

Praying for Time: Early-Onset Alzheimer's
GOOD HOUSEKEEPING
November 2000



November 25, 1999: in Morrison, Colorado, Linda Giere was getting ready for the Thanksgiving dinner she and her husband, Dave, were hosting. When their friends arrived in the late afternoon, Dave poured sodas and entertained everyone on the deck while they waited for Linda to call them in to dinner. More sodas. More conversation. Finally, after an hour and a half, Dave walked into the kitchen to refill a glass. Linda was her usual sweet whirlwind, but he noticed that nothing was ready. No sweet potatoes. No green beans. No salad or cranberry relish or pumpkin pie. Only the turkey, slowly roasting in the oven. "What's going on?" he asked sharply. Linda drew up short at his tone. "What do you mean, 'What's going on?'"

"When were you planning to serve dinner?"

"Oh...." she said vaguely, and laughed.

Dave was confused, then annoyed, then scared. He fixed some instant mashed potatoes, threw some vegetables and a salad together, and—calling their friends in—covered for his wife. But throughout the evening, he worried. Linda was both the kindest and the most organized person he knew. Something wasn't right.

June 28, 2002: driving across the hot, bright colorado plains, I

worry about meeting Linda Giere (pronounced "Geery"). Earlier, I had spoken to Dave and to Linda's mother, Lucy Prichard. But I hadn't talked to Linda herself and had no clue about what confusion I might find. How, I ask myself, does one interview an Alzheimer's patient?

The front door of the Giere home is flung open by a trim, suntanned woman wearing capri pants and a white shell. Linda is grinning, her ice-blue eyes lighting up and her nose crinkling. She has the kind of cropped haircut that looks great even when she plows her fingers up through it like a kid. I am so startled by her cheerful welcome, by how normal everything seems, that I nearly double back to check the address on the mailbox.

The Gieres live in a two-story cedar house in a subdivision carved out of the foothills of the Rocky Mountains. As Linda makes me a cup of coffee and we sit down at the long wood table near the kitchen, I am still trying to fit together what I had expected to see and what I am seeing. I think of what Dave told me on the phone a few days before: that the disease is spotty, that Linda has good days and bad. Clear moments and foggy ones.

She has also been helped by medication—so much so that she can now describe what it's like to have Alzheimer's disease, to fall into a place of utter blankness and to pull yourself back up. Over two days of visits, Linda and I chat like friends, almost as if it were a third person with Alzheimer's that we are discussing. All questions welcome, she dodges nothing.



With a degree in engineering management, Linda spent the 1980s overseeing the development of launch vehicles and missiles at

Martin Marietta Astronautics (now Lockheed Martin). She and Dave, an aerospace engineer, met as members of the team building the Titan II satellite launcher. "Almost everything on Mars today was built here," says Dave, a gentle, good-hearted man, 12 years his wife's senior.

They married when Linda was 35 (a second marriage for both), suffered through infertility, tried in vitro fertilization, and in 1996 became the grateful parents of twin girls, boisterous Hannah and introspective Rebekah.

Drawn increasingly to her faith, Linda left Martin Marietta in 1992 and started a second career in Christian counseling. She earned a master's degree from Denver Seminary and began to work with patients suffering from multiple personality disorder. Once an administrator who kept a hangar of rocket scientists on schedule and on budget, Linda now helped mentally disabled patients organize their thoughts. Naturally, she ran a briskly efficient household and also made time for hiking, golfing, and lunches with friends. In 1995, when she became pregnant with the twins, Linda stopped work altogether, wanting to spend as much time with her babies as possible.

But three years ago, she started behaving oddly. Dave was traveling a lot for work at the time. When he was home, things were off-kilter. "The washing machine is not working," Linda complained one day, showing him that both lights and darks had been washed together. How could that have happened if the machine were running properly?

"At Martin Marietta, Linda had been juggling 20 different tasks of high complexity," Dave says. "Now we started getting calls from her friends, asking, 'Where was Linda this afternoon? I waited for her, but she never showed up.'" Not only was she missing engagements, but Linda also seemed blithely unaware that she'd made them.

The evening she was late picking up the twins from their church youth group, mild-mannered Dave began to get angry and insisted that Linda make an appointment with the family doctor. She did so reluctantly. "My husband thinks I'm experiencing memory loss," she mumbled. Even more reluctantly, she accepted a referral to a neurologist. "We can rule out Alzheimer's," the specialist announced at Linda's first visit, "because early-onset Alzheimer's is hereditary, and you have no family history of the disease. Let's look for organic causes."

Though Linda struggled horribly with the memory portion of a written test, an MRI detected nothing. The neurologist, himself the father of twins, sat the couple down for good news: "It's depression; it's the stress of raising twins. Believe me, I know all about it!" The doctor, who was as happy with the diagnosis as the Gieres were, wrote

out a prescription for Prozac.

Linda started taking the medication, but it didn't seem to help.

One summer afternoon in 2001, she and Dave drove separately to her family cabin at Red Feather Lakes, in the mountains. Dave had Hannah with him, and Linda had Rebekah. "Linda had traveled this route since early childhood and had driven it on her own since she was 16," says Dave. They planned to meet at the cabin around 9:00 p.m.

At ten, Dave called the highway patrol.

"I missed a turn, a turn as well known to me as my driveway," Linda tells me. When she came to herself, she saw that she was not in the mountains. "I was down in some industrial area, utterly lost." Spotting a Wal-Mart, she went in to ask directions, but couldn't find anyone who spoke English. "It was like a nightmare. It was a nightmare," she says now.

Driving on across the flats, Linda saw the lights of a 7-Eleven and asked a man there for directions. "He tried to tell me where to go, but I was too flustered to understand. Then he said, 'Oh, look, here comes my mother,' and this woman, this total stranger, said, 'I'll lead you to your road. Just get in your car and follow me.' They were incredibly kind."

It was 1:00 a.m. when Linda arrived at the cabin. As Dave carried Rebekah in to bed, he thought, Something is very, very wrong here. They have Linda on the wrong medicine.

Dave could only see what was happening externally. But Linda was being shaken by interior events. "I'd step into the backyard," she says of their small patch of close-cropped dry grass and its view of the rocky hills, "and suddenly I was completely lost. Nothing was familiar." Simply sliding open the glass doors and stepping out from the den had caused her to fall off the map of the known world. "I didn't know where I was. I barely knew who I was," Linda says. "I was alone, frightened, and so terribly, terribly sad."

By that summer, such twilight zone episodes were engulfing Linda once or twice a day. Orientation would return piece by piece. "That's the slide of the girls' playhouse," Linda would think. "So that's...the playhouse. And it is sitting beside...the deck. There is...the porch swing. This is the back of my house. I'm home."

The few friends in whom Linda confided tried to assure her that their memory problems were just as bad, that they too forgot words or misplaced their car keys. "It's Alzheimer's!" has become a half-joshing, half-worried wisecrack of aging baby boomers.

But there was a difference. When a friend couldn't find her keys, it was because she'd absentmindedly left them in the ignition or tossed them somewhere as she entered the house. When Linda mislaid her

keys, it was because she had hung them on the hook by the front door—where they belonged, where she had always put them. They were not misplaced. She simply didn't remember that there was such a hook by the front door, if, in fact, she remembered the front door.

The almost-nauseating blankness of being without time, place, or identity stopped whenever a familiar face bobbed into Linda's line of vision. It was as though she'd been looking at the world upside down and then suddenly—as she saw Hannah, Rebekah, Dave, or her mom—she stood up straight again.

Linda became adept at bridging the dislocation, of swinging instantly into action as if her day were not breaking apart like a mountain glacier in the summer. She was covering up. What she was covering up, she didn't know. But it felt important to hide it from Dave.

When she lost herself, hesitated mid-action, and then was startled back into her skin, she wouldn't make eye contact with Dave or even look at his face; she knew exactly which creases of worry would have deepened above and between his eyes. "Girls, now!" she'd say briskly when she returned to herself, "Bath time!" And if they whined, "Mommm-mmy, we just took a bath," Linda felt exposed, found out. She avoided her husband's sad eyes.

By late fall, Dave knew they needed to see another doctor. He is a native of Rochester, Minnesota, home of the internationally renowned Mayo Clinic, and it was there that they headed for tests last December. On the long drive up, Linda and Dave reminded themselves of their neurologist's certainty that Linda was merely stressed by the difficulties of raising twins.

Privately, though, Dave feared much worse news. And privately, Linda struggled to remember where she was, moving her eyes from the scenery to the dashboard to Dave to her lap and around again, to orient herself. "I didn't really know why we were going to Mayo," she tells me.

It was a week of grueling tests—blood work and brain scans and long, exacting memory evaluations. Alzheimer's is essentially diagnosed by ruling out other disorders. "We ask if the memory loss came on gradually, or does the patient say, 'It started on November

12 at 8:00 p.m.," says Ronald C. Petersen, Ph.D., M.D., director of the Mayo Alzheimer's Disease Research Center. "If it's the latter, then we look for a stroke or other event. With Alzheimer's, it's hard to pinpoint the date."

The Mayo doctors worked their way through the checklist. On Wednesday, they told Linda and Dave that they had ruled out depression and stress. They had also ruled out a thyroid disorder, brain tumor, chemical imbalance, and stroke. On Friday, Dr. Petersen and David Tang-Wai, M.D., a fellow at the clinic, gave the Gieres their diagnosis. At 46, Linda had probable Alzheimer's.

The doctors were not only distressed, they were surprised.

"Alzheimer's is uncommon even for people in their 60s," explains Dr. Petersen. "To see a patient in her 40s or 50s is astoundingly rare."

What's more, as the first neurologist had told them, sufferers of early-onset Alzheimer's are often members of families with mutations on one of three chromosomes. But blood tests had shown that Linda Giere had none of these abnormalities, making her case even more unusual.

"We could barely get a handle on this devastating news," says Dave. "This time, the brain scan showed that the blood flow to the right side of her brain was significantly reduced." He begins to weep, then apologizes. "I get so choked up over these things," Dave says. They both cried all the way home to Colorado.

Once there, though, Linda began to chafe. While Dave had anticipated the diagnosis, to Linda it seemed to have come out of nowhere. Feeling more competent than she was being given credit for, she demanded a second chance to drive to the family cabin at Red Feather Lakes. Her husband and mother asked a doctor from the Denver chapter of the Alzheimer's Association if it would be wise. "Let her try," the doctor suggested.

Dave gave Linda a cell phone and waited at home in Morrison, praying that she would call triumphantly, fearing that she would not. She phoned from the cabin five or six hours after she left, briefly mentioning a long detour into Wyoming. The next morning, as Linda headed home, a light snowfall was thickening into a blizzard. Dave watched out the windows with rising anxiety for many hours until she called again. She was lost.

"Tell me what you're seeing," said Dave. She described a valley and offered details until he recognized the geography. He told her to park, lock herself in the car, and wait for him.

"The experiment was not a success," says Linda dryly. "But I needed that. I didn't want to believe what they were telling me. If I had made it to the cabin without trouble, I would have pushed to do

more and more."

She and I are sitting on a rock ledge above her house, where we've hiked on Saturday morning, just the two of us. Looking across the distance to the hillside covered with wildflowers, Linda tells me that she fell into a depression after the trip. "It felt like God had taken away everything fine in my life," she says. Always independent, she despaired that she could no longer be left alone. Her mother was spending more and more time with them to help with the girls and was soon going to move in. "I love my mom, but I felt I was being reduced to a child again," Linda says, a note of sadness in her voice.

The details of Linda's despair and disorientation are painful to hear. But it is remarkable that she is able to talk about them with such clarity. For this, she and Dave both credit Reminyl, a new drug specifically prescribed to treat the symptoms of Alzheimer's (there are two other drugs available). The medicine has enabled Linda to linger indefinitely in an early period of Alzheimer's, a period doctors call "preserved insight." In later stages, patients no longer realize they have a problem, explains Dr. Petersen. "But Linda is still aware that she is being challenged by this disease."

To the Gieres, Reminyl is a miracle drug. Linda feels that she has regained lost memory, and Dave says that her "executive function"—her ability to organize—has improved. "I look back at the way Linda was before the medication, and it scares me terribly," Dave says. "I am so grateful that there was never a terrible incident, a mistake with the girls...."

Reminyl, Dr. Petersen explains in a subsequent phone interview, revs up the brain. It may slow the progression of the disease, but it doesn't halt it. Researchers are working on drugs that will actually stop the deposit of the protein amyloid that triggers the disease—and even on a preventive vaccine. But these are years away.

Can Reminyl allow Linda to tread water until these stronger new pharmaceuticals are on the market? No one knows. All Dr. Petersen can say is that Linda is "extremely fit, bright, young." The statistics—at 70, a diagnosis of Alzheimer's carries about an 8- to 20-year life expectancy—aren't accurate for a woman her age, he notes. "Maybe it's someone like Linda who will give us new insight into the disease."

"So how do you go on?" I ask Linda, meaning how do you raise children and sustain marriage and friendships, with the virtual certainty that memory loss and physical debilitation lie in wait earlier for you than for your peers.

"Well, for starters, you don't lose your sense of humor!" she

answers. These days, when things get screwed up at home, Linda laughs and says, "Hey, don't blame me—I've got Alzheimer's!"

"That is not funny," says Dave, looking up from a nearby armchair.

"He's from Minnesota," she tells me, smiling. "They don't do humor."

Linda joined a support group in Denver for people with Alzheimer's. "The first meeting was called, 'Getting Started with Alzheimer's,'" she says. "Dave and I laughed all the way home about that." She attends all the meetings now and goes on hikes and field trips with the group. "The folks there call me The Kid," she says, smiling.

"It also helps that I've told my friends," she adds. "The Alzheimer's Association encourages you to be open, so I shared the news." Linda is grateful for the friends who were sympathetic and supportive and for those who shared their own private crises in return.

So far, the twins know only that "Mommy has trouble remembering things." But they worry about her and are extra protective. Recently, when they were all out driving and Linda took a wrong turn, neither daughter said a word. "They didn't want her to feel bad," says Linda's mother.

After the diagnosis, the Gieres started to worry about who would help with the girls, especially when they were older. Comfort came from a surprising quarter—Dave's son, Matt, from his first marriage. Their relationship had been strained for a number of years, but it was Matt who phoned one evening to say that he and his wife—themselves parents of two children, with a third on the way—would be there for Hannah and Rebekah. "Dad, I love you and I love those girls," he said.

"We will do everything in our power to help you raise them." Matt was even concerned about the couple's financial situation. "Should I start saving for Rebekah and Hannah's college education?" he asked.

The Reminyl has allowed Linda to sustain a semblance of the life she once had, though she has given up her plans to go back to work and to get a Ph.D. Last January, Dave took early retirement, and in August, Linda's mother, Lucy, officially moved into the Giere home.

"This is where I needed to be," Lucy says simply. "It's important to keep Linda level, to keep a routine going."

Lucy and Dave take turns fixing dinner: "I cook one night and he cleans up. Then he cooks and I clean up." Linda has chosen her own chores, says Lucy. "She loves the garden and her yard work." And if Linda starts to do something around the house and doesn't finish, Lucy quietly takes over. "But I don't want to take Linda's place with the

children," she insists. "They know that she is Mommy and I am Grammy."

Linda says that she is grateful for the loving care, but sometimes feels a little suffocated by the watchfulness. That's why driving is so important to her, the way it is to a teenager with a new license. Linda's new Denver neurologist told them her spatial perception was flawed and that she couldn't get back on the road until she had a professional driving assessment. "I was devastated," Linda says. "I thought, What will I do with myself?" She passed the assessment and is, says Dave, "doing fine with short runs and errands, even driving the girls to school, church, the grocery store." Linda will have another review when her family feels it's time.

On good days, Linda can do a lot—pick up Rebekah's sweater and put it in the right drawer in the upstairs dresser, buy milk at the grocery, set the table, laugh with a friend on the phone after dinner. She still dresses carefully, even stylishly. Always, though, she has trouble with numbers and dates. Dave has posted a sign announcing the day of the week by the coffee-maker, and some days he must remind her to take her medication.

Linda acknowledges that she has to summon up a lot of energy to do tasks. And there are things in her life that she has had to let go: books, for one. It is too hard to grasp fictional situations. It takes all her effort to be in reality.

Sometimes the blankness of Alzheimer's returns. Then Linda is unable to connect to the routines or items that make up ordinary life. Alone—and Dave and Lucy try not to shadow her—she drifts from object to object in her home, as if she were a browsing tourist in a gift shop. She may hear the buzz of the dryer in the basement, she tells me, and she'll turn toward the sound, her body summoned by a task.

But what task? It lies just beyond her mind's grasp. Later, when she sees her mother pop out of the basement with a stack of folded towels in her arms, Linda suddenly pictures the dryer.

Sometimes an object fades out of memory and then back in, as if Linda trained her camera on it and twisted the lens from a blur into focus. Weighing the remote control lying in her hand one afternoon, Linda had no more notion of what it was than a kumquat. Yet a day later, she snatched it up, pointed it at the TV, clicked Off, and told the girls it was bedtime. And she knows that this time she must have been right—it must have been bedtime and not ten in the morning—for when Rebekah and Hannah grumpily got up, they were wearing their pajamas and slippers. Linda privately rejoiced.

She tries hard not to imagine the events she may miss—graduations, weddings, grandchildren—and to lower her sights enough

to have each good day be sufficient. "I start my day with a prayer," she tells me. "Lord, you know I'm here and you know I love my family and I love my life." At night, she thinks, "This was a good day. Thank you."

When nearly all else has gone—and may it be many, many years before Linda Giere drops for the last time off the solid deck of name and place and time, unable to scramble her way back up—what will be ingrained in her memory? The sturdy mountains, perhaps, chiseling a rough border below the blue western sky. An image of the girls as sitting-up babies, gurgling with laughter in front of the fireplace. And Dave, Rebekah, and Hannah lolling in a sloping field of mountain wildflowers. These are her most precious memories. They are the ones she hopes never to lose.