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When dementia upends a marriage: Inside the emotional journey

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The car was already packed for Park City when Dick Marks asked his wife a question that brought their summer plans to an urgent halt and further tested the strength of their 26-year marriage.

Driving 10 hours from Rancho Mirage to northern Utah was already a much simpler journey than the worldwide touring they'd continued together even after Dick suffered a major stroke a decade earlier. Dick's walker hadn't stopped him, with Barbara by his side, from seeing the palaces of St. Petersburg and the grasslands of Africa. Now Barbara had decided that Dick's worsening health made those trips impractical.

Then finally, impossible.

Just the night before, Dick talked excitedly about the trip and summer away in a rented condo. Then the next morning, as Barbara packed her last few things, Dick walked into the bathroom and asked what she was doing.

“I'm packing my cosmetics and then I'm ready to go,” Barbara said.

“But those are Barbara's things,” he said.

The response gave her a chill. The dementia and paranoia she'd maneuvered since Dick's stroke had suddenly advanced to a new horrific stage where he thought his wife was an impostor.

“It was almost like a psychotic break,” Barbara, 75, says now. “We wound up in the hospital. We never went to Park City. And that was the beginning of the end.”

A series of strokes have left Dick with vascular dementia. He is unaware of his living circumstances and will assume he's in a hotel. But he does know Barbara, and that's a small blessing compared to what many spouses and children of dementia patients experience as they see those memories fade in the disease's progression. It took months for Dick to recognize his wife of nearly three decades. Four years later, he's living in a nursing home near the house overlooking a golf course they purchased in 2000, two years before Dick had his first major stroke. Barbara now drives to visit her husband every day, sometimes more than once.

Dementia's toll goes beyond the patient. Family members who step up to care for these patients often feel overwhelmed due to the increased stress and responsibility.

In 2011, more than 15 million Americans spent 17.5 billion hours, or an average of just under 22 hours per week, caring for a family member with dementia, according to the Centers for Disease Control and Prevention.

And it can go on for years. Jerry Sallo can't count the time spent. He was married to his wife, Jane, for 61 years, and she fought Alzheimer's for nearly 10 years.

“It's a gradual, terrible, horrible progression,” says Sallo, 86, whose wife, Jane, died in September after fighting Alzheimer's disease, the leading form of dementia.

Jane was primarily a housewife who raised three kids while staying active in social groups, including terms as president for the family's temple in Burbank and the local Jewish Family Services.

Toward the end, Jane was forgetting her children's names and calling Jerry "daddy." She often talked to herself in the mirror. Once, Jerry stood quietly outside the bathroom door and listened. Jane was talking to her long-dead mother.

The television scared and confused Jane. "Can they see us?" she asked Jerry one day as they sat watching TV.

One afternoon Jerry came home to find Jane and her caregiver watching reruns of "Will & Grace." Jane would have never watched the show, but it was safe now because the commercials were so benign. Otherwise, a commercial for "The Walking Dead" might flash on screen and send Jane into a panic.

"This is what you're dealing with," Jerry says. "You can't comprehend it. Nobody who's not done it can comprehend it."

Dementia covers a group of disorders identified by cognitive impairment and memory loss that typically arise in older adults. Because it's a range of conditions, the exact prevalence of dementia is hard to pinpoint. But one 2013 analysis estimated that between 5 percent and 7 percent of people 60 and older worldwide have some form of dementia.

Alzheimer's, the most common cause of dementia in older adults, is characterized by a gradual decline in memory and brain function caused by the buildup of materials in the brain called plaques and tangles. As many as 5.3 million Americans have Alzheimer's. As the population ages, that number is expected to more than double by 2050.

Medical conditions that affect the brain, including strokes, can cause other forms of permanent dementia. Still, other types are the result of the gradual dying off of brain cells.

With more people living longer, the number of Americans suffering from dementia is also rising. According to the Alzheimer's Association, one in three seniors die of some form of dementia.

Each Wednesday morning, Jerry and Barbara have a chance to talk with people who understand. They are both seasoned veterans in a weekly caregivers support group organized by the Alzheimer's Association that meets in Rancho Mirage.They take their seats in a circle with a dozen people or more, some of whom have become their close friends. Many are caregivers, like Barbara, and usually a spouse. Other members are like Jerry and have lost their wives or husbands, sometimes years ago. One woman, in her 80s, was caring for her son-in-law, in his 70s, and had recently moved him to a nursing home.

Considering that 40 percent of Alzheimer's caregivers die from stress-related disorders before the patient dies, according to one Stanford University study, the group makes the health of the caregiver as important as that of the person they're looking after. The same study found that Alzheimer's caregivers have a 63 percent higher mortality rate than non-caregivers.

Each person has a chance to talk, vent or query the group. And the topics range from the bureaucracies of insurance and legal matters to the extremely personal. One morning in January, a woman came in hours after the man she'd been with for 15 years died. The group then spent much of the next two hours opening up about their own grieving process.

Another time, a woman asked what to do now that her dementia-suffering husband was asking to see his brother, whose death she never shared. The group decided it was OK to tell him he must have forgotten the news, but only if he brought up his brother again.

As a fairly new member, Jerry asked the group what to do about Jane refusing to change her clothes before bed. Let her wear whatever she wants to bed, they told him, this fight was not worth having.

Another morning, Jerry dragged himself into a meeting after several nights of interrupted sleep. A widow looked him over and said, “Jerry, you look terrible.”

He couldn’t deny it. “That kind of honesty was helpful,” he says.

Candi Lindig, 60, began attending meetings after her husband, David, was diagnosed with a mixed form of dementia in 2010. She continues to go regularly since David died in October, on his 84th birthday.

The meetings start at 10 a.m. When they wrap up around noon, Candi is among the members who will often continue talking over lunch. As she dealt with her husband’s disease and how to care for him, the group was Candi’s best resource. She never read any of the many available books or went online seeking answers.

“You don’t know what to trust,” she says. “I trusted the group.”

Bruce Lansbury built a career sending shows like “Wonder Woman,” “Mission: Impossible,” and “Knight Rider” into American living rooms starting in the 1960s. His older sister, Angela, starred in “Murder, She Wrote,” which Bruce wrote and produced in the 1990s.

Angela is acting into her 90s. Edgar Lansbury, Bruce’s twin brother, still works as a painter. But Bruce, 86, is now confined to a La Quinta care facility specially geared toward Alzheimer’s patients.

“Bruce used to be one of those guys that did The New York Times crossword puzzle in ink,” his wife, Gail, says. “And now he can’t sign his name.”

Whereas other friends have receded from her life, the support group members understand what’s happening.

“People who have known us as a couple have disappeared,” Gail says.

Friends from out of town would visit, but Bruce couldn’t remember them and conversations were a struggle. And then those friends didn’t want to come back.

“He’s not much of a conversationalist, but he’s listening,” Gail, 73, says.

Alzheimer’s gradually affects a person’s brain function and memory. It is slow and irreversible. Its causes are not fully understood but are believed to involve genetics plus some combination of environmental and lifestyle factors. Activities that stimulate the body and mind are thought to help, and prescription medication can temporarily slow the progression once early symptoms are detected.

Bruce’s Alzheimer’s began typically, moments of harmless forgetfulness that could have been considered normal signs of aging. When he couldn’t find his way home in the car or follow Gail’s directions over the phone, she decided Bruce could no longer drive. Those dramatic memory problems distinguish dementia from the normal aging process.

Eventually, Bruce couldn’t be left alone, so Gail took him along as she went shopping. He sat in Starbucks drinking coffee while she gathered the groceries. Then Bruce began to fall and was hospitalized after one serious accident. Gail decided she needed help and hired caregivers to be at the house three days a week.

She no longer had to be with Bruce every hour of every day. Those few hours were her time to do the shopping, see friends, attend the support group.

“You squeeze everything that you have to do into the times that caregivers are there,” she says. “And that gets difficult. You can’t be spontaneous. You can’t go out when you want. You’re kind of held hostage in a way because you need to be there.”

The caregivers started coming five days a week. After some time, even that wasn’t enough.

Gail awoke in bed at 3 a.m. one night and saw Bruce wasn’t in bed. Hysterical, she got dressed and ran out the front door. She found Bruce walking down their street lost and completely naked. “I’m so glad you’re here,” he said to her, without any sign of concern. “I couldn’t find the house. ”

The trauma pushed Gail to move Bruce into a nursing home about 10 minutes from their house in La Quinta.

Caregivers often say they waited too long before moving a person with dementia into a full-time care location. For Jerry Sallo, the decision came following those many restless nights that were noticeably draining his energy.

The heavy medications Jane was taking to help her sleep through the night weren’t working. She’d often wake up and wake Jerry in the process. Motion detectors placed in the bedroom helped him know when she was out of bed.

Jerry awoke one night around 2 a.m. to Jane screaming. He ran to her in the bathroom and found a geyser of water shooting up from the toilet and Jane soaking wet and yelling. She had removed a piece from the toilet tank causing water to spray everywhere.

Jerry shut off the water to the toilet, cleaned up his wife, changed her clothes and mopped up the mess in the bathroom. After trying his hardest to keep Jane at home, he says, the continuous lack of sleep “was really what tipped me over.”

Jerry was going out of town for his grand-daughter’s high school graduation. Knowing Jane couldn't travel, he placed Jane in a short-term arrangement known as respite care. What Jerry then thought would be a temporary solution for his wife, turned into a long-term plan.

“I remember after quitting smoking, the temptation to have a cigarette. And after three or four weeks into it, one of the things that would help you is you’d say ‘I’m not going through those three or four weeks again.’” Jerry says. “The pain of placing her, once I’d been through that and had her in a facility, I did not want to go through that again.”

Three months before Jane died, Jerry moved her into hospice care. After making final arrangements for his wife, the funeral director said to Jerry, “This is probably the hardest thing you ever did.”

No, Jerry said, this was nothing compared to how difficult it was to take Jane out of her home.

Despite her daughter’s urging, Candi Lindig never moved her husband into a nursing home. They argued about it, and though Candi looked into options, she never went through with it and continued to care for David at home until he died.

“It was literally draining the life out of her,” says Gabby Lindig, 26. She was helping care for her father while taking college classes. Up late at night studying for finals, she’d hear him pounding on the bedroom walls.

Gabby sees TV ads for the Alzheimer’s drug Namenda XR and gets angry. One ad shows a woman with an older man who could be her father getting ice cream, playing outdoors with kids, and talking to doctors. She places a green capsule in the palm of his hand. The whole thing is slow paced and calming.

“That’s not how it is at all,” Gabby said. “It’s the most stressful thing ever.”

Gabby was able to stay home with her father while Candi was out of the house. The family eventually used David's veterans benefits to bring caregivers to the house four hours a day and then hired full-time care in the final weeks of David's life.

Candi admits that she wanted to keep David at home for somewhat selfish reasons, but she had to consider what impact moving him would have on the family's finances. David lived longer because he stayed in his house, Candi believes.

"He was very much a social person but also a homebody," Candi says. "He liked his surroundings. He liked his familiar things around him. I think that's what helped him."

Jerry remembers his wife first showing signs of Alzheimer's about eight or nine years ago. Jane struggled playing with her granddaughters, and eventually her children asked Jerry what was wrong with mom. Then friends outside of the family noticed. When Jane was having trouble keeping up with her moshang club, she voluntarily quit before the other women asked her to stop.

"She never admitted she had Alzheimer's out loud, but I think she kind of knew it inside," Jerry says. "That had a good and bad side. The bad side is that we never really had a chance to say goodbye (and) we never had a chance to talk about what was happening. The good side is maybe she didn't really know what was happening to her."

Jane adamantly refused to undergo brain scans that would have helped diagnose what was happening to her, but did relent to questions from a neurologist.

At the hospital, the doctor asked Jane where she was. She didn't answer right away.

"He wants to know the name of the hospital," Jerry said, helping his wife.

Jane knew that answer: Eisenhower.

But the doctor knew better than to stop there. "Who was Eisenhower?" he asked.

Dementia care: when staying home is no longer an option

Jane, who got married the same year Dwight Eisenhower assumed the presidency, had no idea what the name meant.

David Lindig's memory problems also began as minor annoyances. Once a bottle of Windex ended up in the refrigerator. Then in 2008, he forgot to make the house payment and they were hit with a late charge.

Candi asked her husband what happened and he seemed indifferent. The statement was on his desk but he never bothered to mail the check.

"I started to take over the bills then," she says.

Money caused other problems. Even if David didn't retain a sense of its value, he wanted to have it.

David would go to the ATM and withdraw large amounts of cash. When he could no longer drive, he convinced friends or neighbors to take him to the bank, telling them Candi knew what he was doing.

Once, Candi was struggling to balance the checking account. She came up $400 short. She asked David about it and he denied knowing anything.

That night, while David was sleeping, she checked his wallet. Inside was the missing $400.

The workaround the family devised for David's money fixation was to give him small bills. Ten dollars, just in singles, was all it took. In David's birthday card, he got $1 bills, but he thought it was a fortune.

"They get to the point when they need to be watched just like a child," Candi says.

These were the kinds of special accommodations needed for a former U.S. Army man who served in Korea and specialized in juggling multiple roles. He found joy flying commercial airplanes and at one point ran a hot dog cart in San Diego and even appeared in a few films. While living in Ramona he answered a casting call for extras and ended up on screen in "Titanic."

When Candi was laid off from her job managing a retail store, she decided to stay home and care for David instead of going back to work. Losing her paycheck added to the the family's financial strain, even with the veteran's medical benefits David received.

"I could have gotten a job somewhere else as a manager or assistant manager, but I have no regrets because I got to spend more time with him," she says.

A simple treat would be taking David to Walmart. He'd get a haircut and some exercise walking around with Candi as she did the shopping.

While most members of the support group are retirees who have managed to afford to place their loved ones or bring in some level of part-time in-home care, some talk about the added stress of having to balance a work schedule on top of everything else. A woman who took her husband to daycare while she worked shifts at a department store admitted feeling guilty about taking him there even when she has a day off.

Gail Lansbury feels lucky to have the help of her famous sister-in-law. "I certainly couldn't do it myself," she says. "It would take up all of my savings and everything we've worked for."

At support group meetings, the stories of people struggling with finances are a reminder for Barbara Marks that, despite her own challenges with Dick, money hasn't been one of them. They met while pursuing business careers in New York City; Barbara was doing promotional work for Lifesavers candy and Dick was the company's vice president of sales. Dick ("Mr. Lifesavers" to respectful colleagues) continued to consult well past his retirement.

"I'm grateful that we worked really hard, and that we had a really good financial adviser, and that we put money aside when we were younger, and we saved and did all of that because it makes a lot of stuff possible," Barbara says. "It means that if you're paying $100,000 to put your husband in a facility then you can do it, and he can be someplace wonderful."

Barbara describes herself as Dick's "advocate," and she consistently reinforces the need for group members to have a similar attitude. It's a role she's taken on since Dick's major stroke, when he was in a coma and she sat in the hospital knitting scarves.

Six days into his coma, she awoke from the realization that her husband had been in his hospital room all of that time without the TV on. A former salesman, Dick was used to having the TV on in his hotel rooms as he traveled. Barbara went straight to the hospital and implored the nurses to keep the TV on. About 24 hours later, Dick started to wake up.

These days, she's still actively involved in her husband's care and meets regularly with the nursing home staff to suggest improvements. She brings his laundry home even though the nursing home will do it for a price.

“One thing I’ve learned is that even though my husband is in a facility doesn’t mean I’m out sipping cocktails somewhere.”

Before Alzheimer’s struck, Bruce and Gail Lansbury would take trips at least twice a year. Now Gail sometimes travels alone, like when she went to New York City for the holidays to see her son and daughter-in-law.

“Bruce is not Bruce,” she says. “He’s a cared for — and very well cared for — love of my life.”

They met in 1997 when Gail sold Bruce a home in Venice. The connection was immediate, but Gail waited three months after closing escrow to ask him to dinner. Their marriage the following year was the second for both of them. Gail was in her 50s and Bruce was in his 60s.

She knows it’s corny, but she’s convinced they’re soulmates.

“This was not in my plan for old age, let me tell you,” Gail says. “It’s not called the long goodbye for nothing. It’s a very long process. Bruce is now 86 years old, and he could go another 10 years or more.”

The grieving process also goes on for years, even before the person with dementia dies. In the support group, the men and women who’ve been through a death talk about the sense of the relief that can come along with the great sadness. Then there’s the finality of it and the realization that it’s time to enter a new stage of life.

Jerry’s gradual mourning process with Jane made her death easier to handle than what others might face. He was already used to sleeping alone when she died, but the sadness and the longing are still there.

“When my daughter tells me of the things she’d like to be able to tell her mother, I say, ‘You know, I’m 86 and there are still things I’d like to be able to tell my mother.’ So that never really goes away,” he says.

Something else that helped him was meeting someone new. Jerry isn’t the only member of the support group to try dating again before a spouse has died. When she started seeing another woman about a year before Jane died, his children were OK with it.

“That has helped me tremendously,” he says of that new relationship, “maybe kept me alive.”

When he looks back on dementia and his time with Jane, Jerry sees the lessons learned. One is that he’s capable of doing much more than he ever realized, capable of caring much more than he thought was possible. Another is about anger.

“It’s so easy to be angry with them when they keep asking you the same questions over and over again,” he says. “But I’m very angry at what happened to her, and I’m still angry.”

Spending 15 minutes with Jane was enough time to make Jerry so angry that he would get back to his car, slam the door and fume over what had happened to his wife. Driving home, he called his daughter to talk it out and to hear a familiar voice.

“It wasn’t so much poor me and what happened to me … but the horrible thing that she was going through and my inability to care for her,” he says. “I spent a lot of years taking care of this person and she took care of me. That was our deal.”

Barbara Marks has found comfort in the activities she’s always enjoyed. She’s reading for two book clubs, going to the theater whenever she can and planning trips with her grandchildren.

“I consider myself a wit,” she says, “a widow in training.”

Barbara has been grieving for years. Her husband is still there, but the relationship is slowly dying. Dick knows who she is and still has the same sense of humor Barbara has loved for 30 years, but he's often confused about where is. He sleeps a lot. His days of world travels are long gone.

"I've had all of these other experiences, so I don't miss having a man in my life because I still have my husband in my life," Barbara says. "It's not the same, but a lot of it is he can still get me more than anybody else I've ever met."

This past Valentine's Day, Barbara and Dick Marks celebrated their 30th wedding anniversary. Dick, who years ago thought another woman was impersonating his wife, was anticipating the celebration and waiting outside his nursing home for Barbara to arrive.

She came bearing his favorite foods — barbecue ribs, corn bread and chocolate covered strawberries — and a letter with a message of commitment to their marriage.

She reminded Dick of their wedding in Florida 30 years ago surrounded by their daughters and siblings, and a justice of the peace from the local traffic court. She reminded Dick of how they renewed their vows for their 20th anniversary with a black tie event and ceremony officiated by rabbi. Their six grand-children attended and harpist played wedding music.

"Today on our 30th anniversary, I once again want to recommit to our marriage." Barbara recited to Dick that day.

"You are and always will be the great love of my life. I promise to love, honor, respect and cherish you for as long as we both shall live. I will care for you and comfort you in sickness and in health. I will always be here for you."

Months after their anniversary, Barbara still carries around a folded up copy of that letter.

"It reminds me of my commitment to him," she says. "That's important when things get difficult."

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