# Living with Alzheimer's

A Resource Guide for Families and Caregivers

**Revised Edition 2011** 



# alzheimer's $\mathfrak{B}$ association®

# Living with **Alzheimer's**

A Resource Guide for Families and Caregivers

**Revised Edition 2011** 

Prepared and Produced by the: Alzheimer's Association Mississippi Chapter

Funded by: St. Dominic Health Services Mississippi Health Care Association Alzheimer's Association Mississippi Chapter Various Individual Supporters With much gratitude, we would like to extend our appreciation to the following contributors:



Thank you also to our various donors and supporters. We greatly appreciate your contributions to assist us in furthering the mission of the Alzheimer's Association.

# Foreword

In early 1998, the vision to produce a single resource guide for families living with Alzheimer's in Mississippi was a seemingly impossible dream. The dream became reality in 1999; and with grant funding awarded through the Mississippi Department of Mental Health, the Chapter produced 15,000 copies of the original 60-page resource guide. The guide received favorable results throughout the state with demand for the guide exhausting the supply within 18 months.

*Living with Alzheimer's*, the revised edition 2004, continued the original theme as a resource guide for families caring for a loved one with Alzheimer's or a related dementia. The guide was a compilation of more than 50 publications of the Association. In addition, chapter staff wrote portions of the guide with references cited. Resources have been updated and nearly 50 pages added. Every effort has been made to verify the accuracy of resources. We apologize for any omissions, choosing to err by eliminating data where conflicting information was apparent. *Living with Alzheimer's* 2006 revision expanded the 2004 revised edition by adding several new sections and correcting resources that changed due to Hurricane Katrina August 2005.

*Living with Alzheimer's* 2011 revision has expanded the 2009 revised edition by adding new resources and educational content. This guide is a compilation of publications from the National Alzheimer's Association and its Chapters. Every effort has been made to assure the accuracy of resources known to the Mississippi Chapter at the time of this printing. We apologize for any omissions or mistakes. We would appreciate your notifying the Chapter office about additions or corrections.

*Living with Alzheimer's* is a consolidated source to assist families as they live through the disease process. It has virtually no neurological, physiology, psychological or technical information and has been designed primarily for family caregivers. The first edition, however, was widely used by professional caregivers in their day-to-day management of persons with Alzheimer's in healthcare settings. This guide continues to be a favorite resource for professionals.

Print materials are available in Spanish by contacting the National Office.

# Acknowledgements

Special thanks from the Alzheimer's Association Mississippi Chapter...

On behalf of the nearly 53,000 plus persons with Alzheimer's disease or a related dementia in Mississippi, the Alzheimer's Association wishes to express its deepest appreciation to the Administration on Aging, Department of Health and Human Service in Washington, D.C., for its healthcare priority to expand home and community based services to families and caregivers affected by Alzheimer's disease.

Many thanks to Dr. Randel Hendrix, Past-Executive Director of the Mississippi Department of Mental Health, for his role in the initial collaborative partnership between the Alzheimer's Association and the Mississippi Department of Mental Health Division of Alzheimer's Disease and Other Dementia, to expand services to families affected by Alzheimer's disease throughout the state. Continued thanks to Mr. Edwin C. LeGrand III, current Executive Director of the Mississippi Department of Mental Health, for his continued support of this collaboration.

Additional thanks to Kathy Van Cleave-Director, Dianne Arnold and Melora Jackson-Regional Field Staff of the Division of Alzheimer's, MS Department of Mental Health; Sara Murphy-Outreach Coordinator and Patty Dunn-Executive Director of the Alzheimer's Association for their efforts in research, data collecting, editing, and layout of the expansion of the 2011 revised edition. Special thanks to Julie Orr, MA, MCP, LPC and volunteer for sharing her time and editing skills to prepare the 2011 edition for publication.

The Board of Directors Alzheimer's Association Mississippi Chapter

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#### **Overview of Alzheimer's Disease**

Ten years ago, few Americans had ever heard of Alzheimer's disease. Yet, today, this progressive and irreversible brain disease is recognized as one of the most devastating maladies of our time.

> Alzheimer's disease causes a steady decline in memory and is the leading cause of dementia or the loss of intellectual abilities, thinking, remembering and reasoning – severe enough to interfere with a person's daily functioning at work or home.

> > An estimated 5.4 million Americans have Alzheimer's disease, nearly 53,000 in Mississippi. Alzheimer's disease affects people regardless of sex, race, ethnic group or socio-economic circumstances. It is the seventh leading cause of death among American adults.

With the graying of the American population, Alzheimer's disease will be the epidemic of the 21st century. By the time babyboomers reach the age of greatest risk, 14 million Americans will have the disease.

Alzheimer's disease is the most common cause of dementia. In 2011, every 69 seconds someone in America develops Alzheimer's. By mid-century, the annual total number of newly diagnosed cases of Alzheimer's are projected to double the 2011 rate in the U.S.

# What is Alzheimer's Disease?

Alzheimer's disease pronounced (AHLZ-hi-merz) is one of several disorders that causes the gradual loss of brain cells. The disease was first described by German physician Dr. Alois Alzheimer in 1906. Although the disease was once considered rare, research has shown that it is the leading cause of dementia.

#### Dementia

Dementia is an umbrella term for several symptoms related to a decline in thinking skills. Common symptoms include a gradual loss of memory, problems with reasoning, judgment, disorientation, difficulty in learning, loss of language skills, and decline in the ability to perform routine tasks.

People with dementia exhibit changes in their personalities and behavior such as agitation, anxiety, delusions (*believing* in a reality that does not exist), and hallucinations (*perceiving* things that do not exist).

#### **Disorders that Cause Dementia**

Several disorders similar to Alzheimer's can cause dementia. Each disorder involves processes that destroy brain cells. Some treatable conditions – such as depression, drug interactions, and thyroid problems – can cause dementia. With early intervention these forms of dementia may be effectively treated and even reversed.

#### Mild cognitive impairment (MCI)

In MCI, a person has problems with memory or one of the other core functions affected by dementia. These problems are severe enough to be noticeable to other people and to show up on tests of mental function, but not serious enough to interfere with daily life. When symptoms do not disrupt daily activities, a person does not meet criteria for being diagnosed with dementia. Individuals with MCI have an increased risk of developing Alzheimer's disease over the next few years, especially when their main problem involves memory. However, not everyone diagnosed with MCI progresses to Alzheimer's or another kind of dementia.

# All types of dementia involve mental decline that:

- occurred from a higher level (for example, the person didn't always have a poor memory)
- is severe enough to interfere with usual activities and daily life
- affects more than one of the following four core mental abilities:
  - recent memory (the ability to learn and recall new information)
  - language (the ability to write or speak, or to understand written or spoken words)
  - visuospatial function (the ability to understand and use symbols, maps, etc., and the brain's ability to translate visual signals into a correct impression of where objects are in space)
  - executive function (the ability to plan, reason, solve problems and focus on a task)

#### Alzheimer's disease

Although symptoms can vary widely, the first problem many people with Alzheimer's notice is forgetfulness severe enough to affect their work, lifelong hobbies or social life. Other symptoms include confusion, trouble with organizing and expressing thoughts, misplacing things, getting lost in familiar places, and changes in personality and behavior. Alzheimer's disease advances at different rates.

These symptoms result from damage to the brain's nerve cells. The disease gradually gets worse as more cells are damaged and destroyed. Eventually, the person with Alzheimer's will need complete care. Even if the individual has no other serious illness, the loss of brain function will ultimately lead to death. Scientists do not yet know why brain cells malfunction and die, but two prime suspects are abnormal microscopic structures called plaques and tangles.

#### **Overview of Alzheimer's Disease**

#### Vascular dementia (VaD)

Many experts consider vascular dementia the second most common type, after Alzheimer's disease. It occurs when clots block blood flow to parts of the brain, depriving nerve cells of food and oxygen. If it develops soon after a single major stroke blocks a large blood vessel, it is sometimes called "post-stroke dementia." It can also occur when a series of very small strokes, or infarcts, clog tiny blood vessels. Individually, these strokes do not cause major symptoms, but over time their combined effect is damaging. This type used to be called "multi-infarct dementia." Symptoms of vascular dementia can vary, depending on the brain regions involved. Forgetfulness may or may not be a prominent symptom, depending on whether memory areas are affected. Other common symptoms include difficulty focusing attention and confusion. Decline may occur in "steps," where there is a fairly sudden change in function. People who develop vascular dementia may have a history of heart attacks. High blood pressure or cholesterol, diabetes or other risk factors for heart disease are often present.

#### **Mixed dementia**

In mixed dementia, Alzheimer's disease and vascular dementia occur at the same time. Many experts believe mixed dementia develops more often than was previously realized and that it may become increasingly common as people age. This belief is based on autopsies showing that the brains of up to 45 percent of people with dementia have signs of both Alzheimer's and vascular disease. Decline may follow a pattern similar to either Alzheimer's or vascular dementia or a combination of the two. Some experts recommend suspecting mixed dementia whenever a person has both (1) evidence of cardiovascular disease and (2) dementia symptoms that get worse slowly.

#### Dementia with Lewy bodies (DLB)

In DLB, abnormal deposits of a protein called alpha-synuclein form inside the brain's nerve cells. These deposits are called "Lewy bodies" after the scientist who first described them. Lewy bodies have been found in several brain disorders, including dementia with Lewy bodies, Parkinson's disease and some cases of Alzheimer's.

Symptoms of DLB include:

- Memory problems, poor judgment, confusion and other symptoms that can overlap with Alzheimer's disease
- Movement symptoms are also common, including stiffness, shuffling walk, shakiness, lack of facial expression, problems with balance and falls
- Excessive daytime drowsiness
- Visual hallucinations
- Mental symptoms and level of alertness may get better or worse (fluctuate) during the day or from one day to another
- In about 50 percent of cases, DLB is associated with a condition called rapid eye movement (REM) sleep disorder. REM sleep is the stage where people usually dream. During normal REM sleep, body movement is blocked and people do not "act out" their dreams. In REM sleep disorder, movements are not blocked and people act out their dreams, sometimes vividly and violently.

#### Parkinson's disease (PD)

Parkinson's is another disease involving Lewy bodies. The cells that are damaged and destroyed are chiefly in a brain area important in controlling movement. Symptoms include tremors and shakiness; stiffness; difficulty with walking, muscle control, and balance; lack of facial expression; and impaired speech. Many individuals with Parkinson's develop dementia in later stages of the disease.

#### Frontotemporal dementia (FTD)

FTD is a rare disorder chiefly affecting the front and sides of the brain. Because these regions often, but not always, shrink, brain imaging can help in diagnosis. There is no specific abnormality found in the brain in FTD. In one type called Pick's disease, there are sometimes (but not always) abnormal microscopic deposits called Pick bodies. FTD progresses more quickly than Alzheimer's disease and tends to occur at a younger age. The first symptoms often involve changes in personality, judgment, planning and social skills. Individuals may make rude or off-color remarks to family or strangers, or make unwise decisions about finances or personal matters. They may show feelings disconnected from the situation, such as indifference or excessive excitement. They may have an unusually strong urge to eat and gain weight as a result.

#### Creutzfeldt-Jakob disease (CJD)

Creutzfeldt-Jakob disease (pronounced CROYZ-felt YAH-cob) is a rare, rapidly fatal disorder affecting about 1 in a million people per year worldwide. It usually affects individuals older than 60. CJD is one of the prion (PREE-awn) diseases. These disorders occur when prion protein, a protein normally present in the brain, begins to fold into an abnormal three-dimensional shape. This shape gradually triggers the protein throughout the brain to fold into the same abnormal shape, leading to increasing damage and destruction of brain cells. Recently, "variant Creutzfeldt-Jakob disease" (vCJD) was identified as the human disorder believed to be caused by eating meat from cattle affected by "mad cow disease." It tends to occur in much younger individuals, in some cases as early as their teens.

The first symptoms of CJD may involve:

- impairment in memory, thinking and reasoning
- changes in personality and behavior
- depression or agitation also tend to occur early
- problems with movement may be present from the beginning or appear shortly after the other symptoms

#### Normal pressure hydrocephalus (NPH)

The three chief symptoms of NPH are:

- (1) difficulty walking
- (2) loss of bladder control
- (3) mental decline, usually involving an overall slowing in understanding and reacting to information

Normal pressure hydrocephalus (high-droh-CEFF-a-luss) is another rare disorder in which fluid surrounding the brain and spinal cord is unable to drain normally. The fluid builds up, enlarging the ventricles (fluid-filled chambers) inside the brain. As the chambers expand, they can compress and damage nearby tissue. "Normal pressure" refers to the fact that the spinal fluid pressure often, although not always, falls within the normal range on a spinal tap.

CJD progresses rapidly and is usually fatal within a year.

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#### **Overview of Alzheimer's Disease**

NPH can occasionally be treated by surgically inserting a long thin tube called a shunt to drain fluid from the brain to the abdomen. However, most experts believe it is unlikely that significant numbers of people diagnosed with Alzheimer's or Parkinson's actually have NPH that could be corrected with surgery. NPH is rare, and it looks different from Alzheimer's or Parkinson's to a physician with experience in assessing brain disorders. When shunting surgery is successful, it tends to help more with walking and bladder control than with mental decline.

A person's responses are delayed, but they tend to be accurate and appropriate to the situation when they finally come.

#### Huntington's disease (HD)

HD is a fatal brain disorder caused by inherited changes in a single gene. These changes lead to destruction of nerve cells in certain brain regions. Anyone with a parent with Huntington's has a 50 percent chance of inheriting the gene, and everyone who inherits it will eventually develop the disorder. In about 1 to 3 percent of cases, no history of the disease can be found in other family members. The age when symptoms develop and the rate of progression vary.

Symptoms of Huntington's disease include twitches, spasms, and other involuntary movements; problems with balance and coordination; personality changes; and trouble with memory, concentration or making decisions.

#### Wernicke-Korsakoff syndrome

Wernicke-Korsakoff syndrome is a two-stage disorder caused by a deficiency of thiamine (vitamin B-1). Thiamine helps brain cells produce energy from sugar. When levels of the vitamin fall too low, cells are unable to generate enough energy to function properly. Wernicke encephalopathy is the first, acute phase, and Korsakoff psychosis is the long-lasting, chronic stage.

The most common cause is alcoholism. Symptoms of Wernicke-Korsakoff syndrome include:

- confusion, permanent gaps in memory and problems with learning new information
- individuals may have a tendency to "confabulate," or make up information they can't remember
- unsteadiness, weakness and lack of coordination

If the condition is caught early and drinking stops, treatment with highdose thiamine may reverse some, but usually not all, of the damage. In later stages, damage is more severe and does not respond to treatment.

The Alzheimer's Association is the leading voluntary health organization in Alzheimer care, support and research. Unraveling the Mystery of Alzheimer's

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"Everyone who has Alzheimer's has dementia, but everyone with dementia does not have Alzheimer's."

# **Causes and Risk Factors**

No one knows exactly what causes Alzheimer's disease (AD). Researchers are learning more about what happens to the brain as we age, what happens to brain cells in those with Alzheimer's disease, and possible genes associated with Alzheimer's. Most researchers agree that Alzheimer's is caused by a complex set of factors.

#### **Biology of Alzheimer's Disease**

There are two abnormal structures in the brain associated with AD. Amyloid plaques (pronounced AM-i-loyd) are clumps of protein fragments that accumulate outside of cells. Neurofibrillary tangles (pronounced NUR-o-FI-bri-lair-ee) are clumps of altered proteins inside cells. Research has provided clues about why cells die, but scientists have not determined exactly what role plaques and tangles play in the disease process, and/or whether these are the key factors.

#### Age, Family History and Genetics

Studies have shown that the greatest risk factor for developing AD is increasing age and as many as 13 percent of all people, 65 years of age and older, have Alzheimer's. Nearly 50 percent of all people 85 and

older have the disease.

A family history of the disease is another known risk factor. Having a parent or sibling with the disease increases an individual's chances of developing Alzheimer's. A recent 10-year study of the risk of hereditary dementia of the Alzheimer's type put the risk at 22 percent for Caucasians and 44 percent for African Americans. Researchers speculate that the high risk of vascular disease among African Americans contributes to their increased risks.

Scientists have identified three genes that cause rare, inherited forms of the disease that tend to occur before age 65. Researchers have also identified one gene that indicates an increased risk of the more common form of AD that affects older people.

#### **Other Risk Factors**

Much dementia research has focused on vascular risk factors, which are factors related to the blood circulatory system. A great deal of evidence shows that disorders such as high cholesterol and high blood pressure – factors that also cause strokes and heart disease – may increase the risk for developing Alzheimer's as well. Unraveling the Mystery of Alzheimer's

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A recent 10-year study of the *hereditary risk* of getting dementia of the Alzheimer's type put the risk at 22% for Caucasians and at 44% for African Americans.



# **10 Warning Signs You Should Know**

#### 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 performing familiar tasks.

People with dementia often find it hard to plan or complete everyday tasks. Individuals may lose track of the steps to prepare a meal, place a telephone call or play a game.

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

#### 3. Problems with language.

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. Disorientation to 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. Poor or decreased judgment.

Those with Alzheimer's may dress inappropriately, wearing several layers on a warm day or little clothing in the cold. They may show poor judgment about money, like giving away large sums to telemarketers. What's normal? Making a questionable or debatable 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.

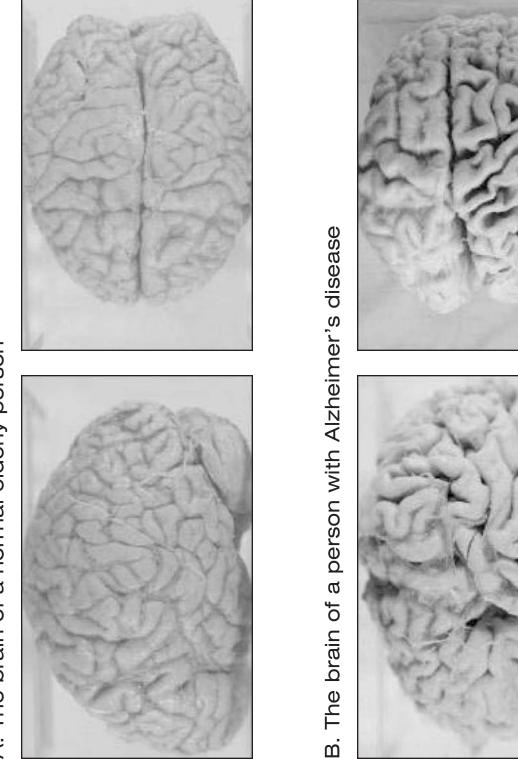
The personalities of people with dementia can change dramatically. They may become extremely confused, suspicious, fearful or dependent on a family member.

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

#### 10. Loss of initiative.

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.



# Visual Representation of Alzheimer's Disease

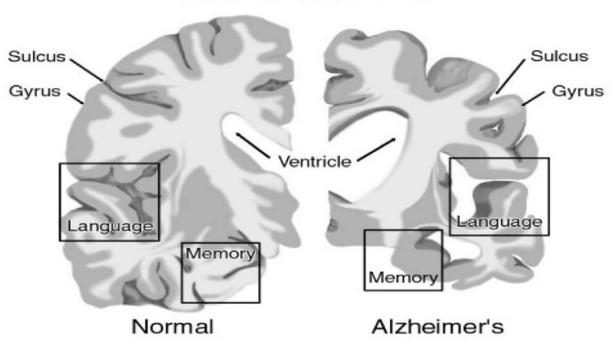
#### **Overview of Alzheimer's Disease**

#### **Visual Representation of Alzheimer's Disease**

These frontal cross-sections of the brain provide a view of a normal brain and a brain of someone who has Alzheimer's disease. The front part of the brain is at the bottom of the image looking towards the back of the brain.

Brain scans that show an overall shrinkage of the tissue indicate Alzheimer's is present. The grooves of the brain are noticeably wider indicating shrinkage of the brain folds. In the brain of someone with Alzheimer's, the ventricles that contain cerebrospinal fluid become larger or create big spaces.

Short-term memory begins to decline in the early stage when the cells in the hippocampus begin to die. Activities of Daily Living (ADLs) or the ability to perform routine tasks begins to decline to a point where the person may need some assistance. Judgment declines, emotional outbursts may occur and language skills become impaired. As more nerve cells die, behavior changes, such as wandering and agitation, begin. As the disease progresses, recognizing faces and communication become more difficult and completely lost in the final stages. Total care is eventually needed.



Brain Cross-Sections

# Stages of Alzheimer's Disease Early Stage

There is no such thing as a mild case of Alzheimer's disease. Whether it is younger-onset or late-onset, Alzheimer's destroys the mind by killing millions of brain cells. This does not happen overnight. Scientists now know that the disease begins to attack the brain at least 20 years before the first symptoms appear. By the time it is obvious a person has Alzheimer's disease, it is too late to stop the process as too many brain cells have already died.

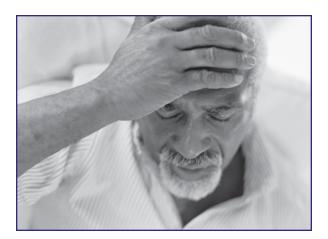
Cognitively, persons in the early stage are frequently unable to recall major events and aspects of their current lives. Distant memory can suffer to the extent that persons may not recall major life experiences and relationships.

Difficulties with numerical calculation are 2 to 4 years in duration of such magnitude that an educated person from the time of diagnosis has difficulty counting backward from 20 by 2's. Often in this stage, persons with dementia cannot choose clothes but can dress, sometimes putting on extra layers in warm weather and not enough layers during colder months.

Sometimes the most recognizable sign that something is wrong is when a person gets lost while driving to a familiar place like the grocery store or church or when preparing a meal becomes difficult.

At other times you may find some of the following behaviors:

- Has problems remembering most recent events
- Forgets what was just told to them
- Loses interest even in important things
- Has trouble concentrating
- Takes longer doing routine tasks like dressing
- Has trouble doing familiar tasks/chores, following a recipe, balancing the checkbook
- Has problems finding the correct wording, such as, "that thing you tell time with" instead of "a watch or clock"
- Lacks motivation to begin an activity by themselves
- Is bored or tired
- May follow you around, become your shadow
- Experiences personality changes
- Is impatient
- Is often angry
- Has less energy
- Loses sense of humor
- Cannot learn new things
- Exhibits a lack of interest in new things
- Is upset by changes



#### **Early Stage**

2 to 4 years in duration from the time of diagnosis

#### Characterized by RECENT MEMORY LOSS

Confusion about places – getting lost on the way to work

- Loses or misplaces things more often
- Has trouble handling money forgets which bills are paid, sometimes paying twice or not at all
- Exhibits poor judgment makes bad decisions
- Experiences mood/personality changes avoids people
- Takes longer with routine chores

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Remember: It is difficult to place a person with Alzheimer's in a specific stage as stages may overlap.

NOTES:

#### How you can help

- Try to understand anger and confusion
- Offer support in times of frustration
- Simplify daily routines
- Do things one step at a time
- Encourage person to be independent
- Provide rest
- Live "in the moment"
- Attend a support group
- Learn as much as you can about the disease process

#### Strengths that remain

- Has ability to use senses for enjoyment of taste, touch and smells
- Has some physical abilities when no other medical conditions prohibit it
- Can still discuss what is happening
- Can still provide insight
- Is able to perform certain types of volunteer work
- May still be able to drive
- Can still hold down a job

#### **Middle Stage**

The ability to perform basic activities of daily living becomes compromised during the middle stage. Unless supervised, patients may put their clothing on backwards, have difficulty putting their arm in the correct sleeve, or may dress in the wrong sequence.

During the middle stage, persons with Alzheimer's develop deficits in daily hygiene such as brushing teeth, bathing, and eating independently. As the disease progresses, families begin to average 40+ hours per week caring for their loved ones at home, and it often becomes 24/7 care. Behavioral challenges become evident during this stage and families often begin their search for in-home care.

It is at this time family members will begin to see more forgetfulness. Often they cannot remember visits right after you leave. They may even forget their own name or names of their spouse, children and others. Also, they may not recognize themselves, family, friends, places and things.

When judgment decreases, they become vulnerable to fraud and abuse from others. Concentration, planning and understanding become more difficult because they cannot think clearly and often make bad decisions.



Mood, personality and behavior may be drastic compared to previous situations. Sometimes they say inappropriate things or act out with unsuitable sexual behavior. Hallucinations may begin to cause them to see and hear things that are not there. They may be looking for someone who has been deceased, looking for the children who are now grown, or looking for something they believe has been stolen from them.

#### NOTES:

#### Middle Stage

2 to 10 years duration after diagnosis (longest stage)

#### Characterized by INCREASING MEMORY LOSS AND CONFUSION

- Problems recognizing family and close friends
- Repetitive statements and/or movements
- Restlessness, especially at late afternoon and at night
- Occasional muscle twitches or jerks
- Difficulty organizing thoughts
- Inability to find right words, trouble with reading, and writing numbers
- Suspiciousness
- Loss of impulse control
- Weight gain or loss
- Seeing or hearing things that are not there
- Need for full-time supervision
- Resistance to bathing and changing clothes.

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Remember: Symptoms seem to progress in a recognizable pattern and these stages provide a framework for understanding this disease.

#### How you can help

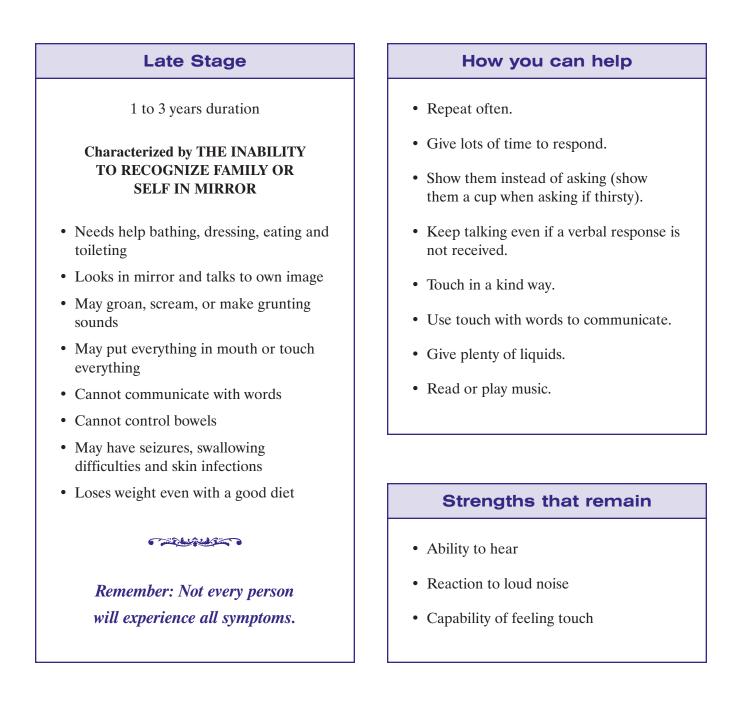
- Use simple memory aids such as a picture of a toilet on the bathroom door, names of family under their photos, labels on the outside of cabinets/drawers with list of contents.
- Keep a routine; do the same things the same way.
- Give one-step directions.
- Remind and repeat gently without sounding angry.
- Limit noise and activity that can be distracting.
- Avoid lengthy plays, concerts, church services.
- Speak in gentle, low, slow voice.
- Try not to make them conform to your reality.
- Do not attempt to reason.
- Use distraction and pleasant events or come back later and try again.
- Reassure through kind, gentle touch, hold hands, and give hugs.
- Allow them to do what they can do for as long as they can do it.
- Attend a support group; take care of yourself.

#### Strengths that remain

- Capability of holding and touching objects
- Enjoyment of music and prayer
- Relating to routine
- Relating to reassurance of relationships

#### Late Stage

In the late stage, persons with AD eventually lose their ability to walk independently, and other neurological and physical changes become increasingly evident. One change is physical rigidity, a precursor to overt physical deformities or contractures. Contractures make full range of movement impossible, causing the person to cry out in severe pain. It is during this late stage that persons with Alzheimer's will be rendered incapable of caring for themselves. Until a cure is found, death is inevitable.



# **Functional Stages in Normal Human Development and Alzheimer's Disease**

ACQUIRED ABILITIES		LOST ABILITIES	
Approximate Age	Ability	Ability	Alzheimer's Stage
12+ years	Holds a job	Holds a job	3 – Incipient
8-12 years	Handles simple finances	Handles simple finances	4 – Mild
5-7 years	Selects proper clothing	Selects proper clothing	5 – Moderate
5 years	Puts clothes on independently	Puts clothes on independently	6 – Moderately Severe
4 years	Showers independently	Showers independently	001010
4 years	Toilets independently	Toilets independently	
3-4 1/2 years	Controls urine	Controls urine	
2-3 years	Controls bowel	Controls bowels	
15 months	Speaks 5-6 words	Speaks 5-6 words	7 – Severe
1 year	Speaks 1 word	Speaks 1 word	
1 year	Walks independently	Walks independently	
6-10 months	Sits up independently	Sits up independently	
2-4 months	Smiles	Smiles	
1-3 months	Holds head up	Holds head up	

Adapted from Reisberg, B., Dementia: A Systematic Approach to Identifying Reversible Causes. Geriatrics 1986.

#### Younger-onset

#### I'm too young to have Alzheimer's disease

Alzheimer's is not just a disease of old age. Younger-onset Alzheimer's disease affects people who are under age 65. Many people with younger-onset are in their 40s and 50s, but sometimes the individual can be in their 30s. Up to 10 percent of people with Alzheimer's have younger-onset. In the United States, that's about 500,000 people.

#### Link to genes

Most people with younger-onset have the common type of Alzheimer's which is not directly linked to genes. Doctors do not know why symptoms appear at an unusually young age in these cases. In a few hundred families worldwide, scientists have found several rare genes that directly cause Alzheimer's. People who inherit these rare genes tend to develop symptoms in their 30s, 40s and 50s.

#### Living with younger-onset Alzheimer's

If you have younger-onset Alzheimer's disease, it's important to know that your life is not over. You can still live a meaningful and productive life. You can still take part in activities you enjoy. You can still find comfort in your family and friends. Living with Alzheimer's does mean dealing with life changes sooner than you had planned.

It is important to know that:

- The disease affects each person differently, and symptoms will vary.
- You will have good days and bad.
- You are not alone.
- People who understand what you are going through can help you and your family.

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# What's the difference between younger-onset Alzheimer's and early-stage Alzheimer's?

**Younger-onset** is a diagnosis of the disease when the person is younger than 65.

**Early-stage** is the early part of Alzheimer's disease, when problems with memory and concentration may begin to appear in a doctor's interview or medical test.

#### **Overview of Alzheimer's Disease – Younger-onset**

The Alzheimer's Association offers ideas to help make things easier for you. Following are some ways to approach your feelings, family, friends, job, money matters, well-being and future plans:

# **Feelings**

After the diagnosis, you may be going through a range of emotions:

- Anger Your life is taking a different course than the one you and your family had planned.
- Denial The diagnosis seems impossible to believe.
- Depression You may feel sad or hopeless about the life changes you're facing.
- Fear You wonder what the future holds for you and your family, your friends and your job.
- Frustration You can't cure the disease or make yourself understood.
- Isolation No one seems to understand what you're going through.
- Sense of loss It's hard to accept changes in your abilities or status in your community or job.

#### What you can do about your feelings:

- Find ways to express your frustrations and emotions. Don't keep your feelings to yourself.
- Join an Alzheimer's Association support group. Some are just for those with younger-onset.
- Work with a well-qualified counselor.
- Share your feelings with your friends, family, and someone who can help with spiritual needs.
- Visit the message boards and chat rooms on the Alzheimer's Association web site at www.alz.org and other Alzheimer-related web sites. (While the Alzheimer's Association web site contains reliable information, confirm with your doctor the accuracy of information you receive on the internet, especially on message boards or in chat rooms.)

# Family

#### Your spouse

Most people with Alzheimer's disease continue to live in the home even as the disease progresses. Your spouse may have to manage the household and your care. He or she may feel a sense of loss over the changes the disease brings to your relationship. You may both experience differences in how you relate to each other sexually.

#### What you can do to help your spouse:

- Continue to take part in all the activities that you can.
- Adapt activities to fit what you are comfortable doing.
- Work with your spouse to put together a file with information you may need later about caregiver services and their costs, including housekeeping and respite (caregiver relief) care.
- Discuss with a professional counselor any role changes in the relationship as well as sexuality issues.
- Continue to find ways for you and your spouse to fulfill the need for intimacy.
- Encourage your spouse to attend a support group for caregivers.

#### Your children

Children often experience a wide range of emotions. Younger children may be afraid that they will get the disease or that they did something to cause it. Teenagers may become resentful when they have to take on more responsibilities for helping around the home. Or they may feel embarrassed that their parent is "different."

#### What you can do to help your children:

- Talk openly about the changes you are experiencing because of the disease.
- Find out what their emotional needs are. Find ways to support them, like meeting with a counselor who specializes in children who have a loved one with Alzheimer's.
- Notify school social workers and teachers about your situation. Give them information about the disease.
- Invite children to attend support group meetings.
- Include them in counseling sessions.
- Record your thoughts, feelings and wisdom in writing, audio or video. Your children can use this counsel when they grow older. Important life stages you might want to discuss include: graduation, dating, marriage, births, death.



# **Friends**

Friends, co-workers and neighbors may not understand what is happening to you. Some may keep their distance or resist keeping in touch. Often they do not know what to do or say. They may be waiting for you to reach out to them.

#### What you can do to help your friends:

- Share your experience of living with Alzheimer's disease.
- Invite them to Alzheimer's Association education programs.
- Continue social activities as much as possible.
- Let them know when you need help and support tell them what they can do.

#### Job

You may find work-related tasks more difficult to perform as the disease advances. Talk to your doctor to plan when and what you'll tell your employer about the disease, and at what point you should no longer work. Your local Alzheimer's Association office has information about the disease that you can share with your employer.

#### Overview of Alzheimer's Disease - Younger-onset

#### What you can do about your job:

- Continue to work as long as you and your doctor feel you are able.
- Use a daily planning calendar, memos and other memory aids to help you organize the details of your job.
- Ask your employer if you can switch to a position that better matches your abilities and strengths or consider reducing your work hours.
- Look into early-retirement options.
- Educate yourself, as well as your spouse or close friend or relative, about the benefits available to you and how to claim them.

#### **Money matters**

If your earnings are the family's main source of income, you may be concerned about financially supporting your family now and in the future. Insurance and other benefits may be more difficult to obtain. Future health care costs should be considered.

#### What you can do about money matters:

- Meet with a qualified financial consultant or an attorney to discuss current and future investments, insurance and retirement options. See if long-term care insurance is still an option.
- Find out about government assistance programs such as Social Security, Medicare and Medicaid.
- Review your employer-provided or personal disability insurance policies.
- Organize financial documents and other important information in one place. Go over them with your spouse. These include: birth certificates, insurance policies, retirement accounts, social security information and wills.
- Research college scholarship and grant money for your children.
- Give Power of Attorney to a reliable source.

#### Well-being

Two of the most important ways you can take good care of yourself are to stay healthy and to stay safe.

#### Health

Take care of your body.

#### What you can do about your health:

- Get regular check-ups.
- Exercise regularly, with doctor's approval.
- Rest when tired.
- Cut down on alcohol.
- Take care of your spiritual needs.
- Reach out for help
- Learn new ways to relax.
- Eat properly.
- Drink ample fluids.



#### Safety

Symptoms of Alzheimer's, like loss of memory and decision-making ability, can bring about new safety concerns.

#### What you can do about your safety:

- Keep important phone numbers nearby.
- Post reminders to lock doors and turn off electrical appliances.
- Arrange for an in-home helper to assist you when your spouse or caregiver needs to be away from home.
- Arrange for other ways to get around when it is no longer safe for you to drive.
- Enroll in MedicAlert<sup>®</sup> + Alzheimer's Association Safe Return<sup>®</sup> for services to assist you should you ever wander.

# **Future plans**

When you are in the early stages of Alzheimer's, it's important to take steps right away to plan for the future.

- Work with a well-qualified attorney, accountant and/or a care manager to make financial and legal plans.
- Legally appoint a person you trust to make financial and health care decisions when you cannot. Tell the person your wishes for the future, including where you want to live and what types of treatments you want or don't want.
- Find adult day care programs and/or residential care settings that assist people with younger-onset Alzheimer's.
- Gather all thoughts, memories and family history you want to pass on to your loved ones. Work together with your family to create journals, scrapbooks or home movies.

#### 10 Quick Tips for Living with Younger-onset Alzheimer's

- 1. Expect to have good days and bad days.
- 2. Find ways to express your feelings.
- 3. Discuss changes in relationships with a counselor.
- 4. Talk openly with loved ones about the changes the disease is causing.
- 5. Reach out to your friends.
- 6. Consider adapting your job hours or duties.
- 7. Get professional legal and financial help.
- 8. Keep up your health and reduce stress.
- 9. Take steps to make your home safer.
- 10. Record your thoughts, memories and family history.

# Treating Alzheimer's Disease

NOTES:

- Medication Intervention
- Medications and Overmedication
- Behavioral Intervention
- Getting a Diagnosis

# **Treating Alzheimer's Disease**

The primary symptoms of Alzheimer's disease include memory loss, disorientation, confusion, and problems with thinking and reasoning. These symptoms worsen as brain cells die and the connections between cells are lost. Although current drugs cannot alter the progressive loss of cells, they may help minimize or stabilize symptoms. Medications may also delay the need for nursing home care.

#### **Medication Intervention**

#### **Cholinesterase Inhibitors for Memory Loss**

All of the prescription medications currently approved by the U.S. Food and Drug Administration (FDA) to treat Alzheimer's symptoms in early to moderate stages are in a class of drugs called cholinesterase inhibitors. Three cholinesterase inhibitors are commonly prescribed: Aricept, approved in 1996; Exelon, approved in 2000; and Reminyl, approved in 2001 but, later changed name to Razadyne. Cognex, the first drug in this class, was approved in 1993 but is rarely prescribed today because of associated side effects that include possible liver damage.

All of these drugs are designed to prevent the breakdown of acetylcholine (pronounced a-SEA-til-KOH-lean), a chemical messenger in the brain that is important for memory and other thinking skills. The drugs work to keep levels of the chemical messenger high, even while the cells that produce the messenger continue to become damaged or die. About half of the people who take cholinesterase inhibitors experience a modest improvement in cognitive symptoms.

#### **NMDA Receptor for Memory Loss**

Namenda (Memantine HCI) was approved by the FDA in 2003 for the treatment of moderate to severe Alzheimer's disease. Namenda is a NMDA (N-methyl-D-aspartate) receptor antagonist that blocks the effects associated with abnormal transmission of glutamate which is associated with learning and memory. The moderate to severe stages stretch out for years and can be difficult for both the patient and the caregiver to manage. The loss of function and independence, including the ability to hold conversations or bathe and dress oneself is devastating. Further delaying the loss of daily functions will enable physicians an opportunity to assist patients that have been at risk of being left behind. Namenda can be used by itself or with other Alzheimer's disease treatments.

#### **Fast Facts**

Currently, there are prescription drugs available for the treatment of Alzheimer's for individuals in early to moderate stages.

- Aricept
- Exelon
- Razadyne

There is one prescription drug for treatment of moderate to severe stage.

• Namenda

#### **Prescription Drug Treatments**

- Aricept<sup>®</sup> is a tablet and can be administered once daily. Generally, the initial dose is 5 mg a day (usually given at night). After four to six weeks, if it is well-tolerated, the dose is often increased to the therapeutic goal of 10 mg a day. Aricept 23 mg is now available and is for moderate to severe Alzheimer's disease. Before starting on Aricept 23 mg a day, individuals should be on Aricept 10 mg a day for at least three months.
- Exelon<sup>®</sup> is available as a capsule, as a patch, or as a liquid. The dosage is gradually increased to minimize side effects. Usually the oral medication is started at 1.5 mg daily. After two weeks, the dosage is increased to 1.5 mg twice a day. The therapeutic goal is to increase the dosage gradually every two weeks to reach 6 to 12 mg a day. There is a greater frequency of side effects at these higher doses; however, taking medications with meals may be helpful in reducing the occurrence of side effects. Dosage for the patch typically begins with 4.6 mg daily for four weeks, followed by a maintenance dose of 9.5 mg daily after that.
- **Razadyne**<sup>®</sup> is supplied in the form of tablets in strengths of 4, 8, and 12 mg. The recommended starting dose is 4 mg twice a day. If well-tolerated after four weeks or more of treatment, the dose is increased to 8 mg twice a day. There was no statistical benefit in clinical trials for 12 mg twice a day over the dose of 8 mg twice a day, but if 8 mg twice a day is well-tolerated after four weeks, the dose can be increased to 12 mg twice a day at the physician's discretion.
- Namenda<sup>®</sup> is taken twice daily. It is available in tablet or liquid form for those who prefer taking a liquid or have difficulty swallowing tablets. Therapy begins at 5 mg and gradually increases to the target dose of 10 mg twice/day. The recommended dose for the 4-week starting period begins with one 5 mg tablet in the morning for Week 1; Week 2 one 5 mg tablet is taken in the morning and one in the evening; Week 3 a 10 mg tablet is taken in the morning and one 5 mg tablet at night; and Week 4 a 10 mg tablet is taken in the morning and one 10 mg tablet is taken in the evening. When the daily dose has reached 20 mg (i.e., 10 mg, twice a day), patients taking Namenda can continue with that daily regimen, unless otherwise instructed by their doctor. Namenda can be taken with or without food.

# **Medications and Overmedication**

As a caregiver it is critical to understand the use of medications and be alert to possible overmedication and adverse reactions to drug combinations. No medications prevent or cure Alzheimer's disease, but physicians rely on several drugs to manage delusions and hallucinations, depression, agitation, and sleeplessness.

Although these medications may affect specific disease symptoms and assist in managing them, they can also produce side effects such as agitation, dry mouth, drowsiness, problems in walking, tremors, falling or constipation.

Even though a physician might prescribe a drug for a limited period of time, it can sometimes take up to four weeks for a drug to leave the patient's system after use is discontinued. So-called anti-cholinergic drugs can also block the production of a chemical within the brain called acetylcholine and further alter the patient's memory. To understand the effects of medications and how to manage their use, consider the following tips:

The stand The Some medications can contribute to the Alzheimer's patient's problems and make some symptoms even worse. For example, a person who begins taking drugs for high blood pressure or a heart problem might appear to be more confused than before he began taking the drugs.

#### **Get Medical Advice**

Be cautious about giving any medication-whether it's an over-thecounter type or prescription.

- Begin by asking your physician or pharmacist to review all medications, in order to check for any possible interactions between drugs.
- Make sure that every physician involved in the person's care knows about all prescribed medications.
- Find out as much as possible about every medication, its name, purpose, dosage, frequency, and possible side effects. If serious side effects occur, report them immediately to your physician.



#### **Be Prudent**

Under no circumstances should you change dosages without first consulting your physician. In addition, avoid the temptation to exaggerate or overreport symptoms in order to persuade your physician to prescribe a new drug or to increase the patient's dosage. Do not share medications with other caregivers or keep medication bottles from old prescriptions.

#### **Rely on Your Pharmacist for Information**

Your local pharmacist can also check for interactions between drugs. Keep in mind that pharmacists can neither prescribe drugs nor alter drug doses.

#### Treating Alzheimer's Disease

#### **Be Candid and Direct**

Giving medication in a specific way at specific times of the day or evening will help to reduce conflicts. However, if the person refuses to take the medication, stop and try again at a later time. Never assume the individual will take medications on his own. It may be necessary to check to see whether the medicine has been swallowed. At some point in the progression of the disease, you will need to assume responsibility for giving medications.

#### **Stay Organized**

- Separating pills into a plastic container with small compartments labeled "day" and "evening" or "Monday," "Tuesday," "Wednesday," etc. will help in tracking medications.
- Other caregivers find it useful to give medications in individual cups or envelopes or to keep a calendar and checkoff each dose as it's taken.

#### Adapt to the Person

• If the person has problems swallowing pills or spits out the pills, you might try crushing the pills and mixing them with applesauce or cottage cheese. Some medications might also be available in liquid form.

#### **Take Safety Precautions**

- Put a lock on the medicine cabinet or place the medications in a locked drawer.
- If the person spits out pills, make sure these aren't picked up and eaten by children or pets.
- Avoid leaving the person alone with medication bottles in the room.
- Be sure to throw out all old medicines.

#### **Be Prepared for Emergencies**

- Research the name and telephone numbers of the pharmacies or taxi services that deliver medication.
- List the names of pharmacies that are open on Sundays and weekends.
- Keep the number of your local poison control center and emergency room handy.
- If you suspect a medication overdose, call Poison Control (1-800-222-1222) before inducing vomiting or taking any other actions.



Keep a written record of all current medications, including the name of the medication, dosage, and starting date, and carry a copy of this list with you in your wallet or purse at all times. This record will be invaluable in the event of a serious drug interaction or overdose.



# **Behavioral Intervention**

A number of behavioral problems may be associated with AD. The word agitation is often used as an umbrella term to describe these behaviors. As Alzheimer's progresses, most people with the disease experience agitation in addition to memory loss and other cognitive skills.

In the early stages of the disease, people with Alzheimer's may experience personality changes such as irritability, anxiety, or depression. As the disease progresses, other symptoms may occur, including sleep disturbances, delusions (firmly held belief in things that are not real), hallucinations (seeing, hearing, or feeling things that are not there), pacing, constant movement or restlessness, checking and rechecking door locks or appliances, tearing tissues, general emotional distress, and uncharacteristic cursing or threatening language.

Agitation may be caused by a number of different medical conditions and drug interactions or by any circumstances that worsen the person's ability to think. Situations that may lead to agitated behavior include moving to a new residence or nursing home, changes in the environment or caregiver arrangements, misperceived threats, or fear and fatigue resulting from trying to make sense out of a confusing world.



Agitated behavior can be disruptive and painful to both the person with the disease and the caregiver. Agitation may interfere with the ability of the person with the disease to carry out the activities of daily living, and it may increase the risk of harm to the affected individual and others. Caregivers may be frightened, upset, or simply exhausted by the demands of caring for a person who is agitated.

#### **Behavioral Interventions for Agitation**

There are two distinct types of treatments of agitation: behavioral interventions and prescription medications. Behavioral interventions should be tried first. In general, steps to managing agitation include: (1) identifying the behavior, (2) understanding its cause and (3) adapting the caregiver environment to remedy the situation. Correctly identifying what has triggered agitated behavior can often help in selecting the best behavioral intervention. Often the trigger is some sort of change in the person's environment:

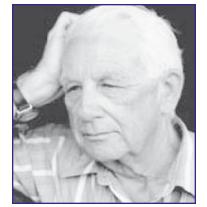
- Change in caregiver
- Change in living arrangements
- Travel
- Hospitalization
- Presence of house guests
- Bathing
- Being asked to change clothing



#### Treating Alzheimer's Disease

A key principle to intervention is redirecting the affected individual's attention rather than arguing, disagreeing or being confrontational with the person. Additional intervention strategies include:

- Removing guns
- Using lighting to reduce confusion and restlessness at night
- Equipping doors and gates with safety locks
- Using labels to cue or remind the person
- Simplifying the environment
- Simplifying tasks and routines
- Allowing adequate rest between stimulating events



#### **Medications to Treat Agitation**

Medications can be effective in the management of some symptoms of agitation, but they must be used carefully and are most effective when combined with behavioral or environmental changes. Medications should target specific symptoms so that improvement can be monitored. People with Alzheimer's are susceptible to side effects that require close observation. Be especially cautious when using antipsychotic, antidepressants or anxiolytics medication with side effects that could cause:

- **Memory Loss** Try not to add to the dementia problem with medications that have memory loss as a side effect.
- Chewing and Swallowing Difficulties As Alzheimer's progresses, it causes chewing and swallowing problems in late stage. A build-up of some antipsychotic medications with this side effect could also cause premature eating difficulties. In the most severe cases of prolonged use of these medications, the person may never chew or swallow again. Talk to your physician and be very clear about short term use only.

Be especially cautious when using antipsychotics, antidepressants or anxiolytics or any medications with side effects that could cause memory loss, chewing and swallowing difficulties.

NOTES:

# Getting a Diagnosis

Experts estimate a skilled physician can diagnose Alzheimer's with more than 90 percent accuracy. The first step in following up on symptoms is finding a doctor you feel comfortable with. Many people contact their regular primary care physician or internist about their concerns regarding memory loss. Primary care doctors often oversee the diagnostic process themselves.

Your primary care doctor may refer you to a physician who specializes in the diagnosis and treatment of Alzheimer's disease and related dimentias.

There is no single test that can tell if a person has a serious memory problem. A diagnosis is made through a complete assessment that considers all possible causes. If the evaluation does not indicate Alzheimer's disease or a related illness, but the symptoms continue to get worse over time, your doctor may need to order more tests. If you are still not satisfied, you may want to get a second opinion from a specialist (e.g., neurologist).

During your office visit, the doctor should...

- **Explain** the diagnosis, let you know what to expect in the future, and tell you where to get more information and help
- **Tell** you about the possible treatments. Together, you can select what's best for the patient.
- Schedule your next visit and let you know how often he/she would like to see you before you leave

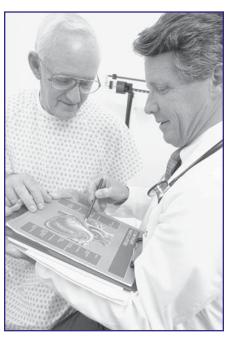
#### **Medical Evaluation**

A complete medical evaluation for memory loss should include:

- A medical and psychiatric history
- A physical and neurological exam, which may include brain imaging techniques, such as CT or MRI scans
- Lab tests (blood, B-12, folic acid, thyroid and urine)
- An evaluation of the patient's ability to perform common daily activities, such as balancing a checkbook or taking medications
- A 'mental status exam' to measure the patient's thinking and memory
- A family or caregiver interview

#### **Get Prepared**

- Doctors only have a limited amount of time to spend with each patient. You can help by being prepared.
- Take all medications, both over-the-counter (vitamins, aspirin) and prescription, to the visit.
- Take a list of past and current medical problems. Have other family members had illnesses that caused memory problems?
- Answer the doctor's questions honestly and to the best of your ability.



#### Treating Alzheimer's Disease

- Write a list of symptoms, when they began, and how frequently they occur.
- Be specific. For example, "Last Tuesday, I (my husband) got lost on the way home from the store. It was scary."
- Ask the doctor to explain any tests and how long it will take to get a diagnosis.

#### **Importance of Early Diagnosis**

Although the onset of Alzheimer's disease cannot yet be stopped or reversed, an early diagnosis allows people with dementia and their families:

- A better chance of benefiting from treatment
- More time to <u>plan for the future</u>
- Lessened anxieties about unknown problems
- Increased chances of participating in clinical drug trials, helping advance research
- An opportunity to participate in decisions about care, transportation, <u>living options</u>, <u>financial</u> and <u>legal matters</u>
- Time to develop a relationship with doctors and care partners
- Benefit from care and support services, making it easier for them and their family to manage the disease

#### **Importance of Clinical Trials**

Clinical trials are the engine that powers medical progress. Through clinical trials, researchers test new ways to detect, treat and prevent Alzheimer's disease and related dementias. Without clinical trials, there can be no new treatments or cures. Recruiting and retaining trial participants is now the greatest obstacle, other than funding, to developing the next generation of Alzheimer's treatments.

Participation in clinical studies provides an opportunity to advance and accelerate medical research and to contribute to the better health of future generations. Use the Alzheimer's Association TrialMatch service to find a clinical trial: 1-800-272-3900, 7 a.m.-7 p.m. CT, Monday-Friday.

#### **Different Tests for Alzheimer's Disease and Dementia**

#### **Genetic Testing**

Researchers have identified certain genes that increase the risk of developing Alzheimer's and other rare "deterministic" genes that directly cause Alzheimer's. Although genetic tests are available for some of these genes, health professionals do not currently recommend routine genetic testing for Alzheimer's disease.

**Risk genes:** While there is a blood test for **APOE-e4**, the strongest risk gene for Alzheimer's, this test is mainly used in clinical trials to identify people at higher risk of developing Alzheimer's. Carrying this gene mutation only indicates a greater risk; it does not indicate whether a person will develop Alzheimer's or whether a person has Alzheimer's. Genetic testing for APOE-e4 is controversial and should only be undertaken after discussion with a physician or genetic counselor.

## Treating Alzheimer's Disease

**Deterministic genes:** Testing also is available for genes that cause **autosomal dominant Alzheimer's disease (ADAD)** or "familial Alzheimer's," a rare form of Alzheimer's that accounts for less than 5 percent of all cases. ADAD runs strongly in families and tends to begin earlier in life. Many people in these families do not wish to know their genetic status, but some get tested to learn whether they will eventually develop the disease. Some ADAD families have joined clinical studies to help researchers better understand Alzheimer's.

## **Neurological Exam**

**During a neurological exam, the physician will closely evaluate the person for problems that may signal brain disorders other than Alzheimer's.** The doctor will look for signs of small or large strokes, Parkinson's disease, brain tumors, fluid accumulation on the brain, and other illnesses that may impair memory or thinking.

The physician will test:

- Reflexes
- Coordination, muscle tone and strength
- Eye movement
- Speech
- Sensation

If the evaluation does not indicate Alzheimer's disease or a related dementia, but the symptoms continue to get worse over time, your doctor may need to order more tests or you may wish to get a second opinion.

The neurological exam may also include a brain imaging study.

## Home Screening Tests for Dementia

A number of dementia screening tests have been marketed directly to consumers. The Alzheimer's Association believes that home screening tests cannot and should not be used as a substitute for a thorough examination by a skilled doctor. The whole process of assessment and diagnosis should be carried out within the context of an ongoing relationship with a responsible health care professional.

## **Mental Status Tests**

Mental status testing evaluates memory, ability to solve simple problems and other thinking skills. Such tests give an overall sense of whether a person

- Is aware of symptoms
- Knows the date, time, and where he or she is
- Can remember a short list of words, follow instructions and do simple calculations

The mini-mental state exam and the mini-cog test are two commonly used tests.

## Treating Alzheimer's Disease

#### Mini-mental state exam (MMSE)

During the MMSE, a health professional asks a patient a series of questions designed to test a range of everyday mental skills.

Examples of questions include:

- Remember and repeat a few minutes later the names of three common objects (for instance, horse, flower, penny)
- State the year, season, day of the week and date
- Count backward from 100 by 7's or spell "world" backwards
- Name two familiar objects in the office as the examiner points to them
- Identify the location of the examiner's office (state, city, street address, floor)
- Repeat a common phrase or saying after the examiner
- Copy a picture of two interlocking shapes
- Follow a three-part instruction, such as: take a piece of paper in your right hand, fold it in half, and place it on the floor

The maximum MMSE score is 30 points. A score of 20 to 24 suggests mild dementia, 13 to 20 suggests moderate dementia, and less than 12 indicates severe dementia. On average, the MMSE score of a person with Alzheimer's declines about two to four points each year.

#### Mini-cog

During the mini-cog, a person is asked to complete two tasks:

- 1. Remember and a few minutes later repeat the names of three common objects
- 2. Draw a face of a clock showing all 12 numbers in the right places and a time specified by the examiner

The results of this brief test can help a physician determine if further evaluation is needed.

#### Mood Assessment

In addition to assessing mental status, the doctor will evaluate a person's sense of well-being to detect depression or other mood disorders that can cause memory problems, loss of interest in life, and other symptoms that can overlap with dementia.

## **Brain Imaging**

A standard medical workup for Alzheimer's disease often includes structural imaging with MRI or CT; these tests are primarily used to rule out other conditions that may cause symptoms similar to Alzheimer's but require different treatment. Structural imaging can reveal tumors, evidence of small or large strokes, damage from severe head trauma or a buildup of fluid in the brain.

Imaging technologies have revolutionized our understanding of the structure and function of the living brain. Researchers are exploring whether the use of brain imaging may be expanded to play a more direct role in diagnosing Alzheimer's and detecting the disease early on.

## **Questions to ask your doctor**

## Diagnosis

- What does the diagnosis mean?
- Can you explain it in a way that I will understand?
- What can we expect in the near future and over time?
- Do you have any written material on this disease? If not, who does?
- Are there any organizations or community services that can help?



## Treatment

- Are there any treatments that don't involve medications?
- Is there anything that we can change at home to make things easier or safer?
- What medications are available for memory loss? For behavior changes? What are the risks and benefits?
- What are the side effects? How long will the patient take this medicine? Is there anything else we should know?
- Should we consider participating in a drug trial? What are the risks and benefits?

## **Other Concerns**

- Will the patient continue to be able to work? To drive?
- What will our regular appointment schedule be?
- Under what circumstances should we contact your office?
- Can we schedule our next appointment?



#### For your convenience...

The Information and Referral Services section of this guide has a list of specialists to aid in the diagnosis of your loved one.



## **Principles for a Dignified Diagnosis**

Principles for a Dignified Diagnosis is the first statement of its kind written by people with dementia on the subject of the Alzheimer diagnosis experience.

In the 2008 report Voices of Alzheimer's Disease: A Summary Report on the Nationwide Town Hall Meetings for People with Early Stage Dementia, the Alzheimer's Association identified diagnostic challenges and dissatisfying interactions with the medical community as two major challenges articulated by people living with the disease. These principles are their insights on how to make that experience better.

- Talk to me directly, the person with dementia. I am the person with the disease, and though my loved ones will also be affected, I am the person who needs to know first.
- *Tell the truth.* Even if you don't have all the answers, be honest about what you do know and why you believe it to be so.
- **Test early.** Helping me get an accurate diagnosis as soon as possible gives me more time to cope and live to my fullest potential and to get information about appropriate clinical trials.
- Take my concerns seriously, regardless of my age. Age may be the biggest risk factor for Alzheimer's, but Alzheimer's is not a normal part of aging. Don't discount my concerns because I am old. At the same time, don't forget that Alzheimer's can also affect people in their 40s, 50s and 60s.
- Deliver the news in plain but sensitive language. This may be one of the most important things I ever hear. Please use language that I can understand and is sensitive to how this may make me feel.
- Coordinate with other care providers. I may be seeing more than one specialist – it is important that you talk to my other providers

to ensure you all have the information so that changes can be identified early on and that I don't have to repeat any tests unnecessarily.

- Explain the purpose of different tests and what you hope to learn. Testing can be very physically and emotionally challenging. It would help me to know what the purpose of the test is, how long it will take and what you expect to learn from the process. I would also appreciate the option of breaks during longer tests and an opportunity to ask questions.
- Give me tools for living with this disease. Please don't give me my diagnosis and then leave me alone to confront it. I need to know what will happen to me, and I need to know not only about medical treatment options but also what support is available through the Alzheimer's Association and other resources in my community.
- Work with me on a plan for healthy living. Medication may help modify some of my neurological symptoms, but I am also interested in other recommendations for keeping myself as healthy as possible through diet, exercise and social engagement.
- Recognize that I am an individual and the way I experience this disease is unique.

This disease affects each person in different ways and at a different pace. Please be sure to couch your explanation of how this disease may change my life with this in mind.

 Alzheimer's is a journey, not a destination. Treatment doesn't end with the writing of a prescription. Please continue to be an advocate – not just for my medical care but for my quality of life as I continue to live with Alzheimer's.

# Hygiene and Personal Care

NOTES:

- Grooming
- Dressing
- Incontinence
- Bathing
- Eating

# **Hygiene and Personal Care**

People with Alzheimer's need progressively more help with routine activities related to grooming and hygiene. The need for assistance can be very difficult for them because it signifies a loss of independence and privacy. It can also be difficult for caregivers, especially when they assist with activities that interfere with the individual's privacy.

Caregivers must be aware of the capabilities and limitations of their loved ones in order to provide them with necessary daily care.

Routine hygiene and personal care activities can include:

- Dressing
- Grooming
- Bathing
- Toileting
- Eating
- Dental Care



## Grooming

The person with Alzheimer's disease may forget how to perform grooming tasks such as combing hair, caring for fingernails, and shaving. He may also be afraid of grooming tools such as razors and nail clippers. Helping the Alzheimer's patient with grooming and dressing will allow him to maintain a sense of dignity and positive self-esteem. It's important to remember to let the person perform daily dressing routines for as long as possible. Try the following:

#### **Maintain Grooming Routines**

If the person has always gone to the beauty shop or barber, continue to take him. If the experience becomes overwhelming, it may be possible to have the barber or hairstylist come to your home. Allow the person to continue to use favorite toiletries and cosmetics.

## Perform Tasks Alongside the Person

Comb your hair while encouraging the person to imitate your motions.

#### **Use Low-Tech Implements**

Emery boards and electric shavers can be less threatening than clippers and razors.

# Dressing

Physical appearance is important to everyone's sense of self-esteem. For the person with AD, the simple act of putting on clothing can be frustrating. The person may not remember how to dress or be overwhelmed with the choices. For this reason, you need to manage dressing difficulties one-by-one. Some of the reasons why the person with AD might have problems dressing include:

## **Physical Problems**

• Does the person have problems with balance or with motor skills that are needed to fasten buttons or close zippers?

## **Intellectual Problems**

- Does the person remember how to dress?
- Does he recognize his clothes?
- Is he aware of the time of day or season of the year?

## **Environmental Problems**

• Is the person troubled by lack of privacy, cold room, poor lighting or loud noises?

## **Other Concerns**

- Are you pressuring the person to get dressed quickly?
- Are you giving the person clear step-by-step instructions on how to dress?
- Is the person embarrassed or humiliated by dressing in front of a non-family caregiver?

## **Make Clothing Selections**

- Lay out clothes for the person.
- If the person insists on wearing the same clothes every day, try to launder these clothes often and get duplicates of favorite outfits.
- Remove excess clothing from the closet. Seeing many clothes can be overwhelming and upsetting to the person.

## Pay Attention to the Feet

- To give the person's feet support, encourage them to wear shoes instead of slippers.
- Slip-on styles with elasticized inserts on the top are easy to put on and remove.
- Shoes with crepe soles can help to prevent falls. Keep an extra pair of shoes handy in case the person's feet swell. Keep the feet warm with loose-fitting easy to wear socks.

## **Choose Practical Clothes**

- Select fabrics that are lightweight, flexible and feel comfortable on the person's skin.
- Choose clothing that is washable, flame retardant and easy to put on and remove.
- Lay out clothes in the order the person will put them on and then assist through each step of the dressing process.
- Cardigans or tops that fasten in front are easier to work with than pullovers.
- Give easy-to-understand instructions and simple clothing selections so the person can dress independently for as long as possible.



## Hygiene and Personal Care

## Incontinence

Incontinence, which includes loss of bladder and/or bowel control and bedwetting, is a difficult and very common problem for an Alzheimer's patient.

Although incontinence can be managed by changing the patient's routine, clothing or environment, at some point incontinence may become a permanent condition of the disease. If incontinence is a new behavior, the first and most important step is to identify the possible reasons for this loss of control. Consider the following questions:

## **Medical Conditions**

- Could the reason be medical? Could the person have a urinary tract infection, constipation, or a prostate problem?
- Is there an illness such as diabetes, stroke, or Parkinson's disease?
- Do mobility difficulties make it hard for the patient to get to the bathroom in time? If the answer to any of these is "yes," consult your physician.

#### Stress

- Is the incontinence caused by stress or movement? For example, does the person release urine with a sneeze or cough or laugh?
- Does fear of an embarrassing accident make the person want to constantly visit the bathroom?
- Keep in mind weak pelvic muscles in a woman could cause uncontrollable loss of urine.

#### Medication

- Is the person on medication that might intensify the behavior?
- Is it possible that tranquilizers, sedatives, or diuretics contribute to incontinence? Keep in mind, for example, that some tranquilizers can relax bladder muscles.
- Medication used to treat incontinence can also cause side effects such as dry mouth or eye problems.

## Beverages such as coffee, tea, and sodas can produce a diuretic effect and might contribute to incontinence.

#### Dehydration

• Did you withhold fluids when the person started to lose bladder control? If so, the person might become dehydrated. Dehydration can create a urinary tract infection which can lead to incontinence.

## Environment

- Is it possible that the person can't find the bathroom? Does the person have too far to travel to reach the bathroom in time?
- Is the person afraid of falling? Are there obstacles in the path such as chairs or throw rugs? Is the path well lit?

## Plan Ahead

- Train yourself to respond to the person's routine and schedule. Identify when accidents most often occur and plan ahead.
- If an accident occurs every two hours, get the person to the bathroom before that time. Temporarily keep a logbook that notes when the person uses the bathroom.

## Clothing

- Does the person have problems undressing in the bathroom? Are the zippers and buttons on clothing causing problems?
- Keep the person's dress simple and practical. Choose easy-to-remove and easy-to-clean clothing such as sweat pants with elastic waistbands.
- Consider using pads or protective bedding, adult diapers, or panty liners.

#### Communicate

Encourage the person to tell you when they need to use the bathroom. The person may not be able to say, "I need to use the bathroom." Watch for visible cues that the person needs to use the bathroom. For example, the person may get restless, make unusual sounds or faces, or pace around the room.

## Innovate

- Be willing to experiment with new concepts and ideas. Keep in mind that every person is different.
- What works for one person may not work for another. Remember that accidents are embarrassing.

## Understand

- When the person is successful, use praise, encouragement and reassurance.
- Be matter-of-fact and understanding and avoid blaming or scolding the individual.

## **Change and Adjust**

- Be patient and allow the person adequate time in the bathroom.
- Rearrange the environment to make it easier for the person to use the bathroom. For example, leave on a nightlight in the bathroom and bedroom.
- Put a picture of a toilet on the bathroom door, or paint the bathroom door a color different than the wall.
- If accidents occur at night, consider a portable commode or urinal near the bed.

## Follow-up

- Make sure the person uses the bathroom regularly. You may need to assist in removing clothes, wiping or flushing.
- You might also want to stimulate urination by giving the person a drink of water or running water in the sink.
- Keep sensitive skin areas clean with regular washing and application of a powder or ointment.

## Control

- To help control night incontinence, limit the person's intake of liquids after dinner and in the evening and cut down on drinks such as cola, coffee, tea, and grapefruit juice.
- Encourage the person to drink at least one-and-a-half quarts (six cups) of fluids daily. For variety, you might want to introduce decaffeinated herbal teas, decaffeinated coffee, jello, or fruit juice.
- Help the person with Alzheimer's retain a sense of dignity despite the problems with incontinence. Reassuring and non-judgmental statements will help lessen feelings of embarrassment and frustration.



## Hygiene and Personal Care

## **Bathing**

Keeping the Alzheimer's patient clean can be a challenge for the caregiver. A depressed person might have lost his desire to bathe while another person might feel embarrassed about getting undressed or might become frightened by running water or mirrors.

Bathing is often the most difficult personal care activity that caregivers face. Because it is such an intimate experience, the person with Alzheimer's may perceive it as unpleasant or threatening and in turn, exhibit disruptive behaviors such as screaming, resisting, and hitting. This often occurs because the person doesn't understand the bathing process and can only focus on the related discomforts.

For the person who has Alzheimer's, it's easy to feel confused and overwhelmed by simple daily routines such as bathing and grooming. If the person seems afraid, stressed or resistant to bathing, try to determine the reasons why by asking the following questions.

#### **Physical/Psychological Factors**

- Does the person seem depressed? Is there a physical illness or infection?
- Does the person seem overly sensitive to water or changes in water temperature?

#### **Environmental Factors**

- Is the person sensitive about having someone else in the bathroom?
- Is the person able to find the bathroom and see clearly once he enters it?
- Is the room temperature too cold? Is the water temperature too hot or cold?
- Is the water pressure too intense?
- Is the water in the tub too deep?

## **Special Concerns**

• Is the person afraid of falling, running water or soap? Or is the person confused over such tasks as turning on the water or filling the sink?



#### Things You Can Do

- Have reasonable expectations keep in mind that the frequency of washing and bathing are a personal preference. Some people may not feel the need to shower and/or wash their hair every day. Try to alternate sponge baths with a tub bath or shower.
- Adapt to the patient's needs, routines, and preferences if the person is used to taking a shower in the morning or a bath at night, try to maintain that routine. Changing from day to night might distress the person. Also, expect that a person may refuse to take a bath for an unfamiliar caregiver of the opposite sex.

#### Prepare the bathroom in advance:

- Have the towels ready.
- Pre-measure the shampoo.
- Make a soap pocket in the washcloth so that the person can wash himself.
- Keep the bathroom warm and comfortable.
- Gently prepare the patient for the bath be direct at bath-time by using phrases such as, "Your bath is ready." In this way, the person will focus on each step of the task instead of whether or not he needs or wants a bath. If the individual continues to resist the idea of bathing, distract him for a few moments and then try again.

## Make the Bathroom Safe

Always check the temperature of the water. Keep in mind the person may not be able to judge temperature and that showers are often more dangerous and frightening to people with Alzheimer's disease than baths. If you must use a shower, install grab bars and use a tub seat. Avoid using bubble bath or bath oils that would make the tub or shower slippery.

## **Prevent Falls**

To prevent falls, install grab bars on the wall and tub edge, place nonslip mats on floors, and use a tub bench or bath chair with adjustable heights. Use only two or three inches of water in the tub and test the temperature in advance to prevent burns. Never leave the person alone in the bathroom.

## Help the Person Feel in Control

Involve and coach the person through each step of the process, reminding them of the areas that need washing. You may need to experiment to determine if the individual prefers tub baths or showers and what is the best time of day for bathing.

## Include the Person in the Process

Be sure the person has a role in the bathing process. For example, have them hold a washcloth or a shampoo bottle.

It may not be necessary for individuals to be bathed in the tub every day. Sponge baths can be effective between showers or baths.

## **Respect the Person's Dignity**

Some individuals may be self-conscious about being naked. Letting the person hold a towel in front of the body, in and out of the shower or tub, may ease anxiety.

## **Be Gentle**

The person's skin may be very sensitive. Avoid scrubbing and pat dry instead of rubbing. You may want to use a handheld shower to wash hard to reach areas.

## **Be Flexible**

Washing the person's hair may be a difficult task. Use a washcloth to soap and rinse hair in the sink to reduce the amount of water on the person's face.

## Take Care in Giving the Bath

- Avoid using harsh deodorant soaps unless there's a serious problem with incontinence, in which case there are special soaps available.
- Make sure the person washes the genital area especially if incontinence is a problem.
- Make sure the person washes within folds of flesh and under the breasts.
- After bath or shower, check to see that the person is completely dry.
- Check the person's skin for rashes and sores. If the problem is serious, consult a doctor.
- Keep in mind that pressure sores and skin ulcers can develop quickly on people who sit or lie down much of the time.
- Use a body powder, cornstarch or baby power under the breasts or in folds of the skin, and use lotion to keep skin flexible. If the person resists deodorant, try baking soda.



## Hygiene and Personal Care

## Eating

Many Alzheimer's patients have problems with eating. For example, a person might lose his appetite or the ability to determine if food is too hot or too cold. In addition, a person might forget that he's eaten and ask you for another meal. Begin by assessing the problem. Ask yourself: "Why is the person having difficulty eating?" The following questions are helpful:





Monitor whether the person can eat without assistance; and



when necessary, assist the person with eating.

#### **Physical Difficulties**

Is the problem physical? Sores in the mouth, poor-fitting dentures, gum disease, or dry mouth may make eating difficult. A visit to your physician might be helpful.

#### Disease

Does the person have an additional chronic disease? Intestinal or cardiac problems or diabetes might lead to loss of appetite. Constipation or depression can also decrease appetite.

#### **Agitation/Distraction**

Is the person agitated or distracted? If agitated, the person probably won't sit still long enough to eat an entire meal. If the person is distracted, you might want to think about how you can reduce distractions in the room.

#### Eating Style

Have you recently changed eating styles? Does the person have a preferred eating style? Some Alzheimer's patients who aren't accustomed to sitting down at the table for three full meals may prefer to have several smaller meals or snacks.

#### **Visual Problems**

Can the person see adequately? An Alzheimer's patient who had been losing weight began to eat when she started wearing her glasses at mealtimes.

#### Environment

Are there odors or harsh noises in the room that might interfere with the person's digestion?

#### **Food Quality**

Is the food appealing in appearance, smell and taste?

#### Adapt to the Person's Food Preferences

Remember that you're dealing with a person who has long-standing personal preferences and tastes. Try to keep these likes and dislikes in mind when you're preparing food. On the other hand, the person may no longer remember favorite foods, so focus on nutrition.

## **Try to Reduce Mealtime Confusion**

- Provide a calm environment at mealtimes. Minimize distractions, loud noises, and abrupt movements.
- Offer meals at regular times.
- Make mealtime a pleasant but simple event. For example, put only one item of food on the plate at a time.
- Give the person only one utensil at a time. You may want to omit the knife from the place setting. Avoid using plastic utensils because they may break.
- Avoid patterned plates, tablecloths and placemats that might confuse and distract the patient. In most cases, use plain white plates or bowls and a contrasting placemat.
- Deliver simple, easy-to-understand instructions. For example, "Pick up your fork. Put some food on it. Raise it to your mouth."
- Don't criticize the person's eating habits or urge him to eat faster.
- Speak slowly and clearly. Be consistent and repeat instructions in the same words each time.
- Be realistic about going out to eat. Avoid noisy or large restaurants and choose those that are small, comfortable, and familiar. Only you can decide if the person can order directly from the menu. Or you might want to order for the person.
- Make positive use of distractions. If the person resists eating, take a break, involve her in another activity, and return to eating later.
- Use memory aids to remind the person about meal times. You might try a clock with large numbers, an easy-to-read appointment calendar with large letters and numbers, or a chalk or bulletin board for recording the daily schedule.

## Minimize Problems in Chewing and Swallowing

- Avoid foods such as nuts, popcorn, and raw carrots which may get lodged in the throat. Instead, grind foods or cut them into bite-size pieces. Pureed and frozen foods can be stored in plastic bags.
- Explain to the person they should chew slowly, and then swallow.
- Encourage the person to sit up straight with the head slightly forward. If the person's head tilts backwards, move it to a forward position.
- Serve soft foods such as applesauce, cottage cheese and scrambled eggs.
- Serve thicker liquids such as shakes, nectar and thick juices.
- Learn the Heimlich maneuver in order to prevent choking.

## **Experiment with Solutions to Decreased Appetite**

- Serve a glass of juice before the meal to stimulate the appetite.
- Prepare some of the person's favorite foods.
- Increase the person's physical activity.
- Plan for several small meals rather than three large meals.
- Give the person plenty to drink especially in warm weather.
- Consider the use of food supplements such as instant breakfast, eggnog, yogurt and milk shakes.

## **Eating Well**



#### **Reduce Confusion**

- Avoid plates with patterns
- Omit the knife
- Use plain white dishes
- Avoid plastic utensils



Use Memory Aids to remind the person to eat



Serve Thicker Liquids to reduce problems with swallowing

## Hygiene and Personal Care

## Allow the Person to Function Independently

- Serve finger foods or serve the meal in the form of a sandwich.
- Serve food in large bowls instead of plates or use plates with rims or protective edges.
- Use spoons with large handles instead of forks.
- Set bowls and plates on a non-skid surface such as a cloth or towel.
- Use cups and mugs with lids to prevent spilling and fill glasses half full
- Use straws that bend.
- Use plastic tablecloths, napkins, or aprons to make clean-up easier.
- Gently place the person's hand on or near an eating utensil.
- Show the person how to eat by demonstrating eating behavior or by doing hand-in-hand feeding.
- Give the person plenty of time to eat. Keep in mind that it can take an hour or more to complete a meal.
- Give the person the opportunity to eat with other family members for as long as possible.

#### Work to Prevent Eating and Nutrition Problems

- Use vitamin supplements only on the recommendation of a physician. Monitor their use.
- Don't serve steaming or extremely hot foods or liquids. Remember, the person might not be able to tell if the food or beverage is too hot to eat or drink.
- Limit or eliminate highly salted foods or sweets if the patient has a chronic health problem such as diabetes or hypertension.
- Control potential weight gains. If the person always seems hungry, serve smaller portions of food at more frequent intervals. Fill gaps between regular meals with healthy snacks.
- After the meal is over, check to see that the person swallowed the food and nothing remains in the mouth.
- Restrict portions when appropriate. A person with Alzheimer's may have no concept of how much she's eaten.
- Help the person maintain good oral hygiene. If it's difficult to use a toothbrush, try oral swabs. Regular visits to the dentist are important.

Keep in mind that the person may not remember when or if she ate. If the individual continues to ask about eating breakfast, you might consider serving several breakfast juices, followed by toast, followed by cereal.



#### **NOTES:**

- Effective Communication
- Planning Daily Activities
- Therapeutic Care Approaches
- Visiting
- Adult Day Care and Group Respite
- Maintain Your Brain®

## **Effective Communication**

A person can live with Alzheimer's three to twenty years after diagnosis. The average life span is eight to ten years. Families and caregivers can maintain the quality of life when caring for their loved ones at home for several years, reduce caregiver stress levels, and delay nursing home placement with a family plan. This plan should include effective communication, planned daily activities, adult day/group respite care, and modification of the home environment. The family dynamics will change drastically over the course of the disease, but there is hope when family and friends make adjustments for the gradual and progressive decline in memory loss and ability.

As Alzheimer's progresses, communication can become increasingly challenging. Sensitive, ongoing communication is important, no matter how difficult it may become or how confused the person may appear. Although the person may not always respond, he still requires and benefits from direct communication. The following tips can improve interactions:

#### Be Aware of the Tone You Use

- Speak slowly and distinctly. Address the person by name.
- Use a gentle and relaxed tone of voice.
- Convey an easy-going manner of speaking.
- Be aware of your feelings as they are often communicated through your tone of voice.

#### Pay Special Attention to Your Body Language

- Always approach the person from the front.
- Identify yourself.
- Maintain eye contact.
- Be aware of your stance to avoid sending a negative message.
- Use positive and friendly facial expressions.
- Use non-verbal expressions such as pointing.

## **Fast Facts**

Reduce caregiver stress and delay nursing home placement with a family plan that includes:

- Effective communication
- Planned daily activities
- Adult day/group respite
- Modifying the environment

## When Giving Instructions

- Give one-step directions break tasks and instructions into clear, simple steps.
- Ask one question at a time do not overwhelm with too many questions.
- Wait patiently for a response it may take extra time to process your request.
- Repeat information or questions. If no response, wait a moment and ask again.

#### Watch Your Terminology

- Avoid pronouns Instead of saying "Here it is", try "Here is your hat."
- Emphasize key words "Here is your coffee."
- Avoid questions such as "What is my name?" or "Who am I?"

Like many people in their later years, the person with Alzheimer's disease must cope and adjust to many changes – from body image and retirement, to shifts in lifestyle and preparation for disability and death. Many people also look back over their lives and try to make sense of what they've accomplished.

The caregiver can learn to help the person with AD deal with these issues by understanding the person's reactions to the effects of the disease. You can assist the family member in dealing with feelings by exercising patience, sensitivity and a sense of humor. Try to:

## Treat the "Patient" as a Person

- Appreciate and acknowledge the Alzheimer's patient as a person. Through words and touch, try to do everything you can to relate to this individual as a valued human being with emotional and spiritual needs.
- Avoid talking about the person. People with AD are often hurt when caregivers talk about them as if they are in another room. Avoid comments such as:
  - "She's giving us a lot of trouble!"
  - "Yesterday was a bad time for her!"
  - "She kept me up all night again!"

Instead of talking about the person, assume that she understands everything you're saying:

- Call the person with Alzheimer's by name.
- Avoid cruel and dehumanizing descriptions such as "the bedwetter."
- Avoid isolating the individual from visitors.

## **Communicate Slowly and Calmly**

- Speak slowly and in simple sentences. Lower the pitch of your voice.
- Give the person with AD time to hear your words and prepare a response. Keep in mind that it can take up to a minute for the person with this disease to respond.
- Keep communication on an adult-to-adult level. Avoid baby talk or demeaning expressions.
- Smiles and handshakes go a long way to set the tone for adult interactions.
- Communicate one message at a time. The person with AD can become confused by a string of messages such as, "Good morning. Let's get dressed and come down and eat our breakfast."

Divide the message into sections such as:

- "Good morning. You need to get up now."
- "OK, you're up. Now let's get dressed."
- "OK, why don't we go downstairs now?"
- "It's time for breakfast."



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Alzheimer's affects a person's ability to think, communicate, and perform the *most basic activities* of daily living. But like people of all ages, the Alzheimer's patient experiences feelings of joy, sadness, fear, anger and jealousy. As a caregiver, you need to recognize and respond to these feelings. A person with this disease needs to feel valued, worthwhile, and positive about life.

#### **Be Positive and Reassuring**

- Be positive, optimistic and reassuring to the person. Give praise for the simplest achievements and successes. Use expressions such as "Everything will be OK." "We're doing great." Expressing your feelings will help you release tension and comfort the person.
- Use comforting and non-controlling statements. Try to identify feelings rather than argue about facts. For example, instead of arguing with the person about going outside, you can agree by saying, "Yes it would be fun to go outside." Or put limits on the request by saying, "I want to go outside, too. Let's do it after we eat. I'm hungry!"

#### Tell the Person What to Expect

- Prepare the person for what's about to happen. Instead of pulling the patient out of a chair or pushing the patient across the room, make such comments as, "We need to get up now." Then, assist the person to get out of the chair.
- Provide suggestions and structure. For example, don't ask, "Do you want to take a bath?" Instead, say, "It's time to take your bath now."

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Avoid taking responsibilities away from the person through such comments as, "Here, you can't do that. Give it to me. I'll do it for you." Instead of assuming that the person can't perform certain tasks, put the emphasis on what the person can do.

#### Match your Actions and Words

- Be aware of your body language. Even though you might use kind and gentle words, the person with Alzheimer's disease will pick up tension in your face and body. Your feelings will come out through the tone of your voice.
- Subtle differences in word choice and sentence structure will probably confuse the person. Use the same words whenever possible.
- Maintain eye contact, smile, and use touch to comfort and reassure.

#### Help the Person Remain Independent

- Maintain your sense of humor and don't be afraid to tease and joke with the individual. A person's sense of humor can remain intact during the various stages of AD.
- Keep in mind that the person with Alzheimer's disease wants to contribute to the family's well-being. Don't be afraid to ask for help and cooperation with such requests as, "Could you please help me put these plates on the table?" The person might take twice as long to perform a task but will feel the enjoyment of being helpful.

#### **Talk About and Name Emotions**

• Help the person with AD label emotions by making such comments as, "You look sad. This must be really frustrating for you," or "You're really feeling angry right now, aren't you? You know, it's OK to feel angry." Acknowledging an emotion and giving it a label may encourage the person to discuss these feelings further. In addition, don't be afraid to share your feelings with such comments as, "I feel sad too, but I'm here to help you get through this."

#### **Choosing Your Words**

The person with AD won't see the similarity between the following statements:

"Please sit down here."

"Why don't you come here and have a seat?"

## Helping the Person Communicate

- Let the person know you're listening and trying to understand what is being said.
- Maintain good eye contact. Show the person that you care about what is being said.
- If he or she is having trouble communicating, let the person know that it's OK. Encourage the person to continue to explain their thoughts.
- Let the person think about and describe whatever they want to. Be careful not to interrupt.
- Don't tell the person what they are saying is incorrect. Instead, listen and try to find the meaning in what is being said. Repeat what was said if it helps to clarify the thought.
- If the person says something you don't agree with, let it be. Arguing usually only makes things worse.
- If the person uses the wrong word or cannot find a word, try guessing the right one. If you understand what the person means, you may not need to give the correct word. Be careful not to cause unnecessary frustration.
- If you don't understand what is being said, ask the person to point or gesture.
- Sometimes the emotions being expressed are more important than what is being said. Look for the feelings behind the words. At times, tone of voice and other actions may provide clues.

## **People with Vision Limitations**

- Avoid startling the person.
- Don't make loud noises or sudden movements.
- Identify yourself as you approach the person.
- Tell the person of your intentions before you begin.
- Use large-print or audiotape materials, if available.
- If they have glasses, encourage the person to wear them.
- Keep glasses clean.
- Have the prescription checked regularly.

## **People with Hearing Limitations**

- Approach the person from the front.
- Stand directly in front of the person when speaking to him or her.
- Get the person's attention by saying his or her name, and give a gentle touch.
- Speak slowly and clearly.
- Use a lower tone of voice.
- Use unspoken communication like pointing, gesturing, or touch.
- Write things down, if needed.
- If he or she has a hearing aid, encourage the person to wear it; check the battery often.

## **Quick Tips**

- 1. Be calm and supportive.
- 2. Focus on the feelings, not the facts.
- 3. Pay attention to tone of voice.
- 4. Address the person by their name.
- 5. Speak slowly, and use short, simple words.
- 6. Ask one question at a time.
- 7. Avoid vague words and negative statements.
- 8. Don't talk about the person as if they weren't there.
- 9. Use unspoken communication, like pointing.
- 10. Be patient, flexible and understanding.
- 11. Use humor and laughter.
- 12. Don't talk "Baby Talk."
- 13. TAKE CARE OF YOURSELF!!

## **Planning Daily Activities**

While scientists are searching for the cause and cure of Alzheimer's and conducting tests to identify medications that control symptoms, caregivers can contribute immensely to the quality of life for loved ones with Alzheimer's through meaningful daily activity. Activities that are planned and fill their daily schedule are important because they give zest to life. In the life of a person with Alzheimer's, every event of the day, be it a bath, meal, song, or smile, is an activity that can either be the source of frustration or fulfillment.

One of the greatest tragedies of Alzheimer's disease is that it removes from the living the capacity to do things years and years before the body is ready to stop. Sometimes for a person with Alzheimer's, it is impossible to get a task started. Other times things they try to do on their own cause a conflict with a family member. Caregivers sometimes think the person is being negative and uncooperative. This leaves the person with nothing they can do confidently – no way to express their talents and abilities, make contact with others to maintain their social roles, or experience the satisfaction of a job well done. The result is often withdrawal, frustration, and restlessness.

Most people with Alzheimer's still have the energy and desire to do things or participate in activities of daily living, but lack the ability to organize, plan, initiate and successfully complete even simple tasks of daily life.

## **Fast Facts**

Alzheimer's is a disease of brain cell death.

Inactivity destroys brain cells.

Participating in daily activities stimulates brain cells.



During the middle stages, a person with Alzheimer's needs help organizing the day. Planned activities for the person can take many forms and represent different facets of daily living. Activities can be active or passive, done alone or in the company of others. They enhance a person's sense of dignity and self-esteem by giving purpose and meaning to life. Activities can also lessen undesirable behaviors such as wandering or agitation. When structuring the day, consider:

- **Creative activities:** Painting, drawing, listening to music, or playing the piano
- **Craft activities:** Quilting, knitting, crocheting, crossstitching, or embroidering
- **Outdoor activities:** Planting and tending flowers or a small garden, or fishing
- Physical activities: Walking or very light exercise to music
- Indoor activities: Board games such as checkers or bingo
- **Reading activities:** Discussion of newspaper and magazines articles, or Bible study
- Visits to the museum, zoo, neighbors, relatives, or window browsing at the mall

## Music, Art, and Other Therapies

Music, art, pet, and other types of therapies can help enrich the lives of people with Alzheimer's. Pets, for instance, have been shown to reduce depression and boost self-esteem. Art provides an outlet for expression. Music stirs memories, emotions, and when accompanied by singing, encourages group activity. Create guidelines for all activities in order to ensure their effectiveness.

## **Music Therapy Guidelines**

- Identify music that's familiar and enjoyable to the listeners.
- Use live music, tapes, or CDs; radio programs interrupted by too many commercials can cause confusion.
- Use music to create the mood you want.
- Link music with other reminiscence activities; use questions or photographs to help stir memories.
- Encourage movement such as dancing to add to the enjoyment.
- Avoid sensory overload; eliminate competing noises by shutting windows and doors and by turning off the television.

## Art Therapy Guidelines

- Keep the project on an adult level. Avoid using crayons or anything else that might be demeaning or seem child-like.
- Build conversation into the project. Provide encouragement, discuss what the person is creating, and try to initiate a bit of creative storytelling or reminiscence.
- Help the person begin the activity. If the person is painting, you may need to start the brush movement. Most other projects should only require basic instruction and assistance.
- Use safe materials. Avoid toxic substances and sharp tools.
- Allow plenty of time to complete the art project.
- The person doesn't have to finish the project in one sitting. And remember: The artwork is complete when the person says it is.

## Pet Therapy Guidelines

- Not everyone will react positively to animals. Those who owned pets previously tend to be more responsive.
- Match the animal's activity and energy level with that of the individual. For example, a lively dog might be appropriate for someone who can go out for a walk; a cat may be more appropriate for a person who is less mobile.

## Therapies

## Music



Stirs memories and emotion

Art



An outlet for expression

Pets



Reduce depression and boost self esteem

## **Therapeutic Care Approaches**

## Virtual Dementia Tour™

The Virtual Dementia Tour<sup>™</sup> (VDT), available in both group and individual editions, is a hands-on, experiential tool kit created for anyone seeking to understand the physical and mental challenges of those with Dementia. These unique, interactive products have been proven to improve communication and care. Proceeds from the purchase of any kits in this series go toward the fulfillment of dreams for residents of nursing homes and assisted living facilities.

## Sensory Stimulation and Snoezelen™

Research has shown that multi-sensory environments offer a wealth of benefits, often affording the participant and caregiver an opportunity to improve communication, enhance their understanding of each other, and build trust in their relationship. SNOEZELEN is the concept of such a multi-sensory environment, developed in Europe over 20 years ago, and is a wonderful experience to enjoy and share-a place that replenishes the spirit. SNOEZELEN<sup>\*</sup> is a registered trademark of ROMPA<sup>\*</sup> Ltd. All Rights Reserved.

Whether you need a relaxing retreat for yourself or have a loved one who needs a soothing place to go during the day, a sensory stimulation room can provide the sanctuary from hustle that you need. It is also a great place for a person with dementia to get the stimulation they need to encourage them to interact with their environment and increase or maintain functional skills. There are many resources for putting together a sensory stimulation area in your own home. For ideas, contact the Alzheimer's Association or the Alzheimer's Division, MS Dept. of Mental Health.

## Montessori-Based Dementia Programming

A method of creating and presenting activities based upon models of learning and rehabilitation. The goal of the Montessori method is to create persons who are as independent as possible, able to make choices, and who are treated with respect and dignity. It equips individuals who suffer from dementia with environmental supports that build on existing abilities – with the purpose of maintaining or improving existing skills. When those with dementia are actively involved in stimulating, meaningful activities they are not bored and restless. Problematic behaviors such as wandering, repetitive questioning, hitting and screaming become diminished or eradicated.

## **Spaced Retrieval Technique**

This is a technique for calling on abilities that are relatively preserved in persons with AD and related dementias, and how these can be used as the basis for interventions. In other words, spaced-retrieval is a method in which information that is to be remembered is repeatedly retrieved at increasingly longer intervals of time. A specific form of intervention, spaced-retrieval, is used to circumvent memory deficits in persons with AD and related dementias. The ultimate goal of Spaced Retrieval is retention of and ability to recall information over very long intervals of time (weeks, months, etc.) and can be used with a variety of conditions in a variety of settings.

## Habilitation

Habilitation uses easy techniques to help people with the disease and their care partners on the journey through Alzheimer's disease. It means capitalizing on the remaining emotions of the patient, offering opportunities to feel successful by reaching past the recognized losses, ignoring the failures, rejoicing in the remaining skills, and sharing whatever still defines the memory-impaired person's unique humanness. Learning to Speak Alzheimer's, by Joanne Koenig Coste, is a book about the concept of habilitation and how to confront the challenges of daily life in the context of Alzheimer's disease.



## For your convenience...

The Information and Referral Services section of this guide has a list of websites regarding therapeutic care approaches.



## **Moment by Moment Activities**

## Environment

An enriched environment promotes natural and spontaneous interaction between the people or persons with Alzheimer's and their surroundings.

- A chair by the window that looks onto a bird feeder encourages bird watching.
- Boxes of materials for folding, sorting or otherwise handling can give the restless and searching person something safe and enjoyable to do.
- Indoor strolling spaces at familiar places like the shopping mall provide light exercise.

## Self Care

Dressing, bathing, and grooming are at the core of our individuality. These are our most intimate, personally meaningful, and comforting activities. Yet these activities are the first to be removed from an individual's control upon entering a long-term care facility. These activities form an important part of any program that aims to reinforce individual identity and a sense of autonomy.

## **Daily Housekeeping**

Folding laundry, raking, sweeping, dusting, clearing and setting tables, and making beds are well-suited tasks because they require no new learning. These simple but essential tasks can help persons with Alzheimer's feel useful and productive.

## **Plan Events and Activities**

The variety of activities available here is limited only by the experience and creativity of the planners and the experience, abilities, and interests of the participants.

## Reminiscence

Reviewing the past – Memories remain intact throughout the early and middle stages of Alzheimer's. Few activities have as calming an effect on persons with dementia as speaking about pleasant experiences from the past. By focusing on this remaining skill and using suitable cues and prompts, you can bolster the individual's feelings of self worth.

## Smell

The sense of smell can often be impaired in persons affected by Alzheimer's disease. It can be gently stimulated by providing fragrances that are relevant to the person's life. The purpose is to stimulate memorymaking and provide sensory stimulation, not to identify specific scents.



## **Memory Box**

Help the person make a memory box consisting of objects from his past. Any memorabilia from his life will be useful. The box will also include items from his childhood. Keep the box beside the person's chair to provide a stimulus for discussion, stimulate memory-making, and generate clues for a good conversation.

## Visiting

Visiting allows the caregiver and the person with AD to enjoy the company of others. Maintaining social contacts takes planning and effort by the caregiver. As the caregiver, you can assist family and friends with ideas to make visits meaningful and comfortable and to use communication techniques which will enhance their interactions with the impaired person.

Often, people may hesitate to spend time with the person with Alzheimer's because they worry about not knowing what to do or say. Others may not understand the behavior changes that are caused by the disease and feel uncomfortable about visiting.

By working through the concerns of friends and family members, you can continue to give yourself and the person with Alzheimer's important social outlets. Listed next are tips to assist you in having visitors outside the home and visitors in the home.





## Visiting Outside the Home:

- Prepare your host/hostess for the visit. You may want to explain that your visit may be relatively short, or that in the middle of it you may need to take a walk or shift the person's focus to another activity. You may want to bring along a favorite album, book, or audio-tape to help occupy the person.
- Think of a visit as a brief vacation. Unlike vacations that often involve changes in food or surroundings, visits to others' homes provide you with a sense of "normal" life, a link with the past, and a brief memorable time with friends or family.
- Take pictures of friends and relatives to preserve a happy memory for yourself and the person.

## **Invite Visitors to Your Home**

- Don't wait for friends and family to ask if they may stop by for a visit. Instead, take the initiative to contact them and explain that while Alzheimer's disease has changed your lives in some ways, you value their friendship and support and want it to continue. Then suggest a time when they might come for a visit.
- Plan for a successful visit. While the visit certainly doesn't need to be perfect, it should be relaxing and comfortable for everyone visitor, caregiver, loved one, and family members.



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- Prepare visitors before the visit. Educate visitors about how the person with Alzheimer's may have changed physically, emotionally, and intellectually. Mention specific changes in behavior such as wandering or incontinence. Provide suggestions about how to communicate more easily with the person by talking to him one-on-one, or by understanding that he may repeat things, or ask the visitor a question already answered. The information can help lessen the visitor's anxiety.
- Clarify the purpose of the visit. Some people are reluctant to visit because they don't want to be drawn into the heavy responsibilities of caregiving. Be sure to mention that the purpose of the visit is purely social and not to relieve you of caregiving. Make sure that visitors know that their time is a momentary gift of love to the person and a gift of support to you.

#### Help Move the Visit Along

- Suggest specific activities such as taking the person to lunch, sitting on the porch, taking a walk, or looking through a photograph album together.
- Remain accessible to visitors. One of the greatest fears visitors have is that they will be left alone to communicate with or care for the person with dementia. If you're close by, visitors can share specific questions or problems with you. Visitors also may want the chance to talk to you privately.
- Adjust the nature of the visit to the visitor. Some visitors feel they must bring something in order to make the visit worthwhile. You may want to suggest that the visitors bring flowers or special cards, read a chapter from a favorite book, or sing a special song. It's important that they conclude the visit feeling they have delivered something of value.
- Be patient with people and encourage people to be patient with the impaired person. Practice forgiveness. Even people in such caring professions as social work or pastoral care may have difficulty coming to terms with Alzheimer's. Some people whom you thought you could depend on may avoid you, while others will rally to your side.

Inform visitors that the person's condition may change from month to month, week to week, day to day, hour to hour. For example, it may be better for some patients to have morning visitors, while others may benefit from late afternoon visits.

#### NOTES:

## **Adult Day Care and Group Respite**

Adult day care and group respite centers provide a structured setting in which people with Alzheimer's disease and other disabilities may enjoy group activities such as exercise and craft-making and benefit from personal counseling, therapy and other services.

## **Reasons for Using Adult Day Care or Group Respite**

Most likely one of the reasons you may be considering using a day care center is to provide an opportunity for relief time from caregiving. Give yourself permission to use day care or group respite. These services benefit both the caregiver and the person with Alzheimer's. By using day care or group respite, you will have time to rest, rejuvenate yourself, and finish other tasks.

As a result, you will return to the task of caregiving feeling refreshed and renewed. If you are feeling guilty, ask yourself: "If I wear myself out to the point of total exhaustion, what good will I be to my family member? If I do not take a break from caregiving, will I be able to handle his needs?"

## Selecting a Center

Centers may vary widely, and it is important to examine the keys to finding the best setting for your family member. By asking the right questions, you can find a center arrangement that's right for you and the person with Alzheimer's.

You may want to begin with the following:

- Consult a variety of sources to find an appropriate day care center. Ask for the recommendations of other caregivers, especially ones that are members of a mutual support group.
- Give the center a chance. Consider using adult day care at least twice a week for a month before making a final decision. Occasional use will not give you an accurate picture of how the center operates. In addition, give your loved one time to adjust to the experience of going to the center. While some people resist going to the center at first, they often look forward to the visit after several weeks of attending, meeting people, and joining in activities.
- Re-evaluate your need for the service. At some point, the person with Alzheimer's may need more care than the center can provide. Center staff and support groups can help evaluate your needs for future care.





#### For your convenience...

The Information and Referral Services section of this guide has a list of your county's adult day care and group respite centers.



## Adult Day Care and Respite - Things You Can Do

Consider the following issues in evaluating a day care center to meet your needs:

## **Center Clients**

Does the center provide services for people with other types of impairments as well as those in good physical health?

## Assessment

Will the center evaluate the person's needs? How will this evaluation be accomplished and how often will it be repeated? Will it cover their medical needs, social and family history, cognitive functioning, and social skills? Some centers perform assessments in the person's home.

## Services

Does the center offer the services the person with dementia needs? Remember only a few programs offer all of the services described and not all of these services are necessary for a program to be of high quality.

## Counseling

Will the center provide support for clients and families? For example, can they offer guidance on outside resources and arrange for supportive care in the home?

## **Health Services**

Will the center provide blood pressure checks and physical, dental, foot, eye and ear examinations? Will the center dispense medication or offer medication reminders?

## Nutrition

Does the center provide nutritious meals and snacks? To make sure, you may want to sample one of the meals. In addition, can the center accommodate special diets or provide culturally specific menus?

## **Personal Care**

Will the center's staff provide help with hairstyling, toileting, eating, showering, and other tasks?

## Recreation

Does the center offer activities the person with dementia can participate in and enjoy?

## **Behavior Management**

Is the center prepared to deal with wandering, incontinence, hallucinations, sexually inappropriate behavior, or speech difficulties?

## **Respite Care**

Respite care is generally defined as 24 hour short-term relief for the caregiver for extended periods such as weekends, during a caregiver's hospital stay or vacation. Respite care is almost non-existent in the state of Mississippi, except in Assisted Living Facilities or Personal Care Homes.

## **Fast Facts**

Adult day care and group respite programs benefit the person with Alzheimer's by stimulating brain cells through activities, exercise and socialization with others.

Caregivers benefit as well with relief from their caregiving duties.

When we think about staying fit, we generally think from the neck down. But brain health plays a critical role in almost everything we do – thinking, feeling, remembering, working, playing – even sleeping. The good news is we now know there are things we can do to keep our brain healthier as we age – and these steps might reduce our risk of Alzheimer's.

## **10 Ways to Maintain Your Brain®**

#### 1. Head first.

Good health starts with your brain. It's one of the most vital body organs, and it needs care and maintenance.

#### 2. Take brain health to heart.

What's good for the heart is good for the brain. Do something every day to prevent heart disease, high blood pressure, diabetes and stroke – all of which can increase your risk of Alzheimer's.

#### 3. Your numbers count.

Keep your body weight, blood pressure, cholesterol and blood sugar levels within recommended ranges.

#### 4. Feed your brain.

Eat less fat and more antioxidant-rich foods.

#### 5. Work your body.

Physical exercise keeps the blood flowing and may encourage new brain cells. Do what you can – like walking 30 minutes a day – to keep both body and mind active.

#### 6. Jog your mind.

Keeping your brain active and engaged increases its vitality and builds reserves of brain cells and connections. Read, write, play games, learn new things, do crossword puzzles.

#### 7. Connect with others.

Leisure activities that combine physical, mental and social elements may be most likely to prevent dementia. Be social, converse, volunteer, join a club or take a class.

#### 8. Heads up! Protect your brain.

Take precautions against head injuries. Use your car seat belts; un-clutter your house to avoid falls; and wear a helmet when cycling or in-line skating.

#### 9. Use your head.

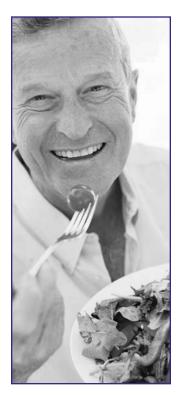
Avoid unhealthy habits. Don't smoke, drink excessive alcohol or use street drugs.

#### 10. Think ahead - start today!

You can do something today to protect your tomorrow.

## Make Brain-Healthy Lifestyle Choices

• Manage your numbers – Controlling your body weight, blood pressure, cholesterol and blood sugar helps reduce your risk of heart disease and stroke. Remember, what's good for the heart is good for the brain.



- Eat wisely Research suggests that high cholesterol may contribute to stroke and brain cell damage. A low-fat, low-cholesterol diet is advisable. And there is growing evidence that a diet rich in dark vegetables and fruits, which contain antioxidants, may help protect brain cells.
- Stay physically active Physical exercise helps maintain good blood flow to the brain, which is essential for brain health, and also alters brain chemicals that help protect the brain.
- Keep mentally active Mentally stimulating activities strengthen brain cells and the connections between them, and may even create new nerve cells.
- Remain socially involved Social activity not only makes physical and mental activity more enjoyable, it can reduce stress levels, which helps maintain healthy connections among brain cells.

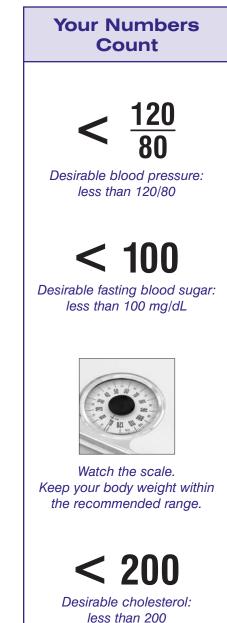
## Lifestyle and risk factors you can control

There is growing evidence that lifestyle can affect your brain health and even your risk for dementia. There are things you can do to reduce your risk and take care of your brain as well as your body.

Manage your overall health. Heart disease, high blood pressure and stroke affect blood flow to the brain and are risk factors for dementia.

Recent research indicates that diabetes may increase the risk of Alzheimer's, possibly because of increased risk of heart disease and impaired insulin function. Avoiding or managing these health conditions is one way to take care of your brain.

> For more information on healthy aging and ways to Maintain Your Brain<sup>©</sup> go to: www.alz.org 1.800.272.3900



# Modifying the Environment

**NOTES:** 

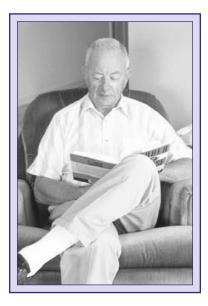
- Consistency
- Use of Color
- Flooring
- Furnishings
- Pets
- Safety Devices
- Lighting

# **Modifying the Environment**

Research has shown that with a few physical changes to the environment, people with Alzheimer's can maintain a productive and active lifestyle. Alzheimer's, during the middle stage, impedes a person's ability to distinguish depth and other space relationships. The use of simple yet contrasting colors in kitchens and dining rooms will reduce the potential for accidents by helping the person distinguish between counter tops or tables and floors. Adding grab bars around toilets and tubs, installing handrails on stairways, and placing light switches at the top and bottom of the stairs will encourage mobility and autonomy.

Persons with Alzheimer's are often unable to remember where they are at any given moment. Sometimes they see their surroundings as threatening because they are unfamiliar. The reason may not be in the environment, but in the feelings of disorientation that are part of Alzheimer's disease. While most people can easily distinguish among many different noises, colors, or patterns in a room, the person with Alzheimer's is more likely to feel confused or overwhelmed. This kind of over stimulation can make the person feel hostile or worried. For these reasons, you need to create a calm, quiet, familiar, enjoyable, comfortable and organized home environment.

If the person feels safe and secure, you might be able to better manage problems of wandering, anger, or agitated behavior. Keep in mind that something as simple as rearranging the living room furniture or stepping into a neighbor's kitchen might be unsettling to the person with Alzheimer's. A familiar, well-organized living area helps both you and the patient. In looking at your living environment, you should consider the following:



## **Focus on Consistency**

- Strive for consistency. Keep furniture in the same place.
- *Help the person maintain a connection to the past* with such familiar objects as old framed photographs, a favorite chair, cabinet or lamp, a piece of clothing such as a hat, or wall hanging.

## **Use Color and Contrasts**

Changes in vision may make it difficult for the person to distinguish colors and understand what is seen. Consider making the following changes.

- *Work to achieve a calming effect through color.* Instead of relying on bright primary colors such as stark white, yellow, orange, or red, use more soothing pastel shades, such as peach, pink, beige, ivory, and light blues, greens and lavender. In addition, use flat paint rather than semi-gloss or high gloss to prevent glare.
- *Use contrast.* A person with Alzheimer's disease might not be able to distinguish between and off-white wall and a beige door or handrail. For this reason, you may want to have light walls and dark doors and handrails.

## Modifying the Environment

## **Pay Attention to Flooring**

- Keep floor surfaces uncomplicated. The person might perceive checkerboard tile or linoleum squares as holes and certain patterns as cracks to be avoided.
- Use flooring that cuts down on glare. A shiny floor might prevent the person from seeing obstacles in his path. Some of the newer texture vinyls cut down on glare and are less slippery.



• Consider using carpeting to help absorb noise or to prevent slipping. However, because of problems with incontinence, some caregivers choose to eliminate carpeting on the floor.

## **Consider Special Furniture**

• Find non-absorbent material to cover furniture or buy a comfortable recliner. If you purchase a special chair, make sure it has stable arms that extend past the seat so the person can get up easily.

#### **Limit Distractions**

- Limit distractions and control noise. Provide soft, enjoyable background music and include some of the individual's favorite songs. In addition, control excessive switching of television channels and ringing of telephones.
- Avoid lighting that casts shadows that might disturb the patient. Whenever possible, use natural light and focus it directly on the areas where it is needed.

## **Orient the Person**

- Experiment with labels, pictures, and numbers to help the person understand where he is.
- Take responsibility for safety. Keep pathways clear and be especially aware of the dangers of cluttered furniture and throw rugs. Use locks on doors and cupboards, and hidden switches for controls for the stove, thermostat and hot water heater.

#### Wallcoverings Make a Difference

- Use wall hangings made of various textured materials. Many people with Alzheimer's enjoy feeling textured materials such as yarn or wool, and find these decorations less disorienting than those made of mirrors or glass.
- Avoid small, distracting wallpaper prints. In one nursing home, residents mistook the pattern in a wallpaper for snakes and began to beat on the wall. The individual might also try to pick flowers off the wall.

## Pets in the House

• Use pets as part of the environment. Many people with AD find great pleasure in watching fish or birds. Just make sure that you supervise the activity and keep the aquarium or cage locked. Also keep in mind that the person might not be able to assist in caring for the pets.



## Other Methods to Modify the Home Include: Installing Locks Out of Sight

- Place deadbolt locks either high or low on exterior doors to make it difficult for the person with Alzheimer's to wander out of the house.
- Keep an extra set of keys hidden near the door for easy accessibility. Remove locks in bathrooms or bedrooms so the person will not get locked inside.

## **Using Special Safety Devices**

- Child-proof locks and door knobs limit access to places where knives, appliances, equipment, cleaning fluids and other poisonous products are stored.
- Use automatic shut-off devices for appliances such as an iron or coffee maker.

## **Using Different Colors**

- Place contrasting colored rugs in front of doors or steps to help the individual anticipate staircases and room entrances.
- Avoid using very dark colored rugs since they may be perceived as holes.
- Apply colored decals to glass doors and large windows, because the person may think they are open doors.

## **Diffusing Bright Light**

- Cover windows with blinds, shades or sheer draperies to block bright sunlight.
- Avoid using bare light bulbs or clear "decorator" bulbs without shades.

## Limit the Use of Certain Appliances

- Remove electrical appliances such as electric razors or hairdryers, from the bathroom to reduce the risk of electrical shock.
- Put away other appliances including knives, mixers, grills, guns, lawn mowers and power tools, since the person may not remember how to use them safely.

## Be Aware of Plants

- Use house plants for decoration, especially if they've been an important part of the person's life, but first make sure that the plants are non-toxic.
- Consider the back-yard or patio as part of the living environment. Give the person an opportunity to garden, walk, or work outdoors in a safe, supervised area.

# Make simple changes

to help prevent falls, reduce hallucinations and wandering

#### Be aware of plants



## Diffuse bright light



# Managing Challenging Behaviors

**NOTES:** 

- Repetition
- Hallucinations
- Aggressive or Combative Behavior
- Suspicious Thoughts
- Sexuality
- Sundowning
- Driving
- Home Safety
- Travel Safety
- Wandering and MedicAlert<sup>®</sup> + Safe Return<sup>®</sup>

# **Managing Challenging Behaviors**

Alzheimer's disease can cause a person to act in different or unpredictable ways. Some individuals become anxious or aggressive. Others repeat certain questions or gestures. Each person with Alzheimer's is different, so the behaviors or changes he experiences will also be different. For the person with Alzheimer's, changes in behavior may be caused by:

- Physical discomfort (illness, medication)
- Over stimulation (loud noises, busy or active environment)
- Unfamiliar surroundings (new places, inability to recognize home)
- Complicated tasks (difficulty with activities or chores)
- Frustrating interactions (inability to communicate effectively)

While there are many different behaviors exhibited by persons with Alzheimer's, only those most challenging to caregivers will be highlighted in this guide.



## Repetition

A person with Alzheimer's may do or say something over and over. He may repeat a word, question or action. In the span of one hour, a person with Alzheimer's may ask the same question 10 times. In most cases, the person is probably looking for security and familiarity.

The person may also pace or undo what has just been finished. These actions are often harmless for the person with Alzheimer's, but can be stressful for the caregiver.

## **Repetition: Things You Can Do**

Look for a reason behind the behavior and eliminate it.

- Answer the person even if you have to repeat the answer several times.
- Use memory aids remind the person with notes, clocks, calendars, or photographs.
- Respond to the emotion not the behavior focus on how he is feeling, not what he is doing.
- Engage the person in an activity the person may be bored and need something to do.
- Provide structure engage the person in a pleasant activity.
- Stay calm and be patient reassure the person with a calm voice and gentle touch.
- Accept the behavior and work with it if it is not harmful, let it be.
- Consult a physician repetitive behaviors may be a side effect from medication.



## Managing Challenging Behaviors

## Hallucinations

When a person with Alzheimer's suffers with hallucinations he can see, hear, smell, taste or even feel something that is not really there. For example, he may see the face of a former friend in a curtain or he may see insects crawling on his hands. In other cases, he may hear voices talking to him and may even talk to the imagined person.

## Hallucinations: Things You Can Do

## **Consult a Physician**

Ask a physician to evaluate the person to determine if medication is needed or medications currently being used might be causing the problem. In some cases, hallucinations are caused by schizophrenia, a disease unrelated to Alzheimer's.

- Have a physician look for physical disorders such as a kidney or bladder infection, intense pain, dehydration, or alcohol or drug abuse conditions that can cause hallucinations.
- Have the person's eyesight and hearing checked and make sure they wear their glasses and/or hearing aid routinely.

#### **Respond with Caution**

Do not argue with the person about what he sees or hears. For example, "Can you hear them?" You may want to answer with words such as, "I know that you hear something, but I do not." In this way, you are not denying what the person hears or getting involved in an argument. Unless the behavior becomes dangerous, you might not need to intervene.

## **Use Distractions**

Suggest the person come with you on a walk or sit next to you in another room. Frightening hallucinations often subside in welllit areas where there are other people. You might also try to turn the person's attention to other features in the room. Other potential distractions include music, drawing, conversation, looking at photos or counting coins.

## Check Out the Reality of the Situation

Ask the person to point to the area where he sees or hears something. Glare from a window may look like snow to the patient and dark squares on a tiled floor may look like dangerous holes. · milling and it is

Hallucinations can be frightening to the person and the caregiver. On some occasions, the individual may see threatening images or *just ordinary pictures* of people, situations or objects from the past. Although you can create an environment to manage wandering, you may not be able to control the person's hallucinations or prevent them from occurring.

# **Aggressive or Combative Behavior**

Aggressive or combative behaviors may be verbal (shouting, name-calling) or physical (hitting, pushing). These behaviors can occur suddenly without apparent cause, or result from a frustrating situation. Consider the following factors as possible sources of frustration:

- **Dressing** The person who cannot get his arm through a sweater may grow increasingly upset and start to thrash around.
- **Bathing** The person who is frightened by running water in the bathtub may simply try to push your hand away, while at other times the person may resist or strike you.
- Eating The person who does not like a certain type of food may refuse to eat.

Deal with combativeness by trying to examine the underlying causes. Consider:

- **Physical Causes** Is the person tired because of inadequate rest? Are medications such as sedatives and tranquilizers creating side effects? Is the person able to express the fact that they are in pain?
- Environmental Causes Is the person overstimulated by loud noises, people or physical clutter? Is the environment unfamiliar? Does the person feel lost or abandoned by the caregiver?
- **Poor Communication** Are you asking too many questions or making too many statements at once? Are your instructions simple and easy to understand? Is the person picking up on your own stress and irritability? Are you making the person more frustrated by being overly negative or critical?

Whatever the situation, it is important to try to understand what is causing the person to become angry or upset and resulting in aggressive or combative behavior.

## Aggressive or Combative: Things You Can Do

- Be on the Lookout for Frustration Look for early signs of frustration in such activities as bathing, dressing or eating and respond in a calm and reassuring tone.
- Do Not Take Aggression and Combativeness Personally Keep in mind that the person is not necessarily angry at you. Instead, he may misunderstand the situation or be frustrated with his own disabilities.
- Use Distractions Do not persist in making the person perform a particular task, especially if he has repeatedly been unsuccessful. If you see the person getting frustrated with buttoning a shirt, try to distract him with another activity such as putting on a pair of pants. After time, you can return to the shirt or take the person to a quiet room, have a cup of tea or go for a walk.
- Avoid Teaching Instead offer encouragement, but keep in mind the person's capabilities and do not expect more than they can do. Avoid elaborate explanations or arguments.
- **Decrease your Level of Danger –** Assess the level of danger for yourself and for the person. Ask yourself, "How much trouble am I in and what can I realistically do about it?"

## Managing Challenging Behaviors

## **Suspicious Thoughts**

Due to memory loss and confusion, the person with Alzheimer's might see things differently. He may become suspicious of those around him and accuse them of infidelity or other improper behavior. These false ideas are delusions and can sometimes originate in a misinterpretation of a situation. One common delusion is that family members are stealing.

- Let them know you care.
- Do not argue.
- Offer a simple answer.
- Duplicate lost items.



Suspicious thoughts are especially harmful when children or teenagers are accused of stealing by grandparents who have Alzheimer's disease.

## Suspicious Thoughts: Things You Can Do

#### Let Them Know You Care

Listen to what is troubling the person and try to understand their reality. Be reassuring and let them know you care.

#### Do Not Argue or Try to Convince

Allow the person to express his opinions. Agree with their assumptions and acknowledge their thoughts.

#### **Offer a Simple Answer**

A person with Alzheimer's disease may accuse a person of various activities or misinterpret certain situations.

- Share your thoughts with them, but do not overwhelm the person with lengthy explanations or reasons.
- Switch his attention to another activity.
- Try to engage the person in an activity or ask them to help with a chore.

#### **Duplicate Lost Items**

If the person is looking for a specific item, have several available. For example, if the person is always looking for their wallet, purchase two of the same kind.

# Sexuality

All human beings need to be touched, caressed and held. For Alzheimer's patients and caregivers, this need is especially important. Alzheimer's disease affects people in varying ways. One person may have an increased interest in sex while another may have no interest. Changes in the sexuality of people with Alzheimer's disease include the following:

## **Bold Behavior**

The person may forget his marital status and begin to flirt or make inappropriate advances towards members of the opposite sex.

## Exposure

The person may attempt to dress or undress at inappropriate times and in unusual settings. For example, a woman may remove a blouse or shirt simply because it is too tight and she feels uncomfortable. The person does not realize or understand that clothes should not be removed in public places.

## Fondling

The person may forget social etiquette and fondle himself in public. It may appear the person is trying to harass others, but he really does not understand that his behavior is inappropriate.

## Misinterpretations

The person may make sexual advances to a stranger who resembles a former spouse or companion. In addition, the person may forget they are married and approach a person in a sexual manner.

## **Physical Illness**

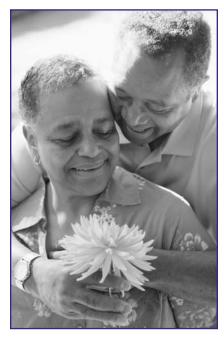
Physical illness may cause the person to lose interest in sex or make sexual intercourse difficult or painful. Reactions to medication may also reduce sexual desire.

## Depression

Depression can reduce interest in sex by the patient and their spouse or loved one. Some caregivers have reported experiencing changes in sexual feelings toward their loved one after providing daily caretaking activities.

## Paranoia

The person may become unreasonably jealous and suspicious. For example, the person may think that his wife has a boyfriend and accuse her of going to see him.



## Managing Challenging Behaviors

## Sexuality: Things You Can Do

- Respond carefully to threats and accusations. If the person levels accusations or becomes extremely suspicious, do not waste time arguing. Instead, try to distract the person with another activity or reassure him with a hug or touch.
- Look for a reason behind the behavior. Keep in mind that if the person exposes himself he may simply need to go to the bathroom. If the person begins to take off his clothes, he may want to go to bed.
- React with patience and gentleness. If the person is engaging in unusual sexual behavior, carefully remind them that the behavior is inappropriate. Then lead the person to a private place or try to distract with another activity. But take care not to get angry with the person or laugh and giggle at the behavior. Anger and ridicule cause negative reactions.
- Adjust the person's clothing. Provide the person with pull-on pants with no zipper.
- Increase the level of appropriate physical contact. Give the person plenty of physical contact in the form of stroking, patting and hugging. In many cases, the person is anxious and needs reassurance through touch and gentle, loving communication.
- Adjust to changes in sexual desire. As the disease progresses, a spouse may choose to sleep apart, especially if the person becomes overly demanding, jealous or irrational.
- Seek outside help to deal with sexual issues. If you consult an outside expert about sexual problems, make sure the professional understands the disease and will discuss sexual issues openly.



As the disease progresses, a spouse may choose to sleep apart, especially if the person becomes overly demanding, jealous or irrational.

# Sundowning

Individuals with diseases such as Alzheimer's often have behavior problems in the late afternoon and evening. They may become demanding, suspicious, upset, disoriented, and see or hear things that are not



there. Additionally, they may believe things that are not true, or they may pace or wander around the house when others are asleep. While experts are unsure how or why this behavior occurs, they suspect that the problem of late afternoon confusion, which is sometimes called sundowning or sundowning syndrome, may be due to these factors:

- The person with Alzheimer's cannot see well in dim light and becomes confused.
- The person may have a hormone imbalance or a disturbance in his biological clock.
- The person with Alzheimer's tires at the end of the day and is less able to cope with stress.
- The person is involved in activities all day long and grows restless if there is nothing to do in the late afternoon.

## Sundowning: Things to Do

Try these ways to lessen the behaviors of sundowning:

- Make afternoon and evening hours less hectic. Schedule appointments, trips, and activities such as baths or showers early in the day.
- Help the person to use up extra energy through exercise. For the person who tends to pace or wander in the evening, you may want to arrange at least one or two brisk walks during the day.
- Control the person's diet. Reduce foods and beverages with caffeine (chocolate, tea, coffee, and soda) or restrict them to the morning hours to reduce agitation and sleeplessness. An early dinner or late afternoon snack may also help.
- It's important to provide regular activities and you may want to discourage napping during the day if nighttime sleeplessness is a problem.
- You may want to reduce the level of noise from radios, televisions or stereos, control the number of people who visit in the evening hours, or confine noisier family activities to another area of the house.
- Consult with your physician. Your physician may be able prescribe medication to encourage sleep. At the same time, your physician can check for signs of depression or for physical problems such as prostate difficulties that might lead to frequent urination. This condition can cause pain and make sleep uncomfortable.

## Managing Challenging Behaviors

## Driving

Driving is a complex activity which requires quick reactions, clear sensory abilities, and split-second decision making. For the person with Alzheimer's disease, driving becomes a safety issue. While he or she may not recognize that changes in cognitive and sensory skills impair driving abilities, you and other family members will need to be firm in your efforts to prevent the person from driving. When taking action to remove driving privileges, help the person understand that he can no longer drive safely.

## **Study Results**

To better understand the effects of Alzheimer's on driving, research is focusing on people with early Alzheimer's disease. Results from studies conducted at Johns Hopkins University and at the National Institute on Aging (NIA) support the belief that people should not be allowed to drive after a diagnosis of Alzheimer's disease. In California, preliminary road and laboratory studies indicate that even persons with early Alzheimer's have markedly eroded driving skills. As a caregiver, it is important that you take time to realistically evaluate the person's driving ability and be aware of methods you can use to discourage the person from driving.

## Assess the Person's Ability to Drive

- Consider having the impaired person's driving ability tested. Some state agencies have special drive tests to determine how well a person sees, judges distance and responds to traffic. Ask the person who administers the test to explain the results to you and the person with Alzheimer's.
- Look for signs of driving problems, here are some signs of unsafe driving:
  - Forgetting how to locate familiar places
  - Failing to observe traffic signs
  - Making slow or poor decisions in traffic
  - Driving at an inappropriate speed
  - Becoming angry or confused while driving
- Consult a physician. In some states, the physician must report a diagnosis of Alzheimer's to the health department, which then reports it to the department of motor vehicles. That agency then may revoke the person's license.
- Do not allow driving if the person with dementia cannot drive safely. Instead of allowing the person to drive, tell him or her that you can drive or arrange for someone else to drive. If you don't know how to drive, investigate drivers' education courses and defensive driving programs designed for adults. For more information on these courses, contact the American Association of Retired Persons (AARP).



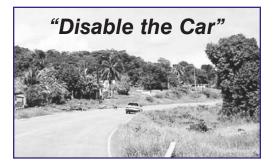
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In the Hopkins study, more than 44% of patients studied had been in an accident after a diagnosis of the disease. In addition, 11% had caused accidents, 44% had gotten lost routinely, and 75% continually drove below the speed limit.

## **Driving: Things to Do**

- Solicit the support of others. Ask your physician to instruct the impaired person not to drive. Involving your physician in a family conference on driving is generally more effective than trying by yourself to persuade the person not to drive. Ask the physician to write a letter stating that the person with Alzheimer's must not drive. Or ask the physician to write a prescription that says, "No driving." You can use the letter or prescription to tell family members what's been decided.
- Ask a respected family authority figure or your attorney to reinforce the message about not driving. Also ask your insurance agent to provide documentation that your loved one will no longer be provided with insurance coverage.
- Experiment with ways to distract the person from driving. Insist that someone else should drive because you're taking a new route, because driving conditions are dangerous and he is tired and needs to rest. If the person is in an advanced stage or has a history of anger and aggressiveness, it's best not to drive alone with the person.
- Control access to the car keys. Designate one person who will do all the driving and give that individual exclusive access to the car keys.
- Disable the car. If the person with Alzheimer's is insistent about driving, remove the distributor cap or the battery or starter wire. Or ask a mechanic to install a "kill wire" that will prevent the car from starting unless the switch is thrown. Or give the person a set of keys that looks like her old set, but that doesn't work to start the car.



- Move the car. Drive the car to another block, a neighbor's driveway, or a private garage or lot.
- In some states it might be best to alert the department of motor vehicles. Write a letter directly to the authority and express your concerns, or request that the person's license be revoked. The letter should state "(the person's full name) is a hazard on the road" and offer the reason. The state may require a statement from your physician certifying the person is no longer able to drive.
- Substitute the person's driver's license with a photo identification card. Take no chances. Don't assume that taking away her driver's license will discourage driving. The person may not remember that she no longer has a license to drive, or even that she needs a license.
- Consider selling the car. You may be able to save enough in insurance premiums, gas, and maintenance costs to pay for public transportation, including taxicab rides.
- Be firm and positive about driving. Avoid arguing with the person, or giving long explanations for why he/she cannot drive. Spend your time and energy helping to preserve the person's dignity by focusing on the activities he or she can still do and enjoy.

# **Home Safety**

## Make Potentially Dangerous Places Less Accessible

The person with dementia may be at risk if he or she can reach certain areas of the home or the outdoors.

- Lock or disguise hazardous areas. Cover doors and locks with a painted mural or cloth. Use "Dutch" (half) doors, swinging doors or folding doors to hide entrances to the kitchen, stairwell, workroom and storage areas.
- Install door locks out of sight. Place dead bolts either high or low on exterior doors to make it difficult for the person to wander out of the house. Keep an extra set of keys hidden near the door for easy access. Remove locks in bathrooms or bedrooms so the person cannot get locked inside.
- Use special safety devices, such as child-proof locks and door knobs, to limit access to places where knives, appliances, equipment, and cleaning fluids are stored. Use automatic shut-off devices for appliances like irons, toaster ovens and coffeemakers.

## Adapt for Visual Limitations

As the disease progresses, changes in vision may make it difficult for the person to distinguish colors and understand what is being seen.

- Diffuse bright light by removing or covering mirrors and highly-polished furniture, and block bright light by covering windows with blinds, shades, or sheer draperies. Avoid using bare light bulbs or clear "decorator" bulbs without shades.
- Create an even level of lighting by adding extra lighting in entries, outside landings, areas between rooms, stairways, and bathrooms because changes in levels of light can be disorienting.
- Use different colors by placing contrasting colored rugs in front of doors or steps to help the individual anticipate staircases and room entrances. But avoid using a dark-colored rug because it may appear to be a "hole." Put colored stickers on glass doors and large windows so the person doesn't think they're open.

## **Avoid Injury During Daily Activities**

Most accidents in the home occur during daily activities such as eating, bathing and using the restroom. Take special precautions at these times.

• Watch temperatures, as the disease progresses, the person may become less aware of temperature. To avoid burns, consider setting hot water heaters at no more than 120 degrees. Install automatic-mixing or anti-scalding devices in the faucets. Meanwhile, help the person mix hot and cold water, and always turn off the hot water first when finished. Check food temperatures before serving to make sure food is not too hot or too cold to eat.

## Managing Challenging Behaviors

- Prevent falls by installing walk-in showers and grab bars in the shower or tub and at the edge of the vanity to allow the person to move around safely and independently. Shower seats and commode chairs are also helpful if the person has limited ability to get around. Add textured stickers to slippery surfaces. Apply adhesives to keep throw rugs and carpeting in place or remove rugs completely. Place padding on any of the sharp edges of counters and bathroom fixtures.
- Supervise medications, a person with dementia may have trouble properly using prescription and overthe-counter medications. He or she may forget to take them or take too much. Consider using a locked pill dispenser that works on a self-timer if the person can understand its use. Install locks to limit access to any cabinets containing medications.

## **Beware of Hazardous Objects/Substances**

Even the most basic appliance or household object can become dangerous for the person with dementia. Be sure to take precautions that will ensure these items do not become safety hazards.

- Use appliances that have an auto shut-off feature. Keep them away from water sources (e.g., kitchen and bathroom sinks).
- Install a hidden gas valve or circuit breaker on the stove so a person with dementia cannot turn it on. Or, consider removing the knobs from the burners.
- Store grills, lawn mowers, power tools, knives, firearms and cleaning products in a secure place.
- Be aware of items mistaken for food such as small rocks, dirt, plants, flowers and flower bulbs. Discard toxic plants and decorative fruits that may be mistaken for real food.
- Remove vitamins, prescription drugs, sugar substitutes and seasonings from the kitchen table and counters. Medications should be kept in a locked area at all times.
- Supervise the use of tobacco and alcohol. Both may have harmful side effects and may interact dangerously with some medications.
- Secure household chemicals by keeping cleaning supplies, like laundry detergent and dishwashing soap, and other dangerous liquids in a safe place so the person cannot mistakenly drink them.
- Keep the refrigerator safe, a person with dementia may be unable to tell the difference between fresh and rotten food. Clean out the refrigerator regularly, throwing out any old food. Keep foods that are safe to eat in the front of the refrigerator at eye level where the person can easily see them.
- Keep walking areas clear and reduce the chance of injury by removing objects such as magazine racks, coffee tables and floor lamps. Keep floors and other surfaces clutter-free.

#### **Be Prepared for Emergencies**

- Keep a list of emergency phone numbers and addresses for local police and fire departments, hospitals, and poison control help lines.
- Check fire extinguishers and smoke alarms, and conduct fire drills regularly.



## Safety checklist Tips for a safe and supportive home

#### **Kitchen**

- ✓ Lock up cleaning supplies
- ✓ Turn off electricity to the garbage disposal
- ✓ Hide knives and other utensils
- ✓ Store small appliances (toaster, blender)
- ✓ Unplug larger appliances (microwave)
- Remove knobs from the stove; hook up stove to a hidden gas valve or electric switch
- ✓ Keep fire extinguisher nearby
- ✓ Clean out refrigerator regularly

#### Bathroom

- ✓ Set water temperature at 120 degrees or less
- ✓ Install grab bars
- ✓ Add textured stickers to slippery surfaces
- ✓ Supervise the use of hair dryers, curling irons, and electric and hand razors
- $\checkmark$  Remove locks from the bathroom door
- ✓ Take dangerous items out of medicine chests

#### **Bedroom**

- ✓ Avoid using electric blankets
- ✓ Monitor use of heating pads
- ✓ Install night lights between the bedroom and bathroom

#### Garage

- ✓ Lock up hand and power tools (drills, axes, saws, picks)
- ✓ Limit access to large equipment (lawn mower, weed trimmer, snow blower)
- ✓ Lock up poisonous chemicals (paints, fertilizers)

#### Throughout the home

- ✓ Disguise outdoor locks or install dead bolts
- ✓ Remove or tape down throw rugs and carpeting
- ✓ Apply colored stickers to large windows and sliding glass doors
- ✓ Remove poisonous plants
- ✓ Create an even level of lighting near doorways, stairways and between rooms
- ✓ Remove objects that block walking paths
- Remove and disable guns or other weapons

## Outdoors

- ✓ Disconnect gas from gas grill
- ✓ Lock fence gates
- ✓ Supervise the person, especially in areas that are not enclosed
- ✓ Put away car keys

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Did you know? The presence of a weapon in the home of a person with dementia may lead to unexpected danger. Dementia can cause a person to mistakenly believe that a familiar caregiver is an intruder.

# **Travel safety**

Having dementia does not mean that it's necessary to stop traveling; it just requires careful planning to ensure safety, comfort and enjoyment for everyone. To make sure you have a safe, enjoyable trip, remember to pack the following:

- Copies of important documents:
  - Doctors' names and contact information
  - A list of current medications and dosages
  - Phone numbers and addresses of the local police and fire departments; hospitals; and poison control
  - A list of food or drug allergies
  - Copies of legal papers (living will, advanced directives, power of attorney, etc.)
  - Names and contact information of friends and family members to call in case of emergencies
  - Insurance information (policy number, member name)
- Medication
- Travel itinerary
- Comfortable change of clothes
- Water
- Snacks
- Activities

## Tips for safe travel

- A change in environment can trigger wandering behavior. Enroll in MedicAlert<sup>®</sup> + Alzheimer's Association Safe Return<sup>®</sup> program or, if you are already enrolled, notify safe return of travel plans.
- Stick with the familiar. Travel to known destinations that involve as few changes in daily routine as possible.
- If you will be staying in a hotel, inform the staff ahead of time of your specific needs so they can be prepared to assist you.
- Travel during the time of day that is best for the person with dementia.
- Contact the Alzheimer's Association to learn if there is a local Association office that can provide assistance at your destination.

## Air travel

Traveling in airports requires plenty of focus and attention. At times, the level of activity can be distracting, overwhelming or difficult to understand. If you are traveling by plane, here are a few things to keep in mind:

- Inform the airline and airport medical service department ahead of time of your needs to make sure they can help you.
- Remind airport employees and in-flight crew members of your needs.
- Even if walking is not difficult, consider requesting a wheelchair so that an airport employee is assigned to help you get from place to place in the airport.

Having dementia does not mean that it's necessary to stop traveling; it just requires careful planning.

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## Managing Challenging Behaviors

## Wandering

Alzheimer's disease gradually destroys brain cells that help individuals recognize familiar places and/or faces. Nearly 70 percent of persons with dementia will wander at some point in the disease process. Confused and disoriented, they can become lost, even in their own neighborhoods, in danger from traffic, the weather and those who prey on the helpless. One study found 50 percent of memory impaired adults who wandered and became lost died if not located within 24 hours, typically succumbing to hypothermia or dehydration.

Wandering is the most common and potentially life-threatening behavior associated with AD. Persons with dementia are at serious risk of death or injury if not found quickly. Searching for lost individuals with Alzheimer's disease is complicated by the fact that these individuals do not usually cry out for help or respond to shouts.

For some people, it is an almost constant behavior. For others, wandering behavior is rarely, if ever, exhibited. There are many reasons why an individual with dementia wanders from home or a well-known path or area, including:

- Concerns about fulfilling past obligations involving a former job or home
- Not being able to find something specific such as food, drink, or the bathroom
- Confusion related to the time of day or night
- New or changed environment
- Unfamiliar objects, surroundings or people
- Delusions, hallucinations or misinterpreted sights/sounds
- Lack of activity during the day
- Stress, noise, crowds or isolation
- Side effects from medication resulting in restlessness and confusion

## MedicAlert<sup>®</sup> + Alzheimer's Association Safe Return<sup>®</sup> Program

The Alzheimer's Association and MedicAlert Foundation International have formed an alliance to improve the safety of individuals with Alzheimer's or a related dementia. The MedicAlert<sup>®</sup> + Safe Return<sup>®</sup> (MA+SR) program is a 24-hour nationwide emergency response service for individuals who wander or have a medical emergency. Caregivers can call the 24-hour emergency response line, 1-800-625-3780, and get assistance no matter when or where the person is reported missing.

#### Four easy ways to join:

- 1. Mail a registration form. Forms are available through local Alzheimer's Association chapters.
- 2. Call 1-888-572-8566.
- 3. Visit www.medicalert.org/safereturn and register online.
- 4. Fax registration form to 1-800-863-3429.

#### Cost for MedicAlert<sup>®</sup> + Safe Return<sup>®</sup> products

- The enrollment fee is \$49.95 with an annual renewal fee of \$25. The enrollment kit includes 24-hour emergency response system, ID jewelry (bracelet or necklace), personalized emergency wallet card, personal health record, and "6 Steps to a Safe Return" refrigerator magnet, which provides useful tips when someone is missing.
- Companion caregiver jewelry can be purchased for \$25 with an annual renewal fee of \$25, which includes everything listed above.



## **Comfort Zone**

Alzheimer's Association Comfort Zone®, powered by Omnilink, is a Web-based GPS location management service. Family members can monitor a person's location, while the individual with Alzheimer's can maintain their independence and enjoy the emotional security of familiar routines and surroundings.

Comfort Zone plans start at \$42.99 per month plus a \$45 activation fee. A Comfort Zone plan is designed specifically to each device. More information: 1.877.259.4850 or www.alz.org/comfortzone

## **Ten Tips To Reduce Wandering**

- 1. **Be Prepared** There is no way to predict who will wander, when or how it might happen. The best advice is to be prepared and to register in the Alzheimer's Association Safe Return Program before a loved one gets lost.
- 2. Encourage Movement and Exercise Make a shared exercise, such as walking, part of your daily routine together and allow them access to a safe, enclosed area.
- 3. Be Objective Do not take the person's wandering behavior personally.
- 4. **Be Aware of Hazards** Places that look safe may be dangerous for someone with Alzheimer's. Look in and around the home for possible hazards: fences and gates, bodies of water, pools, dense foliage, bus stops, steep stairways, high balconies, and roadways where there is heavy traffic. Change what you can or block access.
- 5. Secure the Living Area Do what you can to make your home safe and secure. Place locks out of the normal line of vision either very high or very low on doors. Use doorknobs that prevent the person with Alzheimer's from opening the door. Other safety actions include: Placing locks on gates, camouflaging doors, fencing in the patio or yard, installing electronic alarms or chimes on doors and using familiar objects, signs and night lights to guide the person around safely.
- 6. **Communicate with the Person** Regularly remind and reassure the person with Alzheimer's that you know how to find him and that he is in the right place.
- Identify the Person Have the person wear an identification bracelet or necklace. Use sew-on or iron-on labels or permanent markers to mark clothing. Place identification on shoes, keys, eyeglasses and in wallets and purses.
- 8. **Involve the Neighbors** Inform your neighbors of your loved one's condition and keep a list of their names and phone numbers handy.
- 9. **Involve the Police** Some police departments will keep photos and fingerprints of people with Alzheimer's on file. Have this information ready in case of an emergency including information such as the person's age, hair color, medication, dental work, and jewelry.
- 10. **Be Prepared for Other Modes of Wandering** Although most wandering takes place on foot, some persons with AD have been known to drive hundreds of miles, sometimes in a vehicle that belongs to someone else. Prevent this problem by keeping car keys out of sight or temporarily disabling the car by removing the distributor cap. People with Alzheimer's also have traveled great distances by train or airplane, or have ridden public transportation.

**MedicAlert**<sup>®</sup> + Alzheimer's Association Safe Return<sup>®</sup> Program has a 97% success record for all registered persons.

# Late Stage Alzheimer's Care

- Food and Liquid Intake
- Healthy Skin and Body
- Bladder and Bowel Function
- Risk of Infections and Pneumonia
- Recognizing Pain or Illness
- Staying Connected
- Moving Your Loved One to a New Home
- Deciding on Hospice Care

# The late stage of Alzheimer's may last anywhere from several weeks to several vears. Intensive, around-the clock assistance is

weeks to several years. Intensive, around-the clock assistance is usually required. Caring for the person with Alzheimer's disease is most successful when the focus is on preserving quality of life and dignity and treating the person with compassion.

Late Stage Alzheimer's Care

In the late stage of Alzheimer's disease, a person usually:

- Has difficulty eating and swallowing
- Needs assistance walking and eventually becomes bedridden or chair-bound
- Needs full-time help with personal care, including toileting
- Is vulnerable to infections and pneumonia
- Loses the ability to communicate with words

The following information will help families provide for the person's basic care and comfort needs and maintain a connection with their loved one.



## **Encouraging Food and Liquid Intake**

Nutrition and hydration are important in maintaining a person's physical well-being. However, a person with late stage Alzheimer's may have difficulty swallowing food and liquids. This may cause aspiration into the airway and lungs and, eventually, pneumonia. Here are some suggestions to help the person eat and drink safely:

#### Provide a Quiet and Calm Environment

Serve meals away from the television and other distractions. If the person can continue to dine at the table, keep the setting simple, with a plate or bowl, placemat, cup, and utensils.

#### Allow Adequate Time for Meals

Mealtimes may last longer than in previous stages of the disease. Allow at least one hour for mealtimes, and do not rush the person or force him or her to eat. You may want to see if the person prefers smaller meals or snacks throughout the day rather than three larger meals.

#### Adapt Foods to the Person's Needs

Choose foods that are soft and can be chewed and swallowed easily. The person may prefer bite-sized finger foods, such as slices of cheese, tater tots, or chicken nuggets. If the person can no longer eat solid food, mash or pure it in a blender.

## Late Stage Alzheimer's Care

#### Encourage Self-Feeding

Sometimes a person needs cues to get started. Try demonstrating eating by lifting the spoon to your mouth or using hand-over-hand prompting. Or, start the person by putting food onto the spoon, gently placing the person's hand on it, and guiding it to his or her mouth.

#### Assist the Person with Feeding if Needed

Offer the food or liquid slowly and make sure it's swallowed before continuing. Try alternating bites of food with a drink. You may have to remind the person to chew or swallow. Avoid putting your fingers in the person's mouth in case he or she bites down.

#### Encourage Fluid Intake

A person with the disease may not always realize that he or she is thirsty or may forget to drink water or other fluids. If the person has trouble swallowing water, substitute fruit juice, gelatin, sherbet, or soup instead. Check the temperature of warm or hot liquids before the person consumes them.

#### Thicken Liquids

The person with Alzheimer's disease is at a higher risk for choking due to swallowing problems. Thicken liquids by adding a little cornstarch or unflavored gelatin to water, juice, milk, broth, and soup. You can also purchase commercial food thickeners at a pharmacy or health care supply store. You may want to try serving pudding or ice cream, or substitute milk with plain yogurt.

#### Monitor Weight

Weight loss may indicate inadequate nutrition or medication side effects. Consult the physician to determine the cause of the person's weight loss.

## What to do if the Person Chokes

Difficulty with swallowing can lead to coughing and choking. Be prepared for an emergency and learn the Heimlich maneuver. Instructional classes are typically available through your local hospital or community center.

# Learn the Heimlich Maneuver!



Encourage

Thicken Liquids

# Maintaining Healthy Skin And Body

A person in the late stage of the disease can become bed-ridden or chair-bound. A lack of mobility may lead to skin breakdown, pressure sores, and contractures.

## Alleviate Body Pressure

Change the person's position at least every two hours to relieve pressure and improve skin moisture. Make sure the person is comfortable and is kept in good body alignment. Use pillows to support arms and legs. Consult a health care professional about the proper technique to lift and turn your loved ones.

## Keep the Skin Clean and Dry

The skin can tear or bruise easily. Use minimal force and friction when cleaning fragile skin. Wash the skin with mild soap and blot dry. Check the skin daily for rashes, sores, or skin breakdowns.

## Prevent Contractures

Limb contractures or "freezing" of the joints can occur when a person is confined to a chair or bed. To maintain the person's range of motion in the joints, carefully and slowly move his or her arms and legs two to three times a day. Perform these exercises when the person's skin and muscles are warm, such as immediately after bathing. A physical therapist can show you the proper technique for range of motion exercises.

## **Maintaining Bladder and Bowel Function**

A person with AD may experience incontinence due to such factors as a urinary tract infection or fecal impaction. Consult with a physician to rule out any medical problems. To help the person maintain bladder and bowel function try:

## Setting a Toileting Schedule

Keep a written record of when the person went to the bathroom and when and how much he or she eats and drinks. This will help you determine the person's natural toileting routine. If the person is not able to travel to the toilet, use a bedside commode.

## Eliminate Caffeinated Drinks

Beverages with caffeine, such as coffee, cola, and tea, act as diuretics and stimulate urination.

## Limit Liquids Before Bedtime

Limit liquids at least two hours before bedtime, but be sure to provide adequate hydration throughout the day.

## Use Absorbent and Protective Products

Use adult briefs and bed pads at night as a backup to daytime toileting schedule.

## Monitor the Frequency of Bowel Movements

The person need not have a bowel movement every day. If he goes three days without a bowel movement, however, the person may be constipated. Adding natural laxatives to the person's diet, such as prunes, or fiber-rich foods, such as bran or whole grain breads, may help.



## **Decreasing the Risk of Infections and Pneumonia**

*Immobility in the late stage of Alzheimer's disease can make a person more vulnerable to infections. Try preventing them by:* 

#### Paying Careful Attention to Oral Hygiene

Good oral health reduces the risk of bacteria in the mouth, which can lead to infection. Brush the person's teeth after each meal. If the person wears dentures, remove and clean them every night.

#### Cleaning all Soft Tissues of the Mouth

Use a soft toothbrush or moistened gauze pad to clean soft tissues of the mouth (e.g., gums and tongue) at least once a day to prevent tooth decay and gingivitis.

#### Treating Cuts and Abrasions Immediately

Clean cuts with warm soapy water and apply an antibiotic ointment. If the cut is deep, seek the help of a medical professional.

#### Protecting Against the Flu and Pneumonia

Because influenza, or the flu, can lead to pneumonia, the person and his or her caregivers should obtain a yearly flu vaccine to help reduce the risk. Also, there is a vaccine against pneumococcal pneumonia that one can receive every five years.

## **Recognizing Pain or Illness**

Promoting quality of life means keeping those in the late stage of AD comfortable. However, persons in this stage of the disease have difficulty communicating their pain. Here are some ways to recognize pain:

#### Look for Physical Signs

A pale or flushed skin tone; dry, pale gums; mouth sores; vomiting; feverish skin; or swelling of any part of the body can indicate illness.

#### Pay Attention to Non-verbal Signs

Keep track of the person's gestures, vocalization, and facial expressions (e.g., wincing) that may indicate pain or discomfort.

#### Be Alert for Changes in Behavior

Anxiety, agitation, shouting, and sleep disturbances can all indicate pain.

Consult the physician to determine the cause of the person's pain. In some cases, pain medication may be prescribed.



# Staying Connected to the Person with Alzheimer's

When persons with late stage Alzheimer's have lost most of their cognitive abilities, they experience the world through their senses. Although you may not be able to communicate with them verbally, there are many things you can do.

## **Comfort by Touch**

Touch can be a powerful connector. Hold your loved one's hand; give a gentle massage to the hands, legs, or feet; give a kiss; or brush his or her hair.

## Stimulate the Senses

The person may enjoy the smell of a favorite perfume, flower, food or scented lotion or the feel of stroking a beloved pet or fabrics with different textures. If the person can walk with assistance or uses a wheelchair, he or she may enjoy going to see a garden or watch birds. You can also position the person to gaze out a window, being careful that the sun is not too bright or will make the person too warm.

## **Use Your Voice to Soothe**

It does not matter what you say but rather how you say it. Speak gently and with affection. Your tone can help the person feel safe and relaxed.

## **Play Music and Videos**

Choose music your loved one enjoyed when he or she was a young adult or something from his or her ethnic or spiritual background. Videos can also be relaxing to the person with Alzheimer's disease. Select one with scenes of nature and soft, calming sounds.

## **Read to the Person**

Even if the person does not understand the words, the tone and rhythm of your voice can be soothing. Read a favorite story, poem, scripture passage, or blessing.

## **Reminisce and Share**

Fill a box with photographs and items that represent the person's interests, favorite activities, or past work or military history. Have the person take out an item and share with him or her the significance of or story about the item. An example might be a family photograph from a favorite vacation, a recipe card with a traditional family dish that is made during the holidays, or a military medal and why the person received it.





## Late Stage Alzheimer's Care

## Deciding to Move Your Loved One to a New Home

By the time your loved one reaches the late stage of Alzheimer's disease, it is likely that you have been caring for him or her for many years. During this time, problems may occur that lead to moving a person into a residential care setting. For example, you may become ill yourself, preventing you from being able to care for the person.

Another reason for deciding to move into a new care setting is the amount of time required to care for a person in the late stage of Alzheimer's disease. It is common for the person to need 24-hour assistance. If there is no one with whom to share caregiving responsibilities, a sole caregiver may be unable to meet the needs of their loved one.

#### Tips for Caring for a Person with Late Stage Alzheimer's

- Focus on what the person is still able to do or what the person still enjoys. For example, the person may not be able to sing a favorite song, but he may be able to tap his feet to the music.
- Learn techniques for lifting and transferring individuals with limited mobility to prevent injury to yourself and your loved one.
- To ensure proper nutrition for the person with Alzheimer's, check with the person's physician to see if a supplement, such as a multivitamin or high-protein drink, is needed.
- If the person refuses to eat, try to determine the reason. It may simply be that the food is not appetizing. He does not understand the purpose of food or fears eating. Sore teeth or gums or poorly fitting dentures can make eating an unpleasant activity. At other times, the person may not feel well.
- Use a bendable straw to help encourage the person to drink fluids.
- If the person is losing weight, contact the physician.
- Consider assistance from a family member, friend, or a hired home care nurse or health aide.

#### NOTES:

A person with Late
Stage Alzheimer's
continues to need
and benefit from
interactions with
others. Your
presence, along
with that of other
family members,
friends, and clergy,
can reassure and
comfort the person.

# **Deciding on Hospice Care**

Hospice is end-of-life care that provides comfort and support for persons with life-limiting conditions as well as their families. To receive hospice, the person must get a referral from their physician stating that if the person's disease follows its normal course, death may be expected in 6 months.

The hospice team will provide the following services to in the home, wherever one may consider home to be:

- Manage pain and other symptoms;
- Support the patient through the emotional, psychosocial and spiritual aspects of dying;
- Provide the patient with medications, medical supplies and equipment;
- Teach the family skills to help them care for the patient;
- Deliver special services like speech and physical therapy if needed;
- Make short-term inpatient care available when pain or other symptoms become too difficult to manage at home or if the family needs respite time; and,
- Provide grief support and counseling to the patient's loved ones.

Hospice is provided regardless of one's ability to pay. Hospice is paid for by the Medicare Hospice Benefit, Medicaid Hospice Benefit and most private insurers. If a person does not have coverage through Medicare, Medicaid or a private insurance company, hospice will work with the person and their family to ensure services can be provided. Private insurance coverage varies but generally includes at least some hospice coverage. Contact your insurance provider to verify your level of coverage for these services.

Hospice benefits are available to Medicare beneficiaries who:

- Are certified by two doctors, typically the personal physician and the hospice medical director, as having a life-limiting diagnosis with a life expectancy of six months or less;
- Sign a statement choosing hospice care using the Medicare Hospice Benefit, rather than curative treatment and standard Medicare covered benefits for their hospice diagnosis; and,
- Enroll in a Medicare-certified hospice program.

It is important to note that Medicare will continue to pay for covered benefits for any health problems that are not related to the hospice diagnosis.

## For your convenience...

The Information and Referral Services section of this guide has a listing for the National Hospice & Palliative Care Organization.

# Finding Home Care

- Steps to Finding Care at Home
- Evaluate your Resources
- Types of Home Care

# **Finding Home Care**

Seventy percent of America's 5.3 million Alzheimer's patients are cared for in the home. This job is a demanding one that often leaves little time or energy for anything else.

Family members should know that relief from caregiving duties is available. Home care workers such as nurses, homemakers and companions can provide valuable respite services, easing the burden and allowing *"breaks"* from caregiving. As a result, you may be able to care for your loved one at home longer than might otherwise be possible.

Finding home care can be as challenging as choosing nursing home or institutional care. There are many issues to explore and questions to answer about the services you need. An organized, systematic approach can make finding home care less stressful and more successful.

# **Steps to Finding Care at Home**

## Step 1 - Assess Your Situation and Define Your Needs

Some caregivers do not begin to look for home care until they reach the point where caring for their loved one without assistance is nearly impossible. Keep in mind that bringing care into your home may benefit both the person with Alzheimer's and you. In-home care will give your loved one a chance to interact with someone new and you time to do other things.

## **Family Involvement**

As you begin to consider home care, try to hold a family gathering to involve other "key players" in your plan. During the meeting, suggest that family members try to remain open-minded. Everyone should be given the chance to be heard. You will want to discuss the responsibilities of individual family members with respect to the person with Alzheimer's. For example, ask how much time each family member is able to devote to the impaired person. Perhaps your sister helps out one morning a week and your children every other weekend. Also note which family members are responsible for various tasks such as feeding, visiting the doctor, shopping and leisure activities.

Ask if there are ways your family members can expand their caregiver involvement. If no one responds, offer a suggestion such as, "Let's each give one extra hour over the next two weeks and see what a difference it makes." Keep in mind that some family members may offer less assistance than others. Suggest that all family members find some ways to contribute, such as contacting organizations for information or providing financial assistance.

## Step 2 - Evaluate Your Resources

## Finances

One of your biggest concerns about home care may be your ability to pay for it. You are probably wondering how much care costs, and whether you are eligible for any financial assistance. Unfortunately, financial questions are sometimes the most difficult to answer because so many factors are involved. Some forms of home care are provided on a voluntary basis. Others, like many types of health care, can be expensive – as much as \$9 to \$20 per hour.

## **Finding Home Care**

Area Agencies on Aging have comprehensive home based services around the state. Recent state and federal legislation increased funding levels to these services. Services that might interest you include homemakers, meals, in-home respite, transportation, and medicaid waivers for adult day care. Unfortunately, the need for services continues to outweigh the availability.



For your convenience...

The Information and Referral Services section of this guide has a list of the Area Agencies on Aging.



## Medicare

Medicare does not pay for long term care services in the home such as home health services. Nor does Medicare pay for care in nursing homes or personal care homes to persons with conditions such as Alzheimer's disease that need custodial but not skilled care. Instead, benefits cover costs associated with rehabilitation or restoration care after a hospital stay. Medicare will pay for hospice care.

## Medicaid

A Mississippi state law requires that prior to nursing home placement, pre-assessments be made by a physician to determine if a person could live at home or in a community based facility if appropriate services were made available. The law further requires that a home or community "care plan" be created and services provided.

## **Social Security Disability**

This program helps wage earners under age 65 who can no longer work because of a disability. The applicant must have worked a minimum of five of the past ten years and prove "functional disability." Recently, the understanding of functional disability has been expanded to include Alzheimer's disease (about 10 percent of persons with Alzheimer's are in their 40's and 50's.)

#### Insurance

Some private insurance and major medical policies include only partial coverage for home care. Most companies who offer such a policy have extensive requirements for eligibility. You will need to contact your insurance company to see whether your policy covers the home care services you need.

## Veteran Benefits

Long term care facilities for veterans are among the most affordable in the state. Military dependents needing in-home care are often eligible for benefits. Benefits pay at least half, if not more, for the cost of care in nursing homes. Benefits also include one year of adult day care.

After you assess your situation and define your needs, evaluate your resources for finding and maintaining home care.

# Types Of Home Care

Once your family has discussed the allocation of responsibility, define how much and what type of help you need to care for your loved one. Consider the variety of home care workers such as home health aides, homemakers, companions, nurses, occupational therapists, physical therapists, certified nursing assistants and sitters. Also compare the variety of services:

## **Personal Care**

For help with daily activities, including bathing, dressing and eating, try utilizing aides or assistants. Workers may also help manage incontinence, wandering, and communication problems.

## **Health Care**

For skilled nursing care, LPNs or RNs can help supervise your family member's nutrition, monitor pulse, blood pressure and other vital signs, administer medication and therapy, and provide various types of acute health care.

## **Homemaking Service**

Try homemaking services for help with housekeeping, shopping, preparing meals, and running errands.

## Companions

Companions spend time helping with exercise, games, and other activities.

## **Hospice Care**

During the terminal stages of Alzheimer's disease, hospice care can be particularly beneficial to individuals with Alzheimer's disease and their family members. Hospice is available at home or in an institutional setting. Medicare will pay nearly 100 percent of the costs of hospice for eligible patients. Contact a hospice service to determine if they meet your needs.

## **Combining Care Programs**

If you need assistance around the clock, you might consider hiring a live-in home care worker. In this case, you may need to make adjustments to your home to provide living space and other accommodations for the worker. You may be able to hire a home care worker who can provide a combination of the types of care described above. For example, a home health aide may help the person bathe and get dressed, as well as, cook and run errands for you.

## Home Care Agencies vs. Independent Workers

Home care workers may be employed by an agency or work independently. Using an agency to help you find and maintain home care may increase your chances of finding reliable help and save you paperwork and time. However, hiring help without the assistance of an agency could save you money.



# Choosing A New Home

- Begin with a Plan
- Determine Type of Setting
- Making Site Visits
- Know Your Rights

#### Alzheimer's Association • (800) 272-3900 • (601) 987-0020 • www.alz.org/ms

# **Choosing A New Home**

When the time comes for a person with Alzheimer's to move to a residential care setting (e.g., group home, assisted living, nursing home, etc.), it can be really difficult for both the person and family. In addition, finding the right residential care setting to meet the needs of the person with dementia can be challenging and time consuming.

## **Begin with a Plan**

Ideally, planning for a move into a residential care setting should begin before admission is needed. This allows time to learn about the types of residential care available and determine which will best meet your needs. Before you begin looking at residential care settings, determine the needs of the person with dementia and your needs as a caregiver. Ask your doctor, a social worker, the Alzheimer's Association chapter or another community agency for assistance with determining your needs. The amount of care required, the atmosphere desired, and your financial resources will determine the type of residential care setting(s) you should choose:

- Is 24-hour supervision needed?
- What are some characteristics of the person with dementia that may require special skills? For example, communication difficulties, toileting and bathing assistance, need to walk/move around and need for direction and assistance.
- Does the person with dementia need help to take medications?
- Do you prefer a private or a shared room?
- How much and what type of social activity do you want?
- Do you want a setting that only cares for persons with dementia?
- What types of meals are required? Do all meals need to be prepared by someone else?
- How will costs be covered?

## **Determine the Type of Setting Preferred**

There are several types of residential care options available in most communities. Some types are licensed and are required to follow set regulations, others are not. It is important to remember that not all settings will be appropriate for people with dementia, or may not be able to provide care throughout the progression of the disease. Keep in mind that moving a person with dementia into a new environment can cause increased agitation. Residential care settings fall into one of the following categories:

## Assisted Living: Room, Board and Minimal Assistance

Assisted living settings provide a room (private or shared), one to three meals daily, and in some cases, a small kitchenette. There is usually a 24-hour staff, but not necessarily 24-hour awake staff. In addition, the staff will have different levels of skill and knowledge about caring for persons with dementia. The amount of care provided by staff will vary greatly from setting to setting. Most places will provide some type of structured activity program. These settings are most appropriate for persons in the early to early middle stages of the disease.



## **Choosing a New Home**

#### 24-Hour Care with Skilled Nursing Services

Referred to as a skilled nursing facility, nursing home, Alzheimer's special care units, personal care and rehabilitation or health care center, these settings provide room and board with 24-hour awake staff and care. Resident rooms may be private or shared. A few settings may have special units that care exclusively for persons with dementia. All meals are provided and monitored by a registered dietician. Skilled care provided by a licensed nurse, is available 24 hours a day. The number of staff to resident ratio will be different from place to place, as will the knowledge and training of staff in caring for persons with dementia. Settings of this type are appropriate for



persons in the middle, late and end stage of the disease. Persons in the early stages of the disease who have a medical need may also be appropriate for this type of setting.

#### Continuum Care Retirement Communities (CCRC)

These are settings that provide all of the different types of options described above. In these settings, a person may receive all of the different levels of care on one campus. However, the person may need to be moved between buildings to receive the different services. These settings are ideal but only a few exist in the state with services that include the care of persons with Alzheimer's.

## **Making Site Visits**

Once you have determined which type of residential care setting will best meet your needs and you have identified places that provide this type of care, think about questions to ask and what to look for when you visit each setting. Arrange a time with a staff person at the setting for your initial visit. Look for a residential setting that is committed to providing care to persons with dementia. Ask staff what is special about the dementia care provided for residents. Specifically:

## What Is the Approach to Alzheimer's/Dementia Care?

#### Ask:

- What is the program's mission and philosophy? Ask to see a copy. The philosophy should address the unique needs of persons with dementia.
- Will progression of the disease result in transfer or discharge from the program?
- What type of care is provided for persons with late stage dementia?
- Does the unit serve only persons with dementia or are they integrated with others?
- How are issues/concerns resolved? What role does the family play in problem-solving?
- Is there a family council and/or support group?

#### Look For:

- Available information about Alzheimer's disease (books, posters, brochures, etc.).
- A copy of the most recent survey (licensed setting only) that you can read.
- A list of Resident's Rights and determine if staff are protecting those rights.

# What Is the Process for Developing a Care Plan?

All residential care settings (except housing only) will have staff conduct periodic assessments and develop care plans. An assessment is a way of gathering information about a person that can be used to personalize care. The plan tells the caregiving staff how to care for the person.

## Ask:

- How are care plans created and reviewed? Family members and the person with dementia (when able) should be included in the process.
- How are changes of condition monitored and addressed? Examples include injuries, illnesses, falls, changes in behaviors, nutritional intake and medications.
- How are families notified of care needs and changes?

## Look For:

- Residents being allowed to make simple decisions or choices.
- Staff treating residents as unique individuals.
- Families talking to and asking questions of staff.

More than anything else, you want to be confident that the person with dementia is receiving the best care possible with or without your presence. You also want to know that the staff recognizes him as an individual and treats him with dignity and respect.

#### Ask:

- What approaches are used when providing care?
- Providing simple directions or limiting choices are answers to listen for to determine if staff has an understanding of the needs of persons with dementia.
- How do you work with behaviors?
- What is your policy regarding the use of physical restraints that prevent free movement?
- How are adequate nutrition and hydration assured?
- How much personal care and assistance is provided and what is the cost? Make sure you determine all extra cost up front.

#### Look For:

- Clean and well-groomed residents.
- Residents smiling and looking happy and comfortable.
- Staff talking kindly to residents, not talking over them as if they were not there.
- Appetizing food.
- Staff gently encouraging residents to do things for themselves (walking, eating).
- A copy of the weekly or monthly menu.





## **Choosing a New Home**

## What Types of Activities Are Offered?

It is important for persons with dementia to receive activity throughout the day that provides pleasure, creates a sense of usefulness, and triggers memories of familiar activities from the past. Activities in a care setting consist of more than just structured group activities. They also include dressing, eating, bathing, and spending time alone, if desired.

#### Ask:

- How often are organized activities offered?
- Are there organized activities during the evenings? On weekends?
- Where do activities take place? Examples: inside facility, outdoors, off grounds.
- How are activities specifically designed for persons with dementia? Activities should be individualized and meet the specific needs, interests and abilities of each individual.

#### Look For:

- Residents appearing to enjoy the activity.
- Residents doing something that appears meaningful to them.



• Residents sitting in small groups or clusters engaged in some type of stimulation rather than alone in their rooms or grouped around the nurses' station or lounge area and not receiving any type of stimulation.

Individuals providing care to the person with dementia are an important factor in the quality of care that is received. You will want staff to be kind and friendly, skilled and knowledgeable about caring for someone with dementia.

## What Are Your Staff Qualifications and Staffing Levels?

#### Ask :

- What training does staff receive? It should include special training in dementia care.
- How often does staff receive training?
- How many direct care staff are on days? Evenings? Nights? Weekends?
- How many residents is each direct care staff member responsible for each shift? This will help you determine how much individual attention your family member will receive.

#### Look For:

- Friendliness of staff towards you, residents, visitors and each other.
- Genuineness of staff interactions with residents and family members.
- Staff addressing residents by name.
- Staff appearing content, not unhappy or stressed.

## How Does Your Environment Support Persons with Dementia?

Remember that the environment includes more than just the physical look of the setting. A safe environment is equally, if not more, important for persons with dementia.

## Ask:

- What measures are in place to provide a safe and secure environment for persons with dementia? Examples: Secure doors, safety and lighting features in the bathrooms and hallways.
- Are there safe areas that allow for independent wandering?
- Is there an outdoor area for residents that is safe and secure?
- How does the environment promote independence? Examples include clues in the environment that help individuals locate key areas, and identify the time of day, such as a picture of a toilet on the bathroom door.

## Look For:

- A pleasing atmosphere in the dining area.
- Personal belongings decorating resident rooms.
- Residents moving about freely in a safe area.
- Pleasant smells (no unusual or unexplainable odors).
- Clutter free hallways.
- Appropriate noise level that will not cause increased agitation (overhead speakers, buzzer, television regardless of anyone watching, etc.).

## **Choose the Right Place**

After you choose the residential care facility that is right for you and the person with dementia, consider revisiting that facility unannounced. It may also be beneficial to go at a different time of day than your first visit, in the late afternoon, after five p.m. or on a weekend. During the visit:

- Walk through the setting and continue to make observations.
- Take your time and try to get a real feel for everything discussed previously.
- Determine if the atmosphere appears similar to when you toured with staff.



# **Know Your Rights**

## **Care and Treatment in a Nursing Home**

## I. The Right to Be Fully Informed

- 1. The right to be informed of all services available and all charges
- 2. The right to a copy of the facility's policies, procedures and regulations
- 3. The right to be informed of the address and telephone number of the State Ombudsman, the State Licensure Office and other advocacy groups and the facility shall post these numbers
- 4. The right to see the State survey reports on the facility
- 5. The right to daily communication in one's own language
- 6. The right to assistance if there is sensory impairment

## II. The Right to Participate in Care

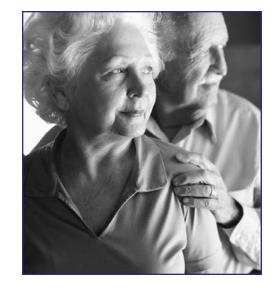
- 1. The right to receive adequate or appropriate health care
- 2. The right to be informed of one's medical condition and to participate, with or without a representative, in treatment planning
- 3. The right to refuse medication and treatment
- 4. The right to participate in discharge planning
- 5. The right to review medical records

## **III. The Right to Make Independent Choices**

- 1. The right to know the choices available
- 2. The right to make independent personal decisions
- 3. The right to choose one's own physician
- 4. The right to participate in activities of the community inside and outside the facility

## IV. The Right to Privacy and Confidentiality

- 1. The right to private and unrestricted communication with any person of the resident's choice. This includes receiving mail unopened, having privacy for telephone calls, and meetings with family, friends and other residents
- 2. The right to privacy in treatment and caring for personal needs
- 3. The right to reasonable access to any entity or individual that provides health, social or legal services
- 4. The right to confidentiality regarding medical, personal and financial affairs



## V. The Right to Dignity, Respect and Freedom

- 1. The right to be treated with consideration, respect and with the fullest measure of dignity
- 2. The right to be free from mental and physical abuse
- 3. The right to be free from physical and chemical restraints
- 4. The right to self-determination

## VI. The Right to Security for Possessions

- 1. The right to manage one's own financial affairs
- 2. The right to file a complaint with the state survey and certification agency for abuse, neglect or misappropriation of property

## VII. The Right to Remain in the Facility

- 1. The right to be transferred or discharged only for medical reasons, for one's own welfare if one's needs cannot be met in the facility, if the health or safety of others is endangered, for non-payment of stay, or if the facility closes
- 2. The right to receive notice of transfer. A thirty-day notice for transfer out of the facility must be given in most instances. The notices must include the reason for transfer, the effective date, the location to which the resident is discharged, a statement of the right to appeal, the name, address and telephone number of the state long term care ombudsman

## **Know Your Rights**

- The right to be informed
- The right to participate in care
- The right to make choices
- The right of privacy
- The right of dignity and respect
- The right of security of possessions
- The right to remain in a facility
- The right to raise concerns
- 3. The right to receive from the facility sufficient preparation to ensure a safe and orderly transfer

## VIII. The Right to Raise Concerns or Complaints

- 1. The right to present grievances for one's self or for others to the staff of the nursing home, or to any other person, without fear of reprisal
- 2. The right to prompt efforts by the facility to resolve grievances



For your convenience...

The Information and Referral Services section of this guide has a list of Alzheimer's Care Units.



# Ethical Considerations

Writing a will is one of the most important ways you can protect your property and loved ones.

- Capacity for Healthcare Decisions
- Advance Directives
- Healthcare Surrogate
- Family Communication about Healthcare Values
- Treatment Withdrawal/Refusal

# **Ethical Considerations**

For an individual with Alzheimer's disease, advanced planning is essential to fulfilling end-of-life wishes. The physicians and care team play an important role in initiating discussion with the individual and family regarding these wishes. Although Alzheimer's can run a course of up to 20 years, it is terminal. Ideally, the physician and care team should discuss values and preferences related to death and dying with all older persons on a regular basis. Early discussion will help to clarify the individual's wishes before the onset of dementia.

# **Capacity for Healthcare Decisions**

Individuals have a moral and legal right to make their own healthcare or medical treatment decisions, including to limit or forgo medical or life sustaining treatment (including the use of artificial feeding, mechanical ventilators, cardiopulmonary resuscitation, antibiotics, dialysis and other invasive technologies). Making valid healthcare decisions requires the individual to have a minimum level of "**capacity**" to make such



decisions. The Mississippi Uniform Healthcare Decisions Act defines decision-making capacity as "an individual's ability to understand the significant benefits, risks and alternatives to proposed health care and to make and communicate a health care decision." A person who can do these things can make a valid decision regarding approval or rejection of healthcare. Mississippi law also recognizes that capacity may be ebb and flow and that a person may have a **"lucid moment"** or **"lucid interval"** during which there is the required level of capacity, even though this interval is preceded and followed by periods of incapacity. It is important to note that persons with sufficient capacity may make their own healthcare decision even though they have designated an agent in an advance directive as described below.

## **Advance Directives**

It is important to designate one or more trusted persons as healthcare "agents" in a written advance directive, so that those persons will have legal authority to make medical decisions for the individual in the event he becomes incapacitated to do so. An advance directive must be made and signed while the individual has the capacity to understand the effects of such a directive. Until recently, the two common forms of advance directives were a "living will" and a durable power of attorney for health care. The living will stated whether the signer did or did not want heroic life-support treatment (such as mechanical ventilators) employed to prolong life if that person came to be in a terminally ill condition with critical end-of-life decline. The durable power of attorney for health care document named the person(s) who would make healthcare decisions for the individual. Since the repeal of these laws in 1998, these documents are no longer recognized by state law, although "living will" and durable healthcare powers of attorney that were validly executed prior to repeal remain valid for their limited purposes. In 1998, the legislature passed the Uniform Health Care Decisions Act, document. This document contains sections where the individual may (a) designate the agents for healthcare decisions in order of priority, (b) express the individual's wishes regarding terminal illness or other end-of-life medical treatments, including artificial feeding, and (c) identify any doctor who should be consulted in such events. A sample form for health care directive can be obtained from the MS Department of Health or can be downloaded on their website: www.msdh.state.ms.us. Consult and attorney if yo have an existing living will or durable power of attorney for health care to see how the new law affects you. Also, in light of the stringent privacy regulations under the Health Insurance Portability and Accountability Act (HIPAA) governing the release

## **Ethical Considerations**

of personal medical information, it is wise to include specific language in the directive that identifies the agent as your "personal representative" who is entitled to request and receive your medical information for HIPAA purposes. (This provision is not in the state form and may be included in a directive prepared by an elder law attorney.)

## **Healthcare Surrogate**

Additionally, the Uniform Healthcare Decisions Act of Mississippi provides for the making of health care decisions by a **"surrogate"** who is neither a guardian nor an agent named under an advance healthcare directive. The surrogate must be within the designated classes of persons authorized to act as surrogate, which are in order of priority: (i) spouse, unless legally separated; (ii) adult child; (iii) parent; (iv) adult brother or sister; or (v) an adult who has exhibited special care and concern for patient, who is familiar with patient's personal values, and who is reasonably available to act. A surrogate must make any healthcare decisions of the patient in accordance with the patient's individual instructions, if any, and other wishes to the extent known to the surrogate ("substituted judgment" test); otherwise, the surrogate must make the decision in accordance with surrogate's determination of the patient's best interest, taking into consideration the patient's personal values to the extent known to surrogate ("best interest" test). Even when the patient's incapacity may prevent the medical provider from asking the patient's consent to discuss her care or payment with a family member or other person, HIPAA privacy rules permits the provider to share this information with the third person when, in exercising professional judgment, it determines that doing so would be in the best interest of the patient.

## **Family Communication about Healthcare Values**

Personal values and choices about healthcare and end-of-life issues should be discussed with loved ones who will be expected to make such decisions. The law generally requires that a healthcare agent, to the extent he has reason to know the decision that the principal would make under the circumstances, must make that decision also. Therefore, the principal must communicate his or her values and choices about medical care and end-of-life treatment to the agent before the need to use directives arises. (This failure to clearly communicate personal wishes and values in end-of-life situations to her spouse and family was the greatest problem for Terri Schiavo, the severely brain-injured young Florida woman who remained on life support for over 16 years while family members fought in court to determine whether her life support should be removed.)

# **Treatment Withdrawal/Refusal**

If there is an identified agent or surrogate, families should be contacted and involved in the decisionmaking process. Care providers should work closely with the family, in cases where a substitute judgment must be made, to interpret advance directives. If there is a lack of knowledge about the individual, care providers should base a decision on what they feel is in the best interest for that individual. If necessary, the importance of respecting the individual's wishes should be clarified to the family. An individual's right to refuse or withdraw any treatment, including treatment for life-threatening illness (infections, hemorrhaging, heart attacks, etc.), is not the same as assisted suicide or euthanasia. In fact, aggressive medical treatment may seem torturous to the individual because of his or her lack of orientation to the surroundings and lack of understanding of the intentions of care providers.



## For your convenience...

The Information and Referral Services section of this guide has a list of elder law attorneys.



## **Holiday Hints**

#### NOTES:

- Caregiver
- Person with Alzheimer's
- Visitor
- Gift-Giving Ideas

## **Holiday Hints**

The holiday seasons, for many families, are filled with opportunity for togetherness each year. They are times when everyone can gather to share good food, memories, laughter, and companionship. But holidays can also be filled with stress, disappointment, and sadness.

Because of changes brought about by the disease process, the person with Alzheimer's may feel a special sense of loss and may exhibit unusual behaviors during these special seasons. At the same time, caregivers may feel overwhelmed with efforts to maintain holiday traditions on top of caring for the person with this disease. Caregivers may hesitate to invite family and friends to share holidays, for fear there will be negative reaction to the behavior changes in the family member.

Feelings of guilt, anger, frustration, or being trapped before, during and after these celebrations may be present for the caregiver. It may help to know that these feelings are normal and that you are not alone. Here are some helpful hints that may reduce the stress for all involved:

## Caregiver

- Adjust your expectations for yourself and others.
- Maintain your regular routine as much as possible.
- Keep a regular sleep schedule.
- Honor family customs within reason.
- Give yourself permission to do only what you can reasonably manage.
- Give yourself permission to say no to obligations, but accept invitations to enjoy being with others even if your loved one cannot attend.
- Be willing to ask for and accept help.
- Make lists of tasks and responsibilities others can do. When they say "What can I do to help?" you can respond with specific ideas.
- Ask others to bring food vs. doing all the cooking yourself. Make menus simple, preferably "potluck".
- Consider lunch or brunch to avoid evening confusion.
- Consider inviting 5-6 vs. the normal 15-20.
- Keep number of visitors to a minimum at any one time.
- Prepare family & visitors about:
  - changes in behavior
  - changes in appearance
  - changes in memory may not recognize them or confuse them with someone else
- Attend an Alzheimer's/dementia support group or arrange for respite care.
- Take care of yourself, maintain exercise and eating habits. Relax and enjoy!

Be Flexible! Plan Ahead! Maintain Routine! Involve your loved one! Don't neglect your needs! Relax – Enjoy!!!

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## Holiday Hints

## Person with Alzheimer's

- Involve the person throughout preparations
  - food preparation
  - set table
  - fold towels, laundry
  - do whatever is possible
- Prepare them for visitors; talk about and share pictures of people coming to visit.
- Use name tags for visitors.
- Prepare list of potential activities/tasks to divert attention from over stimulation and agitation.
- Create "To Do" list of activities that can be done by individual or with little assistance so caregiver can complete holiday tasks.
- Minimize decorations that may cause confusion (artificial fruits/vegetables, blinking lights).
- Maintain normal routine and sleep schedule.
- Build on past traditions/memories, rent seasonal videos before holiday, play seasonal music.
- Have "quiet room" if things get too hectic and have someone familiar stay with person.
- Have person attend adult day care or arrange for respite care.
- Limit amount of noise and confusion.

## Visitor

#### In the Home

- Call ahead to a schedule good time for visit.
- Educate yourself about memory loss and Alzheimer's by attending a support group, through the internet www.alz.org or by calling the Alzheimer's Association 1-800-272-3900.
- Keep visit short and quiet, wear a name tag if necessary.
- Bring pictures and reminisce about past holidays.
- Listen to or sing familiar music.
- Ask Caregiver to update you on appearance/behavior before visit.
- Offer to help Caregiver by providing respite, meals, run errands.
- Have Caregiver offer communication techniques; go with the flow!
- Be emotionally available if Caregiver wants to talk about the situation.

#### In long-term care

- Limit amount of noise and confusion; may need to meet in quiet room.
- Visit early in day; visit individually or in small groups.
- Don't expect them to participate in their old roles.
- Allow them to be an observer.
- Prayer and scripture reading are often welcomed.
- Children are a joy, but prepare the children.



## **Gift-Giving Ideas**

#### **Gifts for the Caregiver**

- Money &/or time
- Housecleaning weekly, bi-weekly, monthly
- Respite services
- Meals homemade frozen meals, treat for dinner out, help with meal prep and clean up
- Certificates for meals to be delivered to the home, meals from a restaurant
- Long-distance phone card
- Answering machine
- Cordless phone
- Certificate for manicure, pedicure, beauty shop
- Certificate for frivolous fun spa treatment, massage monthly/quarterly
- Membership in local health club or pool
- Transportation provide rides or cab vouchers
- Make arrangements for groceries, medications to be delivered or do it for them
- Your listening & HUGS!

## Gifts for the Person with Dementia at Home

- Sneakers with Velcro<sup>®</sup>
- Easy care clothes slacks with elastic waist, sweat suits
- Bathroom safety equipment
- Big button or picture phone
- Games simple and familiar like dominoes, checkers, simple jigsaw puzzles, cards
- Photo album with pictures of people and places from past
- Music from their era, old songs, church hymns
- Memory aids wipe off message boards, day-at-a-time calendars, post-it notes
- MedicAlert<sup>®</sup> + Safe Return<sup>®</sup> bracelet, 1-888-572-8566
- Short car trips
- Videos of family members and past vacations
- DO NOT give dangerous tools/ instruments, challenging board games, complicated electronic equipment
- Your listening & HUGS!

## Gifts for the Person in Long Term Care

- Sneakers with Velcro®
- Easy care clothes slacks with elastic waist, sweat suits
- MedicAlert<sup>®</sup> + Safe Return<sup>®</sup> bracelet, 1-888-572-8566
- Bird feeder
- Mobiles
- Large calendars
- Purse/wallets with fake credit cards and money
- · Cookies, candy
- Costume jewelry
- Personal hygiene items hairbrush, comb, kleenex, lotions
- · Cuddly stuffed toy
- Pet visits
- Music from 40's & 50's and favorite church hymns
- Favorite home-made foods
- Night light
- Lotion for hand/body massage
- Travel videos
- Lava lamp
- Afghan or lap robe of bright colors
- Gift certificates haircuts, perms, manicure
- Your listening & HUGS!

## Disaster Preparedness

#### NOTES:

- Advance Preparation
- Tips for When You Relocate

## **Disaster Preparedness**

## What should a family who is caring for someone with dementia do in case of an emergency or natural disaster?

If you know a pending disaster is about to occur:

- Get yourself and the person with Alzheimer's to a safe place.
- Alert others (family, friends, medical personnel) to the fact that you are changing locations, and give them your contact information. Contact them as regularly as you can as you move.
- Be sure there are people other than the primary caregiver who have copies of the person with dementia's medical history, medications, and physician information.
- Purchase extra medications.
- Bring medical records with you.

## **Advance preparations**

#### MedicAlert<sup>®</sup> + Alzheimer's Association Safe Return<sup>®</sup>

As a precaution, register your loved one in the MedicAlert<sup>®</sup> + Alzheimer's Association Safe Return<sup>®</sup> program.

- MedicAlert<sup>®</sup> + Safe Return<sup>®</sup> is an identification and support program that provides assistance for a person with Alzheimer's who wanders off and becomes lost, either locally or far from home.
- If you are already registered, make sure personal contact information, medical information including medications, and doctor information are updated with the program.
- Enroll in MedicAlert<sup>®</sup> + Safe Return<sup>®</sup> by:
  - Mail: MedicAlert<sup>®</sup>, 2323 Colorado Avenue, Turlock, CA 95382
  - Phone: 1-888-572-8566, M-F, 6 a.m.-7 p.m. (PST) and Saturday, 8 a.m.-5 p.m. (PST)
  - Fax: 1-800-863-3429
  - Online: www.medicalert.org/safereturn

#### Emergency kit

Consider preparing an emergency kit in advance. Keep it in a watertight container and store it in an easily accessible location. Your emergency kit might include:

- Easy-on flotation devices, such as Floaties<sup>®</sup> armbands
- Easy on/off clothes (a couple of sets)
- Velcro<sup>®</sup> shoes/sneakers
- Back-up eyeglasses
- Incontinence products
- Wipes
- Lotion (good for soothing the person)
- Pillow, toy or something else to hug
- Favorite items or foods
- Liquid meals
- Supplies of medication
- Extra identification items for the person, such as an ID bracelet and clothing tags
- Copies of legal documents, such as power of attorney and advance directives
- Copies of medical documents that indicate the individual's condition and current medications
- Copies of insurance and Social Security cards
- Zip-lock<sup>®</sup> bags to hold medications and documents
- Physician's name, address and phone numbers (including cell phone)
- MedicAlert<sup>®</sup> + Alzheimer's Association Safe Return<sup>®</sup> phone number To report an incident: Call the MedicAlert<sup>®</sup> emergency response center 24/7 at 800-625-3780
- Recent picture of the person with dementia

More information on disaster preparedness is available from the National Hurricane Center at www.nhc.noaa.gov.

## Tips for when you are relocated

In an emergency, people with dementia and their caregivers may find themselves uprooted or displaced to alternative living arrangements. Extra care and attention must be made to ensure the health and safety of the people with dementia. The change of location, plus unfamiliar noises and activities, may cause them increased stress and confusion. And, certain behaviors of persons with Alzheimer's may puzzle or alarm others.

#### Be calm and supportive

- Remain flexible, patient and calm a person with dementia will respond to the tone you set.
- Respond to an emotion being expressed by the person. Ask, "Are you feeling frightened?" Offer your hand or a hug.
- Offer reassurance, such as "I will take care of you." Or, "Don't worry. You will have everything you need here."
- Don't leave the person with Alzheimer's alone.
- Don't ask a stranger to watch the person. A person who doesn't understand Alzheimer's disease and its effect, and who doesn't know you or the person, won't understand how to react in a difficult situation.

## Create a safe environment

- Try to spend extra time with the person to help him or her adjust to the new environment.
- As much as is possible, maintain daily routines from before the disaster. For instance, accommodate familiar eating and bathing times.
- Maintain regular times for going to bed and arising. Establish a comfortable, secure sleeping environment.
- If possible, label important areas such as the bathroom and sleeping area to help the person become oriented to the new layout.
- Use simple statements to indicate the need to stay where you are. Divert attention to a new topic. For example: "I know you want to go home. For now, we need to stay here. Let's see if we can get some lunch."

- As appropriate, inform people around you that the person has memory loss or dementia.
- If you are in someone's home, arrange to make the house safer by locking up medications, toxic household supplies, sharp objects, alcohol and matches. Place nightlights through the house for nighttime safety and orientation.
- Limit news media exposure (TV, radio, computer) to the disaster.

### Take care of your loved one

- Ensure proper nutrition and hydration.
- Make it a priority to find a doctor and pharmacy to provide for the person's health needs. Be sure you have up-to-date medical information and a current list of medications.
- Take time to reminisce, share family photos and stories.
- Involve the person in daily activities.
- Get daily exercise and get outside for fresh air and sunshine.

#### Take care of yourself, too!

• Take care of yourself by finding a good listener to hear your thoughts and feelings about the event or just take a moment to breathe, meditate, reflect. Seek spiritual support.



# Caring for the Caregiver

**NOTES:** 

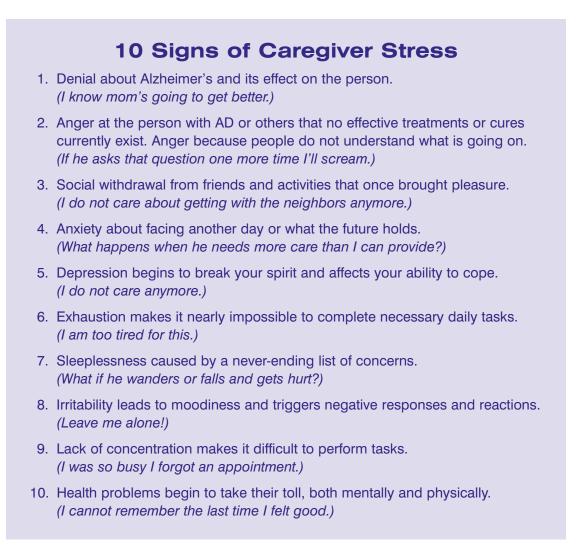
- Signs of Caregiver Stress
- Ways to Reduce Stress
- Ways to Help a Family Living with Alzheimer's
- Kids and Teens as Caregivers
- Caregiver's Prayer
- A Caregiver's Bill of Rights

## **Caring for the Caregiver**

Caregivers providing at home care for a person with Alzheimer's are a unique group. Nearly 40 percent have been providing care for at least one to four years and almost 35 percent have been doing it for more than five years. Over half are employed for at least some of the time they are caregivers. Huge pressures are placed on caregivers. Not just the amount of time, but the type of care they provide makes their caregiving so intense. Many permanently leave the workplace, reduce their hours and turn down promotions. They are more likely to:

- Deal with incontinence and with medication problems;
- Have children or grandchildren under the age of 18 living at home;
- Miss time from work, cut back to part-time, turn down promotions, transfer to less demanding job, choose early retirement or quit work altogether; and
- Pay out of pocket expenses averaging \$220 a month over the life of the disease.

Too much stress can be damaging to both the caregiver and the person with Alzheimer's disease. The following stress indicators experienced frequently or simultaneously can lead to more serious health problems. Learn to recognize signs of stress in yourself. Taking care of yourself will help you become a better caregiver.



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The Alzheimer's caregiver is often called the hidden or second victim of Alzheimer's. The physical results of caregiving can cause stress, fatigue, stomach problems, headaches or difficulty sleeping. The emotional stress of caregiving can cause depression, tension, anger, guilt, loss of self esteem and feelings of being overwhelmed. In addition, many caregivers think that others cannot understand how they feel or may think that their feelings are unacceptable. Unfortunately, most caregivers do not recognize the association between the stress of the caregiver and their own physical and emotional stress.

Caregiving also changes the relationship between the caregiver and the person with Alzheimer's. In addition to providing care, the caregiver must accept the persons previous responsibilities. In some cases, the caregiver's image of herself may change. Perhaps she never used to scream, and now she finds that her frustration results in frequent screaming episodes. Adding to this stress are the financial difficulties that generally accompany caring for a person with Alzheimer's disease.

Research is finding that nursing home placement seldom offers relief for the caregiver. There are no significant differences in stress symptoms between caregivers who provide 24-hour care and those whose loved ones are in a long-term care facility. The reason, scientists believe, is that the commitment to the patient is still strong.

Alzheimer's caregivers suffer from high levels of stress and depression. Unfortunately, the ultimate stress reducer, a cure for Alzheimer's disease, has not yet been discovered. But there are programs, services and care techniques that can help.

## Ways to Reduce Caregiver Stress

#### Get a Diagnosis as Early as Possible

Symptoms of Alzheimer's may appear gradually, and if a person seems physically healthy, it's easy to ignore unusual behavior, or attribute it to something else. See a physician, as some dementia symptoms are treatable.

#### Know What Resources are Available in Your Community

Begin with the Alzheimer's Association HELPLINE for information and referral to identify support services such as adult day care, in-home assistance, visiting nurses and meals on wheels.

#### Join a Support Group

If no group exists in your community, call the Alzheimer's Association and request that one begin. Have a list of potential meeting sites in your neighborhood, such as a church or library.

#### Get Help

Trying to do everything yourself will leave you exhausted. If assistance is not offered from family or friends, ask for it. If stress becomes overwhelming, get professional help.

#### Manage Your Stress Level

Stress can cause physical problems (blurred vision, stomach irritation, high blood pressure) and changes in behavior (irritability, lack of concentration, loss of appetite). Make note of your symptoms. Use relaxation techniques that work for you and consult a physician.

## 10 Ways to Help a Family Living with Alzheimer's



- 1. Stay in touch show you care. A card, a call or a visit can all mean a lot.
- 2. Educate yourself about Alzheimer's. Learn about its effects and how to respond.
- 3. **Treat the person with respect and dignity.** Focus on all that the person can do.
- 4. **Be specific when offering help.** Tackle a task on the family's to do list. Use Lotsa Helping Hands at www.alz.org/caresource to help with daily tasks.
- 5. **Do the little things.** Drop off dinner or run an errand; share a story, tell a joke.
- 6. **Include everyone in activities.** Plan a picnic or dinner at your place; include the person whenever possible
- 7. **Be a good listener.** Support and accept try not to judge.
- 8. **Encourage a healthy lifestyle.** Suggest practical tips to exercise and eat right.
- 9. Allow the family some personal time. Fill in as a caregiver, when needed
- 10. Keep all family members in mind. From kids to elders, everyone reacts differently

#### What is Alzheimer's?

Alzheimer's (AHLZ-high-merz) is a disease of the brain that causes problems with memory, thinking and behavior. One in three adults knows someone living with Alzheimer's disease.

#### What families are feeling

You may want to offer assistance to a family living with Alzheimer's but worry you'll say or do the wrong thing. It may help to be aware of these common experiences.

#### The person with Alzheimer's likely:

- Is adjusting to new schedules and changing roles
- Welcomes your direct contact
- Worries about overwhelming family caregivers
- Strives to keep an active, independent lifestyle

#### Family members often:

- Feel alone and disconnected from friends
- Need assistance or a break but hesitate to ask
- Struggle to run errands or complete daily tasks
- Feel high stress and welcome a good listener

#### You can make a difference

Go beyond the *10 ways to help a family living with Alzheimer's* – join the battle to end this disease:

- Volunteer at your local Alzheimer's Association
- Sign up for Walk To End Alzheimer's<sup>™</sup>
- Advocate for more research funding

### Caring for the Caregiver

## Parents' Guide to Helping Children and Teens Understand Alzheimer's Disease

Alzheimer's disease can have a big impact on every member of the family, including children. Each child will react differently to someone who has Alzheimer's.

The young people in your life might have questions about what is happening. It's important for you to take the time to answer these questions openly and honestly.

It will also help to share with them the changes the disease might bring, now and in the future.

#### How children and teens are affected

Factors that may affect your child include:

- How the child is related to the person (a parent, grandparent, relative, friend)
- How close the child is to this person emotionally
- Where this person lives (in the same home, long-term care home, another state)

#### **Common reactions of children and teens**

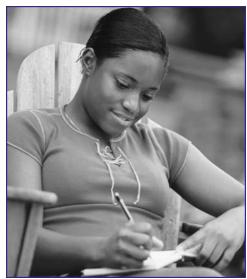
When a family member is living with dementia, a child might feel:

- Sad about how the person is changing
- Curious about how people get the disease
- Confused about why the person acts differently or doesn't recognize him or her
- **Frustrated** by the new things it's necessary to do because of the disease's effects, like repeating words or phrases to the person
- Guilty for getting angry with the person
- Afraid of the different ways in which the person now acts
- Jealous of the additional time and attention given to the person
- Worried that he or she or other loved ones might also get Alzheimer's
- **Embarrassed** to have friends or other visitors to the house, if the person is there and acts strangely
- Unsure how to act around the person

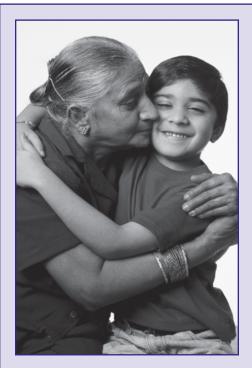
All of these feelings are normal.

It might be difficult to recognize how your child is feeling. A child who is having a hard time understanding or accepting the disease might:

- Withdraw from or lose patience with the person
- Express physical pain, like a stomachache or headache
- Do poorly in school
- Spend more time away from home
- Stop inviting friends to the house



Encourage your child to keep a journal. Writing down feelings might help bring the child comfort.



Make sure your child knows that even though a person with dementia may forget, love and kindness are still felt.

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Your child has special memories about favorite times shared with the person with dementia. Encourage your child to create and decorate a "memory box," filled with five or more things that will be a reminder of those special times.

#### **Questions your child might ask**

Often the whole family is learning about dementia together. Your child might not understand the disease. Encourage your child to ask questions. Answer honestly and in a way that is easy to understand. Use terms that match the child's level of understanding.

Some questions your child might have:

- What is Alzheimer's disease?
- Why are you acting differently?
- Will Mom get Alzheimer's, too?
- Why does Grandpa call me by my dad's name?
- Will Grandma die from Alzheimer's?
- Why does Abuelita keep asking the same question?
- How can I help Papaw?
- Are you going to get better?
- Will I get Alzheimer's if I spend time with Auntie?
- What are some things we can do together?

Your local Alzheimer's Association can help you answer questions and provide information about how the family can work through the changes brought on by the disease.

#### Keep open lines of communication

Good communication is the best way to help your child deal with the changes that are going on.

#### **Answer questions honestly**

Respond simply to questions. Try not to sugar coat the message.

#### Teach your child about the disease

Begin sharing information about the disease and its symptoms as soon as you can. Encourage your child to ask questions. Be patient and use words that are easy to understand.

Reassure the child that just because a person in the family has Alzheimer's, it does not mean that your child or other family members will definitely get the disease.

Great progress has been made in scientific research. Let your child know that better treatments or even a cure could be discovered by the time he or she is grown. If your child might find comfort in learning more about the disease and how the brain works, contact the Alzheimer's Association for more information.

If your child expresses feelings of helplessness, work together to find a way to get involved.

New Kids and Teens Program offered both online and in the classroom. www.alz.org/living\_with\_alzheimers\_just\_for\_kids\_and\_teens.asp

#### Caring for the Caregiver

## Let your child know these feelings are normal

Young people need a way to share their feelings about having a loved one with Alzheimer's disease. Show comfort and support by letting them know that those feelings are normal.

## Create opportunities for your child to express feelings

Make sure your child is getting enough support. Set aside a regular time to be with each other. Activities or outings together can create great opportunities for a child to open up.

Ask the Alzheimer's Association if there are support groups for children in your area and encourage your child to take part.

#### Prepare the child for changes

Alzheimer's gets worse over time. A person with dementia may look healthy on the outside, but on the inside, the brain is not working properly.

Let the child know what changes to expect. Talk about what those changes will mean for your child and your family. Make sure your child understands why you might have less time to spend together.

## Let the child know it's not his or her fault

Dementia can cause a person to direct confusion, fear or anger at the child. If this happens, be sure the child knows the person did not mean to act that way. People with dementia have good days and bad days. Make sure your child does not feel responsible for the kind of day it is. Those who help care for the person with dementia might sometimes seem tired, frustrated, sad or shorttempered. Explain to your child that he or she is not to blame.

## Inform your child's teacher and school counselor

Let them know the ways in which Alzheimer's disease is affecting your child and the family.

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## **Special Issues for Teens**

The disease may bring many changes to your teen's life. For example, you may need to ask your teen to pitch in more around the house or to assist with caregiving.

#### What teens are saying:

- I don't like to talk about what's going on at home with my friends or my teachers
- Sometimes I feel embarrassed about how my grandpa is acting
- I don't feel comfortable having my friends over right now
- When I help out with my uncle, I feel like my family really needs me
- I feel good that I know how to do the little things that make a difference for my dad
- I've never felt closer to my mom than I do now because we're facing this together

## 10 activities children can share with the person with dementia

- 1. Bake cookies
- 2. Take a walk around the neighborhood
- 3. Put a puzzle together
- 4. Play Hangman
- 5. Color or draw pictures
- 6. Make a scrapbook of family photographs
- 7. Read a favorite book or story
- 8. Eat a picnic lunch outside
- 9. Watch your favorite TV show together
- 10. Listen to or sing old songs

Encourage your child to come up with other ideas. Make sure the activity is a good match for the abilities of both individuals.

### Caring for the Caregiver

## A Caregiver's Prayer

Dear God,

Help me through another day to face problems known and unknown, Grant me sensitivity and understanding so I can cope gently with my loved one, who rails at life with bitter accusations and assails me with recriminations I know have no basis in reality.

The harsh words are not really meant for me – the bewildering actions are totally the disordered trauma of this cruelty, this devastating disease that has trapped my loved one in its merciless grasp.

How well I know – but sometimes knowledge fails me and I become frustrated, impatient and unkind – for Lord, I'm one of your imperfect children, with a broken heart, a tired body and an oppressed mind – but I'll go on and on believing, as I hope and pray that somehow, somewhere, there will be a cure one day.

Anonymous

## A Caregiver's Bill of Rights

## I have the right:

• to take care of myself. This is not an act of selfishness. It will give me the capability of taking better care of my relative.

• to seek help from others even though my relative may object. I recognize the limits of my own endurance and strength.

• to maintain facets of my own life that do not include the person I care for, just as I would if he or she were healthy. I know that I do everything that I reasonably can for this person, and I have the right to do some things just for myself.

• to get angry, be depressed, and express other difficult feelings occasionally.

• to reject any attempt by my relative (either conscious or unconscious) to manipulate me through guilt, anger or depression.

• to receive consideration, affection, forgiveness and acceptance for what I do for my loved one for as long as I offer these qualities in return.

• to take pride in what I am accomplishing and to applaud the courage it has sometimes taken to meet the needs of my relative.

• to protect my individuality and my right to make a life for myself that will sustain me in the time when my relative no longer needs my full-time help.

to expect and demand that as new strides are made in finding resources to aid physically and mentally impaired older persons in our country, similar strides will be made toward aiding and supporting caregivers.
 Read the list to yourself every day!

#### NOTES:

## Information and Referral Services

This is not a complete list. Those listed here are ones known as of this printing. If you have additions or corrections, please contact the Alzheimer's Association MS Chapter.

- Physicians: Geriatric Medicine
- Psychiatrists
- Neurologists
- Counseling Services
- Adult Day Care/Group Respite Centers
- Alzheimer's Care Units
- Alzheimer's Geriatric/Psychiatric Units
- Mississippi Legal Services
- Mississippi Resources
- Area Agencies on Aging
- National Resources
- Helpful Websites

## **Physicians: Geriatric Medicine**

All internal medicine and family practice physicians can begin an Alzheimer's diagnosis. You can continue to seek medical services from your primary care physician. However, some physicians are board certified in Geriatric Medicine and have additional training in working with diseases of elders. Others specialize in geriatric medicine.

#### **Adams County**

Russell N. Smith, III 129 Jefferson Davis Blvd. Natchez, MS 39120 (601) 445-6231

#### **Bolivar County**

Charles Brock Steven Clark 810 E. Sunflower Rd-100A Cleveland, MS 38732 (662) 843-3606

Scott Nelson 907 E Sunflower Rd Cleveland, MS 38732 (662) 721-1399

**J.W. Lewis, Jr.** 512 Levee Street Rosedale, MS 38769 (662) 759-6806

#### **Forrest County**

Jeffrey Morris 200 West Hospital Drive Hattiesburg, MS 39402 (601) 296-3000

Kurt F. Bruckmeier 101 Asbury Circle Hattiesburg, MS 39402 (601) 268-5200

#### **Harrison County**

Paulette Galbraith 12100 Hwy 49 North Gulfport, MS 39503 (228) 831-1988 Valerie Lennox 1721 Medical Park Drive #101 Biloxi, MS 39532 (228) 388-0062

Thomas Stevens, Jr. Doctors Plaza 4211 Hospital Street, Suite 207 Pascagoula, MS (228) 938-2907

Katie Catherine Cowan 400 Veterans Avenue Biloxi, MS 39531 (228) 523-5000

Yashashree L. Bethala Bennett W. Cheney Regina Clare Mills Marion Jean Wainwright Gholam Reza Motakhaveri 147 Reynoir Street, Suite 101 Biloxi, MS 39531 (228) 374-2051

#### **Hinds County**

Gwen Windham Mark Meeks Kathy Gregg Kimberly C. Teal Katherine H. Travis University Medical Center Division of Geriatrics 2500 N. State Street Jackson, MS 39216 (601) 984-1000

Holland Addison 501 Marshall Street, Suite 208 Jackson, MS 39202 (601) 352-2273

## Physicians: Geriatric Medicine (continued)

#### Hinds County continued

George Patton 971 Lakeland Drive, Suite 250 Jackson, MS 39216 (601) 982-1283

Chere Hunter Peel 1500 E. Woodrow Wilson Avenue Jackson, MS 39216 (601) 362-4471

#### Jackson County

Robert Donald 4211 Hospital Road, Suite 202 Pascagoula, MS 39581 (228) 762-3466

Todd Coulter 2693 Bienville Blvd, Hwy 90 Ocean Springs, MS 39564 (228) 875-7474

Thomas E. Stevens, Jr. 2809 Denny Avenue Pascagoula, MS 39581 (228) 809-5000

#### Jones County

Jack Evans John Hassell Terry Pitts 1440 Jefferson Street Laurel, MS 39440 (601) 428-0577

#### Lauderdale County

Gary Gordon 1800 12th Street Meridian, MS 39301 (601) 703-9223

**Robert Kiehn** 2024 15th Avenue Meridian, MS 39301 (601) 703-9265

#### Lee County

Kenneth Davis 830 S. Gloster Street Tupelo, MS 38801 (662) 377-3464

Lee Greer 845 South Madison Street Tupelo, MS 38801 (662) 377-5930

Amit Prasad Brockton Jolly Sansing 845 S. Madison Street Tupelo, MS 38801 (662) 377-5040

Ashley Wayne Harris 1665 South Green Street Tupelo, MS 38804 (662) 377-2189

## Physicians: Geriatric Medicine (continued)

#### **Leflore County**

John Hey, III 405 River Road Greenwood, MS 38930-4212 (662) 453-6177

#### **Neshoba County**

Mohamed Bockarie Jah 210 Hospital Drive Choctaw, MS 39350 (601) 656-2211

#### **Pearl River County**

Walter Gipson 1702 Hwy 11 N, Suite A Picayune, MS 39466 (601) 700-3130

Ahmand Haidar 1016 6th Avenue, Suite C Picayune, MS 39466 (601) 799-4777

**Roberto Lopez** 1018 6th Avenue Picayune, MS 39466 (601) 798-7529

James Riser 2274 Hwy 43 South Picayune, MS 39466 (601) 798-5798

#### **Pike County**

Larry Aycock 1054-B Harrison Avenue McComb, MS 39648 (601) 684-7721

Henry Lewis, Jr. 1510 Harrison Avenue McComb, MS 39648 (601) 684-6891

#### **Rankin County**

Michael Albert 187 Doctors Drive Pearl, MS 39208 (601) 939-8921

#### Sunflower County

Walter Rose 122 E. Baker St. Indianola, MS 38732 (662) 887-1212

## **Psychiatrists**

#### **Alcorn County**

Maxie Gordon 119 Alcorn Drive Corinth, MS 38834 (662) 286-3843

#### **Forrest County**

Shannon Johnson Peter Kamp 1 Lincoln Parkway #202 Hattiesburg, MS 39402 (601) 288-8050

#### **Harrison County**

James Rusch 11070 David Street Gulfport, MS 39503 (228) 832-9191

Phillip A. Schaeffer 319 Courthouse Road Gulfport, MS 39505 (228) 897-7730

#### **Hinds County**

Holland Addison 501 Marshall Street Jackson, MS 39202 (601) 352-2273

Jeffrey Ali Grayson Norquist John Norton UMC Dept. of Psychiatry 2500 North State Street Jackson, MS 39216 (601) 984-5805

Andrew Bishop 971 Lakeland Drive, Suite 354 Jackson, MS 39216 (601) 982-1010

Mark Rester 1855 Lakeland Drive, Suite 121 Jackson, MS 39216 (601) 366-4696 Krishan Gupta

1059 Ridgewood Place Jackson, MS 39211 (601) 957-3211

#### **Jackson County**

Roy Deal Bianca Habison 421 Delmas Avenue Pascagoula, MS 39567 (228) 696-9224

#### **Jones County**

William Clark 1603 Old Amy Road Laurel, MS 39440 (601) 428-7100

Stuart Samson Arvinder Kaul 1107 West 6th Street Laurel, MS 39440 (601) 426-9614

#### Lauderdale County

**Terry Jordan** 5000 Highway 39 North Meridian, MS 39301 (601) 482-2400 (800) 482-8212

#### Lee County

Paul Hill 4579 South Eason Tupelo, MS 38801 (662) 377-7590

#### Madison County

Sayed Aamir Raza Mississippi Neuroscience Center 731 S. Pear Orchard Rd., Suite 8 Ridgeland, MS 39157 (601) 952-0015 Ben A. Root Jr. Mark Webb 576 Highland Colony Parkway Ridgeland, MS 39157 (601) 853-2676

Kurt Buechler 576 Highland Colony Parkway Ridgeland, MS 39157 (601) 853-2676

Rodrigo M. Galvez Donald Guild 3531 Lakeland Drive Flowood, MS 39232 (601) 936-6781

Kristen Bevill 3531 Lakeland Drive, Suite 1060 Flowood, MS 39232 (601) 420-5810

#### Newton County

**Terry Jordan** 9421 Eastside Drive Ext. Newton, MS 39440 (601) 683-2031

#### Warren County

Phillip Scurria 115 North Frontage Road P O Box 820154 Vicksburg, MS 39182-0154 (601) 634-8790

#### Washington County

Margaret Cassada 129 East Starling Greenville, MS 38703 (662) 378-8889

## **Neurologists**

#### **Alcorn County**

#### Andrew Kerby

William Owens Shiloh Neurology 2425 Proper Street Corinth, MS 38834 (662) 287-7785

#### **DeSoto County**

#### **Debashis Biswas**

Adult Neurology Clinic 7900 Airways Blvd, Bldg A, Suite 4 Southaven, MS 38671 (662) 536-0577

#### Rahul Vasant Sonone Shankar Shiva Natarajan Karima Benameur

Memphis Neurology, PLLC 401 Southcrest Circle, Suite 105 Southaven, MS 38671 (901) 405-0275

#### **Forrest County**

#### Kathleen Messenger

105 Ashbury Circle, Suite A Hattiesburg, MS 39402 (601) 268-5222 Jose Fernandez, Jr. Geoffrey Hartwig Wendell Helveston Scott Lynn Joshua Maksi Keith McLarnan Ronald Schwartz Gabriella Szatmary Hattiesburg Clinic 415 S. 28th Avenue Hattiesburg, MS 39401 (601) 264-6000

#### **Grenada County**

Karen Plunkett Grenada Neurology Clinic 1300 Sunset Drive, Suite O Grenada, MS 38901 (662) 227-0998

#### **Harrison County**

#### Richard John Gorman

Coast Neurology 147 Reynoir Street, Suite 200 Biloxi, MS 39530 (228) 436-1649

## Neurologists (continued)

#### Harrison County continued

Chelsea R. Grow Abha Mishrsa Lee Voulters 1340 Broad Avenue, Suite 440 Gulfport, MS 39501 (228) 867-4855

Joseph A. Jackson Gregory Alphonse Redmann Gulf Coast Neurology Clinic, PA 1990 Pops Ferry Road Biloxi, MS 39532 (228) 594-2000

Dianne Ross 749 Oakleigh Avenue Gulfport, MS 39507 (228) 896-3317

## John Kendall Webb

81st Medical Group Keesler AFB Medical Center 301 Fisher Street Biloxi, MS 39534 (228) 376-3624

#### **Hinds County**

Alexander Auchus James J. Corbett Robert Herndon Edward Manning Abelardo Wee UMC Department of Neurology 2500 North State Street Jackson, MS 39216 (601) 984-5501

Donald H. Butts Thomas E. Ingram 1920 Chadwick Drive, Ste 109 Jackson, MS 39204-3406 (601) 373-9001

James W. Irby B. Heath Gordon Clinical Neuropsychologist 4500 I-55 North Highland Village, Suite 234 Jackson, MS 39211 (601) 982-8531

## Neurologists (continued)

Hinds County continued

Edward L. Manning, Ph.D. Clinical Neuropsychologist

UMC Department of Neurology 5100 N. State Street Jackson, MS 39216 (601) 984-5520

David G. McHenry Ancel C. Tipton 971 Lakeland Drive, Ste 557 Jackson, MS 39216-4607 (601) 362-1577

Gerald P. Randle Richard E. Weddle Angela Lang Chandler Michael A. Garbee Baptist Neurological Associates 1151 N. State Street, Suite 404 Jackson, MS 39202 (601) 355-3353

Martin A. Schiefer 100 Cedar Cove Clinton, MS 39056 (601) 925-4433

Eric K. Undesser Xinhong Zhang Ethel Rose James Parker 1500 E. Woodrow Wilson Ave. Routing # 127 Jackson, MS 39216 (601) 362-4471

Patrick E. Weldon Axon 1860 Chadwick Drive, Suite 258 Jackson, MS 39204 (601) 376-2004

#### **Jackson County**

Lennon E. Bowen, IV William J. Evans Christopher Patrick Karcher Neuroscience Center 3631 Bienville Blvd., Suite A Ocean Springs, MS 39564 (228) 818-9620

**Richard J. Gorman** 131 Reynoir Street Biloxi, MS 39530-4129 (228) 374-5733

**Terrence John Millette** Neurology Associates of MS 4105 Hospital Street, Suite 104 Pascagoula, MS 39581 (228) 769-0276

#### **Jones County**

Minipuri Gunavan Singh Aremmia D. Tanious 1203 Jefferson Street Laurel, MS 39440-4354 (601) 649-2863

#### Lafayette County

Malcolm M. Roland Oxford Neurology 510 Azalea Drive Oxford, MS 38655 (662) 281-0112

## Neurologists (continued)

#### Lauderdale County

**Rafique Ahmad** 1800 12th Avenue, Suite 2A Meridian, MS 39301-4116 (601) 703-6705

## Zaineb Daud

Aamir Hashmat Meridian Medical Associates 2024 15th Street, Suite 4A Meridian, MS 39301 (601) 553-2000

#### Lee County

Mark H. Fletcher Justin C. Graff Donna L. Harrington Rhodemarie Maron Samuel D. Newell Jr. W. Thomas Oakes Jr. Tupelo Neurology Clinic 609 Brunson Drive Tupelo, MS 38801-4948 (662) 844-7021

### Thomas Joseph McDonald

North MS Neurosurgical Services, PA 4381 S. Eason Blvd., Suite 302 Tupelo, MS 38801 (662) 844-6768

#### **Leflore County**

#### Karen W. Plunkett

1317 River Road Greenwood, MS 38930-4029 (662) 459-2520

#### Lowndes County

#### **Reynolds P. McCain**

516 Lincoln Road, Suite B Columbus, MS 39705-2226 (662) 327-2700

#### **Madison County**

Nathan Lawson 1883 Hwy 43 South, Suite F Canton, MS 39046 (601) 859-8124

#### Abelardo Wee 228 Arapaho Lane Madison, MS 39110

(601) 984-6440

#### Pearl River County

#### Michael B. Mitchell

Hattiesburg Clinic 12 Medical Plaza Blvd., Suite A Picayune, MS 39466 (601) 799-2539

#### Pike County

### Joseph William Farina, Jr. McComb Neurology Center

118 N. Broadway McComb, MS 39648 (601) 249-2491

#### **Rankin County**

Ruth K. Fredericks Larry Parker Adele Thiel 1020 River Oaks Dr., Ste 420 Flowood, MS 39232-9500 (601) 939-0361

## **Counseling Services**

As a caregiver, if you need to talk to someone who understands what you're going through, join a support group. Call the Alzheimer's Association's HELPline or the MS Department of Mental Health Division of Alzheimer's disease to obtain information on mental health services in your community. You could also attend counseling sessions with a licensed psychologist, social worker, counselor or family therapist. The following is a small list of persons specializing in services to families affected by dementia.

#### Amy Adelman, LPC

South Central Behavioral Health Services 1105 Adams Street Laurel, MS 39440 (601) 426-9614

#### Matthew Campbell, Ph.D.

Suite 19, Anchorage Building 426 South Lamar Oxford, MS 38655 mcampell@ifulford.net (662) 513-9936

#### Lee Corlew, MS, LPC, LMFT

The Family Foundation of Jackson, LLC 1765 Lelia Drive, Suite A Jackson, MS 39216 (601) 982-1155

#### William Gasparrini, PhD, ABPP

Applied Psychology Center 2472 Pass Rd Biloxi, MS 39531 (228) 388-9303

#### B. Heath Gordon, Ph.D.

4500 I-55 North Highland Village, Suite 234 Jackson, MS 39211 (601) 982-8531 (Tel) (601) 982-1115 (Fax) http://heathgordonphd.com

#### Kristine M. Jacquin, Ph.D.

Licensed Clinical Psychologist Assistant Professor of Psychology Mississippi State University P.O. Box 6161 Starkville, MS 39762 kmj8@ra.msstate.edu (662) 325-1022

#### W. Criss Lott, Ph.D.

Clinical Director 969 Lakeland Drive St. Dominic Counseling Center Jackson, MS 39216 (601) 200-3108

#### Molly Meeks, MS, NCC

Summit Counseling 431 North State Street Jackson, MS 39201 (601) 949-1949

#### **Katherine Nordal**

The Nordal Clinic, P.A. 1121 Grove Street Vicksburg, MS 39180 (601) 634-0118

#### C. Gerald O'Brien, PhD

640 Lakeland East Drive, Suite F Jackson, MS 39232-9778 drob@netdoor.com (601) 664-6730

#### Jo Ann O'Quin, Ph.D.

Professor of Social Work University of Mississippi PO Box 1848 University, MS 38677 joquin@olemiss.edu (662) 915-7199

## **Adult Day Care and Group Respite Centers**

#### Adams

Natchez Multi-Purpose Senior Center/Day Care 800 Washington Street Natchez, MS 39120 (601) 442-5082

#### Alcorn

Bishop Senior Center Adult Day Care P O Box 1140 Corinth, MS 38835 (662) 286-7748

Sharing Hearts Adult Day Care First Baptist Church of Corinth 501 Main Street Corinth, MS 38834 (662) 286-2208

#### Bolivar

Sunny Seniors 107 South Victoria Cleveland, MS 38732 (662) 843-0541

It's A Blessing Adult Day Care 902 Louisiana Street Shelby, MS 38774 (662) 398-5263

#### Clarke

Handy Elderly Day Care P O Box 462, 114 2nd Street Shubuta, MS 39360 (601) 687-1128

#### Coahoma

SLA Jones Activity Center Adult Day Care 500 Indiana Avenue Clarksdale, MS 38614 (662) 627-2720

#### Forrest

Pine Belt Mental Health Adult Day Care & Respite Center Twin Oaks Senior Center 701 West Pine Street Hattiesburg, MS 39403 (601) 545-5614

#### Greene

We Care Too Adult Day Care 405 Lafayette Street Leakesville, MS 39451 (601) 394-6283

#### Harrison

Lyman Senior Citizen Activities Center 14592 County Farm Road Gulfport, MS 39503 (228) 832-2606

The White House (Adult Living & Adult Day Care) 14146 Highway 15

Biloxi, MS 39532 (228) 396-2750

Gulf Shores Adult Day Care 2301 Atkinson Road Biloxi, MS 39531 (228) 388-1723

Autumn View Senior Day Services

9471 Three Rivers Road, Suite C Gulfport, MS 39503 (228) 206-7654

#### Hinds

Baptist Adult Day Health Service – North Jackson 6250 Old Canton Road Suite 140 Jackson, MS 39211 (601) 956-7794

Baptist Adult Day Health Services 503 E. Northside Drive Clinton, MS 39056

#### Jones

(601) 926-1222

Pine Belt Mental Health Adult Day Care 231 South 14th Avenue Laurel, MS 39440 (601) 649-2933

#### Lafayette

Memory Makers Respite Day Program 125B Heritage Drive Oxford, MS 38655 (662) 234-3332

#### Lauderdale

Christa House 1918 24th Avenue Meridian, MS 39301 (601) 483-5822

#### Lawrence

The Living Center 1134 East Broad Center Monticello, MS 39654 (601) 587-9226

## Adult Day Care and Group Respite Centers (continued)

#### Lawrence County Senior Center ADC

1447 East Sellers Highway Monticello, MS 39654 (601) 587-0936

#### Lee

Lee County Multi-Purpose Day Care Center 5338 Cliff Gookin Blvd. Tupelo, MS 38803 (601) 844-9004

The Hannahouse Adult Day Care, LLC 217 Franklin Street Tupelo, MS 38804 (662) 844-5483

#### Leflore

Garden Park Adult Day Care 2713 Highway 82 E Greenwood, MS 38930 (662) 451-9058

#### Lowndes

Beautiful Life Adult Day Care 1551 2nd Avenue N Columbus, MS 39701 (662) 329-1025

#### Madison

Desmond & Puller Adult Day Care Center, LLC 525 East Center Street Canton, MS 39046 (601) 859-7808

#### Monroe

First Friends P O Box 117 Third Street Amory, MS 38821 (662) 256-9730

#### Newton

Footprints Adult Day Care 851 Northside Drive Newton, MS 39345 (601) 683-4320

#### Noxubee

Sunshine Club Elderly Day Services 500 Lawrence Street Macon, MS 39341-3002 (662) 726-9011

#### Panola

Dignity and Mercy Adult Day Services 569 Hwy 6 West Batesville, MS 38606 (662) 209-1758 dignitymercy@yahoo.com

#### Perry

We Care Day Care Adult Day Care 109 Elm Street E Richton, MS 39476 (601) 788-5799

#### Rankin

Peach Tree Village 6100 Old Brandon Road Brandon, MS 39042 (601) 933-1100

#### Stone

Ramsey Springs Village 258 Vestry Road Perkinston, MS 39573 (601) 945-2862

#### Sunflower

Faith & Hope Adult Day Care 141 N. Main Street Drew, MS 38737 (662) 745-0275

#### Tishomingo

**Tishomingo State Park Day Center** P O Box 335 Dennis, MS 38838 (662) 438-7187

#### Union

Sunshine Inn Assisted Living & Adult Day Care 1645 State Hwy 178 West Myrtle, MS 38650 (662) 988-3959

#### Washington

## R & N Adult Day Care

108 East Avenue Hollandale, MS 38748 (662) 827-5755

We Care Adult Day Services 620 Washington Avenue Greenville, MS 38701 (662) 334-1650

## **Alzheimer's Care Units**

#### Adams County

Adams County Nursing Center 587 John R. Junkin Drive Natchez, MS 39120 (601) 446-8426 Accepts Medicaid

Magnolia House 311 Highland Boulevard Natchez, MS 39120 (601) 446-5097 *Private Pay* 

#### **Alcorn County**

Dogwood Plantation 1101 Levee Road Corinth, MS 38834 (662) 286-7021 Private Pay

#### **Amite County**

Liberty Community Living Center 323 Industrial Park Drive Liberty, MS 39645 (601) 657-1000 Accepts Medicaid

#### **Attala County**

State Veterans Home 310 Autumn Ridge Drive Kosciusko, MS 39090 (662) 289-7809 *Qualified Veterans* 

#### **Bolivar County**

Cleveland Health & Rehab 4036 Highway 8 Cleveland, MS 38732 (662) 843-8971

#### **Coahoma County**

Clarksdale Nursing Center 1120 Ritchie St. Clarksdale, MS 38614 (662) 627-2591 Accepts Medicaid

#### **Covington County**

State Veterans Home – Collins 3261 Highway 49 Collins, MS 39428 (601) 765-0403 *Qualified Veterans* 

#### **DeSoto County**

Beverly Healthcare – Southaven 1730 Dorchester Drive Southaven, MS 38671 (662) 393-0050 Accepts Medicaid

Hermitage Gardens of Southaven 108 Clarington Avenue Southaven, MS 38871 (662) 349-9350 *Private Pay* 

The Arbors at Olive Grove Terrace 9684 Goodman Road Olive Branch, MS 38654 (662) 895-1072

Private Pay

#### **Forrest County**

Alden Pointe #2 Courtland Drive Hattiesburg, MS 39402 (601) 296-9711 *Private Pay* 

Hattiesburg Convalescent Center 514 Bay Street Hattiesburg, MS 39401 (601) 544-4230 Accepts Medicaid

#### Forrest County (continued)

Pine Meadow 107 Fox Chase Drive Hattiesburg, MS 39401 (601) 271-8480 Private Pay

#### Hancock County

Woodland Village 5427-A Gex Road Diamondhead, MS 39525 (228) 255-4832 Accepts Medicaid

#### **Harrison County**

Biloxi Community Living 22790 Atkinson Road Biloxi, MS 39531 (228) 388-1805 Accepts Medicaid

The Courtyard Loyalton of Biloxi 2120 Enterprise Drive Biloxi, MS 39531 (228) 388-0946 *Private Pay* 

Veterans Administration Hospital Extended Care Unit 23 West 400 Veterans Avenue Biloxi, MS 39531 (228) 523-5000 *Qualified Veterans* 

#### **Hinds County**

Cottage Grove Nursing Home 1116 Forest Avenue Jackson, MS 39206 (601) 366-6461 Accepts Medicaid

Willow Creek 49 Willow Creek Lane Byram, MS 39272 (601) 863-4201 Accepts Medicaid

## Alzheimer's Care Units (continued)

#### Hinds County (continued)

Emeritus at Trace Pointe 501 E. Northside Drive Clinton, MS 39056 (601) 924-1495 *Private Pay* 

#### State Veterans Home – Jackson 4607 Lindbergh Drive Jackson, MS 39209 (601) 353-6143 *Qualified Veterans*

#### **Riggs Manor Retirement Community** 2300 Seven Springs Road Raymond, MS 39154

(601) 857-5011

#### **Holmes County**

University Medical Center 239 Bowling Green Lexington, MS 39095 (662) 653-4106 Accepts Medicaid

#### Itawamba County

#### Daniel Health Care/The Meadows Highway 25 South Fulton, MS 38843 (662) 862-2165 Accepts Medicaid

#### **Jackson County**

#### Singing River Nursing & Rehab Center 3401 Main St. Moss Point, MS 39563 (228) 762-7451 Accepts Medicaid

#### Jones County

Magnolia Gardens 945 West Drive Laurel, MS 39440 (601) 649-6660 *Private Pay* 

#### Lafayette County

#### Hermitage Gardens of Oxford 1488 Belk Avenue Oxford, MS 38655 (662) 234-8244 *Private Pay*

State Veterans Home – Oxford 120 Veterans Drive Oxford, MS 38655 (662) 234-7821 *Qualified Veterans* 

#### Lauderdale County

Poplar Springs Nursing Center 6615 Poplar Springs Loop Meridian, MS 39305 (601) 483-5256 Accepts Medicaid

**Silverleaf Manor** 4555-35th Avenue Meridian, MS 39305 (601) 483-4566 *Private Pay* 

#### Lawrence County

Lawrence County Living Center 1134 East Broad Street Monticello, MS 39654 (601) 587-9226 Private Pay, Medicaid Pending

#### **Lowndes County**

Philwood Suites of Windsor Place 81 Windsor Place Columbus, MS 39702 (662) 241-5518 Private Pay

#### **Madison County**

#### The Blake at Township

608 Steed Road Ridgeland, MS 39157 (601) 500-7955 www.blakeliving.com *Private Pay* 

Madison County Nursing Home

1421 E. Peace Street Canton, MS 39046 (601) 855-5760 Accepts Medicaid

**Emeritus at Ridgeland Pointe** 

410 Orchard Park Ridgeland, MS 39157 (601) 957-0727 *Private Pay* 

The Orchard 600 S. Pear Orchard Road Ridgeland, MS 39157 (601) 856-2205 *Private Pay* 

St. Catherine's Village/ Campbell Cove 200 Dominican Drive Madison, MS 39110 (601) 856-0100 Private Pay

#### Marshall County

#### Christopher's House

885 Highway 178 East Holly Springs, MS 38635 (662) 551-1122 *Private Pay* 

## Alzheimer's Care Units (continued)

#### **Monroe County**

#### Golden Living Center

1215 Earl Frye Boulevard Amory, MS 38821 (662) 256-9344 Accepts Medicaid

#### **Neshoba County**

#### Neshoba County Nursing Home

1001 Holland Avenue Philadelphia, MS 39350 (601) 663-1440 Accepts Medicaid

#### **Prentiss County**

#### Landmark Nursing and

Rehabilitation Center 100 Lauren Drive Booneville, MS 38829 (662) 720-0972 Accepts Medicaid

#### **Rankin County**

#### **Emeritus of Heritage House**

140 Castlewood Blvd. Brandon, MS 39042 (601) 919-1208 *Private Pay* 

#### **Jaquith Nursing Home**

Highway 468 PO Box 207, Building 78 Whitfield, MS 39193 (601) 351-8015 Accepts Medicaid

#### **Sharkey County**

#### Heritage Manor of Rolling Fork 431 West Race Street Rolling Fork, MS 39159 (662) 873-6218 Accepts Medicaid

#### **Stone County**

#### Stone County Nursing & Rehab Center 1436 E. Central Avenue Wiggins, MS 39577 (601) 928-1889 Accepts Medicaid

#### **Union County**

Sunshine Assisted Living 1645 State Highway 178 West Myrtle, MS 38650 (662) 988-3959

#### Washington County

Wellington Place of Greenville 1880 Fairgrounds Road Greenville, MS 38703 (662) 334-4646 *Private Pay* 

#### Wilkinson County

Wilkinson County Nursing Center 166 South Lafayette Street Centreville, MS 39631 (601) 645-5253 Accepts Medicaid

#### NOTES:

## **Alzheimer's Geriatric/Psychiatric Units**

#### Adams County

Natchez Regional Medical Center Senior Behavioral Unit 54 Seargent Prentiss Drive Natchez, MS 39121 (601) 443-2131

#### Attala County

Montfort Jones Memorial Hospital Senior Care 220 Highway 12 West Kosciusko, MS 39090 (662) 289-4311

#### **Calhoun County**

Calhoun Health Services Senior Care Unit 140 Burke/Calhoun City Rd. Calhoun City, MS 38916 (662) 628-6611

#### **Chickasaw County**

Trace Regional Hospital Trace Pathways 1004 East Madison Street Houston, MS 38851 (662) 456-1000 - Main Line -

#### **Claiborne County**

Claiborne County Hospital Patients Choice Senior Care Center 123 McComb Avenue Port Gibson, MS 39150 (601) 437-5141

#### **Copiah County**

Hardy Wilson Memorial Hospital Lakeview Mental Wellness Unit 233 Magnolia Street Hazlehurst, MS 39083 (601) 894-4541

#### **Covington County**

Covington County Hospital Senior Care 701 South Holly Street Collins, MS 39428 (601) 756-6711

#### Franklin County

Franklin County Memorial Hospital Senior Care Unit / Journeys 40 Union Church Road Meadville, MS 39653 (601) 384-8180

#### George County

George County Hospital 859 Winter Street Lucedale, MS 39452 (601) 947-3161 (601) 947-9101 - Health & Rehab

#### Grenada County

Grenada Lake Medical Center 960 Avent Drive Grenada, MS 38901 (662) 227-7000

#### Harrison County

Biloxi Regional Medical Center Seniors Harbor 150 Reynoir Street Biloxi, MS 39530 (228) 436-1104

#### Garden Park Medical Center Seasons Behavioral Health 15200 Community Road Gulfport, MS 39503 (228) 575-7115 - Geriatric/Psychiatric Info

#### **Hinds County**

Central MS Medical Center Geri-Psychiatric Unit 1850 Chadwick Dr Jackson, MS 39204 (601) 376-1000

MS Baptist Medical Center Geri-Psychiatric Unit 1225 North State Street Jackson, MS 39202 (601) 968-1000

## Alzheimer's Geriatric/Psychiatric Units (continued)

#### **Humphreys County**

Humphreys County Memorial Hospital Senior Care Unit 500 CCC Road Belzoni, MS 39038 (662) 247-3831 - Main Line

#### **Jefferson County**

Jefferson County Hospital 870 South Main Street Fayette, MS 39069 (601) 786-3401

#### **Jefferson Davis County**

Jefferson Davis Community Hospital Sojourners 1102 Rose Street Prentiss, MS 39474 (601) 792-1130

#### Jones County

South Central Regional Medical Center Senior Care 1220 Jefferson Street Laurel, MS 39441 (601) 426-4300 - Senior Care

#### Lauderdale County

Alliance Health Center 5000 Highway 39 North Meridian, MS 39303 (601) 483-6211

#### Lee County

North MS Medical Center Behavioral Health 4579 South Eason Tupelo, MS 38801 (662) 377-3161

#### **Leflore County**

Greenwood Leflore Hospital New Beginners for Elderly 1401 River Road Greenwood, MS 38935 (662) 459-7000

#### Marshall County

Alliance Healthcare System Alliance Senior Care 1430 Highway 4 East Holly Springs, MS 38635 (662) 551-3442 - Main Line

#### Monroe County

Pioneer Community Hospital of Aberdeen 400 South Chestnut Street Aberdeen, MS 39730-3335 (662) 319-2121

#### **Neshoba County**

Neshoba County General Hospital Senior Life 1001 Holland Avenue Philadelphia, MS 39350 (601) 663-1417 - Senior Life Program

#### Newton County

Pioneer Community Hospital of Newton Sojourners 193 Northside Drive Newton, MS 39345 (601) 683-0571

#### Panola County

Tri-Lakes Behavioral Health Center 155 Keating Road Batesville, MS 38606 (662) 563-5646 or (662) 561-4000

#### **Prentiss County**

Baptist Memorial Hospital - Booneville Senior Care 100 Hospital Street Booneville, MS 38829 (662) 720-5000 - Main Line

#### **Quitman County**

Quitman County Hospital Senior Care Unit 340 Getwell Drive Marks, MS 38646 (662) 326-8031

## Alzheimer's Geriatric/Psychiatric Units (continued)

#### **Rankin County**

Crossgates River Oaks/ Senior Care Program 350 Crossgates Boulevard Brandon, MS 39042 (601) 824-8654 - Senior Care Program (601) 825-2811 - Information

#### Scott County

Lackey Memorial Hospital 330 North Broad Street Forest, MS 39074 (601) 469-4151

#### **Scott Regional Hospital**

317 Highway 13 South Morton, MS 39117 (601) 732-6301

#### **Sharkey County**

Sharkey-Isaquena Community Hospital/ Senior Care Unit 47 South Fourth Street Rolling Fork, MS 39159 (662) 873-4395

#### Simpson County

Simpson General Hospital Senior Care 1842 Simpson, Highway 149 Mendenhall, MS 39114 (601) 849-7129 - Senior Care (601) 847-2221 - Main Line Intensive Outpatient (601) 847-9994

#### **Smith County**

Patient's Choice Medical Center 327 Magnolia Drive Raleigh, MS 39153 (601) 782-9997

#### **Sunflower County**

North Sunflower Medical Center Senior Care & Sunrise Outpatient Clinic 840 North Oak Avenue Ruleville, MS 38711 (662) 756-9910 - Senior Care Unit

#### **Tate County**

North Oak Regional Medical Center 401 Getwell Drive Senatobia, MS 38668 (662) 562-3100

#### **Tippah County**

**Tippah County Hospital** 1005 City Avenue North Ripley, MS 38663 (662) 837-9221

#### Warren County

River Region Health System Generations 2100 Highway 61 North Vicksburg, MS 39183 (800) 843-2131 or (601) 883-3288 - Behavioral Health Unit (601) 883-5000 - Main Line

#### Washington County

Delta Regional Medical Center/West Campus 300 S. Washington Avenue Greenville, MS 38701 (662) 378-2020

#### Winston County

Winston Medical Center/Turning Point 562 East Main Louisville, MS 39339 (662) 779-0173 - Turning Point Unit

#### Yazoo County

Kings Daughters Hospital 823 Grand Avenue Yazoo City, MS 39194 (662) 746-2261

## **Mississippi Legal Services**

## "Contact your Attorney" or Contact an Elder Law Attorney.

Consider consulting an Elder Law Attorney. The following are experienced elder law attorneys.

#### **Richard A. Courtney, CELA**

R. Scanlon Fraley Frascogna Courtney, PLLC Jackson, MS (601) 987-3000 / (866) 353-3752 www.frascourtlaw.com

#### Walt Dallas

Estate Planning 123 130 Riverview Drive, Suite A Flowood, MS 39232 (769) 798-2123 www.estateplanning123.com

#### David Dunn

Dunn & Hemphill, PA Columbus, MS (662) 327-4211 www.marketstreetlaw.com

#### A. M. Edwards, III

Wells, Moore, Simmons, Edwards & Wilbanks, PLLC Jackson, MS (601) 354-5400 www.wellsmoore.com

#### Jeramie J. Fortenberry

Fortenberry Legal P. O. Box 3479 Gulfport, MS 39505 (228) 206-4939 www.fortenberrylaw.com

#### William B. Howell

William B. Howell, Ltd. Jackson, MS Columbus, MS Diamondhead, MS (601) 978-1700 / 800-839-7857 www.msestate.com

#### J. Hale Freeland

Freeland Shull, PLLC 405 Galleria Lane, Suite C Oxford, MS 38655 (662) 234-1711 www.freelandshull.com Barry K. Jones

Wise, Carter, Child & Caraway, PA Jackson, MS (601) 968-5500 www.wisecarter.com

#### Robert M. Logan

Logan & May, PA Newton, MS (601) 683-7888

#### **Ronald Morton**

Morton Law Firm, PLLC 132 Fairmont Street, Suite A Clinton, MS 39056 5740 Getwell Road Southhaven, MS 38627 (601) 925-9797 www.mortonelderlaw.com

#### Jim Wilson

Wilson Elder Law Center Ocean Springs, MS Hattiesburg, MS (888) 423-3133 www.wilsonelderlaw.com

#### R. James Young

Wells, Marble & Hurst, PLLC P. O. Box 131 Jackson, MS 39205 (601) 605-6900 www.wellsmar.com

#### **Richard Young**

The Elder Law Firm of Mississippi, LLC 5500 Plaza Drive, Suite C Flowood, MS 39232 (601) 992-1437 www.theelderlawfirm.net

## **Mississippi Resources**

#### **AA Offices & Resource Centers**

#### Alzheimer's Association (AA)/

Mississippi Chapter 1900 Dunbarton Dr., Suite H Jackson, MS 39216 info@msalz.org www.alz.org/ms (601) 987-0020 TOLL FREE: 1 (800) 272-3900

#### Mississippi Adult Day Care Association

503 East Northside Drive Clinton, MS 39056 (662) 834-3509

#### **MSDMH Offices**

Division of Alzheimer's Disease & Other Dementias MS Department of Mental Health (MSDMH) 1101 Robert E. Lee Building 239 North Lamar Street Jackson, MS 39201-1311 www.dmh.state.ms.us (601) 359-1288 TOLL FREE: 1 (877) 210-8513

#### Division of Alzheimer's/ Boswell Regional Center

P.O. Box 128 Magee, MS 39111 kathy.vancleave@dmh.state.ms.us (601) 867-5000 ext. 75242

#### Division of Alzheimer's/ North MS Regional Center

967 Regional Center Drive Oxford, MS 38655 dianne.arnold@dmh.state.ms.us (662) 846-5335

#### Division of Alzheimer's/ South MS Regional Center

1170 W. Railroad Street Long Beach, MS 39560-4199 melora.jackson@dmh.state.ms.us (228) 214-5556

## Mississippi Resources (continued)

<b>MS Medicaid Office</b> 1 (800) 421-2408
Medicaid Fraud Control of MS, Office of the Attorney General(601) 359-4220
MS Social Security Disability1 (800) 772-1213
MS Department of Mental Health HelpLine1 (877) 210-8513
LA/MS Hospice Organization1 (888) 546-1500
MS Association of Home Care(601) 853-7533
MS Health Care Association(601) 956-3472
MS Independent Nursing Home Association
MS Southern Senior and Family Resources

## When You Need Help

#### State Ombudsman for Long-Term Care

For help with problems in residential care facilities .....1 (601) 359-4927

#### Aging and Adult Protective Services

Aging and Adult Services1 (800) 948-3090
Adult Protective Services 1 (800) 222-8000
Attorney General's Office, Vulnerable Adults
Department of Human Services1 (800) 345-6345

#### NOTES:

## Area Agencies on Aging (AAA)

Area agencies will make referrals for companions, homemaker services, transportation, meals and Medicaid waivers for adult day care. Call the agency in your area.

#### **Central MS Area Agency on Aging**

(601) 981-1511 or 1 (800) 948-3090 Copiah, Hinds, Madison, Rankin, Simpson, Warren, Yazoo

#### East Central Area Agency on Aging

(601) 683-2401 or 1 (800) 264-2007 Clark, Jasper, Kemper, Lauderdale, Leake, Neshoba, Newton, Scott, Smith

#### **Golden Triangle Area Agency on Aging**

(662) 324-4650 or 1 (800) 217-6909 Choctaw, Clay, Lowndes, Noxubee, Oktibbeha, Webster, Winston

North Central Area Agency on Aging (662) 283-2675 or 1 (888) 427-0714 Attala, Carroll, Grenada, Holmes, Leflore, Montgomery

## North Delta Area Agency on Aging

(662) 561-4100 or 1 (800) 844-2433 Coahoma, Desoto, Panola, Quitman, Tallahatchie, Tate, Tunica

#### NOTES:



#### Northeast MS Area Agency on Aging

(662) 728-7038 or 1 (800) 745-6961 Alcorn, Benton, Marshall, Prentiss, Tippah, Tishomingo

#### South Delta Area Agency on Aging

(662) 378-3831 or 1 (800) 898-3055 Bolivar, Humphreys, Issaquena, Sharkey, Sunflower, Washington

#### Southern MS Area Agency on Aging

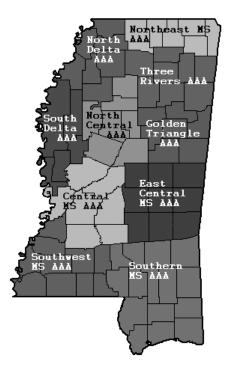
(228) 868-2311 or 1 (800) 444-8014 Covington, Forrest, George, Hancock, Jackson, Jones, Marion, Perry, Wayne, Greene, Harrison, Jefferson Davis, Lamar, Pearl River, Stone

#### Southwest MS Area Agency on Aging

(601) 446-6044 or 1 (800) 338-2049 Adams, Amite, Claiborne, Franklin, Jefferson, Lawrence, Lincoln, Pike, Walthall, Wilkinson

#### **Three Rivers Area Agency on Aging**

(662) 489-2415 or 1 (877) 489-6911 Calhoun, Chickasaw, Itawamba, Lafayette, Lee, Monroe, Pontotoc, Union



## **National Resources**

#### The Website for Family Caregiving Advocacy

1101 Vermont Ave, NW Suite 101 Washington, DC 20005 www.CaregiversCount.com

## Alzheimer's Disease Education and Referral Center (ADEAR)

#### and Referral Center (ADEAR)

P O Box 8250 Silver Spring, MD 20907-8250 1 (800) 438-4380 www.nia.nih.gov/Alzheimers/ adear@alzheimers.org

#### **Children of Aging Parents**

P O Box 7250 Penndel, PA 19047 1 (800) 227-7294 www.caps4caregivers.org caps4caregivers@aol.com

#### National Family Caregivers Association (NFCA)

10400 Connecticut Avenue, Suite 500 Kensington, MD 20895-3944 1 1 (800) 896-3650 www.thefamilycaregiver.org

#### National Council on Aging

300 D Street, SW Suite 801 Washington, DC 20024 1 (202) 479-1200 www.ncoa.org info@ncoa.org

#### The Eldercare Locator

1 (800) 677-1116 www.eldercare.gov eldercarelocator@n4a.org

#### Alzheimer's Association (National Headquarters)

225 North Michigan Avenue 17th Floor Chicago, IL 60601 1 (800) 272-3900 (24/7 Helpline) www.alz.org info@alz.org. 1 (800) 572-1122 (MedicAlert + Safe Return) www.alz.org/safereturn

#### National Caregiving Foundation

801 North Pitt Street #116 Alexandria, VA 22314-1765 1 (800) 930-1357 www.caregivingfoundation.org

#### Family Caregiver Alliance

690 Market Street Suite 600 San Francisco, CA 94104 1 (800) 445-8106 www.caregiver.org info@caregiver.com

#### **Today's Caregiver**

PO Box 2l646 Ft Lauderdale, FL 33335 1 (800) 829-2734 www.caregiver.com editor@caregiver.com

#### Administration on Aging

Washington, DC 20201 1 (202) 619-0724 www.aoa.gov aoainfo@aoa.gov

#### Centers for Medicare & Medicaid Services (CMS)

7500 Security Boulevard Baltimore, MD 21244-1850 1 (877) 267-2323 www.cms.gov

#### National Hospice & Palliative Care Organization

1700 Diagonal Road, Suite 625 Alexandria, VA 22314 (703) 837-1500 (703) 837-1233 (fax) 1 (800) 658-8898 (HelpLine) www.caringinfo.org caringinfo@nhpco.org

#### **Veterans Benefits**

1 (800) 827-1000 www.vba.va.gov/VBA/

## National Resources (continued)

#### Senior Citizens Resources/USA.gov

U.S. General Services Administration Office of Citizen Services and Communications Suite G-142 1800 F Street, NW Washington, DC 20405 1 (800) 333-4636 http://www.usa.gov/Topics/Seniors.shtml

#### Cuidando con Cariño

Compassionate Care HelpLine 1 (877) 658-8896 www.hispanichealth.org cuidando@hispanichealth.org

### Forest Laboratories – NAMENDA (MEMANTINE)

1 (877) 262-6363 www.Namenda.com

Novartis – EXELON 1 (877) 636-6794 www.AlzheimersDisease.com

Ortho - McNeil - RAZADYNE 1 (800) 526-7736 www.razadyneer.com

**Pfizer** – ARICEPT 1 (800) 294-8490 www.aricept.com

#### NOTES:

## **More Helpful Websites**

#### **Alzheimer's Disease**

http://www.alz.org

#### Hispanic Resources:

http://www.alz.org/espanol http://www.alz.org/hispanic/grandpa.asp http://www.alz.org/hispanic/grandpa.asp http://www.alzheimers http://www.alzcast.org http://www.alzcast.org http://www.alzinfo.org http://www.healthcentral.com/alzheimers http://www.alzheimersweekly.com http://www.alzheimersweekly.com http://www.alzbrain.org http://www.memorybridge.org

#### Dementia

http://www.dementiaguide.com http://www.lbda.org http://www.hdsa.org http://www.cjdfoundation.org http://www.apdaparkinson.org http://www.hydroassoc.org http://www.ftd-picks.org http://www.nnpdf.org

## **Caregiving - General**

http://www.nfcacares.org http://www.caregivinghelp.org http://www.agis.com http://www.carepages.com http://www.fullcirclecare.org http://www.fullcirclecare.org http://www.fullcirclecare.org http://www.fullcirclecare.org http://www.fullcirclecare.org http://www.fullcirclecare.org http://www.caregiverstress.com

## Hospice

http://www.hospicefoundation.org http://www.elderhope.com

### **Therapeutic Care Approaches**

http://www.secondwind.org/virtualdementiatour.html http://www.snoezeleninfo.com/main.asp http://www.myersresearch.org http://www.learningtospeakalzheimers.com

#### Brain Games

http://www.lumosity.com http://www.brain.com http://www.sharpbrains.com http://www.photographic-memory.org http://www.fitbrains.com http://www.dakim.com http://www.dakim.com http://www.happy-neuron.com

### **Professional Training**

http://www.elearning.alz.org http://www.hcinteractive.com/professional cares http://www.alz.org/qualitycare

#### NOTES:

## **Suggested Reading**

Bell, Virginia and Troxel, D, *Dignified Life. The Brest Friends Approach to Alzheimer's Care.* Health Professional Press, 2004

Brackey, Jolene, Creating Moments of Joy. Purdue University Press, 2008.

Broyles, F. *Coach Broyles' Playbook for Alzheimer's Caregivers.* Alzheimer's Association, 2006.

Byrd, Lisa, PhD, Caregiver Survival 101: Strategies to Manage Problematic Behaviors Presented in Individuals with Dementia.

Camp, C. Montessori -Based Activities for Persons with Dementia.

Coste, Joanne K., Learning to Speak Alzheimer's. Mariner Books, 2004.

Genova, Lisa, Still Alice. iUniverse, Inc, New York, 2007.

Hoblitzelle, Olivia, *Ten Thousand Joys and Ten Thousand Sorrows: A Couple's Journey Through Alzheimer's*. Tarcher/Penguin, 2010.

Mace, N. and Rabins, P., *The 36-Hour Day*, 4th Ed. A Johns Hopkins Press Health Book, 2006.

Shamy, E, *Guide to the Spiritual Dimension of Care for People with AD and Related Dementia*. Colcom Press, 2003.

Shifton, L. Bowlby, *Alzheimer's Journey: A Compass for Caregivers*. Health Professional Press, Jan. 2004.

Shriver, Maria, *What's Happening to Grandpa?* Little, Brown Books for Young Readers, 2004.

Snyder, Lisa, *Living Your Best with Early Stage: An Essential Guide.* Sunrise River Press, 2010.

Spence, R. And White, L. Alzheimer's Disease and Related Illnesses.

Warner, M, *Complete Guide to Alzheimer's-Proofing Your Home.* Revised and Updated, Purdue University Press, 2000.

White, L. and Spencer, B., *moving a Relative with Memory Loss.* Whisp Publications, 2006.

## **Suggested DVDs**

Alzheimer's Project, HBO Documentary, www.HBO.com/alzheimersproject.

Bathing Without Battle: Personal Care of Individuals with Dementia. www.bathingwithoutabattle.com.unc.edu.

Best Friends/Terra Nova Films. www.terranova.org.

Dementia Care -- Sundowning. www.aduhs.com.

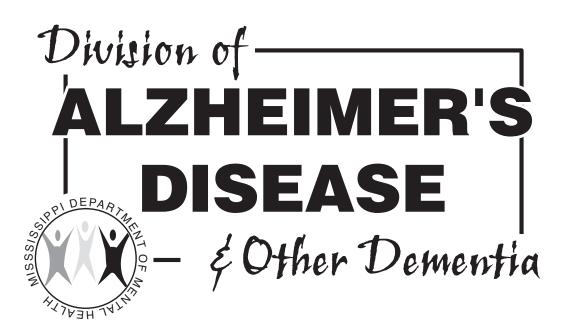
Dementia with Dignity/Terra Nova Films. www.terranova.org.

*Forgetting, The: A Portrait of Alzheimer's, Stories of Love, Courage, and Hope/*Twin Cities Public Television. www.shop <u>bs.org</u>.

Learning to Speak Alzheimer's: An Introduction to the Habitation Approach to Care. www.Aquariusproductions.com

Savvy Caregiver: A Caregiver's Manual. www.memorylossdvd.com.

Mississippi Department of Mental Health Division of Alzheimer's Disease and Other Dementia Contact Information



KATHY VAN CLEAVE, LMSW, LCMHT Director

Mississippi Department of Mental Health Division of Alzheimer's Disease and Other Dementia Boswell Regional Center P.O. Box 128 • Boswell, MS 39111 (601) 867-5000, ext. 75242 kathy.vancleave@dmh.state.ms.us

MELORA JACKSON, MS, CMHT Mississippi Department of Mental Health Division of Alzheimer's Disease and Other Dementia South Mississippi Regional Center 1170 W. Railroad St. • Long Beach, MS 39560 (228) 214-5556 melora.jackson@dmh.state.ms.us

#### DIANNE ARNOLD, MEd, LPC

Mississippi Department of Mental Health Division of Alzheimer's Disease and Other Dementia North Mississippi Regional Center 967 Regional Center Dr. Oxford, MS 38655 (662) 846-5335 dianne.arnold@dmh.state.ms.us

MS DEPT OF MENTAL HEALTH CENTRAL OFFICE 1101 Robert E. Lee Building 239 North Lamar St. Jackson, MS 39201 (601) 359-1288, or toll-free: 1-877-210-8513 Fax: (601) 359-9570

## www.dmh.ms.gov

# alzheimer's $\{S\}$ association<sup>®</sup>

## our mission

To eliminate Alzheimer's disease through the advancement of research; to provide and enhance care and support for all affected; and to reduce the risk of dementia through the promotion of brain health.

## learn

Family Orientations - Provide an introduction to Alzheimer's disease and the association's programs and services for those new to the disease.

**Community Education** - A variety of quality seminars and classes for people with early dementia, family caregivers and professionals, including: Early Memory Loss: Tools for Successful Living; Communication and Behavior; Driving & Dementia; and Know the 10 Signs.

**Professional Education** - The Association's Foundations of Dementia Care program provides evidence-based, specialized training for direct care staff in residential and community settings. Modules include: Enhancing Mealtime; Reducing Pain; Reducing Risk for Falls and many more.

essentiALZ<sup>™</sup> - This certification program is a convenient way for individuals to be recognized for learning guality dementia care practices. The program combines select HealthCare Interactive® CARES® online dementia care trainings with Alzheimer's Association certification exams. Family members as well as professional care providers can benefit from essentiALZ.

**Trial Match<sup>™</sup>** - This online tool matches you with current local clinical research trials based on your location, diagnosis and preferences. Visit alz.org/trialmatch.

connect with us

www.alz.org/ms

www.facebook.com/alzms

www.twitter.com/alzassocmiss

## get support

Helpline - 1.800.272.3900 is our 24/7 service dedicated to providing information, resources and support for families and professionals. Family Consultants assist callers to identify their needs, provide appropriate literature and community resource information.

**Care Consultation** - Offers families an opportunity to meet with a Family Consultant for support and guidance in addressing the needs of the person with Alzheimer's disease or dementia. We provide education about the disease, community resources, and assistance with problem-solving and care-planning.

Support Groups - More than 40 support groups hold regular meetings throughout Mississippi. Groups are offered for family caregivers and people with early dementia to gain emotional support and exchange coping skills. All groups are led by trained facilitators.

MedicAlert® + Safe Return® - A national registry that assists families and emergency responders when an individual with Alzheimer's is missing.

## contribute

Advocacy - Alzheimer's advocates are calling for advancements in research, enhanced care and support at the federal, state and local levels. Your voice can make a difference.

Volunteer - Please join us in helping achieve our vision of creating a world without Alzheimer's disease while optimizing quality of life for people who are affected by Alzheimer's disease and other dementia.

Donate - Our Chapter's funding comes from individuals, foundations, and corporations - people like you. Your gift makes a difference in the lives of families living with Alzheimer's disease and related dementia by providing supportive services and funding research to improve treatment and find a cure.

## Alzheimer's Association **Mississippi Chapter**

196 Charmant Place, Suite 4 Ridgeland, MS 39157 601.987.0020 (phone) 601.853.0850 (fax) info@msalz.org



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