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Message for dementia caregivers: You're not alone

By Tomeka Norton-Brown Special to the Floridan Nov 22, 2019



As a young girl, I never imagined I would become a caregiver for my aunt with dementia. Although at times it was difficult and stressful, now looking back I wouldn't change anything. It has made me who I am today.

Caregivers are some of the strongest people I know. They're dedicated, reliable and selfless. In my line of work, we also know that selflessness — though admirable — can be harmful to your health.

So here in National Family Caregivers Month, we have a two-part message for family caregivers — specifically for African Americans who are caring for a loved one with dementia and are having difficulties coping with the stress. Our message: God bless you for the work you're doing — and please remember that, if you're starting to feel overwhelmed, we're here to help and honor you.

I'm the coordinator of a project called ACTS 2 — shorthand for African-American Alzheimer's Caregiver Training and Support. The project, based in the FSU College of Medicine, offers a range of options for caregivers, all of them free. Our 12-session course provides skills training to handle the challenges of caring for someone with dementia. If you need something more immediate, we can talk with you right away and, if appropriate, refer you to resources to address your specific needs.

We've been doing this more than 12 years. ACTS 2 has expanded to 50 of Florida's 67 counties. Caregivers receive relaxation exercises integrated with prayer and meditation; get guided practice in using assertive communication with family members and health professionals; develop problem-solving skills through setting personal goals; build a social support network; and more.

“The telephone counseling sessions led by a trained faith community worker were conveniently conducted around my busy schedule and focused on dealing with difficult behaviors,” reads one testimonial on our website. “This helped me to keep close to and respect the dignity of my dear mother. ACTS 2 was truly a blessing!”

That caregiver is Tallahassee resident ViElla Lindsey. She cared for her mother, Lillian Balloon, from 2012 to 2016. Like many others, she struggled to balance the demands of caregiving with the demands of everyday life — including a full-time job, two sons in school and heavy involvement in her faith community.

“I was putting my mom in day care,” ViElla said. “I would drop her off each morning, make sure the boys got off to school, then come in to work. In the afternoon I'd reverse the routine. When we got home, there was cooking to do plus homework with the kids. And my mom had other demands on top of all of that. She had started sundowning” — a term for late-day confusion and agitation that some people with Alzheimer's experience.

“She would have these displays of really aggressive behavior. Sometimes it would scare the kids. That’s when I looked into respite care, to give ourselves a break. When I saw how well respite care worked, that’s when I considered getting some help from assisted living.”

But ViElla was feeling guilty that she couldn’t handle her mom on her own. At an AME Women’s Missionary Society symposium, she heard about ACTS 2. Then she decided to reach out.

“Right away, ACTS 2 helped me understand it’s OK to ask for help,” ViElla said. “They told me, ‘You’re not a failure.’ Also, they gave me the tools to deal with my mom’s behaviors. Whenever I meet people who have a loved one dealing with the same disease, I recommend ACTS 2.

“I let them know that they are not alone. Just don’t be afraid to ask for help, even if it’s just giving you an hour break to run to the store or take a walk. Take time to take care of yourself. Otherwise, you’re not going to be able to take care of your loved ones.”

It’s good advice. I know. I was a caregiver, too.

Tomeka Norton-Brown is project coordinator for ACTS 2. It partners with REACH (Resources & Education for Aging, Community, and Health), which is funded by the Geriatrics Workforce Enhancement Program. Find out more at acts2project.org or call toll-free at 1-866-778-2724 (Tallahassee local 850-274-4945).