Tallahassee Democrat.

HEALTH

Keep it simple, safe when caring for loved ones with dementia during holidays

Melissa Powell FSU Communications

Published 12:10 p.m. ET Dec. 21, 2020 | Updated 8:44 a.m. ET Dec. 22, 2020

Upcoming holidays and celebrations are a point of stress for many this year. As a chaotic 2020 comes to a close, COVID-19 cases are on the rise again and families struggle to plan for the holidays. Some envision a celebration over Zoom.

For caregivers of loved ones with dementia, holidays can often bring on additional confusion and anxiety.

ACTS 2 coordinators and past participants want to remind caregivers that the 2020 holidays can still be meaningful, calm and enjoyable for loved ones with dementia, their family care partners, and extended families. ACTS 2 – shorthand for African-American Alzheimer's Caregiver Training and Support Project 2 – offers free, faith-based, skills-training and support for caregivers and is housed at the Florida State University College of Medicine.

Overwhelmed caregivers can ease holiday stress by making small adjustments to holiday activities and traditions, having open communication among family members and care partners, and remembering to appreciate the small things, says ACTS participant and former caregiver, Brenda Frinks.

"Whether it's biological family, church members, your care team, even paid staff who might be assisting you, communication is key in being successful," said Frinks, who was a caregiver for both her cousin and mother for many years. "It's especially important when planning in advance how you're going to handle visitation during COVID-19. Health care leaders emphasize not having family visitations the way that we had them before the pandemic. So how can you do that? How can you still make the holidays special for your loved one with dementia and family members?"

Talking to family and preparing them for in-person or virtual visitation can make loved ones with dementia more comfortable. During her time as a caregiver for her aunt with dementia,

ACTS 2 Project Coordinator Tomeka Norton-Brown learned which small adjustments would make the biggest differences.

"One of the things I noticed is that when people see their grandma, aunt, uncle, whomever it is, for the first time in a while, their first instinct is to go in for a hug. Most people approach them from the front to give a hug, not realizing how scary that can be for someone who has Alzheimer's or dementia," she said. "Loved ones with dementia may not recognize family members and may require a reminder. So, I had to let people know up front, don't go in for a hug because that kind of sets Auntie off, and tell the kids not to run at her at the same time. She'd be fine with a pat on the shoulder, maybe a hug from the side, whatever it might be."

Frinks and ACTS 2 Project staff also suggest briefing family members on specific behaviors or tendencies and how to handle those if gathering via Zoom, as well as other ways to make a safe and calm space for the holidays.

"Keeping routines for your loved one is so important. If they eat early, try to keep them eating early even though you might want to have dinner a little later. You can even make Zoom and social distancing a routine thing by saying 'let's look at Aunt Alice on the computer,' or 'let's open this gift in front of cousin whomever," said Frinks.

"And also, they might know it's the holidays, but some of the things that go along with the holidays can be very disruptive. For example, bright flashing lights from a camera or smartphone can be a trigger for people with dementia. Another thing to consider is not putting out fake fruits because then you have to explain why you shouldn't eat the false fruit versus real fruit," Frinks said.

They also suggest having fewer decorations, avoiding safety hazards like burning candles, and playing favorite holiday music at a relaxing level to help keep your holiday's space familiar, comfortable and safe for loved ones with dementia.

Frank Jenkins Sr., ACTS 2 Project advisory board member and pastor, urges caregivers to remember to take care of themselves as well as to reach out for help whenever needed.

"Don't overexert yourself trying to take care of your loved ones or your friends. Accept the help that's available with not only programs like ACTS 2, but other support services that are available and don't try to go it alone," he said. "Recruit other family members and friends to help you because, as the word teaches us as pastors, if we don't take care of ourselves, then certainly we can't take care of our loved ones, especially elders with dementia."

Norton-Brown echoes his sentiment.

"My suggestion to family caregivers is to just take a deep breath and know that you're doing the best you can under difficult circumstances. Try not to get hung up on thinking that everything needs to be perfect or needs to happen in a specific way," she said. "It's not about making sure all gifts are wrapped on time or the tree is put up just right. At the end of the day, that's not the stuff people remember. They remember the time you actually spent with them."

The ACTS 2 Project partners with several organizations including Black faith denominations across Florida, REACH (Resources & Education for Aging, Community, and Health), and Florida Dept. of Elder Affairs-sponsored Memory Disorder Clinics, Dementia Care and Cure Initiate Task Forces and Area Agencies on Aging. Caregivers receive relaxation exercises integrated with calming prayer and meditation; get guided practice in using assertive communication with family members and health professionals; develop problem-solving skills through setting personal goals and more.

For additional information, call toll-free at 1-866-778-2724 (Tallahassee local 850-274-4945) or go to ACTS2Project.org To support ACTS 2 through donations, click https://www.acts2project.org/Donate.html.

Never miss a story: Subscribe to the Tallahassee Democrat using the link at the top of the page.