

Stories of Life

One Step at a Time: A Male Perspective on Caregiving

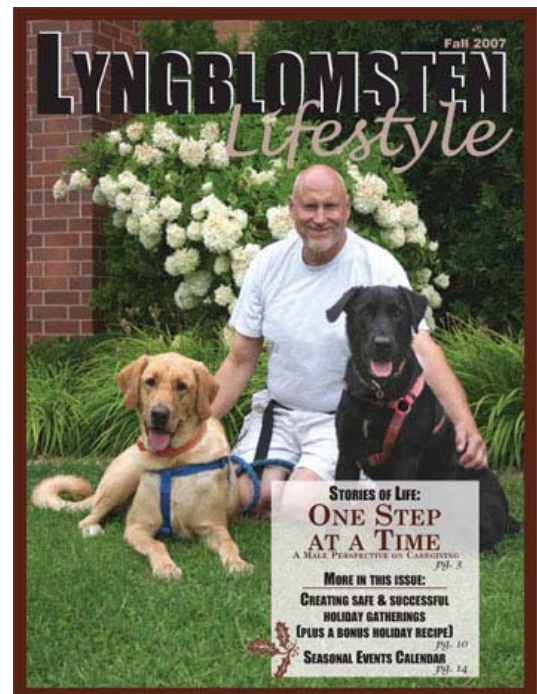
New Challenges

NOTE: This is the full story from the interview with Vaughn Stelmach. A shorter version of this story appeared in the Fall 2007 edition of *Lyngblomsten Lifestyle*.

Meet Vaughn Stelmach. You may know him as “that guy with the dogs” who visits the Lyngblomsten Care Center daily. But do you know his story?

“...for better, for worse; in sickness and in health...” How many times have those words been spoken as part of wedding vows taken by two people who are pledging their love and committing their lives to one another? Countless. What happens when the life you had envisioned together is turned upside down by a medical diagnosis for which there is no cure? Vaughn Stelmach knows a thing or two about facing that challenging situation and becoming the caregiver for his wife, when she, at age 49, was diagnosed with Lewy Body Dementia.

Vaughn and his wife, Sharon, were married in 1965. Together they raised two sons. Sharon worked as the night supervisor in the Dietary Department at Lyngblomsten. Vaughn was a first pressman at a local printing company. In 1998, Sharon’s mother died, and Vaughn started to notice things happening with Sharon. At first he attributed those changes to the stress and sadness she felt surrounding her mother’s death. The main thing Vaughn noticed was her forgetfulness. She’d forget to pay the bills, and that just wasn’t like her. Time passed, more changes happened, and doctors were unable to find a cause for Sharon’s symptoms. One day Sharon had severe chest pain and Vaughn took her to the hospital. More testing ensued. Eventually, a doctor at Mayo Clinic delivered the devastating diagnosis. “The doctor told me Sharon could live two months or 10 or 12 years,” Vaughn reported. “And he said there would be no medals for we’d have to endure.” Having Lewy Body Dementia is like having both Parkinson’s Disease and Alzheimer’s.



Once she was diagnosed, Vaughn took an early retirement so that he could take care of Sharon at home for as long as possible—which turned out to be about four or five years. Sharon continued working for awhile, switching to the day shift, and later was not able to continue. Often after work in those early days, Vaughn and Sharon would walk to a nearby coffee shop and Sharon would talk about her day. “Keeping her job gave her purpose, and that was very important to her,” Vaughn reflected. At first, she just needed a little help getting dressed for work. Over time, of course, the care she needed increased. For awhile they used adult daycare a couple days a week, then five days. Eventually, they would arrive late some mornings, and the staff would ask him whether it was becoming too much for him to take care of Sharon.

“I used to get Sharon out a lot for little outings,” Vaughn reminisced. He continued, “One time I took her to the Back to the 50s at the State Fairgrounds.” He recalls the day, as only a devoted lifetime companion can: “Sharon was convinced that the man sitting in front of them had her tennis shoes on. I explained to her that no, her shoes were at home.” While Vaughn was momentarily looking away becoming engaged in the music, Sharon confronted the man with the shoes, attempting to “get her shoes back.” “The person who was with that man was very understanding,” Vaughn acknowledged.

A nightmare began one day with a simple slip in the bathtub when he was helping Sharon bathe. As you can imagine, trying to quickly catch an adult from falling left bruises. He took her to the doctor. They wanted to run some tests and asked Vaughn to take her to the hospital. Upon their arrival, they were separated—the police took Vaughn away. “I will never forget hearing Sharon screaming ‘help me, help me.’ It was awful,” he recounted. “I didn’t have power of attorney at that time, and they were going to take her away from me,” he shared.

When Vaughn went to court to address the abuse charges, the judge cleared him and also helped expedite conservatorship in about 24 hours—a highly unusual turnaround time.

When it became clear that 24-hour care was needed, there weren’t any rooms available at Lyngblomsten. Sharon was placed in a few different care facilities and experienced more hospitalizations and testing before finally coming to Lyngblomsten in September 2002 where she continues living today. The disease is progressing. She is essentially bed-ridden, and about six months ago lost the ability to speak. More than ever, Vaughn fills the role of advocate for his wife.

It’s noteworthy that Vaughn has also been the caregiver for his 91-year-old mother who, until late August of this year when she passed away, lived in the duplex with him. Except for macular degeneration, she had been relatively healthy until this past year. For the most part, he shouldered the responsibility alone. He has a sister who lives in Maryland. “Sometimes I think it’s harder to be the one who lives away and get news over the phone,” he shared. His two sons who had both been living out of state returned to Minnesota within the past two years.

Everyone’s caregiving journey is different, of course. “It’s been an emotional roller coaster,” Vaughn summarized. He is not bitter, and although he does wonder “why,” he

does not allow that big question to consume any of his time. “Never ask ‘why?,’ he advises. There is no answer.” While his faith has been thoroughly tested through this tumultuous life experience, he still finds solace in daily prayer.

“It has been a journey,” he said. “And on that journey you see a lot of different things. Not everybody takes the same path for a journey, so take the journey your way,” he advises. “One day you may walk a mile, or just a few feet, or take a few steps backwards.”

“It’s hard at some points,” Vaughn shared. “Do you know what the two hardest days have been on my journey?” he asked. “One was the day the doctor told me the diagnosis. The other was the day I walked into Sharon’s room and she asked ‘Who are you?’”

So how does he handle the pressure that comes with caregiving? “Walking with the dogs is my stress reliever,” he said. You can find Vaughn with Sebastian and Buddy Wilson at his sides on his daily walks to Lyngblomsten or around Lake Como. “Pets can help a lot, if you like pets. My dogs are good listeners; they just know when you’re down.”

He tried attending a caregivers support group several years ago. But he and one other man were the only men in the group. “Women cry a lot,” Vaughn stated. “It just wasn’t for me.”

Vaughn also advises, “You have to get away for awhile—even it’s just to your backyard. You need to refresh your mind. If something happens to you as the caregiver, then you can’t take care of your loved one, so you have to take care of yourself. It doesn’t have to be a fancy vacation, just a mini break. Go for a walk. Or just step outside and watch the birds.”

Even if you are not currently in a caregiving role, you can easily help those who are. Vaughn shared that generally he has found people in public to be helpful. “People need to realize that two or three minutes of their time can literally save someone’s [a caregiver’s] day,” he continued. A common situation that occurs when outside the home is needing to take a loved one to the restroom. “Particularly if there is more than one entrance/exit from a restroom, if someone can step up to help watch and make sure your loved one doesn’t exit out the wrong door, that is very helpful,” Vaughn explained.

When asked what he has learned from this journey he is on, he said, “You can do a lot more than you think you can!”

Looking back, Vaughn says, “I’m glad I didn’t know what I’d be facing. You just have to take one step at a time. You and the doctors will know when it’s time for the next step, so you don’t have to worry about the whole situation at one time. Take it one step at a time.”

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