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Creating a Story of Hope in the Face of Dementia

Nancy Gordon

If asked to name what disease they fear the most, one in five Americans names Alzheimer's. Only cancer is named more often.

Just note the momentary panic that we feel when a word or a name is on the “tip of the tongue,” when we can’t find our keys or our glasses, when we realize we’ve forgotten to pay a bill or make an important phone call. We joke about these “senior moments” and fervently hope that it’s just a temporary lapse, not the beginning of something more serious. So what is it that we are so afraid of? Dementia is an umbrella term describing a variety of diseases and conditions that develop when nerve cells in the brain die or no longer function normally. Alzheimer’s disease accounts for 60 to 80 percent of dementia cases. Other types of dementia are vascular dementia, dementia with Lewy bodies, mixed dementia, and Parkinson’s disease.



Alzheimer’s disease and dementias with other causes rob those afflicted of short-term memory and the ability to think logically and coherently. While memory loss is often the most worrisome first sign, it is the lack of cognitive function and ability to problem-solve and find one’s way that become most difficult for the persons afflicted, their family, and their friends. Loss of cognition is also often accompanied by personality changes and life as it’s been known changes incrementally both for the persons afflicted and for all who care for them. It is a difficult and often heart-breaking journey as persons we have known and loved no longer recognize us and can’t remember where they are or even who they are.

We live in a society that some have labeled as “hyper-cognitive” – a society that values the ability to think and remember as the highest good and defines our worth as persons based on our cognitive abilities. Churches too value being smart and, like our wider culture, we don’t like to think about growing older and tend to deny that we are all aging. But the fact remains, we are an aging population and as a result, the number of people afflicted by Alzheimer’s disease and other age-related dementias is growing. In 1900 only 5 percent of the population was older than sixty-five; by 2008 about 13 percent was over sixty-five, and by 2030 that number will be almost 20 percent of our population. Today around one in eight persons over sixty-five has Alzheimer’s, with the total number estimated to be 5.2 million. An additional 200,000 individuals are afflicted with an early onset form of the disease. These numbers will continue to grow as more baby boomers join their parents in the over sixty-five category.

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In this context churches have a unique opportunity to tell a new story and expand understandings about Alzheimer’s disease and other age-related dementias. While much money is being spent on research, there is no cure in sight. We can either succumb to the dread and fear that is rampant around us, or we can embark on the journey of understanding these dementias and create a new story of hope by remembering as God remembers and loving as Jesus loved.

When I was first working in a large retirement community, a co-worker lamented the changes she was seeing in residents and expressed fear about Alzheimer’s disease. I said to her, “We are more than our minds.” I don’t know where that idea came from exactly, but it was something I became more and more convinced of as I worked with the cognitively impaired.

Every chaplain who has worked in long-term care can tell stories of residents who seem not to be present during a worship service and then who come alive, usually while singing an old hymn. Everything about their affect changes – they are present, singing with the group and giving praise to God. Such experiences have convinced me that it does make a difference to bring spiritual and pastoral care to persons with cognitive impairments, and that it doesn’t really matter whether they remember the experience ten minutes later. What matters is that in that moment we are all connecting with one another and with God.

Early in my work with older adults I participated in a program on gerontological pastoral care and the major assignment was to write a theology of aging. My theology started with: “We are created in the image of God and we bear that image for our whole lives.”

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I'm still unpacking the meaning of that, but it helped frame my work by reminding me that the functioning of our minds doesn't determine the status of our personhood – we are persons of value because we bear God's image, and that's enough. While our minds have often been the focus of learning about and knowing God, the mystical tradition within the church reminds us that the soul is the focus of God's activity in our lives. We don't lose our souls when our mind declines. Bearing the image of God speaks to our capacity for relationship with God and with others. Even when we are suffering from severe cognitive impairment we are still able to love and be loved. We are still capable of relationship. And while we tend to equate losing cognitive functions with losing everything, even when our minds aren't working we still have spirit and body and emotions – all of which are pathways for relating to God and to each other.

Our own fear and dread often hamper our ability to be present with those who are no longer cognitively intact. And since there is no medical cure, we can feel hopeless and helpless in facing the reality of this disease. How can we make any difference? And we wonder if there is any value in providing care and presence for someone who will not know us or remember that we've been there.

A colleague I worked with told a great story of going to the Brookfield Zoo with a group of persons from a memory care unit at the nursing home where he worked as chaplain. He told how they got on the bus on a perfect August day in Chicago – it wasn't humid, it wasn't too hot, and the sun was shining. They rode a tram around the zoo seeing all the animals, enjoying the sights, sounds, and smells. They stopped on their tram ride and got off in a picnic area and had lunch. They got back on the tram, finished their journey through the zoo, and took the bus back to the memory care unit. As they walked through the doors they were greeted by staff who said, "How was it?" "Did you have a good time?" My colleague realized by the puzzlement on the residents' faces that they had no memory of all the fun, laughter, and sights they had experienced that day. He wondered, "Does it really make a difference that we do things like this?"

One of the gifts of Alzheimer's is that it reminds us that we all have only this present moment.

He voiced that question to the daughter of one of the residents who had been on the trip with them. She said, "It does make a difference and I'll tell you how I know. I come every Sunday morning and take my mom to church and out to lunch. Later that day or the next day she won't remember that we've done it. But if I have to miss a Sunday, the staff tells me that by the following Tuesday she's climbing the walls. Even though she doesn't

remember, what we do together on Sunday affects her spirit and makes a difference in the quality of her life.”

Could it be that some of us are called to remember those who only have the present moment, and be there with them in that moment? One of the gifts of Alzheimer’s is that it reminds us that we all have only this present moment. In responding to those with this disease we are invited to leave behind our own priorities and distractedness and be fully present with them in that moment in their world. Making that effort is easier if we assume a radical equality between us – if we go into the encounter expecting to receive as well as to give, expecting to learn as well as to teach.

In the Hebrew Scriptures we have story after story of the ways God remembers the people of Israel. For them to be forgotten by God was to die, and to be remembered by God was to live and to thrive. They experienced God’s remembering as actions on their behalf. When “God remembered Noah...God made a wind blow over the earth, and the waters subsided” (Genesis 8:1). This is just one example of God’s remembering that involved action, not an intellectual retrieval of a memory. God remembered God’s people in ways that were lifesaving, life giving, and that came at the time they were needed.

I think that we are called to remember others, particularly those who can no longer remember for themselves, the way that God remembers us. We are called to respond to the needs of those with varying levels of cognitive impairment in ways that are lifesaving, life giving, and come at the moment of need. We can only do this when we put aside our fears and are willing to listen to those with the disease and to their closest caregivers. We can only do this when we realize that whether our conversations, deeds, and activities are remembered by recipients or not, in the end it’s not about us – it’s about them and how our presence enriches their lives and touches their spirits. It means trusting that even when we don’t see “results,” the Spirit is at work in ways that are beyond our understanding. It’s being willing to be uncomfortable when our primary method of communication—lots of words—doesn’t work anymore, and finding new, more creative ways of communicating our love and God’s love and care. It’s being committed to finding ways to affirm our cognitively impaired friends and to include them in the life of the community of faith.

So what can congregations do? Here are some suggestions.

- Learn about Alzheimer’s disease and other dementias. Be intentional in learning how to respond to those affected in ways that meet them where they are. Volunteer at a memory care unit or an adult day services program to learn ways of interacting with and providing meaningful activities for those with advanced forgetfulness.
- Maintain social and spiritual contact with persons diagnosed. Be creative and find supportive ways to enable those with cognitive impairment to continue to serve in ways that they have served. Include them and their family in as many of the events they’ve attended for as long as possible.
- Offer regular respite care to families in the congregation who are caring for someone with Alzheimer’s disease.
- Provide support groups for those with the disease and support groups for caregivers. Training to lead such support groups is offered by the Alzheimer’s Association.

- Bring worship to persons who can no longer come to church in their home or in the care center where they live. See such worship ministry as a way to do outreach and take it to care centers and nursing homes in your area.
- Advocate for funding for programs for persons with Alzheimer's disease and other dementias. Community-based adult day services programs are often hit by budget cuts.

As we intentionally remember those with advanced forgetfulness we will begin to create a new story around Alzheimer's disease and other dementias. It's a story where relationships change but don't end because one person is afflicted. It's a story that has room for hope, for humor, for comfort. I have a social worker friend who recently offered a series of classes to her congregation around these issues. One of the participants was a man who had recently been diagnosed as being in the beginning stages of the disease. After one session, she asked him what it was like for him to be there. "It makes me feel comforted," he said.

His church was learning about his disease and ways they could minister to him and to his primary caregivers. It gave him hope that as the disease progresses they will not be abandoned, but they will be remembered in concrete, life-giving ways. His church is on the way of creating and telling a new hopeful and loving story about aging and cognitive impairment – and it's my hope that many more will join them.

To Learn More about Alzheimer's and Other Dementias

The *New York Times* has a web-based collection of information and videos about the disease here that includes a comprehensive overview of the disease, tips for caregivers, and information about research. One of the most helpful sections for those seeking to minister to those affected is the video Patient Voices: Alzheimer's Disease.

The Alzheimer's Association enhances care and support, advances research, and advocates on behalf of those with the disease. Their website provides educational materials, access to local chapters, and support groups. They publish a yearly statistical summary about the prevalence and impact of the disease. The "2014 Alzheimer's Disease Facts and Figures" can be found here.

Resources for Congregations

No Act of Love Is Ever Wasted: The Spirituality of Caring for Persons with Dementia, by Jane Marie Thibault and Richard L. Morgan (Upper Room Books, 2009). This book provides an accessible overview of the disease and creative ways that individuals and congregations can minister to those affected.

Aging Together: Dementia, Friendship and Flourishing Communities, by Susan H. McFadden and John T. McFadden (Johns Hopkins University Press, 2011). Written by a psychologist (Susan) and a pastor (John), this book invites congregations to be communities of friendship that intentionally include those with dementia. They speak to the dread and the fear that surround the diseases of dementia and how congregations can become places of hope and support by building communities of friendship. The key concepts of this book are summarized by John for congregations in a pamphlet, *Aging*,

Dementia, and the Faith Community: Continuing the Journey of Friendship that can be found in a downloadable PDF [here](#).

California Lutheran Homes Center for Spirituality and Aging has information on “Sensing the Sacred,” an award winning worship program for persons with Alzheimer’s disease that could be used by congregations in a worship ministry. Kits for worship modules and training videos are available. Read about it [here](#). The Center website also has other articles and resources for congregations on ministry to older adults and to those with Alzheimer’s specifically. And you can subscribe to the Spirit e-newsletter which includes resources for congregational older adult ministry in each issue.

A version of this article originally appeared in the Oct. 2012 issue of The Covenant Companion.

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