

## One Family Caregiver's Story of Love, Devotion, and Commitment

By Jennifer Davis, December 2020



As part of their marriage vows many couples promise to “hold each other for better, for worse, for richer, for poorer, in sickness and in health.” Sticking by a partner in “sickness” can be particularly challenging when the sickness is dementia. Yet many couples do exactly that.

### Sandy's Story

Sandy would never dream of any other option than caring for her husband Bob at home as his dementia progresses. Both she and her husband lost their first spouses, whom they loved deeply, to cancer. Sandy believes this experience imbued her with a deep sense of commitment.

“When you lose someone that you love very much, it puts you in a whole other league,” says Sandy. “You know what losing somebody is like and how precious life is. If you get married again after something like that, you know what commitment is.”

Bob and I are husband and wife, and we understood that if one of us got sick the other person would take care of them. It's just natural.”

And as is the case with many family caregivers, that commitment is regularly tested.

### Coping with Risky Behavior

Sandy tells one particular story which dramatically demonstrates what families can be up against when a loved-one is living with dementia.

While Bob's short-term memory is compromised, his long-term memory is still somewhat intact. “He is a very intelligent man, and he was a meteorologist. If you mention anything about the stars or the weather, he can go on for hours,” says Sandy.

It is Bob's past as a meteorologist that once got him into trouble. On one occasion he stormed out of the house after what Sandy thought was a disagreement over what to have for dinner. However, he left with a pre-packed bag of clothing, which confused and scared Sandy.

“Bob left in a huff that night at 8 p.m., in the middle of a ‘Noreaster’ snow storm to drive 200 miles to our Vermont home,” says Sandy.

When he arrived at the farm, he promptly lost his keys and was locked out in the snow. Fortunately, he made his way to a nearby inn, where workers called his family, who were able to retrieve him the next day.

According to Sandy, “The whole thing transpired because as a meteorologist, he had heard on the news that there was going to be a huge snow storm where our farm is located in the Northeast Kingdom of Vermont, and he wasn’t going to miss that. He had packed a bag – no pills – just his boots and whatever he wanted to go out in the snow with. He had his snow measurer.”

### **COVID Has Impacted Disease Progression**

According to Sandy, “Bob’s memory has worsened during this pandemic because I think our routine is so different, and we’ve been much more isolated than before COVID. He can’t remember longer than a minute – I mean a minute! If he asks me what year we got married - and he asks me that many times during the course of a day - I tell him, and in less than a minute he will ask again.

He obviously can’t be alone – ever. He wouldn’t know if he took his pills or how to put the pills together. He doesn’t remember to eat and wouldn’t know how to make his breakfast, or lunch.

I pick out his clothes, I put them out. I remind him about a shower. We’re having a little difficulty with personal activities liking showering. It seems like that’s the next stage in the progression of his illness.”

### **Learning How to Manage Bob’s Condition**

Sandy has developed her own techniques for keeping Bob engaged and to stimulate his long- term memory. As an example, she has worked with Bob’s sister to regularly send him photos from his past, which help him recall people and events that have happened in his life. They are also fortunate to have family who live in separate quarters, but in the same house, including grandchildren who Bob adores and who regularly visit. But Sandy needed more support to deal with the toll her caregiver role was taking on her emotional and physical health.

When she learned about the Savvy Caregiver program, she signed up. “I want to know everything I can about caring for someone with dementia so I signed up immediately,” says Sandy. Sandy is clearly determined to be the best caregiver for Bob that she can be.

### **Sandy’s Savvy Caregiver Program Experience in her Own Words**

“The first thing I got out of Savvy was seeing a half a dozen or so faces online of people who are going through the same thing I am,” says Sandy. “Not that you would wish this on anybody, but it was comforting to know you’re not alone.

The next thing that was huge to me was that we were taught not to beat ourselves up. I was doing that. I found that everybody was losing their patience a bit.

You get tired. This is a hard job. I was finding that after I was asked the same thing 15 times in the course of an hour, I was getting really exasperated. I wasn’t answering Bob the way I should have.

I was feeling tremendously overwhelmed, and I found that it helped if I took even a few minutes for myself, if I just sat someplace – even five minutes – and said to myself he can’t help this, I know that you’re trying to get him to do this and he wants to do that, but he can’t help this.

Taking this time to think put me in a much more relaxed state. Then I was able to go on with the day, and that helped a lot. I learned to do that through Savvy - how not to feel guilty about what was

happening to me during the day, and about how some days I felt like I was losing it. But what I was feeling is normal, and other people were saying the same thing, so they were feeling it too.”

Another tool Sandy learned through Savvy is a technique called ‘re-direct.’ “Whenever Bob is upset about something, I change the subject immediately, which usually works,” explains Sandy. “I also have my wonderful sister-in-law on speed dial, and she calls him. He forgets in an instant what he was angry about. Prior to Savvy, I would try to reason. Re-direct is the best tool.”

Through Savvy, Sandy has also learned patience with Bob and herself, and how to negotiate his behaviors to the benefit of both of them. She gives Bob small tasks to do, even if it means he puts the cups where the laundry supplies go. At bedtime she manages his paranoia by going through the house with him to pull down all the shades and hide any valuables, which in the past resulted in hours of searching for missing items the next day.

Sandy is in it for the long haul. As she says, “I plan to keep Bob home with me in this house to the very end if possible. I don’t think I could ever send him anywhere.”

For better or worse Sandy will be by Bob’s side.