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**Research That Hits Home:
Md. Alzheimer's Facility Conducts Studies With Johns Hopkins,
Applies Findings in Daily Care**

By Beth Baker

In 2001, Ellen Proxmire faced a tough decision regarding her husband - William Proxmire, the Former Democratic senator. Diagnosed seven years earlier with Alzheimer's disease, he frequently wandered from home. He even managed to escape from a locked hospital unit.

When he represented Wisconsin from 1957 to 1989, Proxmire had a reputation as a maverick. But the independent streak prized in a politician was dangerous in a person living with Alzheimer's Disease. One day he eluded the caregiver hired to keep an eye on him at the Library of Congress, where he still enjoyed a private carrel. Hours later he was found walking on the Southeast Freeway. Someone recognized him and picked him up and brought him home, his wife said.

Much as she hated to admit it, Ellen Proxmire knew she could no longer care for her husband at home. She visited some 20 Alzheimer's residential facilities in the Washington area and in Arizona, where she hoped to live. Even those with good reputations she found dismal. "People were drugged and sitting in a corner, tied to chairs," she said. "And there are some places who don't want someone who is difficult."

Then she heard about Copper Ridge. Located 54 miles north of Washington in Sykesville, Md., "They saved our lives," Ellen Proxmire said.

She is fortunate, she knows, to be in a position to pay for premium care. Copper Ridge costs as much as \$95,000 a year for assisted living (from \$173 to \$262 per day, depending on the level of care), up to \$109,000 a year for nursing home care (\$301 a day). Although the facility's nursing home unit accepts people on Medicaid, the assisted living component is strictly private pay. In the nation's 30 largest metropolitan areas, dementia care in assisted living averages \$53,484 a year (about \$148 a day), according to the Annapolis-based National Investment Center's Market Area Profiles (NIC-MAP).

Besides price, what distinguishes Copper Ridge is this: It is one of the world's few residential facilities with a dual mission - conducting academic research on dementia and applying research to resident care. Alzheimer's, the most common form of dementia, is an irreversible, progressive, terminal disease that disrupts brain function. The disease can run from three to 20 years, with an average term of eight years.

An estimated 4.5 million U.S. residents have Alzheimer's; that number is projected to double in the next 20 years as baby boomers age.

Unlike many assisted living facilities for those with dementia. Copper Ridge cares for people until death. (The average resident stays there for two to three years before succumbing to the disease.)

"Copper Ridge is nationally recognized for its integration of research and best dementia care practices," says gerontologist Kevin Eckert, dean of the new Erickson School of Aging Studies at the University of Maryland, Baltimore County.

The facility's research arm, the Copper Ridge Institute, is affiliated with Johns Hopkins University School of Medicine and Hopkins's Alzheimer's Disease Research Center, one of 32 such centers funded by the National Institute on Aging.

Copper Ridge findings support what advocates of nursing home reform have long maintained:

that elderly people (including those with dementia) who need long-term care do best in homey surroundings with as much personalized attention and social interaction as possible.

"A lot of assisted living facilities have done a great job at making the place look attractive," said Sharon Brangman, chief of geriatrics at SUNY Upstate Medical University in Syracuse. "But the trick is to make the care patient-centered and not just another mimic of a nursing home institution."

Among other Copper Ridge findings that have been reported in peer-reviewed journals:

Depression, which once went untreated in people with dementia, can be evaluated, diagnosed and treated.

Quality of life can be measured in dementia patients. For many years, researchers have sought "to define quality of life for people who cannot speak for themselves," said Alva S. Baker, Copper Ridge's vice president for health and wellness services. "We define quality of life as not being in pain, and being engaged and seeming to be happy." Using an assessment scale developed by Johns Hopkins Alzheimer's researcher Peter V. Rabins, Copper Ridge demonstrated that six months after residents moved there, their quality of life improved, a result that was expected but that has been hard to measure in the past. "People move into an institution often because of crises or terrible situations," said Baker. "After they've had time to adjust and appropriate care is put in place, one would hope they would be happier."

Residents who spent a half-hour a few times a week with a staff member — engaged in one-on-one conversation, puzzles, artwork or reading - showed a significant reduction in apathy, a common symptom of dementia.

Surprise Tactics

"Here, there's so much freedom - and safe freedom," Ellen Proxmire said of Copper Ridge.

The facility, which opened in 1994, was one of the first to incorporate a homier design. Each household of 20 residents boasts a family-size kitchen and dining room and a living room with a

fireplace. Most residents have a private bedroom and half-bath. Window seats overlook courtyards. In good weather, residents can walk on paths through enclosed secure gardens or sit on benches, listening to rustling leaves and bubbling fountains.

In designing Copper Ridge, Pittsburgh architect David Hoglund, a national expert in innovative long-term-care design, drew on a three-year study of Woodside Place, a facility in Pennsylvania. Both feature bedrooms with Dutch doors, which afford both privacy and social interaction, and individualized decor in bedrooms and households, to help people stay oriented. "We have great social histories of the residents [at Woodside] and how they responded to the environment," Hoglund said.

Besides regularly scheduled group activities, such as boat rides, pickle tasting and music therapy, each resident has an individualized daily care plan covering bedtime and bathing preferences and favorite activities. "We know from our research that person-centered care is essential, and that is a part of what Copper Ridge does well," said Eckert.

What you don't see at Copper Ridge is much television watching, although there are TVs in common areas. TV news such as the events of Sept. 11, 2001, upset and confuse residents, said Baker. "We did not permit TV at first [in residents' rooms]," he says. "We knuckled under to [family] demands" that Mom be able to watch her favorite programs. The institute plans a study on how watching television affects people with dementia.

Copper Ridge employees, even administrative staff, regularly lead an activity of their choosing. Dornise Henderson, a certified geriatric nursing assistant, leads bread making, singing spiritual songs and taking residents out on walks.

This is the third assisted living facility where Henderson has worked - and the best, she said. "I've learned more about how to react, how to approach and deal with people. It makes it much easier and more rewarding," she said. "In the past, maybe I would approach [a resident] in a way where she would frighten me."

Dealing with difficult behavior is a constant for staff in a dementia facility.

"It's a hard, terrible job," said Baker, a portly man with a trim gray beard and a ready smile. "If you know you're going to get beat up, life is not fun." Aides, he said, need to be taught "to understand that [belligerence] is part of the disease. It takes a lot of training and support for the staff."

Staff members learn that how they treat residents can mean the difference between combativeness and cooperation. Among the lessons:

If a resident insists on wearing the same clothes, even when they're dirty, ask the family to purchase several similar outfits rather than engage in a daily battle over hygiene.

If a woman doesn't want to eat until her husband arrives - and he's been dead for 10 years - don't try to convince her otherwise. Instead, distract her and gently guide her to a seat and encourage her to eat.

If a resident wants to hoard rolls of toilet paper, let him.

Such training seems to be paying off. During a recent lunchtime, the atmosphere was calm.

Most residents sat chatting at small tables. One man with a sweet smile approached a visitor to talk - not the easiest conversation to follow, but pleasant nonetheless. When an agitated woman proclaimed angrily that she was thirsty, an aide hurried to get her something to drink. When another woman made a beeline for an exit, a staff member distracted her in quiet conversation.

Staff training pays off in another way. The facility claims an overall nursing staff turnover rate of 7 percent or lower, far less than the 71 percent turnover nationally for nurse's aides in long-term care and 49 percent for nurses.

Family in Mind

Some 6,000 health professionals have come to Copper Ridge from as far as Greece, Argentina, Hong Kong and Japan to learn about dementia care, said Baker.

Closer to home, Morningside House, with seven residential facilities in Maryland and Virginia, not only trains all its staff using the institute's four-hour CD-ROM dementia care education program, this spring it also sent professional staff to an intensive 40-hour training on the Copper Ridge model of care. After completing the training, said Wanda Harding, Morningside's vice president of health and resident services, "we felt we understood dementia better and were actually able to sit down and educate our family members."

Another Copper Ridge service is its memory assessment clinic, staffed by Johns Hopkins professionals. Some 700 people in seven states have come for this outpatient assessment, with follow-up visits as needed. For a fee of \$50 to \$75, family members of these people can also receive training in how to deal with behavior issues.

"We admit the family into the care system," said Baker. "The family knows the resident and they also need tremendous support." Families can also bring loved ones to Copper Ridge for respite care and for the 14-day "residential fast track" program, where patients are admitted for evaluation and care recommendations.

Programs such as this have made Ellen Proxmire a true believer in Copper Ridge's missions. She is about to host the third annual William Proxmire Awards dinner, which raises money for Copper Ridge research. While she admits she tires of making the hour-plus drive from Washington each week to be with her husband, she says it's worth it.

"This is Bill's comfort cocoon," she said.