Living with Grace

By Ashley Burden

Mary Ann Scheneman can't recall the first time her husband's memory began to change. "He's just an absent-minded professor," she thought. Stephen Scheneman was the Director of the Professional Development Office of Extension at Kansas State University. He had a PhD and a vocabulary to rival the most dedicated novelist; that's why it was strange the first time he struggled with reading.

"We were working together in the yard trying to assemble a project and Steve was staring at the directions. I asked him to read it aloud to me," Mary Ann slows as she explained; "He just looked at me and said 'I can't do it.'"

That was August of 2000 and a turning point for them both. "My stomach dropped," Mary Ann recalls. "I looked at him and said 'we've got problems.'" Steve was 52 years old.

What follows is the story of a family, brought together by a rare diagnosis and a painful reality. Steve Scheneman, married to his college sweetheart, whose youngest daughter was in 6th grade, was experiencing the symptoms of memory loss most associate only with senior citizens.

Needing Answers

The diagnostic process was arduous. They began with a family doctor who suggested a psychiatrist, assuming the symptoms were caused by depression. "After several meetings, the psychiatrist dismissed us saying there was no concern or issue," said Mary Ann.

Steve continued to work and adapt his life to his changing abilities until a month later when he received a message from an old friend. "The best man from our wedding, a lifelong friend of Steve's, called and left a message. Without the slightest hint of recognition, Steve asked me 'Who on earth is this'?" recalled Mary Ann. "I called the psychiatrist the next day for a referral."

A psychologist used a battery of psychometric tests including a standard intelligence test, tests for cognition and memory, and a test for motor skills. "The results were alarming," explained Mary Ann. "This well-educated man with a PhD tested with more than 1½ standard deviation below what is considered normal." Steve and Mary Ann were disappointed in the results as well and realized they needed to dig deeper.

Using an MRI, a neurologist was the first to mention dementia, pointing out aberrations on Steve's brain. After an unfortunate experience with a neurologist at the University of Kansas Hospital, Mary Ann took control of the diagnostic process and began searching the internet for answers. She was directed to Mayo Clinic. Their appointment was for June 1, 2001, a year after Steve's symptoms became concerning.

The diagnostic process for younger onset dementia patients is slow as most physicians overlook dementia, usually focusing on depression, vitamin deficiencies, infections or tumors. Often patients aren't referred for an entire workup until all other possibilities have been exhausted. With as few as 200,000 Americans currently living with younger-onset dementia, defined by onset prior to age 65, the likelihood of a confirmed diagnosis is slim.

Steve went to the appointment at Mayo Clinic apprehensively, knowing he had scored poorly on previous cognition tests. He confided in Mary Ann that his concerns ran deep, explaining the difficulties he was having at work; to write a letter required two hours of intense concentration and frequent references to his desktop dictionary. Mary Ann assured him they would get through this together, but she had her own concerns. She was considering her observations, remembering how he stumbled over the words "Potomac" and "Yosemite" while giving their daughter a spelling test. Though Steve blamed the error on his glasses, she was beginning to see the past with clarity, "The truth was all around me, I just chose not to see it."

Three days of tests followed at Mayo. Steve underwent extensive physical testing including an MRI and fMRI exam, cognitive testing, and a speech and language evaluation. The final results were clear: Steve had Progressive Aphasia, more clearly diagnosed later as Frontotemporal Dementia (FTD).

The Dementias

Dementia is an umbrella term referring to a group of symptoms such as memory loss, changes in behavior, disorientation of time and place, and depression. Alzheimer's disease is the most common form of dementia, but an extensive list of other possibilities exist including Huntington's disease, Pick's disease, vascular dementia, Creutzfeldt-Jakob disease, the list goes on. Frontotemporal dementia is a rare disorder that affects the front (frontal lobes) and the sides (temporal lobes) of the brain. Each form of dementia takes on its own characteristics but to select one as an exclusive diagnosis is not only difficult, it's nearly impossible.

To diagnose Alzheimer's disease with 100 percent certainty an autopsy is required to see the prime suspects of the resulting brain damage – plaques and tangles. For other dementias, brain atrophy is a result of a variety of abnormalities that must be viewed under a microscope. But the living diagnosis of today, when performed comprehensively by an accredited medical staff, is reliable and usually accurate. A definitive diagnosis, though exhausting, usually leaves families with a sense of relief – a chance to finally name the incessant symptoms and plan for the future.

Life Changes

Steve and Mary Ann took a moment to step back from their lives and reassess. With 30 years at the University, Steve decided to dismiss his previous plans of starting a second career and retired from his position. Their three children – two in college and one in middle school – learned what to expect and made adjustments in their expectations. In one year, their whole life changed.

Steve was uncomfortable remaining in Manhattan, Kansas, a small town where everyone would know his fate. He wanted a fresh start and he wanted to return home. The Schenemans packed their bags and moved to Columbia. When they told their youngest daughter Meredith of the move, she understood. "We need to do this for Dad," she responded.

"Steve found the peace he was looking for in the move. He wanted a fresh start where no one would have any particular expectations of him. We would be honest with everyone of Steve's diagnosis, but we wouldn't hide in self-pity," explained Mary Ann.

The Scheneman's fell into a routine. Meredith enrolled in school and tried out for sports. Mary Ann found a position in speech pathology at the University of Missouri. Steve remained at home, capable of doing housework and mowing the lawn. He began a program of speech therapy, designed by Mary Ann, to help him with vocabulary. He worked tirelessly, repeating words from flash cards, memorizing scenarios and answering questions in an effort to exercise his failing brain. Speech therapy gave him a sense of purpose and may have bought him months of independence.

But the incessant disease remained, though Mary Ann admits she was able to dismiss some of his losses. "I saw his abilities through rose-colored glasses," she admits, "which allowed me a more gradual losing process. I didn't realize until later how much I was helping him. Our children could so clearly see the loss, but I couldn't."

The progression of dementia is often slow but always inevitable. The drugs available to treat the symptoms of some dementias are limited in their scope and ability and are only approved for the early and middle stages of the disease. Patients often stay on the drugs to avoid the potential loss that could happen if the medicinal crutch is removed, but eventually the disease catches up.

Steve began a steady decline in ability marked with periods of more accelerated loss. Mary Ann's own outlook changed in correlation. "Each time he took a dive it became harder for me. He would reach a plateau, I would settle into equilibrium, and then he would take the next dive. Each time he declined, the depression weighed on me," she said.

The Time to Move

By the end of Meredith's senior year of high school, Steve had abandoned his speech therapy. His brain was failing, though his body remained strong and healthy. Andrew, their oldest son, had moved home to help aid in his father's care but Mary Ann became apprehensive about errors Steve was making around the house; safety became a concern.

"I was familiar with the Adult Day Connection at MU and so I enrolled Steve. He started small, attending only two days a week, but he was upset as he felt he didn't fit in with the others. Steve wasn't able to see the loss he was experiencing," explained Mary Ann. She enrolled in a program at the Alzheimer's Association Mid-Missouri Chapter, the Caregiver Respite Reimbursement Program, to help families financially with a portion of the cost of respite care. "It was so helpful," she recalls.

Adult day centers provide a valuable service to individuals who are not capable of remaining at home but are not yet appropriate for nursing home placement. Steve was fit, active, and healthy. "Adult Day Connection gave us two years before we had to make the painful decision about where to move him," recalls Mary Ann.

The decision to move a loved one into long-term care is difficult, but necessary when the care needs exceed the ability of the caregiver. Those with dementia require increasing levels of supervision and personal care, and many caregivers experience high levels of stress and negative effects on their health as a result. As the disease progresses, those with dementia may experience sleeplessness, wandering, repetitive speech, and paranoia.

The time had come. A staff member at Adult Day Connection sat down with Mary Ann and outlined her options, "When she suggested I consider nursing home placement for Steve I was devastated. I didn't realize we were at that point. But the staff members were seeing things that I couldn't. They suggested I place him before he was so confused that doing so would overwhelm him."

The day the Schenemans moved Steve into a nursing home was the hardest day of Mary Ann's life. The children returned home to help. They moved his things, set up his room and gathered for dinner at the facility. When it was time to go, Mary Ann couldn't leave.

"Mom, tell dad good night and that you'll see him tomorrow," said Andrew. She froze. She couldn't leave him overnight.

Andrew turned to his father, "Dad, tell mom you'll see her tomorrow."

"Goodnight hon, see you tomorrow," he replied. The family was in tears, sad for this painful decision; yet Steve was dry-eyed. Maybe it was the dementia that didn't allow him to comprehend his situation. Or maybe, after years of selfless care and affection from his family, he loved and trusted them enough to know they made the right decision and that he would be safe.

"Goodnight," Mary Ann whispered.

Reflections

Mary Ann continues to visit Steve in the nursing home. He began to ask to leave with her each time, but she would only take him on Saturdays for outings or a day at home. This continued for a year before his incontinence made it difficult to take him out.

"The last few months have been a big adjustment. He has lost so much over the years that what's left is so bare, it's shattering to lose yet another ability," explained Mary Ann.

To focus her energy, Mary Ann eventually began volunteering for the Alzheimer's Association Mid-Missouri Chapter and participating in Walk to End Alzheimer's. "It's an outlet for me to help others; this is the cause that drives me," she said. Each year she gathers with friends to walk together as a team, in support of the 110,000 Missourians living with dementia. This year, Mary Ann traveled to Washington, DC to the Alzheimer's Action Summit, to gather with advocates from across the country to meet with lawmakers about important legislation. She is also a resource for others whose spouses have FTD.

As she reflects on her life, she interprets her experience with clarity:

"Everyday I'm reminded of the many blessings I have to be grateful for: I have amazing, supportive children, a loving family, and wonderful friends, a roof to sleep under, and a rewarding career. I haven't made it through life unscathed, but it's unrealistic that any of us will," Mary Ann paused to gather her thoughts.

"To experience hardships with grace, as I learned to do from my own mother, shows my children how to cope with life's most difficult challenges. I am thankful everyday for the blessings in my life."

Her favorite quote: "Pain and suffering are inevitable but misery is optional."