



DEMENTIA DEFENSIVE

This is an occasional column about the effects of dementia on sufferers, their families and how to preserve your brain health.

Support for weary caregivers

Groups understand the challenges of Alzheimer's

Tony Dearing

tdearing@njadvancemedia.com

It can be the toughest work ever.

The hours? Forty or more hours a week is common; sometimes it's 24/7.

The pay? There isn't any.

The working conditions? So grueling that your physical health and emotional well-being are likely to suffer.

Such are the demands of caring for a family member with Alzheimer's disease, a role nearly one-third of adults in New Jersey have found themselves thrust into, according to a new survey.

"Nobody my age plans for what I'm facing," says Donna, who lost both her grandmother and father to dementia, and whose husband was diagnosed with early-onset Alzheimer's in 2014.

"If you had told me I was going to be dealing with this, I'd be crying," she says. "And you do have your tears, but you learn how to manage it. It changes who you are, but you have no choice."

Donna was one of six caregivers who gathered at the headquarters of Alzheimer's New Jersey in Denville last month to talk about the relentless demands of what they do, and the crucial role that support groups play in helping them cope.

"We have so many people we talk to

about going to a support group, and the immediate reaction is, 'I have too many

SEE DEARING, 32

problems of my own; why do I want to hear someone else's problems?" says Kenneth Zaentz, president and CEO of Alzheimer's NJ.

But those who try a support group find many reasons to stay.

"It's isolating and you're with people who understand and get it," Zaentz says. "It's the education. It's the ability to connect with other people. It's sharing your story and having people understand. And it's the friendships. Many years ago, a caregiver said to me, 'I didn't need my husband to get Alzheimer's to make some of the best friends I've ever had, but it's what happened.'"

That sense of camaraderie was evident as the caregivers spoke candidly about the hard realities of dealing with Alzheimer's. Their full names are not being used to respect their privacy.

Judy says she's been a caregiver for what "seems like my whole life." She cared of her mother, who had Alzheimer's, for four years. Then her son was diagnosed with a brain tumor, and she cared for him for 17 years until his death. Now her husband has Alzheimer's and she's a caregiver yet again.

"When my son passed away, I felt I couldn't go to a support group," she says. "I felt I didn't want to hear anyone else's troubles; I've got enough of my own. It was a very poor decision. When my husband got Alzheimer's, I had the opportunity to join a support group, and I'm so glad I did. It made a huge difference."

Caring for a loved one



with Alzheimer's is an all-too-common role for New Jerseyans. A survey conducted by Farleigh Dickinson University's PublicMind for Alzheimer's NJ found that 29 percent of respondents are either caring for someone with dementia or have in the past. And it cuts across all ages. While the majority of caregivers are older, 16 percent of people between the ages of 18 and 34 said they've provided care to someone with dementia.

More than one-fourth of caregivers said they devote 40-plus hours a week to those responsibilities. And 65 percent said their finances have been impacted by having a spouse or parent who needs their care.

Yet the toll is much more than financial, with 85 percent agreeing that caring for someone with Alzheimer's has impacted their emotional well-being, and 60 percent saying it's affected their physical health.

Judy says her husband was a capable professional who worked as an advertising vice president, but now his short-term memory is "all but gone."

"I have to take care of everything he used to do," she says. "There's no good end to all of this. Sometimes, I get so frustrated I scream at him. The only saving grace is that he doesn't remember I was screaming at him. I do the best I can for him."

Martin, whose wife was diagnosed with Alzheimer's more than five years ago, says the obligations of caregiving can be relentless.

"As she got worse, I started to feel more trapped," he

says. "I was afraid to take a shower. Where was she going to go while I was showering? I had to make sure I didn't fall into a deep depression, which I felt I was going toward. I knew that if I became depressed, I wouldn't be able to take care of either one of us."

Martin had no reluctance to seek out a support group. "I knew I needed it," he says. "I felt lost. I knew I needed to learn in order to handle the situation, especially to see your loved one deteriorate gradually."

Dawn, who gave up a career in the entertainment industry in Los Angeles to care for her mother, had no qualms about seeking help either.

"I knew quickly I needed the support group," she says. "All off the important information I need, I get from the support group. The doctors are almost useless. I've taught the doctors more than they've taught me."

Dawn's mother was diagnosed with Alzheimer's in 2004, and her father was providing care, but he was ill as well and struggling with that. When her mother wandered away from the house and ended up knocking on the door of a stranger's home 3 miles away, Diane knew what she had to do.

"I loved being in LA, and I could either stay out there and make myself happy, or come home and take care of my mom," she says. "I couldn't live with myself if I didn't do something. Some tragedy was sure to happen. I thought, I'll take six months and get things organized and everything will be fine. That was four years

ago."

She says as dementia progresses, new issues continually arise. For example, how do you handle incontinence?

"Where do you get the diapers? What are the best products?" Diane says "There's very little on the internet about that. At the support group, you get really good practical information."

Mary Ann, whose husband was diagnosed in 2008, says she learned much from others in her support group, and now she's able to return the favor.

"When new people come, it makes me feel good if I can share something that helps them," she says. "They look like a deer in the headlights. They don't know where to turn; they don't even know what questions to ask sometimes. They kind of calm giver. In one of the more striking results from the survey, 72 percent said issues around caregiving have strained family relations."

Most of the caregivers I spoke to for this story have felt that rift. It's often tension involving family members who are not willing to share in the responsibilities of caregiving. One got a knowing laugh from the group when she described what it's like to be an "only child with siblings."

"I really, really feel there's a difference," Judy says. "I believe in my heart that daughters do much more than sons."

"There was a time when I was resentful my brothers didn't do what I thought was their fair share of taking care of my dad," Donna adds. "I think they felt like I didn't have children, so it was fair, and it was my job to do it."

But she says “that happens to everyone,” and talking it through with other members of the support group helped.

“You have two choices,” Donna says. “You either alienate the family and be resentful, or you accept it. They didn’t do what they were supposed to do, but that’s their issue, not yours, and you let it go.”

That stoicism was evident in all of the caregivers I talked to. In the face of unimaginable hardships, they have found an ability to cope that surprises even them.

“I’m shocked by how much I can deal with,” says Dawn. “I just keep going. There’s this resilience that develops.”

One strategy they’ve all learned is to live in the present, and deal with what’s in front of them right now, rather than dwelling on the awfulness of what may be yet to come.

“You don’t look too far ahead,” Martin says. “I take care of my wife now, this week. Next week, I’ll worry about next week. If that next week goes on for 10 years, it’ll only be one week at a time.”

And hard though it is, they find a grace and a purpose in the care they give to the one they love.

“Emotionally, you can’t live mourning someone every day,” Donna says. “You have to find the blessing in the day, and the blessing in him, and every time he laughs or smiles, I feel accomplished. I know what the future is going to be. I can’t plan for that. I have to find something to celebrate

each day.”

Donna says she also draws strength and comfort from those in her support group who lost their spouse or parent years ago, yet come to the meetings to support those still in the midst of their struggle.

“You see people who have been through it to the end and beyond, and they’re laughing, and they’re happy,” she says. “They still love the one who is gone and they will never forget them, but they are living their life and they look healthy. It gives you hope that there is still happiness out there.”

*Tony Dearing, NJ
Advance Media, tdearing*

down. They see there are people who’ve been there, done that.”

Yet even with that support and understanding, the burdens of caregiving are never-ending and it’s often one person who carries most of the load.

Dawn’s mother was recently hospitalized for two days, and Dawn was at her bedside the entire time.

“The social worker told me, ‘Talk to your family and friends and get them involved in caregiving,’” Diane says. “Where are they getting this stuff? Are you kidding me? I couldn’t get the hospital to watch my mom for a minute so I could go to the bathroom and get something to eat.”

According to the Fairleigh Dickinson study, 53 percent of the caregivers who responded said they have the help of one or two people, but 16 percent described themselves as the sole care-

**“I have to
take care of
everything...
sometimes,
I get so
frustrated
I scream at
him. The only
saving grace is
that he doesn’t
remember I
was screaming
at him.”**

*Judy, on taking care of
her husband who suffers
from Alzheimer’s*

Supporting caregivers

Alzheimer’s NJ offers more than 50 support groups in 13 counties.

- › Support groups are free and open to the community, and offer emotional support and education about Alzheimer’s and dementia.
- › Support groups are intended for families and friends, and are not recommended for people with dementia.

Call 973-586-4300 or email programs@alznj.org.