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Giving Alzheimer's Patients Their Way, Even Chocolate

By PAM BELLUCK

PHOENIX — Margaret Nance was, to put it mildly, a difficult case. Agitated, combative, often reluctant to eat, she would hit staff members and fellow residents at nursing homes, several of which kicked her out. But when Beatitudes nursing home agreed to an urgent plea to accept her, all that changed.

Disregarding typical nursing-home rules, Beatitudes allowed Ms. Nance, 96 and afflicted with Alzheimer's, to sleep, be bathed and dine whenever she wanted, even at 2 a.m. She could eat anything, too, no matter how unhealthy, including unlimited chocolate.

And she was given a baby doll, a move that seemed so jarring that a supervisor initially objected until she saw how calm Ms. Nance became when she rocked, caressed and fed her "baby," often agreeing to eat herself after the doll "ate" several spoonfuls.

Dementia patients at Beatitudes are allowed practically anything that brings comfort, even an alcoholic "nip at night," said Tena Alonzo, director of research. "Whatever your vice is, we're your folks," she said.

Once, Ms. Alonzo said: "The state tried to cite us for having chocolate on the nursing chart. They were like, 'It's not a medication.' Yes, it is. It's better than Xanax."

It is an unusual posture for a nursing home, but Beatitudes is actually following some of the latest science. Research suggests that creating positive emotional experiences for Alzheimer's patients diminishes distress and behavior problems.

In fact, science is weighing in on many aspects of taking care of dementia patients, applying evidence-based research to what used to be considered subjective and ad hoc.

With virtually no effective medical treatment for Alzheimer's yet, most dementia therapy is the

caregiving performed by families and nursing homes. Some 11 million people care for Alzheimer's-afflicted relatives at home. In nursing homes, two-thirds of residents have some dementia.

Caregiving is considered so crucial that several federal and state agencies, including the Department of Veterans Affairs, are adopting research-tested programs to support and train caregivers. This month, the Senate Special Committee on Aging held a forum about Alzheimer's caregiving.

"There's actually better evidence and more significant results in caregiver interventions than there is in anything to treat this disease so far," said Lisa P. Gwyther, education director for the Bryan Alzheimer's Disease Research Center at Duke University.

The National Institute on Aging and the Administration on Aging are now financing caregiving studies on "things that just kind of make the life of an Alzheimer's patient and his or her caregiver less burdensome," said Sidney M. Stahl, chief of the Individual Behavioral Processes branch of the Institute on Aging. "At least initially, these seem to be good nonpharmacological techniques."

Techniques include using food, scheduling, art, music and exercise to generate positive emotions; engaging patients in activities that salvage fragments of their skills; and helping caregivers be more accepting and competent.

Changing the Mood

Some efforts involve stopping anti-anxiety or antipsychotic drugs, used to quell hallucinations or aggression, but potentially harmful to dementia patients, who can be especially sensitive to side effects. Instead, some experts recommend primarily giving drugs for pain or depression, addressing what might be making patients unhappy.

Others recommend making cosmetic changes to rooms and buildings to affect behavior or mood.

A study in *The Journal of the American Medical Association* found that brightening lights in dementia facilities decreased depression, cognitive deterioration and loss of functional abilities. Increased light bolsters circadian rhythms and helps patients see better so they can be more active, said Elizabeth C. Brawley, a dementia care design expert not involved in the study, adding, "If I could change one thing in these places it would be the lighting."

Several German nursing homes have fake bus stops outside to keep patients from wandering; they wait for nonexistent buses until they forget where they wanted to go, or agree to come

inside.

And Beatitudes installed a rectangle of black carpet in front of the dementia unit's fourth-floor elevators because residents appear to interpret it as a cliff or hole, no longer darting into elevators and wandering away.

"They'll walk right along the edge but don't want to step in the black," said Ms. Alonzo, who finds it less unsettling than methods some facilities use, bracelets that trigger alarms when residents exit. "People with dementia have visual-spatial problems. We've actually had some people so wary of it that when we have to get them on the elevator to take them somewhere, we put down a white towel or something to cover it up."

When elevator doors open, Beatitudes staff members stand casually in front, distracting residents with "over-the-top" hellos, she said: "We look like Cheshire cats," but "who's going to want to get on the elevator when here's this lovely smiling person greeting you? It gets through to the emotional brain."

New research suggests emotion persists after cognition deteriorates. In a University of Iowa study, people with brain damage producing Alzheimer's-like amnesia viewed film clips evoking tears and sadness ("Sophie's Choice," "Steel Magnolias"), or laughter and happiness (Bill Cosby, "America's Funniest Home Videos").

Six minutes later, participants had trouble recalling the clips. But 30 minutes later, emotion evaluations showed they still felt sad or happy, often more than participants with normal memories. The more memory-impaired patients retained stronger emotions.

Justin Feinstein, the lead author, an advanced neuropsychology doctoral student, said the results, being studied with Alzheimer's patients at Iowa and Harvard, suggest behavioral problems could stem from sadness or anxiety that patients cannot explain.

"Because you don't have a memory, there's this general free-floating state of distress and you can't really figure out why," Mr. Feinstein said. Similarly, happy emotions, even from socializing with patients, "could linger well beyond the memories that actually caused them."

One program for dementia patients cared for by relatives at home creates specific activities related to something they once enjoyed: arranging flowers, filling photo albums, snapping beans.

"A gentleman who loved fishing could still set up a tackle box, so we gave him a plastic tackle

box” to set up every day, said the program’s developer, Laura N. Gitlin, a sociologist at Thomas Jefferson University in Philadelphia and newly appointed director of the Center on Aging and Health at Johns Hopkins University.

After four months, patients seemed happier and more active, and showed fewer behavior problems, especially repetitive questioning and shadowing, following caregivers around. And that gave caregivers breaks, important because studies suggest that “what’s good for the caregiver is good for the patient,” Professor Gwyther said.

Aiding the Caregiver

In fact, reducing caregiver stress is considered significant enough in dementia care that federal and state health agencies are adopting programs giving caregivers education and emotional support.

One, led by Mary S. Mittelman, a New York University dementia expert, found that when people who cared for demented spouses were given six counseling sessions as well as counselors whom they could call in a crisis, it helped them handle caregiving better and delayed by 18 months placing patients in nursing homes.

“The patient did not have fewer symptoms,” Dr. Mittelman said. “It was the caregiver’s reaction that changed.”

The Veterans Affairs Department is adopting another program, Resources for Enhancing Alzheimer’s Caregiver Health, providing 12 counseling sessions and 5 telephone support group sessions. Studies showed that these measures reduced hospital visits and helped family caregivers manage dementia behaviors.

“Investing in caregiver services and support is very worthwhile,” saving money and letting patients remain home, said Deborah Amdur, chief consultant for care management and social work at the Veterans Affairs Department.

Beatitudes, which takes about 30 moderate to severe dementia sufferers, introduced its program 12 years ago, focusing on individualized care.

“In the old days,” Ms. Alonzo said, “we would find out more about somebody from their obituary than we did when they were alive.”

The dementia floor was named Vermillion Cliffs, after colorfully layered rock formations formed

by centuries of erosion, implying that, "although weathered, although tested by dementia, people are beautiful" and "have certain strengths," said Peggy Mullan, the president of Beatitudes.

The facility itself is institutional-looking, dowdy and "extremely outdated," Ms. Mullan said.

"It's ugly," said Jan Dougherty, director of family and community services at Banner Alzheimer's Institute in Phoenix. But "they're probably doing some of the best work" and "virtually have no sundowning," she said, referring to agitated, delusional behavior common with Alzheimer's, especially during afternoon and evening.

Beatitudes eliminated anything potentially considered restraining, from deep-seated wheelchairs that hinder standing up to bedrails (some beds are lowered and protected by mats). It drastically reduced antipsychotics and medications considered primarily for "staff convenience," focusing on relieving pain, Ms. Alonzo said.

It encouraged keeping residents out of diapers if possible, taking them to the toilet to preserve feelings of independence. Some staff members resisted, Ms. Alonzo said, but now "like it because it saves time" and difficult diaper changes.

Family members like Nancy Mendelsohn, whose mother, Rose Taran, was kicked out of facilities for screaming and calling 911, appreciate it. "The last place just put her in diapers, and she was not incontinent at all," Ms. Mendelsohn said.

Ms. Alonzo declined to pay workers more to adopt the additional skills or night work, saying, "We want people to work here because it's your bag."

Finding Favorite Things

For behavior management, Beatitudes plumbs residents' biographies, soothing one woman, Ruth Ann Clapper, by dabbing on White Shoulders perfume, which her biographical survey indicated she had worn before becoming ill. Food became available constantly, a canny move, Ms. Dougherty said, because people with dementia might be "too distracted" to eat during group mealtimes, and later "be acting out when what they actually need is food."

Realizing that nutritious, low-salt, low-fat, doctor-recommended foods might actually discourage people from eating, Ms. Alonzo began carrying chocolate in her pocket. "For God's sake," Ms. Mullan said, "if you like bacon, you can have bacon here."

Comforting food improves behavior and mood because it "sends messages they can still

understand: 'it feels good, therefore I must be in a place where I'm loved,' " Ms. Dougherty said.

Now, when Maribeth Gallagher, Beatitudes' dementia program director, learns someone's favorite foods, "I'm going to pop that on your tongue, and you're going to go 'yum,' " she said. "Isn't that better than an injection?"

Beatitudes also changed activity programming. Instead of group events like bingo, in which few residents could actually participate, staff members, including housekeepers, conduct one-on-one activities: block-building, coloring, simply conversing. State regulators initially objected, saying, "Where's your big group, and what you're doing isn't right and doesn't follow regulations," Ms. Alonzo said.

Ms. Mullan said, "I don't think we ever got cited, but it was a huge fight to make sure we didn't."

These days, hundreds of Arizona physicians, medical students, and staff members at other nursing homes have received Beatitudes' training, and several Illinois nursing homes are adopting it. The program, which received an award from an industry association, the American Association of Homes and Services for the Aging, also appears to save money.

Arlene Washington's family moved her to Beatitudes recently, pulling her from another nursing home because of what they considered inattentive and "improper care," said her husband, William. Mrs. Washington, 86, was heavily medicated, tube fed and unable to communicate, "like she had no life in her," said Sharon Hibbert, a friend.

At Beatitudes, Dr. Gillian Hamilton, administrative medical director, said she found Mrs. Washington "very sedated," took her off antipsychotics, then gradually stopped using the feeding tube. Now Mrs. Washington eats so well she no longer needs the insulin she was receiving. During a recent visit, she was alert, even singing a hymn.

That afternoon, Ms. Nance, in her wheelchair, happily held her baby doll, which she named Benjamin, and commented about raising her sons decades ago.

Ms. Alonzo had at first considered the doll an "undignified" and demeaning security blanket. But Ms. Gallagher explained that "for a lot of people who are parents, what gives them joy is caring for children."

"I was able," Ms. Gallagher said, "to find Margaret's strength."

Ms. Gallagher said she learned when approaching Ms. Nance to "look at her baby doll, and once I

connect with the doll, I can look at her.”

She squatted down, complimented Benjamin's shoes, and said, “You're the best mom I know.”

Ms. Nance nodded earnestly.

“It's good to know,” Ms. Nance said, “that somebody knows that you care.”