

# Stay Healthy

## WHAT IT'S LIKE TO BE AN ALZHEIMER'S CAREGIVER

For every one of the 5.5 million U.S. adults who have Alzheimer's disease or another form of cognitive decline, there's a person working tirelessly to care for them. We asked three caregivers to share their stories. **By Marygrace Taylor**

### DAN GASBY: LEARN TO LIVE WITH UNPREDICTABILITY

"I could look across the room and read her eyes and her body language without seeing her mouth move."

That's the way 64-year-old Gasby describes his relationship with his wife, the restaurateur and former model B. Smith, before she was diagnosed with early-onset Alzheimer's five years ago at age 63.

Now Gasby gets up early in their East Hampton, N.Y., home to have some quiet time and plan out the logistics of their day. Sometimes he can help Smith bathe, get dressed and eat breakfast in 45 minutes. Other days, it might take twice that long. The woman he could once read like a book has become unpredictable. "Every day, I know I'm going to go through a range of emotions, from her hating me and calling me names to her thanking me for being there," he says.

Though Gasby will sometimes lose his patience—and later will feel terribly guilty—he keeps on doing the best

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Dan Gasby and B. Smith

he can. Smith is still the woman that he loves, he says, "and I know if it was in reverse, she would do the same thing."

### ROSITA PEREZ: SOMETIMES YOU'LL FEEL LIKE A FAILURE (BUT YOU'RE NOT!)

Learning how to be a caregiver for her mother, Isabel, wasn't easy. "I had to tread lightly," says Perez, who was in her early 20s when her mom was diagnosed with Alzheimer's in 2003 at age 60. When Isabel grew fearful of water, Perez, who lives in Paulsboro, N.J., put a playful spin on bath time. "I'd tell her we had to get dolled up to go out."

Isabel eventually moved in with her daughter, then came to the orthotics lab Perez manages, with the company's permission. When Perez finally had to put her in a nursing home, "I felt like I had failed," she says.

Perez eventually found invaluable support through the Alzheimer's Association 24/7 Helpline, and she knew she had to pay that gift forward. Even though her mother died in 2016, Perez continues to speak on behalf of the association. "The most important thing is just to be available for caregivers," she says. "Come over so they can go out and grab a bite to eat. Little things like that mean a lot."

### JANICE JONES\*: GETTING SUPPORT CHANGES EVERYTHING

When Jones' husband, John, was diagnosed with Lewy body dementia (a form of dementia accompanied by symptoms of Parkinson's disease) in 2013, she worried about whether she'd be able to care for him. So she started researching as much as she could and joined an online support group for spouses. Now she has the tools to diffuse difficult situations, like when John, 73, has an angry outburst.

### How can I prevent caregiver burnout?

**A.** Caring for someone with Alzheimer's is highly stressful. To make life more comfortable for you and your loved one, build more structure into your days and let go of some of your expectations. A schedule that doesn't change much from day to day tends to make people with Alzheimer's less agitated. Plan meals, errands and bedtimes for the same times, and do tasks in the same order. Resist the urge to correct a loved one who keeps forgetting what day it is or how to work the TV. It's less stressful for them (and you) if you let them make mistakes, or deflect the conversation to a different topic. If you're feeling burned out (and even if you're not), it's important to ask for help and take time for yourself.

—Cleveland Clinic neurologist Jagan Pillai, M.D.

"I'll immediately stop what I'm doing and redirect him. He likes to play Yahtzee or Phase 10 together, or I'll tell him about a good memory," she says. When she's stressed, she texts her daughter or son, who will reply right away with something to make her laugh.

Jones, 71, doesn't deny that caring for her husband can be exhausting. And even though LBD has changed their relationship, not every change has been for the worse. "At first he wasn't appreciative of what I did. He was angry he couldn't do it himself," she says. "Now he expresses how much he appreciates our lives together. There's a softer side to him that I never knew before."

\*Name has been changed for privacy