

(1,501 words)