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When Alzheimer's Hits at 40

Early-Onset Sufferers Juggle Children, Job and Dementia

By SHIRLEY S. WANG

Brian Kammerer, the 45-year-old chief financial officer of a small hedge fund, called his wife one day from a cellphone in the men's room of his Manhattan office building. A colleague had just asked him for something, he whispered, but he had no idea what it was.

"It clicks and it holds papers together," he said.

"A stapler?" Kathy Kammerer asked.

"I think that's what it's called," he replied.

Soon after that exchange in early 2003, the father of three was diagnosed with Alzheimer's disease, capping nearly five years of uncertainty and fear about his increasing forgetfulness and difficulty with language.

While most people who get Alzheimer's are over 65, Mr. Kammerer is one of about 500,000 Americans living with Alzheimer's or other dementias at an atypically young age. Alzheimer's takes a long time to develop—usually, it isn't diagnosed until 10 years after the first symptoms appear—but more Americans are identifying it early, thanks in part to aggressive screening programs pushed in recent years by groups including the Alzheimer's Foundation of America, a national alliance of caregivers.

The disease can be especially torturous when it creeps up on those in their 30s and 40s. As these patients move through Alzheimer's early stages, they are forced to cope with the dread of not knowing what is happening to them, often in the years when they're raising young children and building financial security. As the disease progresses, there are slip-ups to cover, appearances to keep up. When these "early onset" Alzheimer's sufferers are finally diagnosed, they face hard questions—whom to tell and when, and what these

divulgences mean for their jobs and health insurance.

Overall, an estimated 5.2 million Americans have Alzheimer's, with as many as 10% diagnosed under the age of 65—the definition of early onset, according to the Alzheimer's Association, a national research organization. As the population ages, the number of individuals with Alzheimer's is expected to hit 7.7 million in 2030.

There are no Alzheimer's cures now on the market. Current medications mitigate some symptoms but don't slow or halt the disease's progression. Pharmaceutical companies are working on new therapies that reduce or remove amyloid, a sticky substance in the brain thought to play a role in the disease. There are more medicines in development for Alzheimer's than any other neurologic disease except pain, according to Pharmaceutical Research and Manufacturers of America, the industry trade group. It will likely be years before a new generation of drugs makes it to market.

Now 51 years old, Mr. Kammerer, like many Alzheimer's patients, had no history of the disease in his family. He grew up on the north shore of Long Island, where he stood out at school for his talent with numbers. After attending college at the State University of New York-Albany, he got a job on Wall Street.

Mr. Kammerer met his future wife, Kathy, in 1983 at Donaldson, Lufkin & Jenrette, the investment bank where they both worked. Kathy, who had also grown up on Long Island, recalls not quite believing it when the handsome, fun-loving man with thick brown hair she was dating asked her to marry him.

They wed in 1991. Soon they had a son and two daughters, and Mrs. Kammerer stopped working to care for them at their home in Long Island's Massapequa Park.

Mr. Kammerer commuted into Manhattan.

Mr. Kammerer worked long hours in the office, his wife and former colleagues recall. But he also had a lively and self-deprecating sense of humor. Mrs. Kammerer said he was the life of the party. "He always had a cigar hanging out of his mouth," she says.

He had "a blue-collar mentality in a white-collar job," says Martin Jaffe, chief operating officer and co-founder of Silvercrest Asset Management Group LLC, who worked with Mr. Kammerer for 15 years.

Back home, Mr. Kammerer gave his children silly gifts like plastic glasses with fake moustaches and took his wife out dancing on date nights. He whisked the family away on surprise vacations to Florida. In the summers, he loved to barbecue and organized impromptu family slumber parties under the stars, his daughter Kate, now 13, recalls.

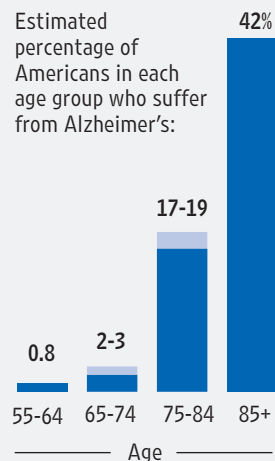
In 1998, Mr. Kammerer started complaining of ringing in his ear. He sometimes felt dizzy, Mrs. Kammerer recalls. Other times he gave his wife a look as though he didn't understand what she had just said. The Kammerers sought out a neurologist, who suggested Mr. Kammerer get a magnetic resonance imaging scan of his brain.

When the MRI results came back, they didn't look normal, the neurologist told the Kammerers. The doctor was unable to give them a diagnosis, however: He couldn't say whether there was something wrong, Mrs. Kammerer recalls, or whether Mr. Kammerer's brain had always looked that way.

Had they even suspected Alzheimer's, it would have been difficult to diagnose. Doctors look for patients or their families to report a collection of symptoms—such as forgetfulness, social withdrawal and difficulty planning

Age of Onset

Estimated percentage of Americans in each age group who suffer from Alzheimer's:



Source: Alzheimer's Association

or finishing complex tasks—that worsen over years. (The dizziness and ringing ears Mr. Kammerer experienced aren't generally considered symptoms.) Currently, Alzheimer's can be diagnosed conclusively only by autopsy.

Mrs. Kammerer recalls staring at the picture of her husband's brain. "This is our future," she thought. She wondered whether she would need to get a job again should her husband be unable to work. The idea of going back to Wall Street terrified her, she says.

The Kammerers agreed that until they knew what was happening, life should go on as usual. They said nothing to the children. Around friends and colleagues, they kept quiet about their concerns, fearing Mr. Kammerer would lose his job if word of his symptoms leaked out. "I lost a lot of sleep," Mrs. Kammerer says.

One day in 1999, Mrs. Kammerer grew more alarmed: Her husband couldn't remember the word "sneaker." Soon after that, he started saying things like "my

(over please)

brain is just not functioning right here," Mrs. Kammerer recalls.

That year, at age 40, Mr. Kammerer was named a Chief Operating Officer of DLJ Mutual Funds, a Donaldson Lufkin division. His new responsibilities included presentations to the board of a Wall Street firm of 11,300 employees.

Within a year, Mr. Kammerer was struggling more often with words, a symptom of the disease called aphasia. But, always gifted at math, he showed no sign of having trouble with numbers, a key part of his job.

To compensate, he worked into the night, when colleagues weren't around. He increasingly called his wife from work, reading her memos he had written to make sure they made sense.

Co-workers say they had no idea what he was going through. Debbi Avidon, who worked for Mr. Kammerer from 1993 to 2001 and is now at J.P. Morgan Chase & Co., says she noticed Mr. Kammerer's longer hours but attributed it to his workaholic tendencies. "He was always very diligent and thorough," Ms. Avidon says.

Mr. Kammerer also withdrew socially. The cigar-smoking stopped. So did social drinking.

Mr. Jaffe, Mr. Kammerer's former boss for much of his time at DLJ, says that had he known about Mr. Kammerer's memory problems, he's not sure what he'd have done. "I would hope we would take the high road," he says. He would have been concerned about whether the condition hampered Mr. Kammerer's command over important numbers, he says, which might have meant a change in job responsibilities. "There probably are many jobs you can do well with that malady," he says.

In late 2000, Swiss banking giant Credit Suisse Group acquired DLJ. As is often the case in takeovers, Credit Suisse cut some of DLJ's top executives. Mr. Kammerer lost his job in June 2001. His severance package included two years of salary and a year of health insurance. He took the rest of the summer off and played a lot of golf.

By then, Mrs. Kammerer says, her husband didn't recognize certain people and couldn't name some objects. He became good at covering, smiling if he didn't know

what he was being asked or calling people whose names he'd forgotten "sweetie" or "buddy."

Mr. Kammerer didn't consider leaving the work force. His kids were all under the age of 12. There were many more years of private-school and college tuition to pay.

But he began to lower his sights. Returning home from a positive interview for a prestigious job—running a European company's U.S. operations—he told his wife: "You know, Kathy, I don't think I can do this."

Instead, he sought out lower-level financial-industry jobs that wouldn't require him to work closely with others. He wrote out cue cards to take with him on interviews and changed the topic when he didn't understand what an interviewer had asked.

In 2002, he landed a position as chief financial officer at a small hedge fund, called Clipper Trading Associates, a position that involved managing the fund's accounting and administration but not making trading decisions.

During this period, Mr. Kammerer visited specialist after specialist, his wife recalls. Suspecting stress was behind his symptoms, he sought out a psychotherapist and was prescribed antidepressants. He took antibiotics for six months to treat what doctors thought might be Lyme disease.

His eldest child, Patrick, noticed that his father seemed particularly absent-minded. One day, Patrick says, he prank-called Mr. Kammerer at his new job and told him he was calling from "Clipper Hedge and Grass Trimming." Though father and son had often teased each other this way, Mr. Kammerer didn't recognize his son's voice or realize it was a joke, Patrick recalls.

One evening in 2003, after yet another test, a type of brain scan called a positron emission tomography, Mr. Kammerer's physician called. Sitting in their bedroom, Mr. and Mrs. Kammerer got on separate phones to listen in.

"Mrs. Kammerer, I have some terrible news," she remembers the doctor saying. "I believe your husband has Alzheimer's."

Mrs. Kammerer dropped to her knees. She recalls that her husband

didn't understand what was going on and told the doctor, "You have to hold on, something's wrong with my wife." They locked the bedroom door so the children couldn't walk in. After Mrs. Kammerer explained to her husband that he had been diagnosed with a form of dementia, they sat quietly. "Your life kind of flashes before your eyes," she says.

Mr. Kammerer had private disability insurance, but he relied on his job at Clipper for the family's health insurance. Another significant concern was the cost of the children's private school education. Mr. Kammerer decided to work as long as possible.

In 2004, Clipper announced it was shutting down.

The fund closed, it said at the time, because its potential risks in the market were outweighing the rewards it was offering its investors. Two of the fund's partners, David Dahlberg and Scott Simon, say they were aware that Mr. Kammerer had been having health issues, specifically "inner ear" problems. "It wasn't something that was affecting his job performance," said Mr. Dahlberg. He added that had the partners known about Mr. Kammerer's memory difficulties, he's not sure how the professional relationship would have changed.

"That's a difficult position for an employer to be in any business, let alone our business, where short-term memory is important," said Mr. Dahlberg.

By then, Mrs. Kammerer says, it was clear to her and her husband that he had deteriorated too much to try to find another job.

Mrs. Kammerer went back to work as an office assistant in the District Court in Hempstead, N.Y., providing the family with a small income and health insurance. His wife's return to work distressed Mr. Kammerer, who saw it as his responsibility to support the family, she recalls.

The Kammerers also filed for Social Security disability benefits. The attorney they hired to help them with the massive paperwork told them the process could take up to 18 months, panicking Mrs. Kammerer. But they caught a break: Their application was approved in five weeks. Mr. Kammerer's private disability

insurance policy, which he took out in the '90s, added several hundred dollars to their monthly Social Security payout and Mrs. Kammerer's court salary.

The Kammerers organized one last family trip to Ft. Lauderdale, Fla. They told Patrick about his father's condition before leaving, but waited until later to tell the younger children, Colleen, now 14, and Kate.

At the end of 2006, the Kammerers transferred their assets to Mrs. Kammerer's name to shield their estate from the treatment costs Mr. Kammerer is likely to face as the disease makes its slow progress. Mrs. Kammerer says her husband's care costs \$5,000 to \$6,000 a year in co-payments on top of what their insurance covers. The costs are likely to escalate: Mr. Kammerer stays home while his wife is working and the kids are at school. In-home care, or a nursing home, would cost more. Mrs. Kammerer says she hopes that day is still years away.

Mrs. Kammerer wrestles with when to take responsibilities away from her husband. He still has his driver's license, though he doesn't drive anymore. The plan is to have him sit in the passenger seat and supervise Patrick, now 16, as he learns to drive this year.

Ten years after he first complained of a buzzing in his ears and five years after he was diagnosed, Mr. Kammerer spends most of his days sitting in a club chair in his bedroom and working intricate number puzzles. Two days a week, he attends a program for adults in their 30s through 50s who have dementia, where his favorite activity is dancing.

His math skills remain sharp, but he has trouble recognizing neighbors he has known for two decades. Rather than fiddle with objects he no longer understands, such as the stove, he ignores them. Sometimes, he takes a cab to a nearby golf course without telling anyone and hitches a ride back from a stranger, which unnerves Mrs. Kammerer.

Mrs. Kammerer says the most difficult aspect of her husband's disease is that the couple used to be a team, but now she has to make the decisions on her own.

"We had a partnership and built a life together, and it was just taken away," she says.

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