

The Caregiver's Perspective

By BECKY URBANSKI, EdD and DIANE C. VAUGHN, RN, C-DONA/LTC, NHA

On a late summer's morning, the 19 residents of the Villa memory care neighborhood at Benedictine Health Center at Innsbruck, in New Brighton, Minn., are gathering for brunch. Among them are a former music teacher, beautifully dressed and her hair perfectly done; a retired Catholic priest in a black beret and quick with a smile; and a resident clad in a purple Vikings jersey, ready to cheer on the home team. Classical music is playing in the background. The four staff caregivers, along with a volunteer and a family member, are assisting with the food, quietly encouraging the residents to eat and, in some cases, to hold the spoons of cooked cereal. It takes more than an hour for the meal to be over. The Villa staff move quickly and efficiently to take care of each resident and get him or her ready for the next scheduled activity.

Memory care residents have some degree of dementia, an irreversible, progressive brain disease that causes memory impairments, word-finding challenges and inability to perform normal tasks such as dressing and grooming. Personality changes can occur. It also can be associated with unpredictable behavior and agitation. The most difficult moment may be when the person with dementia no longer recognizes family and friends.

There are several types of dementia: Alzheimer's, frontotemporal, Lewy body, vascular and mixed. The first case of Alzheimer's disease was documented in 1906 by Dr. Alois Alzheimer. He identified brain plaques and tangles, along with the loss of connections between neurons.

Ninety percent of those with Alzheimer's and related disorders show their first symptoms after age 60, although there are rare cases in which people develop symptoms in their 30s, 40s or 50s. A significant number of peo-

ple with Down Syndrome also develop dementia in their 50s.

Toyi Smythe, a certified nursing assistant, and Abel Whern, a licensed practical nurse, are two of the caregivers who work in the Villa neighborhood. Both have years of experience in long-term care and, specifically, in a memory care unit.

Smythe found caring for older adults to be her calling at age 13, when she took care of her grandmother in Liberia. Whern, also from Liberia, is quick to say being a caregiver is a passion.

"I put myself in their [the resident's] situation,

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because it might be me in the same position someday," he explains. "I know there is a medical reason for the cause of a certain behavior and try to approach it in a positive way. I do what I would want if it was me."

Both staff members say they love what they do, but agree there is a challenge in taking care of individuals who sometimes can't communicate what they want or need. Every day is a little journey.

"Some days are good, some are 50-50," says Smythe. "It depends on the mood of the resident."

Whern adds, "We try to take a positive approach each day and take care to give the best care each day."

Staff members are trained caregivers, and they continue to receive advanced training for working with individuals who have memory care needs. Teamwork with other members of the staff — and with families — is important. Part of what the

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caregivers undertake could be described as detective work.

"All of our residents have a unique history. We try to have them recollect memories from their lives to integrate into their care," says Smythe. "We have lots of strategies to use."

Strategies are important in memory care, especially when an Alzheimer's or dementia patient finds it difficult or impossible to communicate

WHAT MAKES A GOOD CAREGIVER FOR PEOPLE WITH MEMORY ISSUES?

Taking care of individuals with dementia is not for everyone. Diane Vaughn, RN, vice president, clinical services at Benedictine Health System, admires staff members who provide daily care for individuals with dementia. Compassion, caring, patience and flexibility are a must, she says.

The best staff for memory-care neighborhoods are those who understand the disease, who have a natural ease with residents and can live in their world, say Susan Ager, LNHA, administrator/CEO, and Colleen James, RN, BSN, director of nursing, at Benedictine Health Center at Innsbruck. The main reason families choose a secure memory care facility for a loved one is fear the individual will wander away from home. An Alzheimer's or dementia patient can lose track of time and place, and many are easily agitated

or made anxious. Skilled and trained staff who possess a real purpose for serving this population help create a calm environment, a structured program and a sense of sameness.

"We provide advanced training for our staff on an ongoing basis using the most up-to-date information and knowledge in the field," Ager says.

Whether it is a natural talent or it is based on experience, the ability to read people is a particular gift in caregiving work, Ager says. A successful caregiver sees the value in each person and tries to look past the disease to recognize the real person within. These skills can help develop special bonds that make all the difference in working with memory care residents, she says.

"It is an ongoing challenge, how to give care while connecting with the per-

son," Ager says. "We are always teaching about approaches and [how] to tailor the approach to need."

"Staff members who serve in memory care units have to have the right energy, the right vibe," says James. "You can't be negative or hyper. It takes lots of patience and lots of love. It is both a gift and a calling to serve in this capacity, and it is not for everyone."

Having enough caregivers in the near future is a growing issue, Vaughn says. According to the Centers for Disease Control and Prevention, the number of persons over age 65 will grow by 102 percent between 2015-2030, but the workforce will grow by only 8 percent during that same period. Finding enough compassionate caregivers will be challenging, she says.

and reacts in an angry or negative way. For example, Smythe says, she has found that some residents become more responsive to requests — or more accepting when she redirects their behavior — when she sings a familiar song.

And at times, Whern and Smythe say, they have to walk away when a resident is refusing an activity, or they may ask a colleague to take over, which sometimes works. The point is not to take a negative behavior personally.

If a resident isn't able to communicate, caregivers try to learn about his or her life from family members and apply the information to their work.

"We try to have them do things that they used to do before they moved here," Smythe says. For example, on behalf of the former music teacher, "a piano was moved into the dining room, and the resident now plays it regularly," she says.

Ruby Bartlett is the wellness coordinator for the Villa neighborhood. A former preschool and kindergarten teacher, Bartlett plans activities for the residents tailored to each person's cognitive abilities. She observes and talks with each resident and often with the family members to try to best customize activities.

"Not everyone can do this work," she says. "You have to be able to ignore a lot of things that happen — hallucinations, hurtful words and behavior. A person has to be able to handle the bodily fluids. You need to have endless patience and be able to be clear and give short, explicit direction."

"It is also good to be able to go with the flow," she adds. "A caregiver must be able to change the plan midstream depending on what is going on. And it is that way all day long."

The Villa neighborhood is in many ways a big family, and all three caregivers recognize that they are spending what often turns out to be a resident's last months. June 2014 was a particularly difficult time, as it brought four deaths.

"It is hard to see them go, but then I remember and look back at their lives with us, and all the fun, and I hope I was able to give them a little dignity," says Smythe.

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RESOURCES

As the U.S. population ages, Alzheimer's disease and related disorders are considered a national issue and priority. On January 4, 2011, The National Alzheimer's Project Act (NAPA) was signed into law. Administered by the U.S. Department of Health and Human Services, the NAPA plan is to:

- Create and maintain an integrated national plan to overcome Alzheimer's disease
- Coordinate Alzheimer's disease research and services across all federal agencies
- Accelerate the development of treatments that would prevent, halt or reverse the course of Alzheimer's disease
- Improve early diagnosis and coordination of care and treatment of Alzheimer's disease
- Improve outcomes for ethnic and racial minority populations that are at higher risk for Alzheimer's disease
- Coordinate with international bodies to fight Alzheimer's globally
- Establish the Advisory Council on Alzheimer's Research, Care and Services

For updates about the NAPA plan, see aspe.hhs.gov/daltcp/napa/NatlPlan2014.shtml.

OTHER INFORMATIVE SITES

Alzheimer's Association, www.alz.org.

Alzheimer's Foundation of America, www.alzfdn.org.

The National Library of Medicine, www.nlm.nih.gov.

Mayo Clinic, www.mayoclinic.org.

WebMD Alzheimer's Disease Health Center, www.webMD.com/alzheimers.

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