



Nurturing a Dementia- Friendly Church

by Kenneth L. Carder

One of the last words to leave my wife Linda's vocabulary was church. Each week a couple from the congregation brought a meal. When they entered her room, I said, "Linda, John and Emma are here from church. They brought us food. Emma used to sit with you in the Sunday School and hold your hand." Emma gently stroked Linda's hair and told her that she misses her, complimented her, assured her that she was loved. The same congregation sent us a handwritten note and photo regularly. Linda's name appeared in large letters on the front of the crafted notecard. On one occasion when I showed her the card and commented, "It's from the church," she squinted her eyes as she looked. Then with pathos in her voice she said slowly, "Linda! That's me!" It was the last time she read a word! In that fleeting moment, the church reminded her who she was and that she belonged.

Staggering statistics

The median age of adult participants in mainline denominations is approximately 56, which is 10 years older than the median age of the adult population of the United States. The percentage of members who are over 65 is around one-third. According to the Alzheimer's Association, one of every 10 adults age 65 and older has Alzheimer's or another form of dementia; and one-third of older adults die with a form of dementia.

Church members with dementia are often relegated to the margins of the congregation's life and mission, and their gifts and needs are rarely acknowledged. Yet the church is strategically positioned to make a significant difference, and people affected by dementia potentially play a vital role in the life and mission of the church. When they really belong, the church is transformed, and their lives are enriched. Becoming a dementia-friendly church where people with cognitive impairments and their families belong is a theological and ecclesial opportunity and challenge.

Remembering those who are forgotten

An initial step in fostering inclusion of those affected by dementia is identifying who they are. Because of the stigma attached to forms of dementia and the accompanying denial, people with symptoms are often hidden from the congregation. They drop out of activities and withdraw from participation. The initial action in nurturing a dementia-friendly congregation is simply to know those within the community who are living with dementia. Remembering them as God remembers requires entering their worlds, learning their stories, and valuing them as mediators of God's grace-filled presence.

Such remembering involves strategies, programs, and practices that equip the congregation to fully welcome and incorporate those with Alzheimer's and related diseases and their families. Congregational life is usually characterized by order, decorum, prescribed practices, and abstract thinking. People with dementia simply do not "fit in" without deliberate efforts to foster a climate of acceptance. Entering the world of the cognitively impaired and their families and caregivers is like entering another culture with difference in language, worldview, habits, behavior, and needs. Education is necessary to remove the fear of the other and welcome their gifts.

Support groups

Caring for people with dementia is stressful, exhausting, and isolating. Studies over the last two decades of the effects of caregiving on family members have concluded that caregiving constitutes a national health problem in the United States. The detrimental effects on the physical, mental, emotional, and relational health of caregivers are well documented. The isolation and feeling of helplessness are pervasive. Churches are well positioned to counter the deleterious consequences of caregiving by intentionally supporting family members. Support groups for people who are in the early states of dementia are also needed, and they are much less readily available. The diagnosis is shocking and frightening for the individual diagnosed, and he or she needs special support. Dealing with the shock, denial, and anguish experienced by other people confronting similar challenges can be very helpful in overcoming denial and feelings of hopelessness.

Adult day care

A growing number of churches are offering adult day care programs that are designed to provide care and companionship for older adults who need assistance and supervision. Not all such centers are designated exclusively for people with dementia, but those with cognitive impairments are among the most frequent participants. The goals are to delay or prevent institutionalization by providing alternative care, to enhance self-esteem, and to encourage socialization. By providing day programs for persons in early and mid-stage dementia, churches communicate to the congregation and the broader community that persons with dementia matter.

Respite care

Family members of people with dementia need respite from the persistent demands of caregiving. First United Methodist Church in Montgomery, Alabama, offers a creative combination of adult day and respite, with caregivers receiving special attention. A uniquely creative aspect of the program is that people in early-stage dementia serve as volunteers who work with people in a more advanced stage. Efforts are made to diminish the distinction between those with dementia and the caregivers, including volunteers. Barriers are overcome and a community of mutuality emerges.

Simple acts of support

Adult day care and respite care ministries represent important responses, and they involve significant investment of institutional resources. Less intensive but no less significant means of welcoming people affected by dementia exist in every congregation.

The following are a few ordinary expressions of inclusion that counter isolation, lend support, and maximize belonging:

- Recruit, train, and supervise a cadre of visitors/friends of those with dementia and their families and maintain regular (weekly) contact with those confined to home or a facility.
- Provide a weekly meal for families who care for loved ones with dementia.
- Volunteer to sit with a person with the disease while the caregiver gets a break.
- Sit with the person with dementia in worship and assist as needed.
- Intentionally greet and welcome with a smile and genuine compassion those with dementia.
- Simply treat the person with dementia with kindness and enter their world with the expectation you will meet God among “the least of these.”

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This article is condensed and adapted from his book *Ministry with the Forgotten: Dementia through a Spiritual Lens* (Abingdon Press, 2019).