

A story of love, loss, and resilience

Kate participated in the Savvy Caregiver Program, which provides training and support for those actively caring for friends or family members with dementia. Here is her story.

Confronting Cognitive Decline Alone

Kate and Bob were married for 30 years. And until his death, Kate had served as his primary caregiver as his health declined. The story of Bob's cognitive decline is all too familiar. His dementia began at 75, and Kate observed that hospitalization for other conditions seemed to fuel progression of his memory loss. Bob's surgeries, including a hip replacement and open-heart surgery began six and a half years before his death at 81.

With each surgery Bob would suffer a set back and never return to his cognitive capacity before hospitalization. He became more and more confused when he returned home and needed help getting dressed and prompting to wash up. He could comb his hair and brush his teeth, but needed reminding. Kate had taken over giving him his medications years ago.

According to Kate, "Every time Bob went to the hospital or rehab, he didn't do well. He was confused and didn't eat well. The medical community was very capable and competent, and the nurses were always fantastic, but they didn't seem to address his confusion, and I didn't feel support for his or my emotional needs."

Coming to Grip with Exhaustion and Isolation

Eventually, Kate enlisted help from a home care agency to help Bob shower because it had become too trying for her. "He just didn't want to shower, and he would resist me more than he would the aide," says Kate. "She had lots of experience and was able to cajole him into showering every week. She could make him laugh, when I was exhausted."

Kate continued to prompt Bob to take care of his personal hygiene, which sometimes he could, but other times couldn't do. There were moments when he completely forgot the function of common items. One time he tried to ask Kate for a Q-Tip but couldn't think of the word so he motioned with his hand up by his ear. Kate asked him if he needed a Q-Tip. He nodded yes, but when Kate gave it to him, he looked at it and asked how it worked. On another occasion he applied deodorant on the inside of his elbow. Although, completely devoted to her role as Bob's caregiver, Kate was often at a loss as to how to help Bob navigate activities of daily living. That was until she discovered the Savvy Caregiver Program.

Kate had taken a class at a senior center that provided an overview on caregiving, which proved helpful. A year later she bumped into a woman from that group who told Kate she'd taken a great course called the Savvy Caregiver Program, which was more detailed and in-depth than the one they had taken together at the senior center. Kate kept an eye out for the program and signed up.

"It was really terrific for me," says Kate. "The program provided so much practical information about my husband's condition, and I received support not only from the instructors, but also from other members of the class. We became a real cohesive group and learned from each other's experiences."

Kate was struck in the first class by just how alone she had felt as Bob's caregiver. As participants shared their stories, she noticed that many of them had considerable family support. "They all seemed to be hooked up with someone else who could share in the caregiving challenges, and I was all alone," says Kate. "I remember getting very emotional because I felt so isolated."

But Kate credits the group for breaking through her sense of isolation with sympathy and support. The workshops were structured but there was also ample time for group discussion, and people felt more comfortable bringing up personal issues as the class progressed.

Cultivating Compassion for Others and Self

Participants learned not only about the physical and medical underpinnings of dementia but also what their loved-ones might be experiencing emotionally from their confused viewpoint, and bewildered state of mind. “I developed even more compassion for Bob on that level,” says Kate. “But I also learned compassion for us as caregivers and what we’re going through. It’s a very stressful job. Every time I took a class, I had new tools to work with to help me in my role.”

As an example, Kate learned how to manage Bob’s resistance to taking medications. “In the beginning, I would say – Bob, you need these things! I would go through explanations about why he needed to take his medications,” Kate explains. “I learned through the Savvy Caregiver Program that my pleading probably didn’t even register. Their suggestion, which is so logical was to just let it go, distract him and move on to another task and then bring it up 10 minutes or a half hour later. And, sure enough, he would do it.

That was like a light bulb for me. I was talking to him from my perspective as to why he needed the medications, but he certainly couldn’t comprehend or care at that point what the explanation was. He just didn’t want to do it.”

Kate learned not to argue, not only because it didn’t work, but also because it adversely impacted her own physical and mental wellbeing. There were many sleepless nights, and conflict made the situation much worse. Kate learned that Bob mirrored the mood that she projected. If she got angry, he would respond in kind. If she lightened up, was cajoling and used humor, he would become less stressed. Kate learned, “don’t argue -just go with the flow.”

Learning to Cope with Loss and Be OK

Watching Bob decline was painful for Kate. She sums her feelings up beautifully this way, “It’s hard when you’re in the thick of it and exhausted, and you don’t have the knowledge and techniques you need to navigate the progression of dementia as a family caregiver. The Savvy Caregiver Program helped me see Bob at the point where he was in the moment and accept it.

And also, not to feel alone. Everyone in the class had their own personal story and you realize that there are so many people going through this and there is help out there. And that was such a support, mentally, emotionally and practically. I remember laughing a lot, which is unusual when you’re dealing with such a serious issue.”

The Savvy Caregiver Program is an example of the evidence-based programs offered by Elder Services of Merrimack Valley’s Healthy Living Center of Excellence, which means their benefit has been proven or informed by research and evaluation. These programs are designed to promote healthy aging among older people.

A grant from Harvard Pilgrim Health Care Foundation supports two evidence-based programs offered by including the Savvy Caregiver and Matter of Balance Trainings in Massachusetts, Maine and New Hampshire. With this grant the programs aim to train 40 Master Trainers, who in turn will train community-based coaches to implement workshops for close to 750 program participants.