

## Slowly fading away: Families, patients share the toll of Alzheimer's

By Tom Kiskan

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Alan Ringer and his wife, Linda, share a moment recalling the special dinner they had in this room at Westlake Health Care Center in Westlake Village on their last wedding anniversary.

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She was fine two days earlier. Fine meaning she sat in a wheelchair fidgeting with the fabric seat belt that kept her from falling, blowing air through her lips and occasionally saying a word or two.

"Margaret, do you look after me?" Delton Lee Johnson cooed at his wife of 54 years, one of the more than 13,000 people in Ventura County diagnosed with Alzheimer's disease in a number that could double over two decades.

"Yes," she whispered.

As U.S. Department of Health and Human Services officials try to formulate strategies for fighting a disease that kills brain tissues and nerve cells in an ultimately terminal process that can span 20 years, families are trying to help them understand the power Alzheimer's wields over their lives.

Caring for his wife and keeping her out of a nursing home is Johnson's singular focus. He puts a bib on her before feeding her dinner, pieces together a video system so he can monitor her on an iPhone and, at age 79, strains to lift her into his Mercury Villager van for a ride.

On a Friday morning, Johnson's words brimmed with fear. His wife wouldn't wake up. She was so unresponsive the night before he couldn't change her diapers. He tried to call the doctor. He was on vacation.

The retired schoolteacher and antiques collector thought the end might be here. He knew there will be a time when Margaret Johnson's death will be OK. But he didn't believe she was ready yet. He knew he wasn't.

"We do pretty well. In spite of all the trouble, we're happier than most people," he said, his voice trembling. "I don't know how I would ever get along without her. I don't know what I'll do."

This year the federal government will spend about \$450 million — or less than one-tenth of what is spent on cancer — to fight a disease that afflicts 5.4 million people. That population could triple by the century's midpoint, pushed by the landslide of aging baby boomers.

Congress passed the National Alzheimer's Project Act in December to start building the first national strategy for finding medicine and methods to control a disease that has no cure. Government agencies will look at fixing a system that provides only a handful of support services and shoves the burden of care on spouses and adult children.

Alzheimer's advocates contend the only way for government leaders and people fortunate enough not to be touched by the disease to understand is to see it from the inside. Four families in Ventura County allowed The Star into their homes and care facilities. They told their stories about the first clues of memory loss, worries about falls and wandering and the ending that awaits their loved ones.

"I hate it when people say I'm lucky," said Joan Hull of Thousand Oaks, who sometimes hears the comment from other caregivers envious that she has a job that allows her a life outside of her husband's Alzheimer's. "There's nothing about this disease that is lucky."

## Fading away

Vern Hull arrived at a board-and-care home in Westlake Village with a blue Reader's Digest volume of condensed novels, the same book he's been carrying for more than a year.

The 60-year-old Thousand Oaks man with the T-shirt from some long ago 5-kilometer race knows he has Alzheimer's. He calls it his "condition" and says he was diagnosed five years ago. Though his wife says he'll make up facts when he can't remember them, this time he's right.

"It's some kind of thing inside of me," he said, trying to think of a way to explain, then giving up and offering a wan smile. "I'm blank. I hate that."

A lifetime ago, he was an outdoorsman who met his wife-to-be at a whitewater canoe race. It was his kindness that struck her — the poster of starving children he kept in his tiny Torrance studio to remind him to give money.

They moved to Thousand Oaks in 1997. A welder who worked for the same company for 25 years, he switched jobs at age 46 and started working as a construction laborer.

"He started having problems right away," said Joan Hull, who commutes four days a week to her job at [UCLA](#). "He couldn't hold a job down."

The lapses grew. He forgot to pick up his 13-year-old daughter at her friend's house. He'd decide to barbecue on the day Santa Ana winds were gusting. He jogged without water when the temperature was nearly triple digits.

He finally found a job that he could keep, as a school custodian with a supervisor who watched over him. But he still made mistakes. Eventually, a school official peeked into a room and saw Vern Hull staring at a vacuum cleaner. He couldn't remember how to turn it on. The principal summoned Joan Hull and told her it was time for her husband to retire.

He had been diagnosed with Alzheimer's by a UCLA neurologist in 2006 while he was still working. He was part of the 5 percent of the Alzheimer's population where the disease emerges early, in their 40s or 50s.



PHOTO BY KAREN QUINCY LOBERG, VENTURA COUNTY STAR

Tracy Hull, 21, and her father, Vern Hull, 60, arm wrestle, testing his strength at home in Thousand Oaks. Vern Hull says he feels like a burden on his family because of his Alzheimer's disease and has a hard time with feeling down.

Every morning, Joan Hull gets out of bed at 4 a.m. and leaves for her job as an administrative analyst at 5:15 a.m. She returns home at 4 p.m. to do the laundry, serve the dinners she prepares on weekends and help her husband use the television's remote control.

"I can't have a conversation with him. I can't play a game with him. I can't go on a hike with him," she said. "It's kind of like he's my child now."

Once when she was feeling overwhelmed, she vented to her husband.

"I said it must be really nice not having any stress," she said. "He started crying. He said 'You don't think I have any stress? You don't think it's not stressful to put something down and not see it again?' "

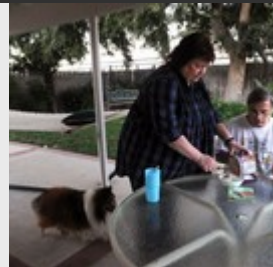
Vern Hull spends his days at an Oxnard adult day health care center, a facility that expects to stay open despite the planned elimination of state funding. Until recently, the center's bus picked him up a couple of hours after his wife left and dropped him off before she returned home.

That daily brush with independence ended when Joan Hull discovered the man who has trouble with stairs dragged a ladder out of the garage and climbed it to start picking oranges.

Now, she takes him to a friend's board and care facility for two hours each morning and two hours each afternoon. Several of the residents have Alzheimer's. One, a retired engineer in his 90s, was widowed but doesn't know it. Operators of the home decided not to tell him because it would hurt him too much in a process that would have to be repeated regularly because he wouldn't remember the news. It's a decision Joan Hull understands.

"I think I wouldn't want him to be told unless he just asked," she said of her husband. "I hate causing him pain."

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## Feeling lucky

Ruth Kennedy is different. She doesn't feel alone. She feels lucky.

"Blessed," she said, sitting at a tiny table in an east Ventura studio apartment, an arm's reach from her husband, Melvin. He rested on an easy chair, his attention and the furniture swiveling between his wife's words and a television tuned to an easy listening channel. The bed was three steps away. So was the refrigerator.

The place is too small but they can afford the rent on the \$1,600 they receive monthly in Social Security, augmented by interest from investments their children made. Ruth Kennedy worries any disruption, anything new, could push her husband into the decline that would push them apart after 64 years together.

"It's a tiny place but it's OK," she said. "I'm not moving. I'm not taking any chances."

Melvin Kennedy, a retired printer who once ran his own plant, was diagnosed with Alzheimer's six years ago, at age 78. He wandered away into the apartment complex earlier this month — the first time he's been lost, according to his wife. A neighbor pointed him home.

He's 84. She's 81 and has problems with her kidneys and her colon. She sees a psychiatrist too.

"The depression snuck up on me. I didn't know I had it," she said, blaming the condition on not taking care of herself.

Her biggest fear is all the dominoes will topple at once. She won't be able to care for her husband anymore.

"It's going to happen. Eventually, he's going to need more care than I can give," she said, preparing for the day by compiling a list of things she wants to do, like take a cruise into Alaska and learn Spanish again. But it's all a coping device.

"My primary focus right now is the same as his — to take care of each other," she said.

He doesn't remember that he has arthritis, knows about the Alzheimer's but says he doesn't think about it much. He says "Bonanza," the 1960s western, is his favorite television show though they haven't watched it in years. He likes reality dancing shows too.

"Beautiful girls? Yes," he said, flashing a gaptoothed grin.

His favorite thing?

"Chase the wife," he said with another grin.

His wife focuses on optimism, pairing every story about limitations or health concerns with a snippet of a silver lining.

"One thing good," she said of Alzheimer's memory loss "is everything is new. Everything is fresh."

Most Saturdays, the Kennedys go to their daughter's home for dinner and a movie. They have three children who live in Ventura County. All are constantly on call. The neighbors in the apartment complex help too.

"I find that people are generally very, very good," said Ruth Kennedy. "I really am lucky. I've got all these people and they're willing to help."

## Never coming home



PHOTO BY KAREN QUINCY LOBERG, VENTURA COUNTY STAR

Linda Ringer, who has Alzheimer's disease, rests her head in her hand as she waits for dinner at Westlake Health Care Center in Westlake Village. Her husband, Alan, cared for her at home until his health was compromised.

Linda Ringer's art — acrylic paintings of poodles, watercolors of lakes and forests — cover the walls of the Westlake Village home with the high, elegant ceilings she won't see again.

"I still feel guilty when I come home," said Alan Ringer of returning here after visiting his wife in a nursing home room she shares with another woman. "I think 'This is our house.' I get to live here and she doesn't and she probably never is going to again."

They've known each other since they were 15 and dated in Columbus, Ohio, before going their separate ways. More than a decade later, after he was divorced and she was widowed, they reunited. They married 43 years ago on a February Wednesday in a tiny chapel in Las Vegas.

She was a stay-at-home mom, a gourmet chef who cooked from scratch and a hostess who decorated her dining room for Thanksgiving and Hanukkah. He was a roofing and sheet metal contractor who sold his business and ended up teaching English as a second language.

Eight years ago, things changed.

"She would wake up at night and not know where she was," said Ringer, telling of the day his wife opened every food container in the kitchen and the morning she woke up and didn't recognize her bedroom.

"She thought she was in a hotel," he said.

He took care of her alone for four years. He changed the bed at night when she had accidents. He called paramedics when she fell in the foyer and couldn't get up.

"I had to call 911 that year 11 times," he said.

He was deteriorating too. Stressed out and exhausted, he went to a doctor who was alarmed and immediately sent him to the emergency room.

"Basically, my system was shutting down," he said, noting his blood pressure had fallen to new lows. "He said it could cause my heart to stop beating any moment."

After eight days, Ringer came back from the hospital and started caring for his wife again, this time with the help of a certified nursing assistant. After several months, Linda Ringer fell again, dragging the nurse down with her. Her husband couldn't shake the fear she would hurt herself and he wouldn't be strong enough to help.

Reluctantly following the advice of his doctor, he placed her in a board-and-care home and, 10 months after that, in a nursing home. He told her it was temporary, knowing it wasn't.

Linda Ringer has days when she tells stories from high school or about the horrible waitress in the restaurant the day they got married. Most days aren't so good. On a Thursday, agitated by unexpected visitors, she covered her face in her hands and moaned, cheering up only at a special dinner when a singer in Willie Nelson braids serenaded her.

Ringer visits five or six times a week. They sit in her room or sometimes roll her wheelchair down a hallway to an activity room with big windows. On their anniversary, the staff cleared everyone else from the room and served them dinner with candles.

They go on outings to his daughter's or son's home. A doctor and a psychiatrist have told him not to take her to the home they made together because leaving again would be too hard. Still, sometimes she asks.

"I sort of evade the question," he said. "I generally try to change the subject or I say 'Not today.'"

## Still happy

Delton Johnson's scare turned out to be just that. A scare.

Unresponsive on a Friday morning, 75-year-old Margaret Johnson was doing better that night. But her husband knows she's in the final stages. He doesn't fixate on it and never considers the possibility that her last days should be spent in a nursing home where he wouldn't have to worry about lifting her into the van, or what to do if she doesn't awaken.

He said she's better with him, on the winding hillside road in Santa Paula, in the house they bought 37 years ago for \$38,500. Together, he said, they're OK. They are happy.

"She would think why did he abandon me and stick me in this place," he said of the alternative.

The insurance benefits that pay for the caregiver who helps them every morning and night run out next year; he's not sure she'll still need care. The "do-not-resuscitate" message on the refrigerator door instructs paramedics not to revive her without talking to him.

He's prepared. But he's not sure how he will react when it's time. He also doesn't know about being certain when it's time.

"Maybe it will never be the right time," he said.



PHOTO BY ROB VARELA,  
VENTURA COUNTY STAR

Delton Johnson smiles at his wife, Margaret, who has Alzheimer's, as they spend a quiet afternoon on the portico of their home overlooking Santa Paula.