

# shedding light on alzheimer's



**a guide for faith leaders**

# What is the importance of spirituality?

Research has shown that individuals who maintain a spiritual connection as they age have a stronger well-being and a greater sense of purpose in life. This well-being helps lessen many of the physical and mental symptoms of Alzheimer's disease, enabling the individual to live a more fulfilling and longer independent life. Religious places are often a space filled with memory, giving an individual or family member a sense of peace, serenity and joy.

Faith leaders play an integral role in the lives of individuals with memory loss. After diagnosis, an individual is more likely to seek help from their faith leader-more than any other specialist. Faith-related activities are also the most common form of voluntary activities among older adults, and nearly 90% of people over the age of 65 pray or have a regular faith practice.

Faith leaders such as clergy, parish nurses, Stephen Ministers and senior ministries can be community "gatekeepers" by providing education to the greater faith community and support for individuals and families affected by Alzheimer's disease.

## Thoughts on Faith and Dementia

- **Spirituality in the form of prayers and songs (for example) often has a deep emotional significance. Perhaps spiritual capacity is heightened while the capacity of rationality fades.**
- **Divine love never abandons the deeply forgetful.**
- **Equal regard under the love of a higher power along with the emotional, relational, and symbolic expressions of persons lead us to reject the notion of "I think, therefore I am". Instead we must believe "I feel and relate, and above all, I am".**
- **Dementia does not eliminate the capacity for a peaceful relationship with a higher power.**
- **The spiritual needs of people with dementia are to be accepted, loved, given worth and honor, to be befriended and listened to, and to receive grace and mercy. These are the same spiritual needs as everyone else.**
- **Ministering to people with dementia calls for patience and perseverance**
- **Approach the situation with love and hope, time and graciousness, and with gentleness and faith.**

### References:

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# About Alzheimer's Disease

## Definition

Alzheimer's disease is a progressive, degenerative disease that attacks the brain and results in impaired memory, thinking and behavior.

Alzheimer's disease (AD), the most common form of dementia, is the sixth-leading cause of death in adults. Dementia is a general term for the loss of thinking, remembering and reasoning so severe that it interferes with an individual's daily functioning.

Dr. Alois Alzheimer first described AD in 1906. Since then, researchers have made great progress in understanding the changes in the brain (cell death) and behaviors that characterize the disease. Identified risk factors are age, gender and family history. Most people diagnosed with AD are age 65 or older; however, AD can occur as early as age 40.

## Symptoms

Symptoms of AD include gradual memory loss, a decline in the ability to perform routine tasks, disorientation, loss of language skills, impaired judgment and personality changes. The time from the onset of symptoms until death averages eight years, but can last up to 20 years. Eventually, persons with AD become incapable of caring for themselves.

## Diagnosis

There is no single test that proves a person has Alzheimer's. The workup is designed to evaluate overall health and identify any conditions that could affect how well the mind is working. When other conditions are ruled out, the doctor can then determine if it is Alzheimer's or another dementia. Experts estimate that a skilled physician can diagnose Alzheimer's with more than 90 percent accuracy. Physicians can almost always determine that a person has dementia, but it may sometimes be difficult to determine the exact cause.

## Treatment

Although no cure for AD is currently available, planning, medical and social management can ease the burdens on the individual and family.

Health-care directives and decisions should be made as early as possible. Exercise, social activity and nutrition are important, and a calm, well-structured environment may help the affected person continue functioning. Four FDA-approved drug treatments are currently available to treat the mild and moderate symptoms of Alzheimer's. Additional treatments may be available soon as research advances.

## Research

The causes of AD are currently receiving intensive scientific investigation. Suspected causes include diseased genes or a genetic predisposition, abnormal protein build-up in the brain and environmental toxins. Scientists are applying the newest knowledge and research techniques to find the causes and treatments for AD.

## Economic impact

At some point, a person with AD will require 24-hour care, including assistance with daily activities. **Alzheimer's disease is the most expensive condition in the nation.** In 2015, the direct costs to American society of caring for those with Alzheimer's will total an estimated \$236 billion, with just under half of the costs borne by Medicare. Despite these staggering figures, Alzheimer's will cost an estimated \$1.1 trillion (in today's dollars) in 2050. Much of the remaining costs are borne by individuals and their families.

The Alzheimer's Association provides leadership to eliminate Alzheimer's disease through the advancement of research while enhancing care and support services for individuals and their families. The association serves as the primary resource for Alzheimer's disease and related disorders through family services, education, public policy and research.



# ALZHEIMER'S STATISTICS GEORGIA

## U.S. STATISTICS

Over **5 million** Americans are living with Alzheimer's, and as many as **16 million** will have the disease in 2050. The cost of caring for those with Alzheimer's and other dementias is estimated to total **\$236 billion** in 2016, increasing to **\$1.1 trillion** (in today's dollars) by mid-century. Nearly **one in every three seniors** who dies each year has Alzheimer's or another dementia.



For more information, view the **2016 Alzheimer's Disease Facts and Figures** report at [alz.org/facts](http://alz.org/facts).

## 65+ Number of people aged 65 and older with Alzheimer's by age\*

Year	65-74	75-84	85+	TOTAL
2016	24,000	60,000	50,000	130,000
2020	29,000	69,000	55,000	150,000
2025	33,000	90,000	63,000	190,000

\* Totals may not add due to rounding

## Percentage change from 2016



## + Medicaid costs of caring for people with Alzheimer's, 2016

# \$1,055 MILLION

## # Number of deaths from Alzheimer's disease in 2013

# 2,048

## Number of Alzheimer's and dementia caregivers, hours of unpaid care, and costs of caregiving

Year	Number of Caregivers	Total Hours of Unpaid Care	Total Value of Unpaid Care	Higher Health Costs of Caregivers
2013	499,000	569,000,000	\$7,080,000,000	\$240,000,000
2014	506,000	576,000,000	\$7,015,000,000	\$251,000,000
2015	513,000	584,000,000	\$7,160,000,000	\$263,000,000

## **Know the 10 Signs: Early Detection Matters**

Being able to recognize early warning signs among congregation members will not only help them get a diagnosis, but give them invaluable time planning for the future and managing symptoms. It's important to know what is a more serious sign of memory loss and what is typical age-related changes. The Alzheimer's Association provides an educational program, *Know the 10 Signs*, which further details the early warning signs.

### ***Memory changes that disrupt daily life***

With typical aging, a person sometimes forgets names or appointments but remembers them later. One of the most common signs of Alzheimer's, especially in the early stages, is forgetting recently learned information. Others include forgetting important dates or events, asking for the same information over and over, relying on memory aids like reminder notes or electronic devices, or relying on family members for things the person used to handle on their own.

### ***Challenges in planning or solving problems***

With typical aging, people may make occasional errors when balancing a checkbook. But with Alzheimer's, an individual may experience changes in their abilities. They may have trouble following a familiar recipe or keeping track of monthly bills. They may have difficulty concentrating and take much longer to do things than they did before.

### ***Difficulty completing familiar tasks***

Typical aging involves occasionally needing help to use the settings on a microwave or to record a television show. People with Alzheimer's often find it hard to complete daily tasks like shopping, cooking, personal grooming or medical care. Sometimes, people may have trouble driving to a familiar location, managing a budget at work, or remembering the rules of a favorite game.

### ***Confusion with time or place***

With typical aging, a person may sometimes get confused about the day of the week but figure it out later. People with Alzheimer's can lose track of dates, seasons and the passage of time. They may have trouble understanding something if it is not happening immediately. Sometimes they may forget where they are or how they got there.

### ***Trouble understanding visual images and spatial relationships***

Typical aging includes vision changes related to the aging of the eyes, like cataracts. But for some people, having vision problems is a sign of Alzheimer's. They may have difficulty reading, judging distance and determining color or contrast. Perception and judging distances have very real implications for driving. The use of rear view mirrors and side mirrors while driving is key to safety. But for someone with the disease, using all of these mirrors while processing the changing view in front of them, and looking over their shoulders to back up, is overwhelming to their senses. They may become upset or make mistakes, both of which can lead to accidents.

### ***New problems with words in speaking or writing***

Typical aging includes sometimes having trouble finding the right word. People with Alzheimer's may have trouble following or joining a conversation. They may stop in the middle of a conversation and have no idea how to continue or they may repeat themselves. They may struggle finding the right word, or call things by the wrong name (like calling a "watch" a "hand clock").

### ***Misplacing things and losing the ability to retrace steps***

Typical aging involves misplacing things from time to time, such as a pair of glasses or the remote control. A person with Alzheimer's disease may put things in unusual places. They may lose things and be unable to go back over their steps to find them again. Sometimes, they may accuse others of stealing.

### ***Decreased or poor judgment***

Typical aging involves making a bad decision once in a while. People with Alzheimer's may experience changes in judgment or decision making. For example, they may use poor judgment when dealing with money, giving large amounts to telemarketers. They may become less able to choose clothing that is appropriate to the weather or the season.

### ***Withdrawal from work or social activities***

With typical aging, someone may periodically feel weary of work, family and social obligations. A person with Alzheimer's may start to remove themselves from hobbies, social activities, work projects or family gatherings because it is harder to follow conversations. They may have trouble keeping up with a favorite sports team or remembering how to engage in a favorite hobby.

### ***Changes in mood and personality***

The mood and personalities of people with Alzheimer's can change with the disease. It is much easier for someone with dementia to do things in very routine ways, with not much change or variety. They can become confused, suspicious, depressed, fearful or anxious when situations call for spontaneous changes or quick responses. As a result, they may be easily upset at home, at work, with friends or in places where they are out of their comfort zone.

# How does a spiritual community support a person with Alzheimer's disease?

It is important to emphasize that those with dementia are still part of the faith community and many, especially those who grew up in religious households, still derive pleasure from attending worship services. Other members of a person's spiritual community may not know how to respond to the changes that they are seeing in a person and they may also not know much about the disease. In your role as a faith leader, you can serve as a guide to your community by providing a model and suggestions for fellow members to follow.

## **In General:**

- Ask about the person with dementia and the caregiver's well-being
- Greet the person warmly, using small sentences and introduce yourself
- Maintain eye contact when talking to them and when listening to them
- Be aware that new behaviors you may be seeing are often a progression of the disease that can't be controlled.
- Respond to behaviors in calm and supportive ways, use gentle voice and tone
- Educate other congregation members about the disease, hold educational programs or health events

## **At Service:**

- Encourage participation in activities appropriate to their ability such as singing in the choir, folding programs, helping decorate a worship space
- Wear nametags at services or community functions
- Incorporate familiar passages or scripture in the service
- Visit with them one-on-one; look at old photo-books, recall past events they've been a part of, listen to their needs and concerns, provide support
- Faith leaders should model compassionate responses if the person with Alzheimer's disease "acts up" during a service, have a space they can go to.
- Pray together, pray for the person and their family

# Strategies for Initiating Meaningful, Quality Home Visits with People Who Have Dementia

## Setting the Stage for a Meaningful Visit

**Get your historic snapshot** - Gather some information ahead of time from congregation members, family or the caregiver. Knowing about the person's previous and current lifestyle and habits, e.g., routines, eating patterns, work life and schedule, hobbies, personality traits, living arrangements, relationships with family friends and neighbors, etc can help steer conversation and structure visits.

**Prepare for meaningful time** - Bring activities that can easily be shared that are of interest to the person and at the level of their ability.

**Enlist support** – If the person struggles with strangers coming into the home, ask a known person to introduce you. Don't be concerned about communicating who you are to the person with dementia; simply frame your visit as someone who is an interested friend who has come to see them.

**Attune the environment** – Wherever possible, visit the person with dementia in his/her own home or room. Familiarity is imperative to a person with dementia feeling safe and comfortable. Be sure that the environment is free from noise, interruptions and distractions; i.e., is quiet, pleasant and calm.

**Prepare to be a mentor to caregivers** - Bring information that can be helpful to caregivers in communicating and spending quality time with the person who has dementia.

**Check your problems at the door** – People with dementia have heightened sensitivity to other people's moods, feelings, body language and tones of voice. Enter the person's space as a friend, with a warm smile and relaxed demeanor. The person needs reassurance and understanding in order to communicate with you.

## **Some Do's and Don'ts**

### **Do:**

- Address the person by name and introduce yourself.
- Use a calm and quiet voice. Keep it leisurely.
- Remember that you do not always have to talk; a quiet moment looking out the window can be just as meaningful.
- Make a commitment (a routine) to visit regularly for short periods at the "best time" for the person and family.
- Recognize and use humor, affection, and praise.
- Focus on one-to-one visits, as they are easier for the person with Alzheimer's.
- Remember that food is the universal language of love...so bring a snack.
- Read together from spiritual books or journals...often these produce ingrained memories that create feelings of joy for the person with dementia.
- Pray with the person, do not forget that dementia does not destroy a person's spirituality or faith.
- Ask the family how best to connect with the person, as they will know the new ways to best communicate with the person.

### **Don't:**

- Rush visits or talk loudly.
- Assume that the person with Alzheimer's cannot understand what you are saying. The tone of your voice will always shine through your words.
- Talk about the person with someone else in his/her presence.
- Try to rationalize with the person. If she thinks that her mother, who died twenty years ago, is still alive let her be peaceful in the thought of her mother being here.
- Take insults or inappropriate behavior personally.
- Assume the family is burdened or resentful of taking care of their loved one.
- Worry that you are not doing enough. A regular visitor from a spiritual friend makes all the difference in the world to the person with dementia and the family.

# Tips for Supporting the Caregiver and Family

## **Keep in Touch**

Cards, calls, and visits to the family are always appreciated.

## **Do Little Things**

Cook and drop off a freezable meal. Ask the family members if you can pick up something for them while you run errands. Surprise the family with gift certificate for a dinner out and offer to help arrange care for their loved one for that evening.

## **Care For and About the Family Caregiver**

Family caregivers are easily depleted, overwhelmed and often feel alone. Let them know they are important to you, not just as caregivers, but also as themselves.

## **Remember All Family Members**

Alzheimer's affects all family members. They may not seek out help because many families feel they should be able to "handle it" alone. Let them know that there is a spiritual community there for support and help.

## **Get the Spiritual Community Involved**

You can sponsor community information forums to sensitize people to the challenges of Alzheimer's. Spiritual communities can sponsor group respite and family support programs; some may even offer to take on household chores such as weatherization and yard work.

## **Give Them a Break**

Spiritual community members can offer to give the caregiver 'a rest' by staying with the person who has Alzheimer's; the caregiver can get out of the house for a couple of hours of private time.

## **Ask the Family for a To-Do List**

Family caregivers could often use a little help with chores like yard work, car repairs, grocery shopping and the like.

## **Be Alert**

Learn about community resources and how to help the family find appropriate help for their loved one.

## **Offer a Change of Scenery**

Invite the family to community activities that will allow them to see familiar faces and stay connected to the spiritual community such as festivals and breakfasts.

## **Listen**

Families facing Alzheimer's may just need someone to talk to about their feelings and needs. You do not have to fix the problem for them—rather offer support and comfort until they feel better.

The Alzheimer's Association is the center of help and hope.

## **Family Services:**

24/7 Helpline: **800.272.3900** - Call 24 hours a day, seven days a week and speak to a trained staff or volunteer qualified to answer questions about all aspects of dementia.

Website: **[www.alz.org/georgia](http://www.alz.org/georgia)**

Care Consultation - Personalized and professional consultations help families make decisions about how to provide the best care for a loved one and plan for his or her future needs.

Support Groups - Share challenges and find concrete solutions for everyday problems through a variety of groups available for both family members and individuals with mild memory loss. Available throughout our chapter service area.

MedicAlert®+Alzheimer's Association Safe Return® - Designed specifically for people living with dementia, our nationwide safety program helps reunite families with enrollees who have become lost, no matter when or where the person is reported missing.

Early Stage Programs Opportunities are available for people with mild memory loss to engage in meaningful and mentally stimulating activities. Held at our chapter office.

Family Education Programs cover a variety of topics from the basics of Alzheimer's, dementia and memory loss to more specific issues.

Additional Support (community resources & chapter library)

## **Community Services:**

Community Education

Professional Education

Advocacy

Walk to End Alzheimer's

Volunteer Opportunities

## **Service Area:**

Headquarters in Atlanta with outreach staff and services in 159 counties in the state of Georgia with 7 offices across the state.