



A Personal Journey

MARTIN SCHREIBER SPEAKS CANDIDLY AS A CAREGIVER

BY CATHY BREITENBUCHER

A life of public service, and decades of political battles won and lost — nothing could have prepared Martin Schreiber for the challenges of caring for a spouse with Alzheimer's.

"You grieve for the loved one you once knew, you become depressed and you develop anxiety about what the future might hold — and you worry," says Schreiber.

"Every time there is a repeat question or a repeat experience, you know where Alzheimer's is headed. It's headed toward further incapacity, and it's headed down toward the end."

The former Wisconsin governor has largely kept his wife's illness out of the public realm. He says he thought "long and hard" before agreeing to be interviewed for this story.

His motivation in coming forward stems from wanting people to understand the toll exacted by dementia on not only patients, but their families, too. He also wants to spark a conversation with health-care providers, insurance companies and employers about the support caregivers desperately need.

"This is a very personal matter," he explains.

"But I believe it's worth it, because we've just got to jar the system so there's more attention given to help with the coping and caring."

Life After Diagnosis

Elaine Schreiber, 74, was diagnosed about seven years ago, following some uncharacteristic, erratic behavior. Widely known as a gracious hostess, she had tried to make for friends a special German meal that she'd been serving for years, but left out some key ingredients.

And, she would get lost for hours while driving once-familiar routes. One day she ended up stranded, surrounded by orange barrels in a construction zone and trying to tell police officers where she had been trying to go.

"It just wasn't like her," says Schreiber, 75, who met his future wife when they were freshmen at Milwaukee Lutheran High School.

When Elaine Schreiber was diagnosed with Alzheimer's, she joined the ranks of some 50,000 people living with the disease in the 11-county area served by the Alzheimer's Association Southeast Wisconsin Chapter.

It was devastating news for a proud woman who had raised four children during her

husband's busy political career and then gone back into the work force, in her late 40s, after his 1988 mayoral campaign had sapped the family's finances.

After her diagnosis of Alzheimer's, Martin Schreiber took on more of the cooking and cleaning chores at the couple's Bay View home. He did the grocery shopping. He drove his wife everywhere she needed to go. He began spending less time running his government relations firm, and almost no time caring for his own health.

"You don't even notice the transition of going from loving spouse to full-time caregiver," he says.

About four years ago, he discontinued his daily workouts at the Milwaukee Athletic Club, and put on 20 pounds. Soon he was short of breath; doctors couldn't agree on why. He even was hospitalized. "After a couple hundred thousand dollars of medical treatment, it began to dawn on me that my problems were not necessarily medical-related," Schreiber recalls. "Some key people with knowledge of Alzheimer's said if I didn't begin to take care of myself, I'd be dead before Elaine, and then she'd be in the nursing home."

Schreiber knew then that he needed time away from his caregiving duties. Finding the right help, however, was a struggle. He tried to bring in help at home, but his wife wouldn't stand for it. Next, he enrolled her at St. Ann Center for Intergenerational Care, hoping she would rediscover her love of swimming there, but it wasn't the right fit. Finally, he found a day program that fit — at the Jewish Home and Care Center — allowing her to receive services in a structured environment and giving him the respite he needed to return to healthy habits.

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"She attends what we call 'classes.' She takes her college notebook with her every day," says Schreiber. "I make sure I get my exercise in and get some time alone. I look forward to picking her up each day."

The former first couple has become involved with the Alzheimer's Association well beyond support groups. Three years ago, Elaine appeared at the Southeast Wisconsin chapter's fundraiser walk to thank the participants.

Her husband is working to urge local companies to join the association's Alzheimer's Workplace Alliance, which promotes wellness activities and corporate policies that support a work-life balance. So far, about 20 companies in the area have signed on.

Schreiber says doctors who diagnose dementia need to focus on caregivers as well. "I believe it would save millions and millions of dollars in health-care costs for the caregiver, and also improve the quality of life for both the patient and the caregiver," he explains. "It would improve the productivity of the caregiver at their place of employment."

The couple — married 53 years in June — still get together with close friends, eat out and attend concerts and plays. They get frequent visits from their children, even the two who live several states away, and their 13 grandchildren. But Elaine's slide into confusion continues. While she still knows family members when she sees them, she often asks her husband how many children they have and cannot remember which one is the parent of a particular grandchild. "She is," says Schreiber, "a very wonderful, loving, caring, confused person."