

HOW THE CHURCH CAN LOVE AND CARE FOR THOSE WITH DEMENTIA

By Michele Hendrix – New Braunsfel, Texas

[Editor's NOTE: Michele Hendrix is past President of Presbyterian Older Adult Ministries Network (POAMN), a Deacon, Stephen Leader, Caregiver Specialist, Speaker and Trainer with expertise in Older Adult Ministry and Caregiving. The focus of her work is on intergenerational and interfaith ministry.]

When someone develops dementia, it is a natural step that we are faced with the loss of someone we know and love, as well as the loss of the relationship. I am aware that caring for someone with dementia is a difficult job. It is one that can cause families and the caregiver a great deal of pressure, anxiety, tension, and worry. However, if you love someone with dementia – a friend, family member, or neighbor – you may now be well aware that each day comes with its challenges and stress.

I have heard it said that dementia is one of the most dreaded declines of aging. I know that to be a true statement professionally. And now, I know that to be true personally. For 35 years I served those in my community and church in the area of Older Adult Ministry and Congregational Care to Older Adults by creating and sometimes *inventing* ministry opportunities on the spot! I was one staff person within a large congregation often referred to as a “Mega Church.”

My professional role and responsibilities would have been impossible without a beloved part-time administrative assistant and a beloved group of trained volunteers who worked and served alongside me sharing the same passion and commitment. Over a period of decades, within our congregation and community, we served and walked alongside caregivers and care recipients as they entered this often unfamiliar and overwhelming territory. The reason for me was simple – this group of saints and servants raised my family and me up in the faith.

When our church team began to recognize the need for this ministry, we set out to develop ministry opportunities that would meet the needs of both the caregiver and the care recipient – fully aware of what they were facing. We recognized that as the dementia progressed, we needed to find a way to offer these caregivers periods of respite, as well as a safe place for their care recipient. Almost all of our caregivers and care recipients felt good about coming to the church. A place so familiar to them after 20-30-40+ years, it felt like home. Grace Presbyterian Church/Houston, Texas was my church home for over 30 years, and I served on staff first as a volunteer, then as a part-time employee, and, finally, as a full-time staff member for nearly 20 years.

These caregivers and care recipients were my beloved pastors, mentors, teachers, leaders, and friends – my/our family of faith. Yes, there were challenges in training volunteers, arranging transportation, providing a meal, finding entertainment, leading a sing-a-long of the old and sacred hymns, offering low impact exercise, bingo, dominoes, or other activities each month. But despite all these challenges, if you love and care for those with dementia, it can be an extremely rewarding experience. It was so for our all-volunteer team because we knew the person we loved was still there behind the dementia. We also recognized that their caregivers desperately needed a break!

Over the years we built what we referred to as “**a three-legged stool.**” The first leg was our Day of Care – A Gathering; the second leg was a Caregiver Support Group; and the third leg was the Powerful Tools for Caregivers six-week caregiver class series, an evidence-based model that also included *The Caregiver Helpbook*. Training was also provided for these all volunteer ministries. Since retiring in 2011, and now serving in POAMN leadership, I have shared this model with many people and congregations. It has a remarkably positive impact on both caregivers and care receivers.

I also want to share that we began this program without a budget. Older Adult Ministry was not in the church budget at that time, so don't let that detail deter your efforts. We reached out to other Continuum of Care Facilities, Community Centers, and other organizations and invited them to join and support us. Then we invited their residents or members to participate. Sometimes I bartered or traded services with them. As this ministry grew and impacted so many of our members, the Older Adult Encore Ministry did make it into the church budget. Some 20+ years later, this ministry is still going strong, and at last count there were some 150 congregations in Houston offering the same program for care recipients and caregivers.

Now my family and I are facing the end of my Mom's life journey as she just recently entered hospice. My Mom has Lewy body dementia. I believe this is the second most common type of dementia after Alzheimer's disease. Over these past few years it has affected her cognitive abilities, motor functions, and her ability to complete activities of daily living. The combination of cognitive, motor, and behavioral symptoms creates a highly challenging set of demands for continuing care. However, it was not until she fell in October 2017, had a brain bleed, required brain surgery, recovered, was transitioned to physical therapy, and, eventually, a Memory Care facility that we faced some very tough decisions. Mom had lived with my sister, who was her caregiver, up until the fall and accident.

One dilemma we faced with the brain surgery was, "Is this God's timing and are we interfering with God's timing?" Her surgeon shared with us that the bleed was on the outer brain, and her health and vital signs were all good. So we made the difficult decision to let our 89-year-old Mother undergo brain surgery. My husband, Dale, and I recently made the trip to Alabama to see her. When Mom saw me she smiled, though she did not call me by name, and said, "You surprised me!" When we left that first day, she told the nurses I was her daughter and that I was coming back in the morning. Sure enough, that is what we did! The days we spent with Mom gave us multiple opportunities to share with her, hold her hand, pray, spend time with her, and to tell her we loved her! Mom always responded, "I love you, too."

When a loved one enters hospice from a disease like Lewy body dementia, emotions run strong. This is an emotional time and as a family, we are sad and grieving. But we are thankful for the extra time (1 year and 9 months have gone by since the fall) and the long life she has lived. Over the next few weeks or months we will continue to spend time with my Mother, holding hands, praying, sharing good memories, or just sitting quietly. Mom may not always know who we are, but we will never forget who she is and whose she is!

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