



## **November is Alzheimer's Awareness and National Caregiver month.**

- Over 5 million persons in the US have Alzheimer's or other dementia.
- An estimated 15 million carers assist them.
- Dementia is a long progressive process and each person is affected uniquely.
- Persons change in many ways over the disease process.
- Congregations are called to minister with persons dementia and their carers.

## **Is your congregation ready to support those with dementia?**

Congregations can actively affirm their relationships with those who struggle with dementia and their carers by becoming dementia friendly "remembering communities." Lutheran tradition, in particular, is rich in music and liturgy that is often remembered when words fail. Scripture stays in memory long into dementia. A person does not need full cognition to share in worship and community life and supporters can focus on what persons still can do, and adapt to what they can't. Even a "moment" shared with a person with dementia is a gift to the person with dementia and the person sharing it.

## **Congregations are not alone in dealing with dementia.**

Congregations can offer spiritual as well as tangible support. Partnering with local organizations that serve those with dementia and their carers can be helpful. In addition, the Alzheimer's Association is a rich resource that distributes materials on Alzheimer's and other dementias. It has a 24/7 helpline, and offers support groups ([www.alz.org](http://www.alz.org) and 1-800-272-3900). The Alzheimer's Association is a rich resource that distributes materials on Alzheimer's and other dementias. It has a 24/7 helpline, and offers support groups. Contact them at [www.alz.org](http://www.alz.org) or 800-272-3900.

## Supporting Persons With Dementia in the Congregation

### Some Basic Considerations

- Relationships with those with dementia and their care partners are **SACRED**. A person with dementia possesses strengths and gifts as well as needs.
- When you have seen one person with dementia, you have seen **ONE** person with dementia. Learn how dementia affects each **PARTICULAR** person.
- There are many kinds of dementia (Alzheimer's Disease is the most common), and the dementia process is progressive. A comprehensive diagnostic workup is important for knowing what a person faces. Persons are being diagnosed earlier in the illness process, so they may struggle a long time with symptoms.
- A person is not a "diagnosis" nor a "victim." He or she is someone with emotional and spiritual strengths and interests.
- Faith communities "serve" rather than "help." Beware of doing more than a person requires.
- Persons with dementia can be "teachers" and "mentors" if congregation members are open to learn. Use language carefully to describe a person with dementia and their situation.
- Even if persons forget, the church cannot forget them. It can remember things for them. "God Never Forgets" persons with dementia. The congregation may become a "remembering congregation" for those with dementia.
- A person does not need full cognition to share in ministry.
- Members of the congregation can remain "friends" to persons with dementia. They can encircle these persons and their carers in support. All can affirm their **INTER**dependency.
- Keeping a sense of "reasonable hope" is paramount in encouraging persons.
- When memory fails, connection to "the moment" is a gift. "Being present" here and now to the person with dementia and care partners is key.
- The idea of care partnering can help build relationships.

## **Church Challenges in Supporting Persons with Dementias and Their Carers**

- Church members often feel unprepared for sharing with those with dementia.
- Changes in memory are frustrating for persons with dementia AND for those around them. Personality and mood changes are upsetting. Behaviors can be embarrassing, especially when they occur in public worship.
- Limited ability to reason or solve problems, and impaired judgment may create challenges in carrying out traditional roles in the congregation. A person may not be able to accomplish tasks that they once did. Offering respectful support can be challenging.
- Care partners may feel isolated and neglected by their church, or may self-isolate because of their loved one's behavior.
- Persons move through different phases in dementia. As needs change and the illness progresses, persons around them may need to rethink their connection to a person and his or her carer.
- End of life decision making becomes more complex with dementia.

## **The Church's Role in Keeping Hope and Heart Alive for Those With Dementia**

- Understand that spiritual concerns may revolve around anger, fear, grief and suffering. Despite being uncomfortable, these feelings need expression.
- Know a person's story and use it in communication and support. Despite mental limitations, faith stories are often strongly remembered.
- Reflect God's love in pastoral counseling, no matter where a person is in their illness.
- Recognize that spirituality is expressed uniquely for each person. "Spiritual" activities can be formal or informal. Help the carer to do things "one on one."
- Pray for those with dementia and their carers privately (and publically, if requested).
- Remember listening is a great gift to those with dementia and their care partners.
- Stand "shoulder to shoulder" with those with dementia and their care partners in dementia's long process.

- Be proactive in preventing isolation of the person with dementia and their care partners by regularly keeping in touch. Ask persons what they need, and make no assumptions.
- Give carers “permission” to ask for and receive assistance. Affirm that requesting help is a strength, not a weakness.
- Be non-judgmental about decisions made by those with dementia and their care partners. Only those experiencing a situation truly understand it.
- Encourage persons on their dementia journey in patience, persistence, gentleness and love.

### **Ways for the Church to Support Those with Dementia**

- Maintain spiritual and social connections to the congregation. Bring worship and other spiritual experiences to the person who can no longer attend worship.
- Affirm and continue the roles persons have held in church. For example, persons may be able to continue as a reader, choir member or usher with the help of a “buddy”.
- Be aware of new persons who come into the faith community (especially for medical care or to be near family) . Learn their life story. Be a “safe place” for persons to share concerns about dementia.
- Use a “walk alongside” approach in relationships within the congregation.
- Celebrate “moments” of joy in the midst of sadness about the disease process. Remember the gift of humor.
- Learn from people with dementia and their care partners.
- Use a health and wellness approach to concerns about dementia. They are a public health issue as well as an “aging” issue.
- Do an environmental survey of congregational facilities to assure safety and accessibility. Intentionally welcome those with dementia and their care partners.
- Assist all in the congregation to understand forgetfulness and dementia through education. Cue persons as needed. The Alzheimer’s Association is a good source of materials.

- Use persons and groups that already provide support (e.g. Eucharistic Ministers, Stephen Ministers, Parish Nurses) to address the concerns of those with dementia and their carers. Educate them to the needs of persons with dementia.
- Offer the church building for support groups or respite care (a “time away” for carers.)
- Develop an easily accessible library of pamphlets, books and other resources on dementia.
- Educate church staff about community resources. Partner with agencies who serve those with dementia. Make sure that the persons who answers the church phone can make good referrals.
- Be open to creative ideas in the community and partner with them. (Memory Cafes, Adult Day Care or Singing for the Brain.)

### **Keeping the Spirit Alive for Those with Dementia and Their Care Partners**

- Acknowledge and work with individual fears about dementia. The whole congregation is affected by dementia one way or another.
- Learn effective communication skills. Emphasize non-verbal communication and incorporate it into sharing.
- Make effective use of long term memory.
- Use music and other creative arts to reach those with dementia. Integrate creativity and flexibility in worship. Provide special worship experiences.
- Create rituals of healing for those with dementia and their carers. Use symbols.
- Have a “buddy system” for services and special activities. These people can assist with cueing.
- Intentionally “be present” to the person with dementia. Connect “soul to soul.”  
When the cognition of a person fails, the spirit stays alive.

## Helpful Resources

- Alzheimer's Association. [www.alz.org](http://www.alz.org)
- Angelica, Jade C. (2014). *Where Two Worlds Touch: A Spiritual Journey Through Alzheimer's*. Boston: Skinner House Books.
- Bell, Virginia M & Troxel, David. (2002). *A Dignified Life: The Best Friends Approach to Alzheimer's Care: A Guide for Family Caregivers*. Deerfield, FL: Health Communications.
- Fazio, Sam. (2008). *The Enduring Self In People with Alzheimer's*. Baltimore: Health Professions Press.
- Keck, David. ((1996). *Forgetting Whose We Are: Alzheimer's Disease and the Love of God*. Nashville: Abingdon Press.
- McFadden, Susan H. & McFadden, John, T. (2011). *Aging Together: Dementia, Friendships and Flourishing Communities*. Baltimore: The Johns Hopkins University Press.
- McKim, Donald (Ed.) (1987). *God Never Forgets: Faith, Hope and Alzheimer's Disease*. Louisville: Westminster John Knox Press.
- Richards, Marty. (2010). *Caresharing: A Reciprocal Approach to Care Giving and Care Receiving in the Complexities of Aging, Illness or Disability*. Woodstock, VT: Skylight Paths.
- Singing for the Brain. A project of Alzheimer's Society UK [www.alzheimers.org](http://www.alzheimers.org)
- Songwriting Works [www.songwritingworks.org](http://www.songwritingworks.org)
- Thibault, Jane Marie & Morgan, Richard L. (2009). *No Act of Love is Ever Wasted: The Spirituality of Caring for Persons with Dementia*. Nashville: Upper Room Books.
- US Department of Health and Human Services [www.alzheimers.gov](http://www.alzheimers.gov)

Prepared by Marty Richards, LICSW. Contact her at [mrichard\\_2002@yahoo.com](mailto:mrichard_2002@yahoo.com)