

# Training eases Alzheimer's caregiving, but it's hard to find ---- or to make time

By LAURAN NEERGAARD - AP Medical Writer | Sunday, May 18, 2008 12:25 AM PDT

The findings are stunning: Offering simple training to people struggling to care for loved ones with Alzheimer's disease not only eases their burden ---- it even can keep patients out of nursing homes for an extra 1.5 years.

But the exciting research also runs headlong into a grim reality.

Alzheimer's caregivers seldom can make time in their daily grind to seek out that kind of help.

And when they do, they too often find waiting lists for services, or programs geared only toward people with advanced disease and not the larger pool in the purgatory that is dementia's decade-long middle ground between independence and helplessness.

That is one of Dolores Melnick's biggest frustrations.

Her husband refused to enroll in the "day care" for Alzheimer's patients near their Hainesport, N.J., home. It was hosting a singalong, and workers were setting up plastic bowling pins, too childish for Bob Melnick.

That meant no time for her to sneak off to a caregiver support group. On weekdays she worries about whether he'll be OK because he's home alone while she's at work.

"I feel bad sometimes because he's home. I feel bad that I have to leave in the mornings," Mrs. Melnick says, eyes brimming with tears. "I think he realizes he can't do much."

## **'What we're up against'**

More than 5 million Americans are living with Alzheimer's disease. It afflicts one in eight people 65 and older, and nearly one in two people over 85.

Worse, as the population ages, Alzheimer's is steadily rising. Sixteen million are forecast to have the mind-destroying illness by 2050, not counting other forms of dementia.

Those figures are cited repeatedly in the push for more research into better treatments. But a frightening parallel goes largely undiscussed: As Alzheimer's skyrockets, who will care for all these people?

And will the long-term stress of that care set up an entire population ---- once-healthy

spouses and children ---- to suffer years of illness, even early death?

"I don't think society and policymakers have fully grasped the future magnitude of what we're up against, and how massive an operation we have to begin ... to deal with this," says Dr. Richard Suzman of the National Institute on Aging.

Already, an estimated 10 million people share the task of caring for a relative or friend with dementia, the Alzheimer's Association estimates. Nearly one in four provides care for 40 hours a week or more.

Handling the wandering, aggressive outbursts and incontinence ---- plus eventual round-the-clock monitoring ---- is very different than, for example, learning to lift someone who's physically impaired but won't fight the caregiver.

Those are skills that families must be taught, says Mary Mittelman of New York University's School of Medicine, who is leading a new movement to develop customized training programs for Alzheimer's care.

Today, most learn through trial and error.

### **'I want to hit you'**

Louise Eckert sits her 85-year-old mother, Dorothy, in a chair backed against the wall and pushes a heavy table in front of her. It keeps her from tipping her chair backward like a schoolchild.

It's noon, but Dorothy roamed her Norristown, Pa., home for much of the night and just woke for breakfast. Louise spoon-feeds her mother: grapes and prunes mixed into cereal; toast cut into bites; Alzheimer's pills crushed into cottage cheese so she no longer can spit them out.

The conversation is, well, unconventional.

"I want to hit you," Dorothy whispers.

"You do not want to hit me," Louise calmly responds. Minutes later, mother and daughter are grinning affectionately.

"She'll hit you and two minutes later, she loves you," says Dorothy's husband, John Eckert, 88.

Not too long ago, the Eckerts despaired of achieving this calm. Dorothy's mild-mannered Alzheimer's suddenly morphed into outright aggression. She climbed furniture, pulled the TV on herself, tried to climb out the window.

Area aging services offered little advice. The Eckerts finally found the right mix of

medication and caregiver tricks. Take Dorothy's night roaming, a dementia trademark. Her husband installed bed rails; she crashed over them. He slept holding a belt tied to her waist; she slipped it off without waking him.

Now the couple sleeps on a mattress on the floor. Large wind chimes jangle when Dorothy's up.

"In the beginning there was pressure. Now we expect it's going to happen," her husband says of new symptoms. "You go along with the flow."

John Eckert brushes aside questions about the strain. He looks fit but has had prostate cancer, a small heart attack and mild stroke. Louise tried to hire a respite-care service so her dad could take a walk. But it requires a four-hour daily minimum, more than they need. Alzheimer's day care runs in the mornings, when Dorothy sleeps.

They manage because Louise, the couple's youngest daughter, lives with them and can rush home from her counseling job at a nearby school if needed.

They're determined to make Dorothy's days as lighthearted as possible.

"You could be mad about it, or constantly sad about the whole thing, but why? This is just who Mom is now," Louise explains.

So, they play Bobby Darin, and Dorothy dances around the dining room. Song done, she curls onto her husband's lap, head tucked under his chin. She can't recall his name, or the last name they've shared for 60 years. But she can cuddle.

"She knows I belong here, I guess," John says.

### **Custom training can help**

NYU's Mittelman says customized training can help caregivers ease the chaos that the Eckerts battled through, and proved it with a one-of-a-kind experiment.

She tested 406 elderly New Yorkers caring for spouses with Alzheimer's. Half received training tailored to their family's unique needs. Half got today's standard: a list of Alzheimer's resources.

Mittelman tracked these families for up to 17 years. Custom-trained caregivers kept their loved ones out of a nursing home for an average of 1.5 years longer than their untrained counterparts.

With annual nursing home costs now averaging \$60,000, that's a savings of \$90,000 per patient, Mittelman reported last fall in the journal *Neurology*.

It didn't come at the spouse's expense as trained caregivers experienced less depression,

and fewer physical health problems.

Importantly, the training was simple: Social workers met with caregivers once a week for six weeks, to assess each family's circumstances, discuss how Alzheimer's worsens, and teach coping skills. Caregivers were given phone numbers to call counselors for more advice whenever they wanted.

That ongoing tailored care is "a really crucial element," stresses Mittelman. Without it, when the patient "has a personality change and hits somebody for the first time in her life, you won't have anyone to turn to."

Mittelman has begun new studies targeting training to early- and middle-stage Alzheimer's.

And the National Institutes of Health is studying a similar program that mixes in-home and telephone training, sessions that include role-playing to let caregivers practice the coping skills they're learning.

The NIH study has tracked 640 dementia caregivers in five states for just six months so far. But initial results agree with Mittelman: Trained caregivers report improved quality of life, and feel they do a better job.

Together, the research represents a major shift in scientists' approach to Alzheimer's caregiving -- from an emphasis on just giving families a break through respite care, to the idea of empowering them to better handle the stress of the job.

The challenge is how to spread those findings.

### **Often-hidden middle stage**

Have a short conversation with Bob Melnick, and it's not immediately clear that anything's wrong with the smiling 67-year-old. He'll reminisce over old fishing photos; proudly tell of his two grown children; ask socially correct questions:

"How are you today?" "Want to come along while I walk the dog?"

Then the phone rings, and this former accountant fumbles it, unsure how to answer. He can't close the sliding glass door in his kitchen. At lunch, he carefully sets his hoagie on his place mat, next to the empty paper plate.

This is the often-hidden middle stage of Alzheimer's disease, the stage where caregivers seem to struggle most.

"Many people have a stereotypical idea that Alzheimer's disease is what you see in a nursing home," Mittelman says. But, "in the middle stage, there are behavioral problems which are difficult to cope with."

Dolores Melnick has looked, in vain, for help.

As her husband was turning 60, Mrs. Melnick noticed he'd lose his wallet or keys a lot. Trouble with routine accounting work soon forced him to retire.

Worried, Mrs. Melnick sought long-term care insurance. She listened in as her husband was screened over the phone, aghast that he was failing simple memory tests. The insurer turned him down, and soon Alzheimer's was diagnosed.

To fill his days, Melnick got a job at a nearby convenience store, mopping floors and doing other easy tasks until he was fired for forgetting instructions.

Mrs. Melnick is 63, two years shy of Medicare and three years away from her normal retirement date. She loves her job, a statistician at a cancer center. But she considered quitting to care for her husband, only to learn that retaining health insurance for herself plus his Medicare expenses would cost a staggering \$700 a month.

"It's kind of hard to retire," she says with a weary smile.

But what to do with Melnick while she's at work?

He can't remember a plot long enough to read or watch movies. He used to take pride in household chores, but now can't work the appliances. Even emptying the dishwasher ended when "dishes were all over and I couldn't find them!" Mrs. Melnick says with a laugh.

He refuses adult day care. Insurance won't pay the \$17 to \$22 an hour that local home-health agencies charge for a visiting aide, and Mrs. Melnick couldn't afford that.

So she cobbled together a compromise: She pays a friend about \$30 a day to stop by around noon for three hours, to make lunch, help walk the dogs and provide some companionship. Melnick spends the mornings and late afternoons alone, outfitted with an electronic tracking bracelet provided by the sheriff's department in case he wanders outside and gets lost.

When she has an out-of-town business meeting, her 85-year-old mother-in-law comes to stay. Every few weekends, her daughter makes the three-hour drive from Washington, D.C., to help out.

And Mrs. Melnick races home from work at 5:15. If she's late, she'll find her husband pacing, wondering where she was. It's a hint of Alzheimer's classic "sundowning," where agitation increases with dusk.

### **Trying to help**

Some states are trying new ways to increase Alzheimer's services. In Colorado, for example, officials experimented with giving \$1,000 stipends to help families hire monitoring for their loved ones so they could attend a six-session training program called the Savvy Caregiver.

That doesn't buy much respite, but it's a good investment, says Cheryl Dunaway of the Colorado Alzheimer's Association.

"The caregiver is the one who sets the stage for whether it's a good day or bad day, calm day or chaotic day, in how they respond to the way the person with dementia is behaving," she explains.

In Congress, Sen. Barbara Mikulski, D-Md., is pushing legislation that would provide a \$3,000 federal income tax credit to offset some of the expenses and lost income incurred by caregivers of patients with Alzheimer's and other diseases.

NIH's Suzman says those costs increase as dementia worsens, from about \$7,400 a year for moderate dementia to \$17,700 for severe dementia.

Back in New Jersey, Mrs. Melnick is anxiously hoping that tax credit will help. Within the year, she expects to have to hire someone to watch her husband all day while she works.

Trying to plan beyond that brings only fear.

"Do I have to think about a nursing home in a year, two years? ... It's not like cancer, where they say you have six months to live. They really can't say that with Alzheimer's."

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<http://www.nctimes.com/articles/2008/05/19/health/z772f1badf4133f5f88257443000a9af0.txt>



Alzheimer's patient Dorothy Eckert and her husband John Eckert, hold hands at their home. They now sleep together on the floor and wind chimes jangle when she's up so he can better control her wanderings. (AP Photo/Matt Rourke)

Alzheimer's patient Robert Melnick, with his wife Delores and one of their dogs, Kiowa, outside their home in Hainesport, N.J. Because he refuses to attend day care, she has hired a friend to make check on him while she is at work. Within the year, she expects to have to hire someone to watch her husband all day while she works. (AP Photo/Mel Evans)

