

## CHAPTER 23

# *A Thousand Cranes*



Right before Kara collapsed in April 1995, we had a Japanese exchange student stay with us for a short visit. Her name was Ayako and she was Kara's age. She had come to Maine with a group of her classmates and they were attending school with their host brothers and sisters and experiencing American food and culture. Mostly, they were having a lot of fun despite the obvious language difference. In February 1996 a package arrived in the mail from Ayako. We opened it to find a beautiful and colorful origami mobile consisting of a thousand cranes. The note to Kara said:

Dear Kara,

Hello, I am Ayako. Do you remember me? I was surprised to learn that you were in the hospital. But you are in the house, aren't you? I am very much concerned about your health. I hope you will get well soon. This is thousand cranes. We call them "senbazuru." Japanese people make a thousand cranes when someone becomes sick. Why we make a thousand cranes? Because, to wish for them recovery. This was made by my family, my friends and me. Smile.

Ayako

I knew the story of *Sadako and the Thousand Paper Cranes* by Eleanor Coerr. It is a book about a Japanese girl, a runner, who dies of leukemia. There was a mobile of a thousand cranes in the playroom of the Pediatric Unit at the Maine Medical Center. I had studied it often as I tried to imagine for whom it had been made. And now Kara had her own one thousand cranes, made with love and sent many miles across many cultures with the messages of health and recovery.

Maybe it was the thousand cranes which helped Kara in her earliest days of speech therapy when she was still safety-strapped into her wheelchair and she struggled to recall the words to identify the sim-

plest objects such as a ball or a brush. Despite her language impairment and dystonia, she still kept her sense of humor. When Susan, the speech therapist, taped Kara using a video camera and microphone, Kara would eye the camera, grab the microphone and sing different tones. As soon as Susan turned her back, Kara would bend down to the microphone, look up at the camera and say "Hi, Mom." Susan once asked Kara to identify five different fruits, and Kara tried to get away with saying: "Apple, banana, banana, banana, banana." Of course, Susan wouldn't let her off that easily and when she gave her appropriate hints, Kara did produce the words for five different fruits. One was blueberries, and when Susan asked Kara if she liked blueberries, she said, "Yuk, hate them." Her teenage likes and dislikes were definitely present. Now her speech is still slightly slow and thick, but she can easily communicate every need. When we have a hard time understanding a particular word or phrase, Kara patiently spells it for us.

Maybe it was the thousand cranes which helped Kara through her feeding difficulties. Kara had always been a picky eater and now she was worse. Feeding Kara orally was a time-consuming frustrating chore. She would store the food in her mouth for many minutes only to spit it out when we realized that she hadn't talked for a while. Once on the Pediatric Unit I thought I had done a good job of feeding Kara and left her room for a few minutes to visit the mother of Kara's next door neighbor. When I came back in the room, there was Dr. Allan holding a styrofoam cup full of Kara's half-digested food. "Oops", I said, "I guess that I forgot something." It is good practice for neurologists to have to deal with this sort of thing. Now her eating is so much better. She even eats broccoli and spinach and seems to have weaned herself from Skittles, her usual food of choice.

Maybe it was the thousand cranes which helped Kara through her severe dystonia. There were days that Tom didn't come home until one or two o'clock in the morning as he tried to soothe Kara through her sleepless dystonic episodes. He would walk her around the hospital halls all evening trying to tire her out. He would sing to her and rub her back as he tried to get her to settle down for a night of slumber. He would come home distraught from watching our daughter pass through this restless and seemingly physically painful period. He felt helpless. But now she falls off to sleep easily each night, all snug and comfy in a bed listening to her favorite tapes. When Guerin first took Kara swim-

ming for her recreational therapy, it would take forever for her to wiggle Kara into her bathing suit as she pried her arms and legs into the appropriate openings. Now Kara is progressing towards dressing herself.

Maybe it was the thousand cranes which helped Kara make the adjustment to school. She started school in October but her endurance was so low that she could barely make it through the day. Her attention span was short and ability to focus on tasks limited. But slowly she got better. Now at the end of a school day she still had the energy to climb the last flight of stairs up to the art room or to go to the YMCA for a swim therapy session. She took speech and chorus with her classmates. She went into regular classes when they had projects that she was capable of doing. I help her with special projects—I now know as much as most astronomers about the winter sky. Her math is at a sixth-grade level and some of her verbal skills are already beyond her age level. People are starting to see not a child to be pitied but a child to be honored for her courage and commitment to recovery.

Maybe it was the thousand cranes which sent Margie and Sarah, Emily and Julia to Kara. Kara is extremely sociable and loves people. Margie and Sarah are the two wonderful people who make sure that Kara's social needs are met. They take her to basketball games, shopping and out for ice cream. If they are with her for meals, they patiently encourage her eating and even feed her. They were her dates to the high school's winter dance and told her how beautiful she looked in her short, little black dress with her black tights and her Doc Marten shoes. They made sure that she never had one lonely moment that night. I don't think that they have any idea what a huge part of Kara's recovery they are. I try to spoil them every chance that I get, but I don't think that I will ever be able to repay all that they have done for our family. Emily and Julia are identical blond blue-eyed twins. They watch over Kara's academic career. It is Emily who is reading Roald Dahl's *Matilda* with Kara and it was Julia's suggestion to the teacher that placed Kara in a regular speech class. One day Emily asked Kara, "Is speech your favorite class?" Kara answered back to her friend, "Emily, it is my only class!" There is nothing wrong with Kara's sense of humor.

Maybe it was the thousand cranes which have made our home life a little easier with each passing day. Having Kara with us at home is a privilege but there is no doubt that our lives have changed dramatically. We still cannot leave Kara home alone because if there were a fire

or if someone came to the door, she couldn't reliably handle the situation. We still have to bathe her, help dress her, help her feed herself and entertain her. But it is easier to do all of these chores than when she first came home in July 1995, and she contributes more to her own care each day.

Everything we do with her we approach as a rehab opportunity because we want to utilize every moment to aid her healing. We read to her and with her, do crossword puzzles together, help create bold Matisse-like paintings, practice using the computer and play games with her. We try to plan family outings that will be both fun and therapeutic for her. All of this takes energy and time and what suffers are those moments every adult so enjoys, the time to read as you listen to music, the time to build our kayak, and the time for Tom and me to rent a movie and enjoy it together. Now by the time nine o'clock rolls around every night, Tom and I are barely able to keep our eyes open. But every day there is a reward, either in what Kara says or what she does. That is what keeps us motivated and lets us know that a day will come when we will smile at each other and know that we did our best for our daughter.

So those thousand cranes are doing their job. Those prayers that you pray for Kara in your Buddhist temples are a testament to the commonality of our human spirits and we are humbly grateful. Thank you, Ayako, Shuji, Asuka, Katsuya, Mizuki, Hirokazu, Hidetoki, Futoshi, Koji, Daiki, Shoichi, Sayaka, Erika K., Reina, Jurika, Yuka, Mayu, Sayuri, Mikako, Asuka, Chinatsu, Yuki, Yuka, Rika, Erika N. and Kazuko.