

REMEMBER THOSE WHO FORGET: BECOMING A DEMENTIA-FRIENDLY CONGREGATION

By Cynthia Ray

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A too-frequent reality

A long-time member and ruling elder, Joan is in her mid-60s and retired early from a career in business. Over the years, Joan served multiple terms on session, taught adult Sunday school and always stepped up whenever help was needed. Known for her wicked sense of humor, Joan formed deep and long-standing friendships in the congregation and community where she and her husband, Jim, raised their children.

But things have been different since Joan began to show signs of memory loss. When she last taught Sunday school, she had difficulty delivering the lesson and seemed confused about participants' comments and questions. Other ruling elders noticed that she was reticent to speak in meetings and seemed off-topic when she did. Two years ago, her "retirement" came somewhat abruptly, earlier than expected and with little celebration.

In recent months, Joan and Jim have attended worship infrequently. Joan held the bulletin, but didn't seem to participate except when a hymn was sung. She smiled when others greeted her, but conversations were brief and stifled. No one seemed to know what to say. A deacon, who is among Joan's long-time friends, visited her on behalf of the congregation, but reported that Joan didn't recognize her and conversation was painfully awkward. The deacon was emotionally shaken by the encounter and asked to be relieved of the assignment. Deacons' visits decreased as Joan's memory loss frustrated both her and her visitors. When a deacon approached Jim, he said that they're doing okay. Not sure what to do, the deacons decided to wait until they heard from Jim. No one has heard anything.

A friend ran into Jim recently at a store and noticed that he appeared very tired. When the friend asked Jim how it was going, Jim responded that there are good days and not so good days. The friend pressed a little and Jim acknowledged that caring for Joan was getting difficult and he was worried about Joan's safety after she wandered outside and got lost recently. He said he was looking into nursing homes, but that would use up their savings in about five years. The friend couldn't help but notice tears welling up in Jim's eyes. In such a public place he didn't want Jim to be embarrassed, so he wrapped up the conversation quickly and let Jim know that he would pray for him and Joan and would be in touch soon. Soon never arrived.

In the span of 36 months, Joan and her husband have become virtually invisible.

Statistically, you surely know someone like Joan. The Alzheimer's Association estimates that more than 1 in 9 Americans who are 65 and older have some form of dementia, a general term for a decline in mental ability that includes memory loss severe enough to interfere with daily life. Alzheimer's disease is the most common type of dementia. Of the estimated 5.3 million adults in America with the disease, nearly 5.1 million are over the age of 65 and more than two thirds are women. The parallel age

and gender demographics with most Presbyterian congregations would indicate that more than 10 percent of the older adult members in most congregations have or are facing Alzheimer's. Chances are, only half of those afflicted have been formally diagnosed.

Dementia is a devastating condition that robs individuals of their sense of self. It imposes detachments in relationships and context while it conversely increases the care and attention required from family and caregivers. Dementia remains a condition that provokes shame and uncertainty; most people are afraid to speak of it or relate to it, which leaves both the person with dementia and their caregivers feeling alone. Such isolation brings great emotional pain and increases the risk for depression, exhaustion and other stress-related conditions.

While the fictional scenario describing Joan, Jim and their congregation may seem harsh, the reality is that, regardless of their intention or compassion, too few congregations are equipped or can find resources to sustain support to individuals or families facing this progressive but intractable condition.

A different approach

What if congregations joined with other institutions and organizations to create an environment that is safe and respectful of individuals with dementia, their families and caregivers? What if the church became a dementia friendly congregation within a dementia friendly community?

If we maintain that all persons, including those with dementia, are created in God's image, how can we uphold and honor them as unique and wonderfully made? How can we keep them connected to the community of grace? If we believe that the Holy Spirit remains at work in them, how do we identify and receive the spiritual gifts they offer? If we understand that "Remember me" is among the highest mandates of Jesus and that faith regenerates through our shared memory, how can we better remember those who forget?

Such a vision of care is already emerging.

It's the vision of a national volunteer-driven initiative known as Dementia Friendly America (DFA), announced at the White House Conference on Aging in July 2015. DFA's goals are to foster dementia friendly communities that will enable people who are living with dementia and their care partners to thrive and to be independent as long as possible. To do so, the movement is calling on businesses, local governments, health care organizations, community-based organizations, churches, synagogues and spiritual communities to create a society by 2020 where every person with dementia in every area of the country not only receives high quality compassionate care and support from diagnosis through end of life care, but remains welcome and connected to the community where they live.

The movement was born in Minnesota through ACT on Alzheimer's, a statewide collaboration that launched in 2011 to equip and engage communities to become "dementia friendly." ACT on Alzheimer's is not a single organization but an extraordinary collaboration of more than 400 participants in over 30 cities and towns in Minnesota. More than 60 nonprofit, governmental and private organizations have stepped up, including two senior living communities of Presbyterian Homes & Services:

Carondelet Village in St. Paul and GracePointe Crossing in Cambridge. While both senior communities offer an option of specialized memory care, their commitment to and leadership with ACT on Alzheimer's extend their ministries deep into their local communities.

Vital to this initiative are the education and deployment of "dementia champions," trained volunteers who conduct information sessions and encourage others to make a positive difference for people living with dementia. In turn, those who attend these sessions become "dementia friends" who have learned about what it's like to live with dementia and share what they've learned in their workplaces, social circles and community relationships.

As this movement rolls out nationwide, congregations and spiritual communities are invited to join the initiative. Churches are already well-positioned to engage with and advocate for those touched by Alzheimer's and related dementias.

What does it mean to be a dementia friendly congregation?

Here are some examples of actions a congregation can take to create a supportive environment:

- Talk to members who are living with dementia and their caregivers to find out their perspectives about what the congregation can do to offer support and sustain their connection.
- Commit to being more inclusive and aware of the needs of people living with dementia, consistent with the congregation's greater commitment to inclusiveness.
- Collaborate with a local senior living community that offers a memory care living option or adult day care. Senior living providers have qualified staff who can educate pastoral and volunteer caregivers and church staff to increase awareness and understanding of dementia and provide training on good communication strategies.
- Consider how worship practices invite or hinder participation. Increasing multi-sensory elements, especially through art and music, can connect with people in ways that words fall short. Address dementia-related issues in preaching. Recruit "worship friends" willing to sit with and assist persons with dementia through the service.
- Invite those with early-stage dementia to join activities or volunteer for tasks that bring them satisfaction. Engage church youth as volunteers in your Alzheimer's-related programs.
- Evaluate the church's physical environment to ensure it is accessible and appropriate for people with dementia. This includes consistent signage and directional cues.
- Review regularly used documents (including bulletins and newsletters) to ensure they use clear, straightforward language and appropriate design. Include written and digital resources about dementia and available support in literature racks, newsletters and on the church website.
- Develop a caregiver ministry to give caregivers a needed break to run errands, meet appointments or just take a break for their well-being.
- Reach out to local business and community organizations to begin a dementia friendly initiative.

- If a local group has formed in your area, offer to host meetings and training for dementia champions and dementia friends as well as an ongoing support group for caregivers.
- Plan a review and continuous improvement cycle to sustain and normalize the emerging dementia-friendly culture of the congregation.

A reimagined story

In her mid-60s Joan began experiencing memory loss that worried her. She was generally aware of the signs of dementia based on education she received through a class offered at her church. Joan went to the doctor and was diagnosed with Alzheimer's disease. Although the news was devastating, Joan was willing to share her situation with her church family, confident that they would embrace her as she and Jim found their way into this new reality.

Joan asked for a reference from the pastor as she worked with her employer to transition to a part-time role. She also enrolled in a support group offered by the congregation. Jim began attending the caregiver's group at the church. Resources available through the church pointed Joan and Jim to home care support, residential care options and financial planning resources in the community.

As Joan's disease progressed, affecting her role in the church, other elders were able to approach her to discuss how she might let go of the responsibilities that brought her stress and find new ways to contribute her time and talent that would bring her joy and be of value to congregation.

When Joan and Jim came to worship she was handed a digital tablet with a collection of paintings and images depicting the readings of the day. Looking through these images during the sermon helped her remain engaged in a worshipful experience. She sang or hummed along to familiar songs, whether they were congregational hymns or choir anthems.

Visiting deacons reported that conversation with Joan took dips and turns, but their training helped them stay in the moment with her and they did not take it personally when she didn't remember their relationship or even their last visit. They also checked in regularly with Jim and scheduled a respite care volunteer when he needed to leave the house to take care of himself.

While Joan continued to experience memory loss that progressively reduced her cognizance, function and mobility, she was able to live in her home with her husband, enjoying her family, welcoming her church friends and neighbors. Jim's emotional, spiritual and physical health remained intact due to the support he received from professionals and volunteers and the added support and compassion from their church family whom they knew and loved.

Can you imagine being a part of that church?

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