

People with Down syndrome are living longer, but the health system still treats many as kids

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It took Samantha Lesmeister's family four months to find a medical

professional who could see that she was struggling with something more than her Down syndrome.

The young woman, known as Sammee, had become unusually sad and lethargic after falling in the shower and hitting her head. She lost her limited ability to speak, stopped laughing, and no longer wanted to leave the house.

General-practice doctors and a neurologist said such mental deterioration was typical for a person with Down [syndrome](#) entering adulthood, recalled her mother, Marilyn Lesmeister. They said nothing could be done.

The family didn't buy it.

Marilyn researched online and learned the University of Kansas Health System has a special medical clinic for adults with Down syndrome. Most other Down syndrome programs nationwide focus on children, even though many people with the condition now live into middle age and often develop [health problems](#) typically associated with seniors. And most of the clinics that focus on adults are in urban areas, making access difficult for many rural patients.

The clinic Marilyn found is in Kansas City, Kansas, 80 miles northwest of the family's cattle farm in central Missouri. She made an appointment for her daughter and drove up.

The program's leader, nurse practitioner Moya Peterson, carefully examined Sammee Lesmeister and ordered more tests.

"She reassured me that, 'Mom, you're right. Something's wrong with your daughter,'" Marilyn Lesmeister said.

With the help of a second neurologist, Peterson determined Sammee Lesmeister had suffered a traumatic brain injury when she hit her head. Since that diagnosis about nine years ago, she has regained much of her strength and spirit with the help of therapy and steady support.

Sammee, now 27, can again speak a few words, including "hi," "bye," and "love you." She smiles and laughs. She likes to go out into her rural community, where she helps choose meals at restaurants, attends horse-riding sessions at a stable, and folds linens at a nursing home.

Without Peterson's insight and encouragement, the family likely would have given up on Sammee's recovery. "She probably would have continued to wither within herself," her mother said. "I think she would have been a stay-at-home person and a recluse."

'A Whole Different Ballgame'

The Lesmeisters wish Peterson's program wasn't such a rarity. A directory published by the Global Down Syndrome Foundation lists just 15 medical programs nationwide that are housed outside of children's hospitals and that accept Down syndrome patients who are 30 or older.

The United States had about three times as many adults with the condition by 2016 as it did in 1970. That's mainly because children born with it are no longer denied lifesaving care, including surgeries to correct birth defects.

Adults with Down syndrome often develop chronic health problems, such as severe sleep apnea, digestive disorders, thyroid conditions, and obesity. Many develop Alzheimer's disease in middle age. Researchers suspect this is related to extra copies of genes that cause overproduction of proteins, which build up in the brain.

"Taking care of kids is a whole different ballgame from taking care of adults," said Peterson, the University of Kansas nurse practitioner.

Samme Lesmeister is an example of the trend toward longer life spans. If she'd been born two generations ago, she probably would have died in childhood.

She had a hole in a wall of her heart, as do about half of babies with Down syndrome. Surgeons can repair those dangerous defects, but in the past, doctors advised most families to forgo the operations, or said the children didn't qualify. Many people with Down syndrome also were denied care for serious breathing issues, digestive problems, or other chronic conditions. People with disabilities were often institutionalized. Many were sterilized without their consent.

Such mistreatment eased from the 1960s into the 1980s, as people with disabilities stood up for their rights, medical ethics progressed, and courts declared it illegal to withhold care. "Those landmark rulings sealed the deal: Children with Down syndrome have the right to the same lifesaving treatment that any other child would deserve," said Brian Skotko, a Harvard University medical geneticist who leads Massachusetts General Hospital's Down Syndrome Program.

The median life expectancy for a baby born in the U.S. with Down syndrome jumped from about four years in 1950 to 58 years in the 2010s, according to a recent report from Skotko and other researchers. In 1950, fewer than 50,000 Americans were living with Down syndrome. By 2017, that number topped 217,000, including tens of thousands of people in middle age or beyond.

The population is expected to continue growing, the report says. A few thousand pregnant women a year now choose abortions after learning they're carrying fetuses with Down syndrome. But those reductions are

offset by the increasing number of women becoming pregnant in their late 30s or 40s, when they are more likely to give birth to a baby with Down syndrome.

Skotko said the medical system has not kept up with the extraordinary increase in the number of adults with Down syndrome. Many medical students learn about the condition only while training to treat pediatric patients, he said.

Few patients can travel to specialized clinics like Skotko's program in Boston. To help those who can't, he founded an online service, Down Syndrome Clinic to You, which helps families and medical practitioners understand the complications and possible treatments.

'If They Say It Hurts, I Listen'

Charlotte Woodward, who has Down syndrome, is a prominent advocate for improved care. She counts herself among the tens of thousands of adults with the condition who likely would have died years ago without proper treatment. Woodward, 33, of Fairfax, Virginia, had four heart surgeries as a child and then a heart transplant in her 20s.

Woodward, who is an education program associate for the National Down Syndrome Society, has campaigned to end discrimination against people with disabilities who need organ transplants.

She said her primary care doctor is excellent. But she has felt treated like a child by other health care providers, who have spoken to her parents instead of to her during appointments.

She said many general-practice doctors seem to have little knowledge about adults with Down syndrome. "That's something that should change," she said. "It shouldn't just be pediatricians that are aware of

these things."

Woodward said adults with the condition should not be expected to seek care at programs housed in children's hospitals. She said the country should set up more specialized clinics and finance more research into health problems that affect people with disabilities as they age. "This is really an issue of civil rights," she said.

Advocates and clinicians say it's crucial for [health care providers](#) to communicate as much as possible with patients who have disabilities. That can lead to long appointments, said Brian Chicoine, a family practice physician who leads the Adult Down Syndrome Center of Advocate Aurora Health in Park Ridge, Illinois, near Chicago.

"It's very important to us that we include the individuals with Down syndrome in their care," he said. "If you're doing that, you have to take your time. You have to explain things. You have to let them process. You have to let them answer. All of that takes more time."

Time costs money, which Peterson believes is why many hospital systems don't set up specialized clinics like the ones she and Chicoine run.

Peterson's methodical approach was evident as she saw new patients on a recent afternoon at her Kansas City clinic. She often spends an hour on each initial appointment, speaking directly to patients and giving them a chance to share their thoughts, even if their vocabularies are limited.

Her patients that day included Christopher Yeo, 44, who lives 100 miles away in the small town of Hartford, Kansas. Yeo had become unable to swallow solid food, and he'd lost 45 pounds over about 1½ years. He complained to his mother, Mandi Nance, that something "tickled" in his chest.

During his exam, he lifted his shirt for Peterson, revealing the scar where he'd had heart surgery as a baby. He grimaced, pointed to his chest, and repeatedly said the word "gas."

Peterson looked Yeo in the eye as she asked him and his mother about his discomfort.

The nurse practitioner takes seriously any such complaints from her patients. "If they say it hurts, I listen," she said. "They're not going to tell you about it until it hurts bad."

Yeo's mother had taken him to a cardiologist and other specialists, but none had determined what was wrong.

Peterson asked numerous questions. When does Yeo's discomfort seem to crop up? Could it be related to what he eats? How is his sleep? What are his stools like?

After his appointment, Peterson referred Yeo to a cardiologist who specializes in adults with congenital heart problems. She ordered a swallowing test, in which Yeo would drink a special liquid that appears on scans as it goes down. And she recommended a test for Celiac disease, an autoimmune disorder that interferes with digestion and is common in people with Down syndrome. No one had previously told Nance about the risk.

Nance, who is a registered nurse, said afterward that she has no idea what the future holds for their family. But she was struck by the patience and attention Peterson and other clinic staff members gave to her son. Such treatment is rare, she said. "I feel like it's a godsend. I do," she said. "I feel like it's an answered prayer."

'Like a Person, and Not a Condition'

Peterson serves as the primary care provider for some of her patients with Down syndrome. But for many others, especially those who live far away, she is someone to consult when complications arise. That's how the Lesmeisters use her clinic.

Mom Marilyn is optimistic Sammee can live a fulfilling life in their community for years to come. "Some people have said I need to put her in a home. And I'm like, 'What do you mean?' And they say, 'You know — a home,'" she said. "I'm like, 'She's in a home. Our home.'"

Sammee's sister, who lives in Texas, has agreed to take her in when their parents become too old to care for her.

Marilyn's voice cracked with emotion as she expressed her gratitude for the help they have received and her hopes for Sammee's future.

"I just want her to be taken care of and loved like I love her," she said. "I want her to be taken care of like a person, and not a condition."

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