

I married an Italian in 1971. so it was very clear that between her and her father taking care of her was the largest concern for me in our new life together. They both told me before the wedding that I had better take good care of her or that I could Face the scary Italian eye look. known to stop anyone in their tracks. My New York father-in-law and later after he passed my wife, would threaten to call Qweto in New York, her Italian godfather. I thought it was wise to be the best caregiver I could.

I have been a caregiver for over 35 years. My first experience was caring for my parents in their home and in nursing care for over eight years. Lots of mistakes were made. Then my wife was diagnosed with myotonic muscular dystrophy at the age of 37, and lived another 37 years with this terrible disease. Her grandmother, we believe, was the first to share the gene. Then it went to her mother, an aunt and uncle, along with one of her brothers, and three of five cousins, who all showed symptoms in their late 50s and early 60s. My wife lived nearly three life spans of this disease. She was a fighter. Helping her made me want to learn more on how to make sure that my caring for her was the best, not because I was afraid of cement shoes, but because I loved her dearly. I started to take classes and search for guidance about caregiving.

I organized my own caregiver group in 2017 at my church and developed into a coach. With Covid we could no longer meet so we joined the Lutheran social services online group to continue learning. It was a great way to meet, but there were many people that weren't into technology because of their age, or the scheduled times of the online sessions didn't fit their time frame.

I started a bi-monthly newsletter group with five people in the spring of 2022 to share more information. It has grown to 40 participants scattered across the country! Today, it is once a month to allow me to also focus on my online class to also become a certified grief coach. I have six others I assist them personally. One example was a 97 year old woman who had no family within a 1000 miles. I was her caregiver for nearly 3 years and was with her when she died a year ago. Her children have not yet picked up her remains from the funeral home, nor some items I store. Sadly, there are far too many of these type of situations where family forget these seniors and don't participate in their end of life care.

My faith has guided me to be a caregiver coach, I try to help families through these difficult times using my personal and learned experiences from all the research that I have done and continue to do on a daily basis. In my newsletters to caregivers, I send 8-12 links from national websites that allow me to share, along with a few personal experiences when it can be helpful. Dementia is the most sought after piece of information.

Minnesota is no different than other states in the nation. Caregivers struggle in their care support because of the trials, commitment, and personal time it requires to care for a loved one. That is the reason 63% of caregivers die or become incapacitated with this heavy responsibility. Families face financial troubles, lost job hours, forced to give up a career for their loved one, and then the expenses to remodel and adapt homes to make it feasible for their loved one to stay in their home. Seniors need to be fair, but hard earned money or property families had planned to go to their own children, similar to what the parent might have received to get started in their new married life, could all disappear. Both caregivers and recipients want the seniors to live in their home, but it is risky as it may become, more expensive, and most often painful. I have a caregiver now, who is experiencing the struggles

of trying to care for her very sick mother who probably should be in a nursing care facility, but is trying to honor her wishes of dying in her home. This means the caregiver, who lives 25 miles away, is giving up time with their family, unable to do home chores, which increases the stress and cost on them.

My wife moved to assisted living because I dropped her while transferring her from a wheelchair to the bed. My surgically fused back gave out, and I couldn't care for her safely. After she moved to her new care home she responded to her doctor when he asked why she was doing so much better than six months earlier, "I left my husband and moved into assisted living!" She actually did get better because of the interaction she didn't have in our apartment complex. I quickly realized not to mess with the bingo time or her evil eye would appear. Care facilities offer a variety of activities, but it comes with a cost. To keep away from those old dungeons that were like storage containers for seniors 75 years ago. Caregiving homes are truly that. A caring home that is safe and gives quality years to the end of a life. No one deserves the old ways. Unfortunately it still happens today.

My caregivers tell me they receive mixed messages regarding finding good answers to their questions and concerns about financial help. Unfortunately, most can't afford an attorney on a retainer for understanding the government red tape. Counties in Minnesota and across the country are backlogged with requests for assistance, which has to be updated yearly. To a person looking for information, a county person usually hands out a packet that looks foreign to most. The Big Beautiful Bill hurt seniors and states by requiring them to pick up most of the tap for care. Seniors are worried on how they will afford care. County and care organizations have high turn over rates for people willing to work in someone's home or even in care facilities. Too often caregivers at facilities have to do double shifts, which forces workers to quit. This is a vicious cycle. The Older Americans Act needs to be reauthorized to help families survive, not just the work of caring for a loved one, but also protect our seniors from understaffed facilities which only leads to poor care and extreme dangers to those seniors who helped build this country.

Thank you for your valuable time. I appreciate you listening to my story and the stories of so many more that I help. We ask you to support the Older Americans Act and get it back to those who have earned it. It is desperately needed, and deserved.