

**Lighting the path for people
affected by Alzheimer's**

African-American clergy guide

alzheimer's  association®



Lighting the path for people affected by Alzheimer's

Today 4.5 million Americans have Alzheimer's.

As our population ages, the number of people with the disease increases. Age is a major risk factor for Alzheimer's:

- One in 10 people older than 65 have Alzheimer's
- Nearly half of those over 85 have Alzheimer's

The statistics are especially striking for African-Americans:

- Millions of baby boomers – the first now turning 60 – are nearing the age of greatest risk; by the year 2030, the number of African-Americans 65 or older is expected to more than double to 6.9 million
- The number of African-Americans age 85 and older is growing quickly and is predicted to increase more than five times to 1.6 million by 2050

Because 70 percent of those with Alzheimer's live at home, the impact extends to millions of family members and friends. Many of these caregivers may hesitate to:

- Accept assistance from others
- Talk about their feelings
- Visit the doctor regularly

African-American clergy guide

More and more, people living with Alzheimer's and other types of dementia will impact your daily life as the leader of your faith community. Rely on the Alzheimer's Association® to assist you in giving comfort and guidance to those affected.

This guide offers suggestions for:

- Recognizing and interacting with a person with Alzheimer's
- Providing the unique spiritual care and comfort needed by people with Alzheimer's and their loved ones
- Leading your congregation in embracing those affected by Alzheimer's

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African-Americans and Alzheimer's disease



Alzheimer's (AHLZ-high-merz) is a disease of the brain that causes problems with memory, thinking and behavior. It is not a normal part of aging or a mental illness.

Alzheimer's gets worse over time. Although symptoms can vary widely, the first problem many people notice is forgetfulness severe enough to affect the ability to function at home or at work, or to enjoy lifelong hobbies.

Other symptoms include confusion, getting lost in familiar places, misplacing things and trouble with language.

Impact of Alzheimer's on African-Americans

Did you know that African-Americans may be at greater risk for Alzheimer's disease?

- African-Americans have a higher risk for diabetes,* a risk factor for Alzheimer's disease and vascular dementia
- High blood pressure is more common among African-Americans*
- A person with high blood pressure or high cholesterol may be more likely to develop Alzheimer's
- African-Americans may have a higher rate of vascular dementia*

*Compared to Caucasian Americans



Heart-brain connection

Every heartbeat pumps about one-fifth of your blood to your brain. Billions of brain cells need the food and oxygen carried by your blood to think, solve problems and remember.

Conditions that damage your heart and blood vessels also interfere with the brain's vital supply lines. These risk factors for heart disease also threaten brain health:

- High blood pressure
- High cholesterol
- Diabetes (high blood sugar)
- Being overweight
- Lack of exercise

African-Americans seem to have a higher risk for diabetes, high blood pressure and other risk factors. That's why it's important to encourage your congregation members to work with their doctor to watch out for these conditions and get them under control.

Telling fact from fiction

Ideas about what might cause Alzheimer's disease have been around for a long time. Discourage any myths that may still exist.

Alzheimer's is not caused by:

- Aluminum cans, pots or pans
- Artificial sweeteners
- A hex or a curse
- Too much worrying or thinking

When memory loss is a warning sign



As we age, most of us eventually notice some slowed thinking and problems remembering certain things. However, serious memory loss, confusion and other major changes in the way our minds work are not a normal part of aging.

What's the difference?

Symptoms of Alzheimer's	Memory changes related to normal aging
Forgetting whole experiences	Forgetting part of an experience
Rarely able to remember later	Often able to remember later
Gradually unable to follow written/spoken directions	Usually able to follow written/spoken directions
Gradually unable to use notes as reminders	Usually able to use notes as reminders
Gradually unable to care for oneself	Usually able to care for oneself

Other types of dementia

Dementia (dih-MEN-shuh) is a general term for the loss of memory and other intellectual abilities serious enough to interfere with daily life.

Alzheimer's is the most common form of dementia, making up 60 to 70 percent of cases of dementia.

Other disorders that can cause memory loss, confusion and other symptoms associated with dementia include:

- Vascular dementia
- Mixed dementia
- Parkinson's disease
- Dementia with Lewy bodies
- Physical injury to the brain
- Huntington's disease
- Creutzfeldt-Jakob disease (CJD), pronounced CROYZ-felt YAH-kob
- Frontotemporal dementia, including Pick's disease
- Normal pressure hydrocephalus (NPH)

Mild cognitive impairment (MCI)

Although a person may have noticeable difficulty with memory or other thinking skills, a doctor may determine these changes are not severe enough to meet criteria for a diagnosis of Alzheimer's or another type of dementia. Some doctors use the term mild cognitive impairment (MCI) in this case.

Research has shown that individuals with MCI have an increased risk of progressing to Alzheimer's disease over the next few years, especially when their main area of difficulty involves memory. But a diagnosis of MCI does not always mean the person will develop Alzheimer's.

Contact the Alzheimer's Association for more information on other types of dementia.

10 warning signs of Alzheimer's disease[©]

You may not be able to identify someone with Alzheimer's by the way the person looks.

In the earlier stages of the disease:

- Many people seem as alert and as physically fit as others their age
- They may handle themselves well in familiar social situations
- Some people may hide or deny their symptoms

This makes it more difficult to recognize a congregation member with Alzheimer's.

There's no clear line that separates normal changes from warning signs. It's a good idea to recommend that a person check with a doctor if his or her abilities seem to be declining.

1. Memory loss

Forgetting recently learned information is one of the most common early signs of dementia. A person begins to forget more often and is unable to recall the information later.

What's normal? Forgetting names or appointments occasionally

2. Difficulty doing familiar tasks

People with dementia often find it hard to plan or complete everyday tasks. Individuals may lose track of the steps involved in preparing a meal, placing a telephone call or playing a game.

What's normal? Occasionally forgetting why you came into a room or what you planned to say

3. Problems with talking or writing

People with Alzheimer's disease often forget simple words or substitute unusual words, making their speech or writing hard to understand. They may be unable to find their toothbrush, for example, and instead ask for "that thing for my mouth."

What's normal? Sometimes having trouble finding the right word

4. Confusion about time and place

People with Alzheimer's disease can become lost in their own neighborhoods, forget where they are and how they got there, and not know how to get back home.

What's normal? Forgetting the day of the week or where you were going

5. Loss of judgment

Those with Alzheimer's may dress inappropriately, wearing several layers on a warm day or too little clothing in the cold. They may show poor judgment about money, like giving away large sums to scam artists.

What's normal? Making a debatable or questionable decision from time to time

6. Problems with abstract thinking

Someone with Alzheimer's disease may have unusual difficulty performing complex mental tasks, like forgetting what numbers are and how they should be used.

What's normal? Finding it challenging to balance a checkbook

7. Misplacing things

A person with Alzheimer's disease may put things in unusual places: an iron in the freezer or a wristwatch in the sugar bowl.

What's normal? Misplacing keys or a wallet temporarily

8. Changes in mood or behavior

Someone with Alzheimer's disease may show rapid mood swings – from calm to tears to anger – for no apparent reason.

What's normal? Occasionally feeling sad or moody

9. Changes in personality

The personalities of people with dementia can change dramatically. They may become extremely confused, suspicious, fearful or dependent on a family member.

What's normal? People's personalities do change somewhat with age

10. Loss of motivation

A person with Alzheimer's disease may become very passive, sitting in front of the TV for hours, sleeping more than usual or not wanting to do usual activities.

What's normal? Sometimes feeling weary of work or social obligations

If you recognize signs of Alzheimer's

As a leader of your faith community, you may be among the first to see signs of Alzheimer's in a congregation member.

A person and his or her family members may not see or may deny the gradual changes taking place. If you suspect Alzheimer's disease, find out if the person has been evaluated by a doctor.

If the person lives alone

Contact the family and share your observations. To prepare for this discussion, consult the Alzheimer's Association for:

- Information to share with the family
- Referrals to local doctors and support services
- Descriptions of programs and services

If the person has no family

Work with your local Alzheimer's Association to locate the best community services for him or her.

Encourage early diagnosis

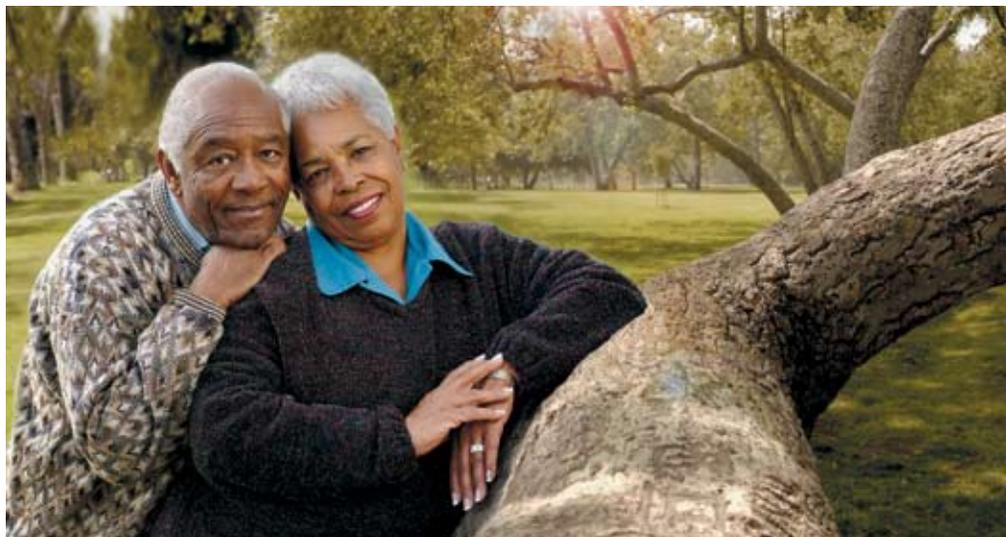
Many people put off getting a diagnosis. They may fear how it will change their lives or they may mistrust the health care system. But an early diagnosis helps the person maintain a better quality of life by opening up opportunities to:

- Plan for the best life experiences in the remaining years
- Choose and receive treatments
- Prepare legal documents concerning care during the more advanced stages of the disease
- Join the fight against Alzheimer's by advocating for public-policy change or enrolling in research programs
- Share experiences in Alzheimer support groups



Diagnosis should be made by a doctor experienced with dementia. Consult the Alzheimer's Association to help families find the right doctor.

Diagnosis and treatment



No single test can identify Alzheimer's.

A probable diagnosis may be made after a comprehensive medical evaluation that includes:

- Complete health history
- Physical exam
- Brain-function tests
- Mental-status tests
- A history of symptoms and behaviors

Currently, there is no cure for Alzheimer's and no way to stop the underlying death of brain cells.

But drugs and non-drug treatments may help with symptoms such as agitation and anxiety, and improve sleep and participation in activities. Contact the Alzheimer's Association for the latest on treatments and about overcoming any barriers, like lack of health insurance.

Living with Alzheimer's

A person with Alzheimer's disease will live an average of 8 years and as many as 20 years or more from the onset of symptoms.

Stages of the disease

Alzheimer's disease gets worse over time. Experts have developed stages to describe how a person's abilities change from normal function to advanced Alzheimer's. Symptoms may vary greatly with each person.

Stage 1

No impairment
Normal function

The person does not experience any memory problems. An interview with a doctor does not show any evidence of symptoms.

Stage 2

Very mild decline
May be normal age-related changes or earliest signs of Alzheimer's

The individual may feel that he or she is having memory lapses. But no symptoms can be detected during a medical exam or by friends, family or co-workers.

Stage 3

Mild cognitive decline
Early-stage Alzheimer's may be diagnosed in some, but not all, individuals at this point

Friends, family or co-workers begin to notice difficulties. During a detailed medical interview, doctors may be able to detect problems in memory or concentration.

Stage 4

Moderate cognitive decline
Mild or early-stage Alzheimer's

A careful medical interview should detect clear-cut problems, like forgetting one's personal history and being withdrawn.

Stage 5

Moderately severe cognitive decline
Moderate or mid-stage Alzheimer's

Gaps in memory and thinking are noticeable. The person begins to need help with daily activities.

Stage 6

Severe cognitive decline
Moderately severe or mid-stage Alzheimer's

Memory continues to worsen, personality changes may take place and individuals need major help with daily activities.

Stage 7

Very severe cognitive decline
Severe or late-stage Alzheimer's

The person loses the ability to respond, converse and, eventually, control movement. He or she needs help with daily personal care, like eating or using the toilet. Muscles grow rigid. Swallowing is impaired.

This seven-stage framework is based on a system developed by Barry Reisberg, M.D., clinical director of the New York University School of Medicine's Silberstein Aging and Dementia Research Center.

Changes in memory and behavior

While each individual's experience is unique, people with Alzheimer's disease often have certain ways of thinking and behaving in common.

Memory loss

In Alzheimer's disease, recent memories are lost first, while distant ones are often retained. The person may not remember his or her:

- Name
- Phone number
- Address
- Close family member or caregiver

Meanwhile, he or she may easily recall verses of favorite hymns, chants or scripture passages that were learned decades ago.

Mood and behavior

A person with Alzheimer's disease may experience changes in mood and behavior as the disease progresses.

Individuals may:

- Cry or speak loudly
- Become angry or upset
- Feel restless or agitated
- Want to get up and move around

Reach out and assure the family that there is no need to be embarrassed or ashamed.

Reinforce to others that the person is not acting this way on purpose.

While these behaviors can happen, they are likely to be rare within the serene, supportive environment of a worship service.



Wandering

When a person experiences wandering, he or she can get lost even in a familiar place, leaving a safe environment.

Wandering can be life-threatening. If not found within 24 hours, up to half of those who wander risk serious injury or death.

During a worship service, you may see a member of your congregation with Alzheimer's:

- Get up and roam around
- Become disoriented in corridors and doorways
- Leave the building

If a person is missing, consider it an emergency. Contact police and Alzheimer's Association Safe Return® immediately.

Wandering and Safe Return

Six out of 10 people with Alzheimer's will wander and become lost. Many do repeatedly.

Alzheimer's Association Safe Return® is a nationwide program that provides assistance when a person with dementia becomes lost or is found.

Wandering happens unexpectedly and without warning. Encourage anyone with a diagnosis of Alzheimer's or a related dementia to enroll in Safe Return today:

1.888.572.8566
www.alz.org/safereturn

Best ways to communicate

People with Alzheimer's often undergo changes in the way they express themselves and understand others.

We know that communication is about much more than talking and listening. It also involves attitude, tone of voice, facial expressions and body language.

These strategies may be helpful when approaching and communicating with the person with Alzheimer's:

Create a soothing environment

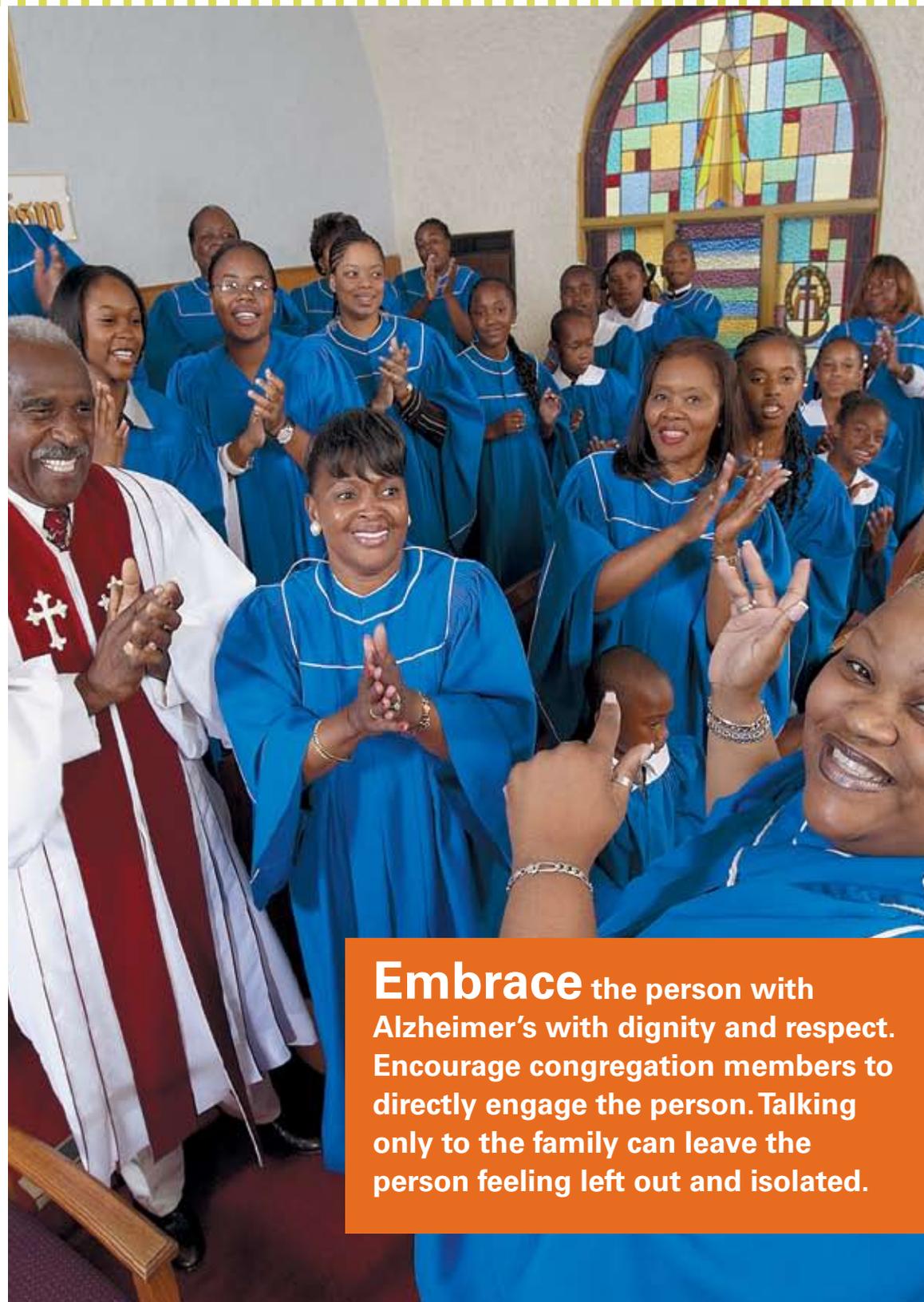
- Approach the person from the front and avoid sudden movements
- Speak slowly and reassuringly
- Use a low-pitched voice
- Identify yourself and your place of worship, even if the person is a long-time member
- Maintain good eye contact

Keep communication simple

- Ask only one question or present one idea at a time
- Use short sentences with familiar words
- Ask questions that require a "yes-or-no" answer
- Try reminiscing about old friends or past events

Go beyond words

- Use gestures, music and symbols of your faith
- Show your affection with smiles, hugs and hand-holding, when appropriate
- Don't be uncomfortable with silence – your presence says a great deal
- Wear traditional clerical attire to help you be more easily recognized, if such clothing applies to your situation



Embrace the person with Alzheimer's with dignity and respect. Encourage congregation members to directly engage the person. Talking only to the family can leave the person feeling left out and isolated.

Spirituality and Alzheimer's disease

People who have Alzheimer's disease, especially those raised in religious households, are uplifted by worship services and pastoral visits. They can often take part in age-old rituals and enjoy hearing favorite hymns and scripture passages.

Some people with the disease may stop attending regular services to avoid social situations they fear or no longer understand, while others find peace and comfort in a place of worship.

Regardless of the person's abilities, your compassion will help fulfill their spiritual needs.

Family members also have spiritual needs. Caring for a loved one can last for years, leaving them weary, isolated, frustrated and depressed. At the same time, they may grieve the loss of who the person once was.

Your presence and support throughout their caregiving journey can be a tremendous source of strength.

Some families may feel embarrassed or reluctant to ask for help from their place of worship. If you are not sure if these congregation members would like assistance, do not wait for them to ask. Although frequent offers of support may be turned down, one day, an offer may be accepted.

Support and empower the person with Alzheimer's

- Engage in short prayers or inspirational stories lasting no more than five minutes
- Use older translations or scriptures – and encourage interaction; the person may no longer relate to the newer, international versions
- Be attuned and flexible to the way the person talks about his or her spirituality

- Foster an atmosphere of joy, trust and comfort
- Make connections through music – traditional songs or old hymns might be better received than modern spiritual music with a heavy, pop-music beat
- Plan short, frequent home visits rather than lengthy ones
- Create a spiritual connection during a home visit with a familiar prayer or scripture – or recount a special event at your place of worship that the person may have once attended
- Use education about Alzheimer's to break down fears that may exist in the congregation and build compassion for those affected by the disease; when possible, have the person give a talk about his or her experiences living with Alzheimer's
- Provide a quiet room where the family or caregiver can take a person who may get anxious during services; reserve seating by the door to allow easy access
- Make sure your facility is safe and accessible for the person with Alzheimer's by providing measures like:
 - Well-lit hallways
 - Pictures and signs that easily identify restrooms
 - Secure handrails
- Encourage the person to take part in services and social events appropriate to his or her abilities, like singing in the choir or attending a congregation dinner
- Get the person involved in activities that connect him or her with others, and that match the person's changing abilities, like:
 - Attending choir concerts or taking part in Sunday school
 - Stuffing bulletins
 - Creating an album or filling a "memory box" with special items
 - Participating in inter-generational programs

Support and empower the caregiver

- Encourage family members to stay strong by eating right; getting regular exercise and rest; and accepting help from others
- Recognize the signs of caregiver stress; help direct the family to resources that help relieve the stress
- When the caregiver is unable to attend in person, provide short worship services or rituals in his or her home
- Help families connect to resources, like your local Alzheimer's Association, social service agencies and support groups
- Prompt the caregiver to use respite care for a break from daily responsibilities; these services can be informal, like having congregation members make home visits, or formal services like adult day care

- Encourage family members to express feelings of loss, frustration, joy and love
- Form a support group with help from your local Alzheimer's Association

10 Ways to be a Healthy Caregiver[®]

The Alzheimer's Association offers information and support to help caregivers stay strong:

1. Get a diagnosis as early as possible
2. Know what resources are available
3. Become an educated caregiver
4. Get help
5. Take care of yourself
6. Manage your level of stress
7. Accept changes as they occur
8. Do legal and financial planning
9. Be realistic
10. Give yourself credit, not guilt

10 Symptoms of Caregiver Stress[®]

Help caregivers stay strong

A caregiver showing many of these signs may be at risk. Encourage the person to see a doctor. Have the Alzheimer's Association connect the person to local support services.

1. Denial about the disease and its effect on the person who has been diagnosed
I know Mamma is going to get better.

2. Anger at the person with Alzheimer's, anger that there's no cure or anger that people just don't understand

If he asks me that one more time, I'll scream!

3. Social withdrawal from friends and activities that used to make you feel good
I don't feel like getting together with the neighbors anymore.

4. Anxiety about the future and facing another day
What happens when he needs more care than I can provide?

5. Depression that begins to break your spirit and ability to cope
I just don't care anymore.

6. Exhaustion that makes it nearly impossible to complete the everyday tasks that need to get done
I'm too tired for this.

7. Sleeplessness caused by a never-ending list of concerns
What if she wanders out of the house or falls and hurts herself?

8. Irritability that leads to moodiness and triggers negative responses and reactions
Leave me alone!

9. Lack of concentration that makes it difficult to do familiar tasks
I was so busy, I forgot my appointment.

10. Health problems that begin to take their toll, both mentally and physically
I can't remember the last time I felt good.

What the congregation can do

The congregation plays a key part in making the person and his or her family feel respected and welcome.

Support and empower the person with Alzheimer's

- Always treat the person with respect
- Greet the person warmly, using simple sentences and a soothing tone of voice
- Wear name tags
- Help unite the person with family if he or she appears to be disoriented or lost
- Attend education programs to better understand the disease and its effect on the individual with the disease and his or her family
- Be patient and accepting of behaviors and appearances
- Respond in calm and supportive ways

Support and empower the family

- Ask family members how they are and how their loved one is doing
- Offer to assist the family to get the person ready for worship services or help arrange transportation
- Express your willingness to spend time with the person so family members can run errands or take a break
- Help provide worship services at the family's home when they can no longer attend in person
- Bring an audio or video tape of the service to the family if they cannot attend
- Send *thinking of you* notes and cards; include bulletins and newsletters from your place of worship to help the family stay connected
- Be a willing listener
- Provide ongoing prayer support for the person with Alzheimer's and his or her family members

Rely on us

When Alzheimer's disease touches a member of your congregation, the Alzheimer's Association is here to help.

We are the trusted resource for reliable information, education, referral and support to the millions of people affected by the disease, their families and health care professionals.

Our nationwide network of chapters, representing 300 local offices from coast to coast, is the core of our support lifeline.

Dedicated professional staff help people navigate through the decisions and uncertainties of the disease.

- Our 24/7 Helpline offers information, referral and care consultation in more than 140 languages.
- Our award-winning Web site at www.alz.org is a rich resource with evidence-based

content that helps inform our diverse audiences.

- Alzheimer's Association Safe Return® is a 24-hour nationwide identification and support program. Safe Return works with local law enforcement to quickly return the person with dementia who has wandered.
- Professionally facilitated support groups offer people with Alzheimer's and their families a confidential, open forum to share concerns and receive support.
- Educational workshops provide people with the information and skills necessary to care for those living with dementia.
- The Alzheimer's Association Green-Field Library is the nation's largest resource center devoted to Alzheimer's disease and dementia.

For reliable information and support, contact the Alzheimer's Association:

**1.800.272.3900
www.alz.org**



The Alzheimer's Association, the world leader in Alzheimer research, care and support, is dedicated to finding prevention methods, treatments and an eventual cure for Alzheimer's.

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1.800.272.3900
www.alz.org

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