

Share the Care

Families who distribute the caregiving load provide better care for the patient—and themselves. Try these tips to get everyone involved.

BY NATALIE POMPILIO



Kathy Vilella (seated at right) with her husband Ed and their next-generation team.

What began for Kathy Vilella as a limp foot and difficulty walking without assistance led to a diagnosis of progressive multiple sclerosis (MS) in 2008. A few years later, she had to retire after 35 years of teaching, use a wheelchair exclusively, and rely on her family—her husband, Ed, daughters Samantha and Nikki, and son, Brent—for care. Fortunately, they fell into caregiving roles that played to each person's strengths.

Ed manages most of his wife's daily needs, including driving her to medical appointments and overseeing finances. Samantha, 38, is the family's advocate, researching new treatments, acting as a liaison with doctors, and managing their nonprofit organization, KV's Krew (kvscrew.org), which works

to increase MS awareness and raise money for research.

Nikki, 36, who was diagnosed with relapsing-remitting MS in 2014, fills in for Ed on weekends, taking Kathy to dinner with former colleagues or to the hairdresser and going along on medical outings, while keeping her own disease in check. Brent, 33, handles home upkeep and repairs, while his wife helps by preparing and delivering food. When out in public with Kathy, the sisters handle toilet visits. Ed is no longer allowed to choose Kathy's jewelry: He once put different earrings on her to be funny.

"There was no sit-down meeting with a long list of responsibilities," says Samantha. "We all have stuff we're really good at."

It's a family disease, she adds. "That's how we live it. It affects all of us."

Expand Your Team

A diagnosis of a neurologic disorder is a call to action for many families. But the Vilella family is unique in how easily they've found roles that help their mother and provide support for one another.

Kathryn Pears, founder of Dementia Care Strategies in Conway, SC, says her own experience as a caregiver and advocate has shown her that "caregiving responsibilities are rife with opportunities for resentment."

"Some families band together, establish clear areas of responsibility, and work effectively as a team, but that seems to be the exception rather than the rule," says Pears. "In my personal and professional experience, responsibility generally falls to one family member. A common pattern seems to be, 'You are doing such a great job of caring for the person that I get a pass.'"

In years past, caregiving was primarily a woman's job, but that's changing, says Beth Kallmyer, vice president of constituent services for the Alzheimer's Association. A 2017 report by the AARP found that the gender breakdown among caregivers was 60 percent women and 40 percent men. Eight years ago, a similar report found that 34 percent of caregivers were men. (The Alzheimer's Association has drawn similar conclusions.)

Ask for and Accept Help

An ongoing challenge, Kallmyer says, is caregiver isolation. A 2017 Alzheimer's Association survey of more than 1,500 adults, including current and past caregivers of Alzheimer's patients, found that 64 percent of caregivers felt isolated or alone in their situations, and more than 84 percent would have liked more support.