

## Robert's Story:

Let me start by saying that I am certainly no expert at being a caregiver. These are merely thoughts, recollections, reflections, suggestions from someone who has been caring for his wife of 52 years at home full-time. She was diagnosed with unspecified dementia (likely Alzheimer's) a couple of years ago. And some of what follows may ramble, but it is all intended to provide a picture of what caregiving is like for those who have not had the experience. I hope that some of what follows may be of help should the need arise. Kathy is a college grad (1970) in Elementary Education, and taught Kindergarten for 35 years, retiring June 2005. She was 'into' all kinds of crafts, always in motion, remembered the names of a large number of the approximately 1,700 students that she taught, did all the meal planning and cooking. When precisely Kathy started showing signs of dementia, such as memory loss, fighting to find the right words, repeating the same word multiple times while trying to communicate a thought, disinterest in the crafts she had always loved, lethargy, etc., eludes me because I think that for a period of time I was in denial when she showed one or more of these symptoms. I frequently made excuses for her to friends who asked about what they thought they saw.

Finally, at some point, I had to admit to myself that something was wrong, and our PCP confirmed the dementia diagnosis. However, it was another year, and a severe panic attack on two separate occasions, both of which required emergency squad transport, ED (emergency department) intervention and ultimately hospitalization, before it became abundantly clear to me that her dementia was already in the early to middle stage. I had already been in 'search mode' for a local memory care facility should the need arise. After the second hospitalization, I realized that she needed to be transported directly to such a facility for respite care because I was not prepared to care for her at home. What was expected to be a two-week respite turned into four weeks, and then another two months at a separate facility. All of this was going on during the pandemic. I spent many, many hours at the facility, and was even often looked upon by residents or visitors as a staff caregiver. I even slept in Kathy's room many nights out of concern for her care. There were times that had I not been there she would not have eaten, or been given her medications.

There are no perfect memory care facilities, and the good ones tried as best they could but the pandemic wreaked havoc on staffing, and I could no longer accept what I was seeing, so... In Sept. 2021 I brought her home to care for her myself, so, having been caring for her to some degree for two years or so already, I have now had this role for a year. And I, of course, am doing this while maintaining our 46-year-old house on ½-acre lot, taking care of our cars, doing all the shopping, laundry, meal prep, cleaning the dishes, bill paying, etc. We were lucky enough to have hired a financial planner over twenty years ago. It was he who led us down the path of creating a trust, designating our Power of Attorney, establishing our wills, AND buying long-term care (LTC) insurance. It is this insurance which is now helping me to be financially able to bring someone in to our home to help with caregiving four hours/day each weekday, and to have someone clean our house every two weeks. Medicare DOES NOT pay for long-term care. Our LTC plan also will pay for care in a memory care facility should that be needed. Some LTC insurance does not pay for home care. I have had to take on all kinds of new tasks. There are times that I must feed her.

There are times that I have to deal with incontinence. I have had to buy her new clothes and she can't help me choose the right size, type, etc. I have to monitor her vital signs. I have to bathe her. I have to dress her. I have to prepare and administer her meds three times a day. I have to gently and calmly ask her if she want 'this' or 'that' to eat and then interpret her reaction, if any, since she is mostly non-verbal. I have to help her in/out car/wheelchair; down/up from bed, couch, chair, toilet. When the caregiver is not with her, I have to monitor her every move, and she likes to roam a lot; since she is somewhat unsteady on her feet (possibly because of the meds), and also because she 'gets into everything' like a child and things disappear. I have had to now make all decisions that impact us by myself; I can't seek counsel from my wife anymore as she is no longer capable of reasoning, or making rational decisions. I have had to make modifications to the house. New additional locks added higher up on the exterior doors. Door alarmed. Grab bars installed in the bathroom. Exterior key box installed on the front door supplied by the fire department. Night lights added throughout the house. High profile toilets installed. Installed a baby monitor in the bedroom so that I can monitor her while she is supposed to be asleep. Removed all loose area rugs. Luckily our house is on one level so stairs are not an issue. A lot of what I need to do I have to do at night after she goes to bed, and is asleep. Because we are restricted to the house a lot, limiting in-store shopping, etc., Amazon Prime, grocery store (Kroger) delivery, and restaurant meal delivery, have become my friends. And streaming services like Prime Video, Disney+ and Apple TV have expanded our range of TV viewing. There are a number of resources that can be tapped, e.g., the local Alzheimer's Association, the local Agency on Aging, local Catholic, or Lutheran, or Jewish Social Services, a free national service called 'A Place for Mom', and hopefully your local network of family/friends. However, I have found that many in our network are no longer keeping in touch like they used to; no visits, no phone calls, no emails, no texts. I can only assume that this is due to their own personal family responsibilities/issues, or perhaps there is some discomfort on their part in regard to how to interact with Kathy, or a desire not to 'bother' me or distract me from her care. On weekends, if nobody calls or visits, I go 64 hours without real adult conversation. As a result of this isolation, I often feel lost, isolated, depressed, angry, overwhelmed, discouraged.

When you are not the primary caregiver, whether you are a family member or a friend, here are some things that you can do to help if you are so inclined and able:

- Stay in touch
- Avoid criticizing
- Be informed
- Assist with finding help, if it is needed
- Take on some tasks to give the caregiver assistance
- Stay with the person who has dementia to give the caregiver time to take a break
- Arrange for help if you cannot provide it yourself, assuming the caregiver is ok with it, and pay for it

A piece of advice. Don't make a generic statement to a caregiver like "Call me and let me know what you need." Better to call and say, "Hey, I'd know you and Kathy both like pizza, so what day is best for you for me to bring you one for dinner?" Or, "Hey, I thought I'd come over some afternoon and help you with your yardwork (or some such task). What day works best for you?"

Having to reach out for help is hard for many people and puts the people being contacted on the spot. Be proactive rather than reactive. Books. "The 36-Hour Day", 7th Edition, by Nancy L. Mace and Peter V. Rabins. "The Caregiver's Guide to Dementia", by Gail Weatherill. "Creative Care. A Revolutionary Approach to Dementia and Elder Care", by Anne Basting. "Alzheimer's Through the Stages. A Caregiver's Guide", by Mary Moller. "Understanding Alzheimer's", Mayo Clinic Magazine, Special Edition, Aug 2022.

Some additional suggestions. Some durable medical devices, e.g., walker, cane, wheelchair, walker/wheelchair combination, grab bars, etc., may be needed. If so, ask a doctor to write a prescription, and then purchase them from a Medicare approved provider. That way Medicare will likely cover all or most of the cost. Also, if a handicap placard is needed, you will need to doctor's prescription to get one from the state Bureau of Motor Vehicles. Also, suggest keeping a daily journal to include meals, medical issues/vital signs, medication schedule, activities of the day, etc. This could be quite helpful when speaking with the doctors.

Remember. Those afflicted with dementia have little to no control over what they do or don't do. Patience is a major requirement of someone caring with those with dementia. I wear an official purple Alzheimer's Association silicon wristband every day to help remind me.

Also, know that fatigue, discouragement, anger, grief, despair, guilt and ambivalence are all normal feelings that may come with caring for a chronically ill person. Such feelings may seem overwhelming and almost constant. The burden can be staggering. Find help, maintain friendships, give yourself a gift, avoid isolation, take time out.