



CARING FOR CAREGIVERS

Connie Siskowski is attracting national attention with her Boca-based program that takes care of children who are caregivers themselves.

BY JENNIFER TORMO
PHOTOGRAPHY BY GINA FONTANA

At age 13, Connie Siskowski lost a part of her childhood forever.

It was 2 a.m. when the young Siskowski woke up to give her grandfather his medication. With busy, working family members, since age 11 Siskowski had been caregiver for her grandfather, who was dying of arteriosclerosis with congestive heart failure. Daily, she bathed him, fed him and set alarms to remind her of the exact time he needed his medication.

And at 2 a.m. that night, she was the one to find him dead.

Fifty-three years later, that moment still sticks with Siskowski. So much so that the 66-year-old former nurse now dedicates her time to helping children with a childhood similar to her own. Her non-profit, the American Association of Caregiving Youth, caught the attention of CNN, which named the Boca resident one of its Top 10 Heroes of 2012. The hero campaign credits the petite, soft-spoken blonde for the more than 600 young lives she has influenced with her program since 2006.

The population of caregiving youths is hidden – many people don't want to believe it exists, Siskowski says. But it does. In fact, more than 25 percent of all Palm Beach County public school students, grades six to 12, have an education adversely affected

by caregiving duties, according to a 2003 survey. There's a certain level of shame attached to Alzheimer's and mental illnesses, she says, and sometimes the children themselves don't even want to admit what's happening at home.

"We're all raised to believe adults should be taking care of children, not that children should be taking care of adults or other people," she says. "Not everybody believes it's in their backyard, but it is."

AACY's Caregiving Youth Project taps into that hidden population in eight middle schools across the county. Students who qualify for the program receive tutoring, counseling and support services, and are invited to attend weekend camping trips. "Instead of worrying about taking care of someone else, we take care of them," she says.

So instead of changing diapers and giving medical injections to their care receivers, the youths spend the weekend trips playing basketball and baseball, and singing and toasting s'mores by campfires. They connect with kids who have similar problems. Most importantly, they aren't allowed to do the dishes or cook. The children are kept busy and their cell phones are taken away, so they won't be constantly worrying and checking on their care

receiver. Arrangements are made for their care receiver while the children are away.

There's a wall in Siskowski's office that is painted with the dreams of children who might once have believed they weren't allowed to have their own dreams. A framed image depicts colorful handprints of middle schoolers in the program. Under each handprint, there is a quote from the students about what they want to be or do when they grow up. One says, "I want to be a writer." Another says, "I want to go to Vegas!"

Some students vow to give up on school if they lose their loved one, but AACY shows them that other students have survived the worst and have still graduated and gone on to college. "There's life beyond caregiving," she says. "It can't consume them."

The program, which begins in sixth grade and aims to take students through their senior year of high school, also teaches life lessons. Siskowski met a young girl who cared for her brother with disabilities. The girl had a friend who liked to make fun of her brother. Siskowski encouraged her to ask: is that person really my friend? "My hope is that when they learn these things they'll take them into adulthood," she says.

For all the work Siskowski has already done for these children, she shies away from praise. "It's really the kids who are the heroes," she says.

As for her, the organization has helped her to cope with the moment that's traumatized her since age 13. She reflects and wonders if she could go back in time, what words she might use to comfort the girl who found the grandfather she loved so much lifeless in the middle of the night. She explains, "One thing that our kids face is that they wonder if it's your fault," she pauses for a minute, before she tearfully chokes out the advice she'd give her younger self, "I'd tell her that it wasn't your fault."

And every day, her organization teaches an important lesson to the children burdened by a loved one's health condition: that none of it is their fault. ■

Support AACY this month:

What: Hearts & Soles annual fundraiser, presenting a day in the life of a caregiving youth over dinner, cocktails and a silent auction

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