

When a Kid Becomes the Caregiver

Like Thousands of Teens, Va. Student Looks After a Chronically Ill Relative

By Michael Alison Chandler
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GREENSBORO, N.C. -- After her first day of classes this week at the [University of North Carolina](#)'s campus here, Aleyna Castillo crossed a field, passing joggers and cyclists and students sprawled on the grass, reading in the sunshine. She didn't linger at her brick dormitory. The [Loudoun County](#) teenager got into her car and drove 10 minutes to her other home.

There, in a darkened bedroom, her mother lay propped up in bed, a fan humming. Castillo brought a damp washcloth for Lynn Turner to wipe her flushed face with and a toothbrush with a Dixie Cup to spit into. She brushed her mother's hair and offered strawberries to supplement her breakfast of [Pop-Tarts](#). Castillo's 9-year-old cousin, Anthony McNeil, dribbled a soccer ball down the hallway. "Change your shirt," she hollered after him.

Castillo, 18, is one of many teenagers across the country who are caregivers for ill or disabled relatives -- a little-known group that labors under unusual stress and with few resources. Her mother has multiple sclerosis, a degenerative neurological disease that has left the 40-year-old in a wheelchair, unable to work, make dinner or shower without help. For the past year and a half, Castillo has bathed her, prepared her meals, emptied her catheter bag and given her two dozen kinds of medication. She helps take care of Anthony, too, getting him off to school and reminding him to take out the trash.

So when Castillo was accepted to her top-choice university, she decided she would not go alone. "I can't totally abandon my mom," she said. "She needs me." While others from the Class of 2007 at [Sterling's Dominion High School](#) were packing a few suitcases to go to college, Castillo boxed up the contents of her [Middleburg](#) home and moved the whole family. Her mother's hospital bed and medicine chest, Anthony's tennis racket and video games, her collection of karate trophies and baby pictures all were moved to [Greensboro](#).

As many as 1.4 million children in the United States from age 8 to 18 care for a chronically ill or disabled relative, according to a 2005 survey by the United Hospital Fund and the National Alliance for Caregiving. Children provide companionship, run errands and balance checkbooks. Some change feeding tubes or adult diapers.

Mood swings and antisocial behavior are more common among teenage caregivers than their peers, the study found. And one in five young caregivers misses a school or after-school activity to help a family member. Still, there is little recognition of the adult-size jobs so many youths perform throughout the United States, and there are few public services to assist them.

The population of young caregivers will probably grow as Americans start families later in life and as medical advances enable patients to live longer and at home, according to demographers and caregiving experts. Single parents rely on children more, as do immigrant parents who count on the younger generation to help with translation and navigate the health-care system. Children from low-income families are most likely to provide unpaid medical care, experts said.

Multiple sclerosis, typically diagnosed in young or middle-age adults, has long been recognized as a disease with a profound impact on children. But children also help parents or grandparents with Alzheimer's disease, drug addictions, mental illness, HIV, brain injuries and cancer.

Such children share feelings of "stress, isolation and fear, thinking they are the only ones," said Connie Siskowski, a registered nurse who started what is believed to be the nation's first program to identify and assist caregivers in public schools, in [Boca Raton, Fla.](#)

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"When there is a serious illness, there's also the fear of not only what's going to happen to that person but what's going to happen to me," she said.

Castillo was 9 when Turner, a single mother, received her diagnosis. "I thought she was going to die," Castillo recalled.

The self-described tomboy cowered each week when her mother gave herself a shot to slow the progression of the disease. "At first, she cried," Turner recalled. "Then she was like, 'Hey Mom, let me do that.'" Turner showed her daughter how to plunge the syringe deep into her thigh, a scary procedure that soon became routine.

For the first few years, Castillo noticed few changes. Her mother still baked banana nut bread and took her shopping and to basketball games. In 2000, Turner married a fast-food manager she met online. Two years later, the family grew again, when Turner became the legal guardian of Anthony, a freckled 4-year-old who was put in foster care when his mother, a crack addict, left him alone in a hotel room.

But as the family was coming together, Turner's health began to fade. By the time Castillo was in middle school, fatigue gripped her mother. Turner stumbled when she walked, started using a cane, then a walker. Her husband, scared by the changes, left.

By Castillo's senior year at Dominion High, her mother was in a wheelchair. After a series of slips and falls, she had to leave her state government job and was relying on a disability check of about \$2,700 a month, nearly half of which went toward health insurance.

That year, Castillo's day began at 6:30 a.m., when she awakened Anthony in the bed across from hers and went down the hall to check on her mom. She emptied the bedside "pee bag" and brought her mom breakfast and lunch. At school, Castillo used every minute of study hall to finish homework. Later, she worked at a day-care center, then hurried home to warm up frozen dinners. She usually set a card table next to her mom's bed so the family could eat together.

Anthony pitched in, too. He often brought Aunt Lynn a peanut butter and jelly sandwich after school or iced tea with the lid twisted off. When Castillo helped her mother into the car, Anthony loaded in her wheelchair. Sometimes, he crouched to guide her foot through the door.

Over time, Castillo's skills grew. She learned to move with her mother, to push her knees back so she wouldn't collapse, to still her legs when they shook with muscle spasms. She stayed calm when her mother cried out in unsteady panic. When her mother fell, Castillo sometimes called the fire department to help lift her from the parking lot or the bathroom floor.

Despite these demands, Castillo kept her focus on college. After a tough junior year, she aced 12th grade with almost all A's. Many other students saddled with such responsibilities do not fare as well. They struggle with grades or attendance or drop out of school, Siskowski said.

"It would have been very easy for her to make excuses, to say, 'This is so hard,'" said Dominion High's assistant principal, Michelle L. Quirin. "But she stayed focused on the future."

Although few teachers and administrators knew the extent of Castillo's responsibilities at home, they tried to be flexible when she came to school late after a morning of caregiving and a long commute.

The sturdy teenager with dimples and an earnest face said she tried not to let the stress overwhelm her. She turned to her grandfather and a friend for support. Her boyfriend, who was in a juvenile detention center, "always seemed to call at the right time," urging her to stay strong, she said.

It was different for Turner. Confined to her bed, with the drone of the television and the sound of her daughter washing dishes in the other room, the mother, usually hopeful and quick to laugh, had thoughts of despair and guilt.

"I hated having to rely on someone for everything," she said. "It wasn't fair to Aleyna. It was her senior year. She wanted to have fun, be successful. It was a tremendous weight on her."

On Christmas Eve, Turner's lowest point, she used a broken light bulb from a bedside lamp to cut her wrists.

After several days in a hospital, the new year looked brighter. Castillo was accepted to [UNC-Greensboro](#) and was applying for scholarships. Anthony had neighborhood friends and a mentor who played tennis with him and took him to church.

But in early spring, social workers from the county's adult and child protective services knocked on the door. "Somebody had complained that Anthony was helping too much," Turner said. The social workers designated Turner an "incapacitated caregiver," she recalled, and said Anthony could not stay without another adult to supervise. Castillo, not yet 18, did not qualify.

Many who work with young caregivers say it's common to avoid seeking outside help, even in desperate situations, because they fear they will be scrutinized for neglect or abuse.

"The thing that younger children fear most of all is being taken away from their families," said Carol Levine, director of the families and health-care project at the [New York](#)-based United Hospital Fund. "In general, the answer is not to take them out of the family, but to provide support for the family and for them."

But few support programs exist. Some disease-specific groups, such as the [National Multiple Sclerosis Society](#), offer counseling or social activities for caregiving children, but at the school or county level, youth caregiving "is practically not recognized," Levine said.

In contrast, [England](#)'s young caregivers are acknowledged in the census and by law entitled to a needs assessment and a number of services. About 350 English organizations help 30,000 youths with counseling, homework and social activities, said Saul Becker, a social policy professor at the University of Nottingham who has studied caregiving youths.

Loudoun social workers arranged for a nurse's aide to visit Turner 30 hours a week, a short-term emergency measure until the family could find a sustainable solution. The help was extended, Turner said, but only until last month. That was when the family moved.

Now in Greensboro, far from relatives and friends, the family members are trying to start over. Saddled with moving expenses, they rely on credit to buy groceries. Castillo's tuition was covered by grants and scholarships, but she was blindsided by the \$500 bill for textbooks.

Turner had contacted a Greensboro social services agency before moving and expected to qualify for similar nursing care. But she didn't understand that the aide would come only eight hours a week. Unable to pay for more nursing care, which can cost upwards of \$15 an hour, she started thinking, "What can I do?"

Lately, Turner and her husband have talked of reconciling, and he might move to Greensboro, she said.

"That would take a lot of pressure off me," Castillo said.

Students were throwing [Frisbees](#) in the parking lot and carrying cases of beer to the pool when Castillo brought her family lunch last weekend. She did a load of laundry, looked through old photos with her mom and reminded Anthony to wash his hair before she left.

She said she's not interested in beer parties. "I grew up a lot faster than a lot of people" she said. For her, college is about "pursuing what I want to do," she said. That could be opening a day-care center, learning sign language or becoming an orthodontist. "I want to do a million things," she said.

She's committed to her family, but she also wants to make friends and relax. That's why she plans to live in her dorm room unless there's an emergency. High above a leafy, cicada-filled courtyard, she finds respite there.

On a Friday night, she and her roommate, Anna Campbell, 17, entertained some new friends from orientation. The visitors pulled up padded desk chairs or plopped down on the side-by-side single beds and harmonized to pop music blaring from laptop speakers.

Campbell asked Castillo for advice on some of the finer points of hip-hop dancing. "What's the difference between shaking it like a salt shaker and shaking it like a Polaroid picture?" she asked referring to lyrics from popular songs.

Castillo offered a pact: "If you teach me how to sing, I'll teach you every dance I know."

As the light outside their window faded, they mused about their schedules and possible majors. "What *is* anthropology?" Campbell asked, holding up her freshly purchased text.

About 9 p.m., the roommates headed to [Wal-Mart](#) to stock up on some essentials: Pop-Tarts, ramen, cleaning supplies. On the way, Castillo made a quick stop at home. She wanted to make sure Anthony was in bed and see whether her mom was all right.

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