

# Nonmedical Caregivers: A Growing Asset in Alzheimer's Care Communities

Georgene Lahm

**M**any care community administrators understand this sad fact all too well: oftentimes it is impossible to know what is going through the mind of a senior with Alzheimer's disease or another dementia illness. That's why residents with such conditions can be among a care community's most daunting challenges. These older adults are lost in time; their behaviors are not only difficult to manage, but hard to explain.

Like many other care community administrators, Chris Blackerby, Executive Director of the Chateau Vestavia, an independent and assisted living community in Birmingham, AL, has witnessed the baffling effects of Alzheimer's and other dementia diseases on the minds and bodies of many seniors. Two past cases, in particular, remain a constant reminder. First, there was the man who disrobed every afternoon. "No matter where he was, his pants would come off at 4 o'clock," Blackerby said. Then there was the woman who, each night, got all dolled up in her best dress, hat, and gloves, and headed to the front door. When she couldn't get out, she became agitated and upset.

Blackerby and his staff were unable to explain these unusual behaviors, and the seniors acting out these daily habits were unable to articulate why. However, the non-medical caregivers who had served both of these individuals knew exactly what was happening.



"The man's nonmedical caregiver told us that the resident had been a farmer, and every afternoon at 4 p.m., he would come in from the mid-afternoon heat, take off his pants, and relax." The woman's story was also explained by her former nonmedical caregiver. "All of her life, she's dressed up early in the evening and left her house to go dancing," the caregiver told Blackerby.

When Blackerby and his staff discovered the motivation for their residents' unseemly activities, it was easy to help. "We just made sure the former farmer was in his room every day by 4 p.m.," Blackerby said. "And our staff used redirecting techniques with the woman who

wanted to go dancing. They told her she was already at the dance." Both solutions worked well to calm these residents.

## **Caregivers Support Transitions and Transportation Needs**

The nonmedical caregiver/companion is not a new phenomenon in care communities. With the growing numbers of older adults with Alzheimer's disease, this option is an increasing trend that families across the country are utilizing to supplement the care by staff in the communities where their loved ones live. Care community administrators interviewed consistently reported that between 20% and 30%

of their residents have a dementia illness, such as Alzheimer's.

Nationally, the numbers are staggering. Up to 4.5 million Americans have Alzheimer's disease, and that number could triple over the next 30 years, according to The George G. Glenner Alzheimer's Family Centers®, Inc., in San Diego, CA. The centers were founded by Joy Glenner and her late husband, George, a pathologist who was the first to discover a cause for Alzheimer's disease.

Maintaining independent environments for Alzheimer's residents as the disease progresses can be a daunting goal for care communities. Yet some administrators have found that nonmedical caregivers, like those Chris Blackerby consulted to explain his residents' behaviors, not only help seniors live calmer and happier lives, but they can keep them independent longer by protecting them from the dangerous side effects of the disease, such as wandering.

The benefit of a nonmedical caregiver most often mentioned in interviews with care community administrators was in transitioning the resident between stages of the disease or into the care community, as was the case with the Blackerby examples. Helping with transportation needs was another popular service mentioned. For these reasons, more care community administrators are recommending that families consider nonmedical caregivers, especially for transition periods. Care communities that have seen the benefits of these caregivers often have several preferred provider companies that they recommend to families when they want additional help for their loved ones. Independent and assisted living communities are among the most common to recommend these services for their residents.

### **Peace of Mind**

"The mean age coming into a care community used to be 80, and now

it's between 84 and 90," said Nancy Verlinde-Meyer, Community Services Representative for Harbour Village, an independent assisted living (AL) facility and dementia AL community in Greendale, WI. "It's a whole different ball game. Non-medical caregivers have always been around, but I'm seeing more of them here because people are staying longer in their homes before they come to the care community. The dementia is more evident. A nonmedical caregiver who begins caring for a senior in their home can help make the determination that they're no longer safe in their environment," she added.

Likewise, a nonmedical caregiver can be an additional measure of

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security for the family, knowing that this person close to mom or dad will be an extra pair of eyes and ears in the care community. "Sometimes, it's more for the families than the residents. The adult son or daughter might be feeling some guilt or remorse about their loved one living in a care community. And it helps them to know that mom can bring along her favorite companion to assist in the transition," said Blackerby.

"Where I tend to refer a family to a nonmedical caregiver is for transportation. We provide transportation to places like doctor's offices, but we can't accompany sen-

iors inside," Blackerby remarked. "We can't trust that a resident with Alzheimer's disease will get to the doctor's office safely. The other issue is that they get in the doctor's office, and later the daughter calls and asks what the doctor said. Residents with dementia might not know, and that can increase the stress on families."

Lucy Seger knows all too well the worry that can plague families when a loved one has Alzheimer's disease. Her late mother had Alzheimer's disease for 15 years while Lucy and her family struggled to figure out what to do. "At the time, we couldn't find any options to keep her independent," Seger said. In 1999, she learned about Home Instead Senior Care® and decided to start her own business in Pittsburgh, PA. Home Instead Senior Care is the world's largest provider of nonmedical CAREGivers<sup>sm</sup> to seniors, with more than 650 franchise offices in the United States and 9 countries.

"I was trying to find a solution not only for other seniors and their families, but also my own," Seger said. Today she is regarded as an expert in her community on the benefits of nonmedical caregivers not only in the home, but the care community as well.

### **Wandering and Other Safety Issues**

A tendency to wander is among the most common and potentially dangerous side effects of Alzheimer's disease. "A senior could call a cab and elope down the street without the regular supervision of a non-medical caregiver," said Christina Martinez, Director of Community Relations for Sunrise Senior Living of Fair Oaks, CA.

"Nonmedical caregivers help ensure the safety of our residents so they can continue to enjoy an independent environment," Martinez said. About 70% of Sunrise's residents are in AL while 30% occupy a memory care neighborhood, which

is a secure community. “Residents have the right to leave, but someone with memory loss can’t always make the right decision,” Martinez stated. “One-on-one companionship can acclimate these residents to their surroundings, provide assistance with activities of daily living, and help them develop a routine. All of that can put a family’s mind at ease.”

As most senior care professionals know, change can be difficult for the Alzheimer’s resident. “A resident who had just entered the community was confused and upset,” Martinez recalled. “A nonmedical caregiver spent time with her, empathizing with and validating her feelings until she was able to make a successful transition.”

Nonmedical caregivers are often hired for residents who are not yet

ready for a memory care neighborhood. “The family might even hire a caregiver for 2 to 3 weeks to help acclimate the resident to a new environment or if the senior is switching medications,” said Martinez, whose care community has worked with 10 different non-medical caregiving companies.

Buck Shaw, who owns 3 Home Instead Senior Care facilities in the Sacramento, CA area, acknowledges that nonmedical caregivers who accompany seniors to care communities to assist in the transition provide a crucial service. “Hiring a nonmedical caregiver allows a person to develop a trust and rapport with someone, and that’s so crucial with Alzheimer’s and dementia residents,” said Shaw. “Those with Alzheimer’s disease have lost the ability to remember and learn, and

tend to operate on feelings more than anything else. Even if a resident doesn’t remember the caregiver, he or she will feel a rapport, and over time that will result in a much calmer senior,” he added.

### **The Value of Caregiver Training**

Caregiver training also is extremely important. Thirty-five of Shaw’s CAREGivers have completed Home Instead Senior Care’s specialized Alzheimer’s training program, which was developed in collaboration with The George G. Glenner Alzheimer’s Family Centers. The first of its kind for nonmedical caregivers, the program is available to Home Instead CAREGivers throughout the country. It provides CAREGivers hands-on experience in dealing with clients who have

## **A CASE STUDY: The Role of Nonmedical Caregivers in Ursula’s Life**

Ursula Bruns came to the United States in 1937 to join her husband who had arrived a year earlier to obtain his medical license and begin practicing medicine. Together, the couple raised 2 boys and Ursula, a trained pharmacist in Germany, worked as the office manager in her husband’s practice for 20 years. “Throughout her life, she’s loved music, gardening, and painting,” said her daughter-in-law, Laurie Bruns of Pittsburgh, PA. “She never exhibited her art, but each Wednesday morning, she had a group at her house that painted,” Bruns said.

“As she aged in her New York home, she began to exhibit memory loss,” said her son, Dr. Frank Bruns, a Pittsburgh nephrologist. She once became lost driving in a neighborhood park near where she’d lived much of her life, which led to her diagnosis of Alzheimer’s disease. After her husband died, the Bruns found a care community in their area that they liked. After a year in the community, Ursula wasn’t engaging in the kind of one-on-one contact that her family felt she needed and she seemed more depressed. “At the time, we talked with 2 of our friends who had hired nonmedical caregivers for their loved ones,” Dr. Bruns said. A broken hip and shoulder injury helped reinforce the need for additional assistance for Ursula.

Now 96 years old, Ursula lives in the skilled nursing area of her care community and has the assistance of nonmedical caregivers 5 days a week. “Ursula loves the opera, but is not able to put a CD in the player. That’s something that her main caregiver, Lynn Thorn, does,” Laurie Bruns said. “My mother-in-law will hum arias and conduct to the sound of the music. The caregiver tries to provide the kind of stimulation that can keep her and the other residents around her from just sitting and staring or sleeping.”

“Traveling to the care community garden, another popular activity with the caregiver, also would be a difficult task without help,” Dr. Bruns said. Her room is filled with plants that the caregiver helps Ursula water. Ursula and her companion go to church at the care community and attend special events. “One of the regular program’s guests speaks German and has conversed with my mother-in-law,” Laurie Bruns recalled. “That wouldn’t have happened if the caregiver had not taken her to those events.”

Lynn Thorn has been Ursula’s caregiver 4 days a week for the past 14 months. “Ursula is such a sweet loveable person. I think we have a good relationship. I love her; she’s a dear who doesn’t talk too much or make friends easily. She likes people, but is a little shy,

issues associated with Alzheimer's disease, such as wandering, repetition, and agitation. "I think the biggest benefit of the program is that it gives our CAREGivers a higher level of confidence and teaches them to be less intimidated," Shaw said. "It opens their minds to creative ways to solve problems."

According to Shaw, an important key to success for nonmedical caregivers working in care communities is the ability to develop a solid partnership, like that his company has with Sunrise. "They know who we are and that we're a guest in their house. There's a good communication chain. The end result is a much higher level of care and more efficient level of care for the community and better quality of life for the resident," he added.

"Another interesting aspect of this issue is that the private caregiver becomes so much a part of our routine that they may start engaging other residents," said Jay Lewkowitz, Executive Director of Oakton Place, an independent care community and skilled nursing facility in Des Plaines, IL. "If you're at a table for 4, including 3 residents and a caregiver, why wouldn't you converse?" he remarked.

"There's a routine here, and it doesn't take long for the caregiver to become an insider. I've seen nonmedical caregivers who no longer care for a resident in the community come back and see our other guests. If you're someone who likes people and stories, there's plenty of that here."

According to statistics, that kind of socialization and mental stimu-

lation is good for everyone. More and more studies have revealed that leisure activities and a stimulating environment are vital to preventing the progress of dementia. That's one of the biggest benefits of having a nonmedical caregiver to assist the resident, sources said.

### **A Total Wellness Benefit**

A study supported by the National Institutes on Aging and released last year found that regular physical activity, mental stimulation, and a diet rich in antioxidants can help keep the brain sharp.<sup>1</sup> Researchers found that a diet fortified with fruits, vegetables, and vitamins, exercise at least twice weekly, and the opportunity to socialize can enable the brain to learn new tasks.

so I've tried to help her overcome that. We go to tea once a month with other residents and she gets to meet all these people. She seems to be learning how to listen and talk to people," said Lynn.

"I think we're just natural with each other," added Lynn, who has received specialized nonmedical Alzheimer's training. "We laugh a lot. As soon as she sees me, she knows my face, even if she can't remember my name."

"Ursula's family still corresponds with relatives in Germany so I read to her, look at pictures, and go over letters. The other day the community showed a movie with Ginger Rogers and Fred Astaire. I asked her if she remembered them and she said it was Virginia and Fred. We were just amazed that she could recall the names so closely."

Debra Dehn, another nonmedical caregiver, is with Ursula for 3 hours every Thursday on Lynn Thorn's day off. "I think the type of companionship we provide seniors like Ursula helps lift them out of depression," Dehn said. "A number of them are not living the lives they want because they've outlived everyone they've loved."

Listening to music and attending musical events at the care community are among Dehn's favorite

pastimes with Ursula. "She knows German and Austrian composers. One afternoon we were listening to symphony music. Ursula was directing and conducting, and had the most pleased smile on her face. She is pulled back into the process of living and enjoying good memories," Dehn added.

"The staff at Ursula's care community has a lot of residents and I feel they do a good job. They are busy and always willing to be helpful, but they can't be in every room all the time," remarked Dehn.

The relationships that nonmedical caregivers form with seniors in care communities are gratifying, say Ursula's family and caregivers. "Lynn said to me that she heard about a store that does something special with fruit and wanted to give such a gift to Ursula on Valentine's Day," Laurie Bruns said. "I insisted that we split the cost of the fruit even though she wanted to do that herself. So she got her chocolate-covered strawberries for Valentine's Day. I see this kind of relationship as something special," Bruns added.

"My daughters say to me, this is what God wants you to do. You just come alive when you work with seniors," Thorn recalled. "It's gratifying just to know I've given them a little pleasure, a little gleam of hope, because Alzheimer's is such a terrible disease."

Care communities around the country are recognizing the benefits of a total wellness approach for dementia residents. For example, Lakeside Village, an Immanuel Senior Living community in Omaha, NE, features a wellness center, which focuses on body, mind, and spirit, geared toward older adults in their senior living community as well as in the city, according to Assisted Living Director, Debra Welk, RN.

Immanuel Senior Living is comprised of 5 AL and independent living communities in eastern Nebraska. Lakeside Village is building a memory support center that is expected to open in the fall of 2007 where 12 residents will live. The Lincoln site already has such a center. Nonmedical caregivers currently help AL residents who have Alzheimer's disease and dementia with certain rituals, such as visiting the wellness center, going for coffee,

walking, reading the Bible, and praying.

According to Welk, "A caregiver can offer consistency for those residents who are losing their memories. They can't always remember people, but they often appreciate being involved in activities they previously enjoyed. A caregiver provides variation in their day and helps fulfill their lives. We provide 3 meals a day, but in addition, the caregiver can help to remind dementia residents to keep up their hydration and eat small snacks. The caregiver gets to know the resident and what they like to do. They're so patient, many times helping the resident complete a task over and over again like it's a new thing every day."

That kind of dedication builds loyalty among residents and their families, who come to appreciate the respite that a nonmedical caregiver can provide. An example from Welk's own family is

a perfect illustration.

"My husband has an aunt with dementia and an uncle who is the primary caregiver. A nonmedical caregiver has been with them for 4 to 5 years, providing care for his aunt and assistance to his uncle. This caregiver returned to her home in Jamaica to be married. The uncle hired another caregiver to care for his wife, and he traveled to Jamaica as an honored guest at the wedding. I think when a trust level is built and people get to know their caregiver, they mean so much to you, they almost become family." ALC

**Georgene Lahm is a freelance writer and communications specialist, based in Omaha, NE.**

## Reference

1. Milgram NW, Head E, Zicker SC, et al. Learning ability in aged dogs is preserved by behavioral enrichment and dietary fortification. *Neurobiol Aging* 2005;26:77-90.

## End-of-Life Care

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virtually impossible to control acute symptoms unless they occur during the time the RN is in the facility.<sup>9</sup> If residents develop symptoms in facilities where hospice services are in place, residents, families, and staff should be educated and encouraged to call the hospice nurse to make an acute visit or provide advice on symptom management with medications that are available. If the resident is able to self-medicate, he or she may utilize the hospice comfort pack, which typically holds medications such as acetaminophen, morphine, and lorazepam to manage symptoms. However, some facilities do not have storage options for comfort packs.<sup>9</sup>

## Looking to the Future

Residents want to be able to age and die in place at AL that have become their homes. Health care

workers need to be ready to discuss palliative goals of care with residents who request symptom management of their disease. To meet the resident's goals and manage their symptoms, the AL staff and the hospice organization need to understand the obstacles to care and collaborate with each other to overcome them. The provision of quality end-of-life care in AL will entail future changes of policies and regulations and enhanced communication between AL and hospice organizations. ALC

**Janet M. Lieto, DO, CMD is a Hospice Physician and Stephen Goldfine, MD, DABHPM (Diplomate of the American Board of Hospice and Palliative Medicine) is Chief Medical Officer at Samaritan Hospice, a not-for-profit independent community-based hospice serving Atlantic, Burlington, Camden, Cape May, Gloucester, and Mercer counties and headquartered in Marlton, NJ.**

## References

1. National Center for Assisted Living. *Assisted Living Independence, Choice and Dignity*. Available at: <http://www.nacl.org/about/concepts.htm>. Accessed May 15, 2006.
2. Kissam S, Gifford R, Mor V, Patry G. Admission and continued-stay criteria for assisted living facilities. *J Am Geriatr Soc* 2003;51:1651-1654.
3. Singer P, Martin D, Kelner M. Quality end-of-life care: patients' perspective. *JAMA* 1999;281:163-198.
4. Ogle K, Hopper K. End-of life care for older adults. *Primary Care: Clinics in Office Practice* 2005;32:811-828.
5. National Hospice and Palliative Care Organization. *Hospice Care: A Physician's Guide*. Alexandria, VA: National Hospice and Palliative Care Organization, 1998.
6. Centers for Medicare and Medicaid Services. Medicare hospice benefits. Available at <http://www.medicare.gov/Publications/Pubs/pdf/02154.pdf>. Accessed May 15, 2006.
7. Centers for Medicare and Medicaid Services. Coverage of hospice services under hospital insurance. In: *Medicare Benefit Policy Manual*, Chapter 9. Washington, DC: Centers for Medicare and Medicaid Services; December 3, 2004. Available at <http://www.cms.hhs.gov/manuals/Downloads/bp102c09.pdf>. Accessed May 25, 2006.
8. Cartwright J, Kayser-Jones J. End-of-life care in assisted living facilities. *J Hospice and Palliative Nursing* 2003;5:143-151.
9. Mitty E. Assisted living: aging in place and palliative care. *Geriatr Nurs* 2004;25:149-156, 163.