

Adding Families to the Care Team

Family Members Hold Keys to Person-Centered Care

A song, an old tale, a book, lamp. These are pleasant tidbits of a life. They also can be vital clues in providing not just professional treatment, but loving and soothing care for people with dementia — a passage in life that Sr. M. Peter Lillian DiMaria refers to as “God’s waiting room.”

Sr. DiMaria is director of the Avila Institute of Gerontology in Germantown, N.Y., the education arm of the Carmelite Sisters for the Aged and Infirm. She has worked in and with the nursing homes served by the order for 30 years and is a strong advocate of person-centered care for people with dementia. She knows that the more nursing home caregivers know about the tastes

and quirks of their residents, the better the care can be.

That means going beyond the already lengthy assessment forms that families fill out when a new resident arrives. Caregivers need to be detectives, asking as many family members as possible as many questions as they can, looking for that little secret that can help calm a resident who is particularly confused, agitated or despondent.

A simple example, she said, would be knowing which 70-year-old Big Band melody to play while trying to calm a resident. “We know that a particular song can perk up a memory of a wonderful time in their lives, when things seem to fit for them,” she said. “There are a million little things we can do. We just have to know which ones.”

Sr. DiMaria isn’t offering these thoughts as a new miracle in medicine. She calls it old wisdom, certainly not a cure. But in the hubbub of admitting new residents and caring for the ones already there, she said, it’s important to remember “that each person has a story, a history that we need to understand.”

“I think we’ve become much better at this,” she said in a recent interview with *Health Progress*. “Saying that someone has dementia doesn’t tell us a thing. We need to know what type of dementia in order to provide appropriate interventions, and we need to know their story. Our residents can’t tell us the story, but each family member will have a different perspective or memory. That’s why it’s so important to have family members be a part of the team.”

Sr. DiMaria has been discussing this theme in her recent seminars and meetings, and was planning to make it part of her presentation Nov. 3 in Cincinnati at a conference titled, “Is it Alzheimer’s?” She will lead a panel discussion on ways to better involve families in caring for residents.

Said nurse and educator Carole Stathis, “Person-centered care keeps the person, not the disorder, in the center. What we do as care



Sr. DiMaria

Sr. M. Peter Lillian DiMaria joined the Carmelite Sisters for the Aged and Infirm in 1978 and worked in several of its nursing homes for 19 years before joining the Avila Institute staff in 1997.

During her college years, she worked in a nursing home in Enfield, Conn., where she had grown up. She went on to teach science and then, while considering a religious vocation and remembering her work at the nursing home, decided to join the Carmelite order. The order was founded in 1929 by Mother M. Angeline Teresa, a native of Ireland and a member of the Little Sisters of the Poor in New York who received permission to establish the Carmelite Sisters for the Aged and Infirm. The order serves in 18 nursing homes in eight states and one in Dublin, Ireland.



During a party at St. Patrick's Manor, Framingham, Mass., a resident dances with a staff member, left, and another resident enjoys the company of her son.

providers does make a real difference in the lives of the person with dementia and in the lives of their loved ones.”

Stathis serves on the Avila Institute board and lectures for the institute as well as for the Alzheimer's Foundation.

Meanwhile, though, learning more about the disease itself will help provide even better care, she said.

“This is an exciting time to be involved in the field of dementia care,” Stathis said. “Years ago we looked at cancer as one disease. We thought we could overcome cancer if only we could find the magic key to unlock its trigger. Today we recognize cancer as a category of disorders, each disorder having its own unique pathology, and we have come to view dementia through the same lens.

“Dementia is a broad categorization of a wide range of disorders, and it is not normal aging. Each of the 60-plus dementias has its own unique pathology; its own unique signs and symptoms; its own course. Alzheimer's disease is the most common dementia, but there is also frontotemporal or Pick's dementia; vascular dementia; Lewy body dementia; normal pressure hydrocephalus; and so many more,” said Stathis.

“In addition to the pathology of the specific dementia that robs the brain of its ability to process information efficiently, to remember, to respond in a socially appropriate manner, indi-

viduals that develop dementia are adults who bring into their later years a wide range of life experiences and physical challenges. As we age, we become increasingly complex. What we now know about the pathology of various dementias has led to breakthroughs in the care of these individuals. At this point in time, there are some drugs that are helpful but research reminds us that our one-to-one interactions are what brings quality of life to all affected by dementia,” she said.

Sr. DiMaria said families of new residents often have conflicted feelings of guilt and “compassion fatigue” from the increasing demands of caring for someone with dementia. “We must be sensitive to the fact that, when admitting a resident to a facility, we are also admitting the family.”

Asking family members to help arrange a new resident's room can make the room more familiar to the resident and allow relatives a sense of participation. “Incorporating the family into the care team is vital for the family members to help them come to terms with the many feelings they confront,” she said.

Because family members often have varying opinions of what is needed, it is important for staff members to “ascertain what the role is for each family member” in helping to provide continuing care.

“What we do is awesome work,” she said. “We

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A volunteer at St. Patrick's Manor, Framingham, Mass., left, assists a resident during a party at the center.

are following the Gospel message. My basic belief is that we should be compassionate in our work. Our foundress reminded us that we need to see Jesus in everyone we care for.”

If knowing about a resident's past can allow for customized care, it also can be useful in easing perplexing blow-ups. Sr. DiMaria recalls an incident at one of the homes when she was conducting a discussion about life on a farm.

“One of the residents became really upset and was crying throughout the presentation,” she said. “Later, we found out through family that it was the worst memory we could have brought back to her. She had lived on a farm long before and hated it.”

Some reactions are more easily solved. Another resident reacted coldly to Sr. DiMaria's religious habit. “Here she is again. Everybody be quiet,” she said.

“It turns out she had always been involved with the nuns at her children's schools in raising money,” Sr. DiMaria said. “I told her not to worry, that we had raised her goal.”

Of course, there are many other times when her garb triggers fonder memories of residents'

school days. Walking down hallways, she has heard residents suddenly begin reciting prayers.

Laurie Gorski, assistant director of nursing at Teresian House, a home served by the Carmelite Sisters in Albany, N.Y., has worked there since the 1980s, starting as a nurse's aide. She said at least 75 percent of the residents at Teresian, a 300-bed home, suffer from dementia, usually Alzheimer's.

“Knowing as much as possible about a resident's past is extremely valuable,” said Gorski, a registered nurse. “We can make people more comfortable being here. We can give them better care. And it can make life easier for everybody.”

When she began working at Teresian House, “the treatment model was ‘reality orientation,’” Gorski said. “If a resident asked about her mother, we were supposed to tell her that her mother was dead. I was 19 years old and said that to a 98-year-old lady. She started crying. I thought, ‘This can't be right. Why am I doing this to her?’”

“What we need to do is learn more about her mother and assure her that her mother is fine,” Gorski said. “Those of us in today's reality might consider that a little white lie, but what we are trying to do is enter the patient's reality. Her mind will never come back, but she's still a human being with a need for care.”

Teresian's nurses, social workers and other staff members work with family members with that in mind, Gorski said. “There is almost always an explanation in a person's past for why they are doing things,” she said. “Sometimes, even the family won't at first be aware of things that can make care more successful. So it's important to continue working with them.”

Gorski said she admires Sr. DiMaria “because she truly loves these residents with all her heart. She is always coming up with innovative ways to help them.”

Sr. DiMaria said the focus must always be on the best way to help each resident live in peace.

“We are honoring our fathers and mothers in God's waiting room,” she said. “What are we doing to make them comfortable on what may be their last day?” ■

This article was reported and written by Tim O'Neil, a writer in St. Louis.



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