

Japan wakes up to reality of dementia, seeks unique solutions



Asayo Sakai banged on the front door, demanding to be let out. She was at her daughter's apartment, where Asayo has lived for the past six years. She has no memory of how she got there or what she's doing there.

As her daughter, Akiko, blocked the way, Asayo, 87 and suffering from dementia, lashed out, hitting and biting. The scene repeated itself with agonizing predictability for a solid year until one day Akiko, exhausted, gave in and opened the door, letting Asayo wander the streets of Osaka.

“I thought, ‘Get out of here, if that’s what you want,’” Akiko said. “Mom turned into a monster and I couldn’t handle her. I thought my life was over.”

What happened next taught Akiko things she never knew about her mother — and herself.

Asayo's walks lasted for hours and hours and into the early morning. At first, her daughter followed from a safe distance. When police assured her they would try to keep an eye on Asayo,

she let her mom roam around the city alone.

It was a risky act of desperation. Yet Akiko soon discovered within her own neighborhood how Japan is trying to become more dementia-friendly. In 2013, the government started a program that helps families and communities deal with dementia sufferers on their own.

Businesses are helping as well.

Asayo's story provides a glimpse of where Japan's policies may be headed, how far the country still has to go, and the extent to which it is providing a road map for other countries.

Crisis in elder care

Akiko is among the tens of thousands of Japanese adult children and other caretakers who, lacking access to nursing homes or sufficient help at home, have been pushed to their psychological limits.

"People are desperate to find ways to handle dementia patients," said Hiroko Sugawara, who runs a government-funded educational campaign on dementia.

That dynamic has given rise to a growing elder care crisis here, where more than 10,000 seniors with dementia went missing last year, according to the National Police Agency.

Some disappear for years, others never return or are eventually found dead. Caretakers have snapped, injuring or even killing their loved ones.

In 2012, 27 seniors were murdered or died from neglect, though it is unclear how many suffered from dementia.

The number of seniors abused by family members jumped 21 percent to more than 15,000 in 2012 from 2006, half of whom suffered from dementia, according to a survey by the Health, Labor and Welfare Ministry.

While other countries are aging, none have done so as rapidly as Japan, where an estimated 8 million people suffer from dementia or show early signs of developing it.

That's about 6 percent of the population.

By 2060, 40 percent of Japanese will be over 65, up from 24 percent today, according to the National Institute of Population and Social Security Research. And as the population ages, the

proportion of tax-paying workers will decrease relative to the swelling ranks of dependent seniors.

Funding for the stay-at-home program, at just ¥3.5 billion this fiscal year, is low compared with spending on the disease by other developed countries.

At the same time, the government has been raising premiums and reducing access to state-funded services as part of a broader effort to reduce spending, adding to caretakers' difficulties. Yet the concept of care that is more humane and less expensive than locking up patients in nursing homes is one that experts say holds promise.

Broad support network

As families struggle with their loved ones at home, businesses are also striving to adapt as shoppers age.

Dementia patients tend to buy the same products over and over again, said Kimika Tsukada, a manager of social affairs at Aeon Co., the nation's largest retailer. They open food packages in stores, eat without paying and get lost in shopping malls.

Banks are also a challenge for forgetful seniors. Elderly customers forget PINs for ATMs or where they've put passbooks, said Yuriko Asahara, for two decades a Tokyo suburban branch manager of Japan Post Holdings Co.

Asahara recalled a 76-year-old woman who lost her passbook nine times within a few weeks. She has been regularly accused over a 20-year period of stealing money by another woman, who is now in her 80s.

The growing number of elderly with dementia wandering Japan's stores have resulted in some unusual care-giving arrangements. Asahara sometimes helps customers who have lost their way get home. Or she helps them replace missing keys, or decipher complicated utility bills.

Both Aeon and Japan Post have programs to teach sales clerks and staff how to handle customers who show signs of dementia. Retail and bank employees are among the 5.4 million people who have taken the government-funded courses.

Aeon's program, which began in 2007, has trained about 10 percent of the retailer's 400,000 employees, Tsukada said. Mizuho Financial Group Inc. requires all of its 1,400 floor clerks to take a class in dealing with customers with dementia. Sumitomo Life Insurance Co. has had a

quarter of its 40,000 employees learn about the condition.

“It’s time for communities to step in and help out,” said Sugawara, the government program’s director.

As the years have passed since Asayo first began her walks, her Osaka neighborhood of Kitahama has become an informal support network.

When Shigeo Asai, 75, the building manager of Akiko’s apartment building, spots Asayo in an elevator on his monitor at, say, 6 a.m., he invites her into his office for a chat. The small talk makes her smile and she then often returns to her apartment, he said.

Asai has also taken to telling other tenants about Asayo’s dementia. He encouraged youngsters in the building to greet her and spread the word to their parents, who now also help if necessary, he said.

“Akiko let everyone see how hard it is to live with her mom,” said Asai, whose elderly sister was recently diagnosed with Alzheimer’s disease. “That’s why we help. That’s the way to go. It can happen to anybody.”

Keiji Hori, 67, who owns the Rivoli cafe a block away, looks out for Asayo when he opens to serve breakfast at 6 a.m. He often sees her by herself with a bag on her shoulder.

One recent morning, he invited Asayo in for a cup of coffee and a slice of toast until her daughter came to look for her. He took an interest after spotting Asayo yelling at her daughter, whenever Akiko tried to follow her.

“I see her daughter does a lot for her mom and I came to respect and support her when I can,” said Hori, who has run the cafe for more than 30 years.

Other locals are also keeping an eye open for Asayo. The area has bars, cafes and restaurants open from 6 a.m. to as late as 3 a.m.

“You’d think people in cities are busy and cold, but they are so heartwarming and helpful,” said Akiko. “They watch out for my mom.”

Asayo, a former nurse and housewife, was diagnosed with Alzheimer’s disease, the most common form of dementia, almost 10 years ago, when she was 77. Her husband, Masao, had died six years earlier and she had become depressed, stopped cooking and lost weight, Akiko

said.

For four years Asayo managed to live by herself. Then her condition worsened.

She constantly rang her neighbors' doorbells, searching for random children and her dead husband.

She restocked far more mayonnaise and bananas than she needed, making piles in her kitchen. A tidy person all her life, Asayo cluttered her living room with cardboard boxes. When she tried to withdraw cash at her bank, she lost her temper, ripping apart her passbook in front of the teller.

In 2005, when Asayo was diagnosed with Alzheimer's, Akiko was so distraught she bought a pack of cigarettes, lighting up for the first time since quitting smoking six years earlier.

"Mom would tell me she was fine living alone and that she was eating well, so I believed her," Akiko said. "That was wrong. I shouldn't have believed her."

Kept mom locked in

Asayo at first refused to move out of her two-story house in a suburb of Osaka, where she had lived for more than three decades. When Akiko finally convinced her mother to move in, she locked Asayo in the apartment to keep her safe.

That didn't keep Asayo from sneaking out in the dead of night. Asayo could never remember where she lived, but she could always give her name to police.

"I felt ashamed to pick up my mom from police stations," said Akiko, who works at home as a freelance editor and runs an art gallery above her living quarters.

Asayo's dementia had progressed to the point where many doctors would prescribe medication and send her to a hospital.

About 12 percent of dementia patients in Japan live in mental hospitals, partly because general practitioners, nurses and even nursing homes don't have enough knowledge or resources to handle them. That compares with less than 1 percent in the U.K. and France.

Physical discomfort, large crowds or unfamiliar faces can make dementia sufferers aggressive, according to the Chicago-based Alzheimer's Association.

Doctors prescribe treatments such as the antipsychotic drugs Abilify or Seroquel. They are used

to prevent patients from harming themselves or their caretakers, said Ronald Petersen, director of Alzheimer's Research Center at the Mayo Clinic.

Asayo had been turned down by two day care centers because of her urge to go outside and her tendency to slap people. On a third try, she was accepted into a three-day-a-week program. That still left long evenings and nights with both mother and daughter holed up in Akiko's duplex apartment.

The day Akiko relented and opened the front door started out in the usual way. Asayo had been jiggling the door, wandering around the apartment, demanding to be let out for an hour. After Asayo dashed out, she walked over 6 km nonstop, said Akiko, who followed her.

Sudden improvement

After that first walk, something remarkable happened.

As Asayo rediscovered her freedom, her anger disappeared and her mood lightened. She was laughing, flirting with strangers and regaling her daughter's friends with tales of her youth.

"Letting her wander saved us and made us happy," Akiko said. "It was unbelievably disturbing and stressful to keep my mom in the house."

Akiko shut her gallery for several months and followed Asayo everywhere. Life, if far from perfect, was immeasurably better than during the endless afternoons and nights when both felt trapped inside.

"We got exercise, we were around other people and we stopped driving each other crazy," Akiko said.

Then Akiko took another chance.

She cut out many of the drugs her mother took for Alzheimer's, diabetes, hypertension, high cholesterol and thinning blood. Asayo became more tranquil.

"There was a risk that her disease would progress," Akiko said. "But I thought it would make both of our lives much easier if she calmed down, even if her memory were lost."

Asayo is down to a few pills for hypertension and elevated cholesterol levels. She no longer takes Aricept, commonly used to slow the progression of the memory loss. It has side effects, including

nausea and diarrhea, in 20 percent of people who take it, according to the Mayo Clinic.

Side effects may have also played a role in Asayo's agitation and violence, said Steve Iliffe, a professor of primary care for elderly people at University College London.

"Patients can't understand or express what they're experiencing," Iliffe said. Akiko "was right to do that," he said. "That's quite bold."

There were still bad days, like when Asayo wandered in and out of the house for 12 hours before entering a high-end Italian restaurant. In front of the other diners, she called her daughter "a smuggler" and demanded a waiter call the police. Akiko grabbed her 152-cm-tall, 45-kg mother, who fought back, and dragged her outside the restaurant.

"You can't imagine how much energy she has and how robust her physique is," Akiko said, pointing to her and her mother's calf muscles, fit from all the walks together. "She looks refreshed and walks the same distance the next day. She's lost her sense for pain. I find it really hard to keep up with her."

Wandering alone

Wandering is common in dementia patients, experts say. About six in 10 people with dementia may not remember names or addresses, and they can become disoriented, said the Alzheimer's Association. While it can be dangerous if unsupervised, walking helps calm down agitated patients, Iliffe said.

"Walking is therapeutic and helps reduce disturbed behavior and sleep," he said.

Wandering alone, though, remains controversial. Many doctors don't like the idea that patients are at risk of physical injury. Social workers counter that everything should be done to allow patients to safely do what they want to do.

"The best interest may be you do lock the door," though not necessarily always, Iliffe said. "We all take risks in some way and are managing risks, so it's about how much risk can we tolerate for somebody who can't remember where they live."

Asayo has tried to walk to the port town of Moji, at the northern tip of the island of Kyushu, over 400 km to the west, where she grew up as the youngest of four children.

Later, she moved to Kasugade, about 5 km west of Osaka, where as a young woman she was a

live-in nurse and helped to treat wounded World War II soldiers or prostitutes infected with syphilis. She has tried to walk there, as well.

In her attempts to get to these places of her past, Asayo has asked businessmen and teenagers to point her in the right direction. She has also hailed taxis: Akiko said she has paid as much as ¥5,000 for drives that often end at the police station.

Teaming with police was another turning point.

Akiko no longer considers it demeaning to end her day with a visit to the police, upon whom she's grown increasingly dependent. She feels comfortable letting her mother wander, knowing police are keeping an eye out for her, she said. Asayo has been brought to all eight police stations within 2.5 km of their house.

No protective laws

Japan has no laws protecting people who lack the capacity to make decisions.

Both they and their caretakers can be sued for damages. About 115 dementia patients died in train accidents in the eight years ending in 2012 and some of the victims' families have been forced to pay damages to the railroads, according to an investigation by the Mainichi Shimbun, based on government statistics on train accidents and police records.

In 2007, a 91-year-old man suffering from dementia in Aichi Prefecture slipped away from his wife and his daughter-in-law, wandered across railroad tracks and was struck and killed by a train.

The family was sued for ¥7.2 million in lost ticket revenue by Central Japan Railway Co. (JR Tokai).

The Nagoya District Court in August 2013 ordered the family to pay the full amount, because the family failed to prevent the man from wandering, according to court records. The case was appealed to the Nagoya High Court, which in April reduced the payment by half, holding only the 85-year-old wife, and no other relatives, accountable.

No serious injuries — yet

Asayo hasn't sustained any serious injuries so far, though she has cut and bruised her face after tripping and falling on the street.

Though her memory isn't returning, Asayo is reveling in a new phase of her life. When she is not wandering, she's regaling shopkeepers and restaurant workers with yarns about her relatives, and the doctors and nurses she once worked with. She talks about her daughter's love affairs, real or imagined, and asks about the husbands or boyfriends of any woman listening.

Whether true or not, her stories make people laugh, encouraging her to talk even more, Akiko said.

"She is like an actress or clown on stage. She loves getting attention," said Akiko. "I am horrified to think that I might never have known this side of my mom."

On a recent day, Asayo was at day care from 9 a.m. to 5 p.m., coloring pictures, solving quizzes, bathing and eating meals and sweets with 20 other elderly people.

About 90 percent of the cost is covered by the universal long-term care system. The out-of-pocket bill, which comes to about ¥60,000 a month, is paid for out of Asayo's pensions and her savings, Akiko said.

Asayo refused to have lunch with a group of elderly women and sat at a corner table with a man in a wheelchair who tightly closed his lips and turned his face when he was spoon-fed by a nurse. As Asayo munched her sauteed pork and rice with her chopsticks, she encouraged the man to eat — to make his mom proud.

The next day as soon as she returned from day care, Asayo started jiggling the door, going up and down the stairs from the living area to the gallery, mumbling and calling for her dead cat Jeff. She wanted to escape to a friend's place in the mountains. No one should worry, she said, because she's a skilled worker and can get a job.

After Akiko opened the door at about 6:40 p.m., Asayo stormed out into a heat wave of 34 degrees. Humidity and heat filled the air as businessmen dressed in white shirts and suit slacks queued in front of bars for after-work drinks. She roamed around, calling her daughter a thief, demanding she go away, and crossed busy roads against traffic.

After 40 minutes, Asayo finally agreed to sit down at a restaurant. She sipped a sweetened ice coffee through a straw and ate the toppings of a margarita pizza with chopsticks. She pointed at two waiters and insisted they were Akiko's boyfriends.

At about 8 p.m., she followed Akiko home, took off her top, and changed into a yellow, cotton

pajama dress, which she wore inside out. She tossed two butter ball candies into each cheek, put four more in her pockets, sat on a red leather couch and waved a paper fan.

Asayo fell asleep without brushing her teeth, her trousers and glasses still on and the fan in her hand.

Akiko doesn't press her to do things differently and leaves Asayo alone for the most part.

"Her remaining life is short. She should live happily as her mood dictates," Akiko said. "I try not to stress us both by caring for her perfectly."

At 8 a.m., Akiko wakes her mother up, and sends her to the day care center. Akiko works, cleans the house, shops for groceries, and, when Asayo comes back later in the day, she cooks dinner and listens to her mother's constant banter.

"It was really hard at first, but I gained a lot from having her around. I've somehow lost a desire to do things for myself," Akiko said. "She forced me to become an adult. I don't really want to admit it, but my mom's illness enriched my life."

One of the many unexpected benefits of the new arrangement: the new friends in Akiko and Asayo's lives — neighbors, restaurant owners and policemen.

Akiko hopes to keep her mother home for as long as possible, she said. And she has learned to let go of the day's tensions.

"You fight one day, mom forgets it all the next day, turns into a charming lady and makes me feel silly for letting it get to me," Akiko said.

"She lives in the present, forgets the past and can't think of the future, so I try to be that way too."