

Navigating Alzheimer's and Related Dementias

A Roadmap for Families

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Foreword

Navigating Alzheimer's and Related Dementias – A Roadmap for Families is a consolidated source to assist families as they live through the disease process. It was designed primarily for family caregivers and is intended to supplement rather than replace the recommendations of physicians and other health care professionals providing direct care to you or your loved one.

The information contained in Navigating Alzheimer's and Related Dementias is a compilation of publications from the National Institutes of Health, the National Institute on Aging, the Centers for Disease Control and Prevention, and other reputable sources. Contributors to the guide include Alzheimer's Mississippi, The MIND Center at the University of Mississippi Medical Center, and The Mississippi Department of Mental Health. Many thanks to the following individuals who dedicated countless hours to the development of this resource: Kathy Van Cleave, Denise Lafferty, Patty Dunn, TJ Harvey, Sue Ann Meng, Melora Jackson, Rebecca Brookshire, Andi Agnew, Jennifer Knight, Maria Allen, and Virgilio Guardado. Every effort has been made to assure the accuracy of resources known to the collaborators at the time of this printing. Please direct any questions you might have, or recommended additions or changes, to one of the contributors listed below.

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1. Overview of Dementia

1.1 Prevalence

Alzheimer's disease (AD) was identified over 100 years ago but research into its causes, risk factors and symptoms has progressed in only the last 35 years. 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 type of dementia or the loss of intellectual abilities, thinking, remembering and reasoning – severe enough to interfere with a person's activities of daily living at work or at home.



- Over 5 million Americans are living with Alzheimer's disease, including an estimated 53,000 in Mississippi.
- By 2050, that number is projected to rise to 16 million Americans.
- Alzheimer's disease is:
 - One of the top 10 causes of death in the United States.
 - The 6th leading cause of death among US adults.
 - The 5th leading cause of death among US adults aged 65–85 years.
 - The only cause of death among the top 10 in the US without a way to prevent it, cure it, or even slow its progression.

Death rates for Alzheimer's disease are increasing, unlike heart disease and cancer death rates that are on the decline. Dementia, including Alzheimer's disease, has been shown to be underreported in death certificates and therefore the proportion of older people who die from Alzheimer's may be considerably higher.

The current growth in both the number and proportion of older adults in America is on the rise. This growth in numbers is driven by Americans living longer and growth in proportion due to the baby boom generation.

According to the Centers for Disease Control and Prevention (“CDC”), the baby boom generation has begun to reach the age range where the risk of developing Alzheimer’s disease is elevated.

In America in 2016, over 15 million families and friends provided 18.2 billion hours of unpaid care to those with Alzheimer’s disease and other demetias - care valued at \$220.1 billion. In Mississippi in 2016, over 206,000 families and friends provided an estimated 234 million hours of unpaid care to those with Alzheimer’s disease and other dementias - care valued at \$2.9 billion.

1.2 What is Alzheimer’s?

Alzheimer’s disease (pronounced AHLZ-hi-merz) is one of several disorders that cause 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 type of dementia.

1.2.1 Dementia

All dementias are now identified as Major or Mild Neurocognitive Disorders in the Diagnostic and Statistical Manual of Mental Disorders Version 5 (DSM5). The DSM5 includes all diagnosis references for mental or brain disorders. 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 may 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).

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)

1.2.2 Disorders that Cause Dementia / Neurocognitive Disorders

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 Neurocognitive Disorder

In mild neurocognitive disorder, 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 mild neurocognitive disorder 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 mild neurocognitive disorder progresses to Alzheimer's or another kind of dementia.

Alzheimer's Disease / Major Neurocognitive Disorder due to 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 in the brain called plaques and tangles.

Vascular Dementia (VaD) / Vascular Neurocognitive Disorder

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." Once called "multi-infarct 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. 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 / Neurocognitive Disorder due to Multiple Etiologies

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 worsen slowly.



Dementia with Lewy Bodies (DLB) / Neurocognitive Disorder with Lewy Bodies

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) / Neurocognitive Disorder due to Parkinson’s Disease

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) / Frontotemporal Neurocognitive Disorder

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, excessive excitement, or repetitive behaviors. They may have an unusually strong urge to eat and gain weight as a result.

Traumatic Brain Injury / Neurocognitive Disorder due to Traumatic Brain Injury (TBI)

Traumatic brain injury occurs when there has been an impact to the head or rapid head movement/displacement of the brain within the skull. It usually involves an injury with loss of consciousness, some immediate amnesia, disorientation and confusion. There is the risk of seizures, visual issues, and paralysis. The neurocognitive disorder presents immediately after the injury and persists past recovery.

Creutzfeldt-Jakob Disease (CJD) / Neurocognitive Disease due to Prion Disease

Prion disease is an infection of the brain that is transmissible. One of the human prion diseases is Creutzfeldt-Jakob disease (pronounced CROYZ-felt YAH-cob), a rare, rapidly fatal disorder affecting about 1 in a million people per year worldwide. It usually affects individuals older than 60. 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

1.2.3 Rare or Less Common Types of Dementia

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:

- 1 Impairment in memory, thinking, and reasoning
- 2 Changes in personality and behavior
- 3 Depression or agitation also tend to occur early
- 4 Problems with movement may be present from the beginning or appear shortly after the other symptoms

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.

Normal Pressure Hydrocephalus (NPH)

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.

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

A person’s responses are delayed, but they are usually accurate and appropriate to the situation.

Huntington’s Disease (HD) / Neurocognitive Disorder due to Huntington’s Disease

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 / Substance- or Medication-Induced Neurocognitive Disorder

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 high-dose thiamine may reverse some, but usually not all, of the damage. In later stages, damage is more severe and does not respond to treatment.

Other substances such as inhalants or some prescription medicines, including sleep medicines, with chronic use can cause dementia.

Down Syndrome

Although it is well known that older people are at higher risk for Alzheimer's disease and dementia, it is less well known that individuals with Down syndrome, are almost at 100% risk of getting the disease. Identifying cognitive decline in people with Down syndrome can be challenging because cognitive difficulties can be related to lifelong deficits or to changes resulting from dementia. Common symptoms include memory loss, disorientation, changes in personality, behavior and speech. Behavioral and personality changes can include aggression, irritability, apathy, and decreased social engagement. People with Down syndrome and Alzheimer's disease may also experience neurological symptoms including seizures and myoclonus – the sudden, involuntary jerking of muscle – to a greater extent than the general population with Alzheimer's disease. Assessing for cognitive impairment with someone with an Intellectual and Developmental Disability (IDD) is

often difficult. It is important to establish a baseline level of functioning between the ages of 25–40 for persons with Down syndrome, and at age 50 for persons with other intellectual disabilities. Periodic reassessments are recommended to identify substantial changes in individuals.

Delirium

Delirium is an acute occurrence of confusion, lack of attention, or inability to make decisions, and at times involves hallucinations and delusions. Delirium occurs in a short period of time and is usually reversible with the treatment of the underlying medical condition. Also, persons with dementia are much more likely to develop a delirium after surgery or with an acute illness. The symptoms of delirium usually resolve and the individual returns to their previous level of functioning with identification of the medical causation and treatment. Many times, persons with moderate to severe dementia cannot verbally identify symptoms of illness. The caregiver may first notice a significant change in mental functioning that would be identified as delirium, which would be an indicator of medical illness.

Unraveling the Mystery of Dementia

Dementia is an umbrella term and Alzheimer's is the most prevalent type of dementia.

1.3 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.

1.3.1 Biology of Alzheimer's Disease

There are two abnormal deposits 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 Tau 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.

1.3.2 Age, Family History and Genetics

Studies have shown that the greatest risk factor for developing AD is increasing age and as many as 11 percent of all people, 65 years of age and older, have Alzheimer's. 1 in 2 people 85 years of age 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. Research shows that the high risk of vascular disease among African Americans contributes to their increased risks.

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

1.3.3 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

Data indicates that in the U.S., older African Americans are twice as likely and Hispanics one and one half times more likely to have Alzheimer’s and other dementias as older whites.

1.4 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

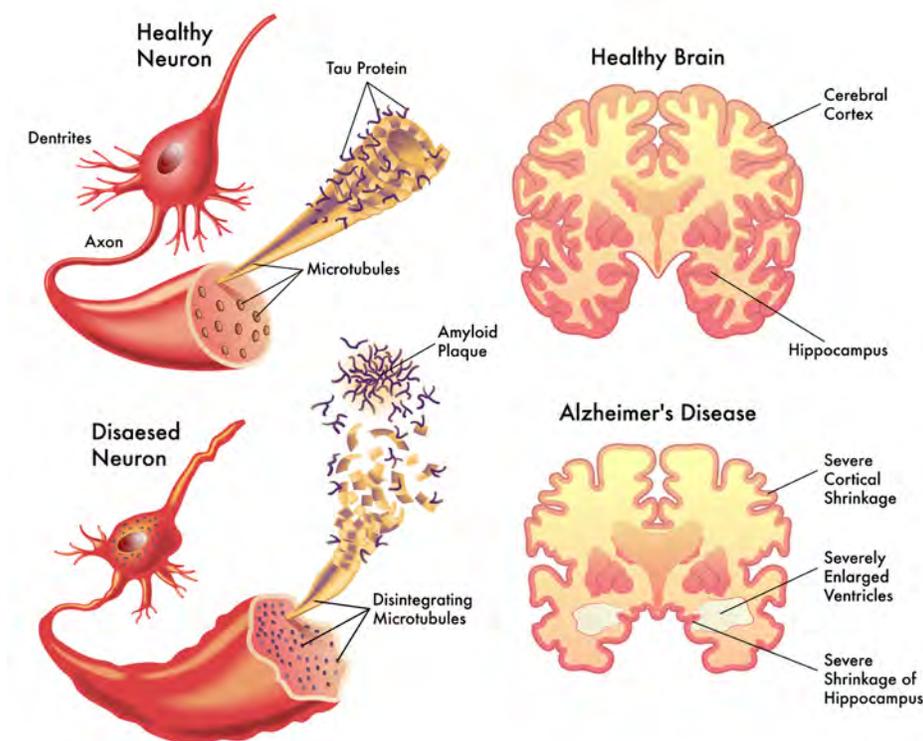
The personalities of people with dementia can change dramatically. They may become extremely confused, suspicious, fearful or dependent on a family member. **What's normal?** People's personalities do change somewhat with age.

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.

1.5 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.

1.6 Stages of Alzheimer's Disease

1.6.1 Early Stage 2 to 4 Years in Duration from the Time of Diagnosis

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 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 in routine
- May get sad or cry

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

Remember

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

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

1.6.3 Middle Stage 2 to 10 Years Duration after Diagnosis (longest 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.

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
- May get sad or cry

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

1.6.5
Late Stage
1 to 3
Years Duration

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.

Characterized by the inability to recognize family or self in mirror

- Needs help bathing, dressing, eating and toileting
- Looks in mirror and talks to own image
- May groan, scream, or make grunting sounds
- May put everything in mouth or touch everything
- Cannot communicate with words
- Cannot control bowel or bladder function
- May have seizures, swallowing difficulties and skin infections
- Loses weight even with a good diet

How you can help

- Repeat questions or instructions often
- Give lots of time to respond
- Show them instead of asking (show them a cup when asking if thirsty)
- Keep talking even if a verbal response is not received
- Touch in a kind way
- Use touch with words to communicate
- Give plenty of liquids
- Read or play music

Strengths that remain

- Ability to hear
- Reaction to loud noise
- Capability of feeling touch

2. Diagnosis and Treatment

2.1 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 dementias.

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, gerontologist).



1 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, MRI or PET 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

2 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.
- 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.

A medical information form that will help you document details your doctor may need can be found at the end of section 2.

3 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.

4 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 plan for the future
- Lessened anxieties about unknown problems
- Increased chances of participating in clinical drug trials and helping advance research
- An opportunity to participate in decisions about care, transportation, living options, financial and legal matters
- Time to develop a relationship with doctors and care partners
- To benefit from care and support services, making it easier for them and their family to manage the disease

Questions to Ask Your Doctor

Source:
Mayo Clinic,
National Institute
on Aging,
and National
Institutes
of Health

Writing down a list of questions can help you make the most of your appointment. If you're seeing your doctor regarding concerns about Alzheimer's disease, some questions to ask include:

- Is my degree of memory change normal for someone my age?
- If not, do you think my symptoms might be due to Alzheimer's disease?
- What tests do I need?
- If my diagnosis is Alzheimer's disease, will you or another doctor manage my ongoing care? Can you help me get a plan in place for ongoing care?
- What treatments or programs are available? How effective are these treatments?
- Will medications help? What are the possible side effects?
- Are there any clinical trials of experimental treatments I should consider?
- How will my disease likely progress over time?
- Will my new symptoms affect how I manage my other health conditions?
- Do you have any brochures or other printed material I can take home with me?
- What websites and support resources do you recommend?
- What can I expect from you (my doctor)?

Your doctor is also likely to have questions for you. Being ready to respond may free up time to focus on any points you want to talk about in-depth. Your doctor may ask:

- What kinds of memory difficulties and mental lapses are you having?
- When did you first notice them?
- Are they steadily getting worse, or are they sometimes better and sometimes worse?
- Have you stopped doing certain activities, like managing finances or shopping because these activities were too mentally challenging?
- Do you feel any sadder or more anxious than usual?
- Have you gotten lost lately on a driving route or in a situation that's usually familiar to you?
- Has anyone expressed unusual concern about your driving?
- Have you noticed any changes in the way you tend to react to people or events?
- Do you have more energy than usual, less than usual or about the same?
- What medications are you taking? Are you taking any vitamins or supplements?
- Do you drink alcohol? How much?
- Have you noticed any trembling or trouble walking?
- Are you having any trouble remembering your medical appointments or when to take your medication?
- Have you had your hearing and vision tested recently?

- Did anyone else in your family ever have memory trouble?
- Was anyone ever diagnosed with Alzheimer's disease or dementia?
- Do you act out your dreams while sleeping (punch, flail, shout, scream)?
- Do you snore?
- Are you depressed?
- How is your mood?

2.1.1 Tests for Alzheimer's Disease and Dementia

There's no specific test today that confirms you have Alzheimer's disease. Your doctor will make a judgment about whether Alzheimer's is the most likely cause of your symptoms based on the information you provide and results of various tests that can help clarify the diagnosis.

Doctors can nearly always determine whether you have dementia, and they can often identify whether your dementia is due to Alzheimer's disease. The diagnosis of Alzheimer's disease has been improved through the introduction of PET scanning of the brain using specialized tracers that allow visualization of the plaques and tangles characteristic of the disease and previously observable only after death by autopsy.

To help distinguish Alzheimer's disease from other causes of memory loss, doctors now typically rely on the following types of tests.

1 Physical and Neurological Exam

Your doctor will perform a physical exam, and is likely to check your overall neurological health by testing your:

- Reflexes
- Muscle tone and strength
- Ability to get up from a chair and walk across the room
- Sense of sight and hearing
- Coordination
- Balance

2 Lab Tests

Blood tests may help your doctor rule out other potential causes of memory loss and confusion, such as thyroid disorders, sexually transmitted diseases (e.g. syphilis), or vitamin deficiencies.

3 Mental Status and Neuropsychological Testing

Your doctor may conduct a brief mental status test to assess your memory and other thinking skills. In addition, your doctor may suggest a more extensive assessment of your thinking and memory. Longer forms of neuropsychological testing may provide additional details about your mental function compared with others' of a similar age and education level.

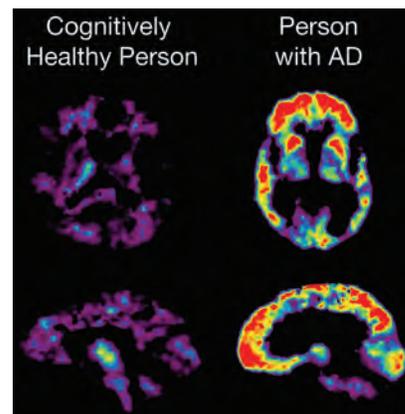
4 Brain Imaging

Images of the brain are now used chiefly to pinpoint visible abnormalities related to conditions other than Alzheimer's disease – such as strokes, trauma or tumors – that may cause cognitive change. New imaging applications – currently used primarily in major medical centers or in clinical trials – may enable doctors to detect specific brain changes caused by Alzheimer's.

Brain-imaging Technologies include:

Magnetic resonance imaging (MRI). An MRI uses radio waves and a strong magnetic field to produce detailed images of your brain. MRIs are used to rule out other conditions that may account for or be adding to cognitive symptoms. In addition, they may be used to assess whether shrinkage in brain regions implicated in Alzheimer's disease has occurred.

Computerized tomography (CT). A CT scan produces cross-sectional images (slices) of your brain. It's currently used chiefly to rule out tumors, strokes and head injuries.



Positron emission tomography (PET). During a PET scan, you'll be injected in a vein with a low-level radioactive tracer. The tracer may be a special form of glucose (sugar) that shows overall activity in various brain regions.

This can show which parts of your brain aren't functioning well. New PET techniques are able to detect your brain level of plaques (amyloid) and tangles (tau), the two hallmark abnormalities linked to Alzheimer's. However, these new PET techniques are generally found in research settings or in clinical trials.

5 Cerebrospinal Fluid

In special circumstances such as rapidly progressive dementia or very young onset dementia, a cerebrospinal fluid examination may be performed. The spinal fluid can be tested for biomarkers that indicate the likelihood of Alzheimer's disease.

6 The Genetics of Disease

Some diseases are caused by a genetic mutation, or permanent change in one or more specific genes. If a person inherits from a parent a genetic

mutation that causes a certain disease, then he or she will usually get the disease. Sickle cell anemia, cystic fibrosis, and early-onset familial Alzheimer's disease are examples of inherited genetic disorders.

In other diseases, a genetic variant may occur. A single gene can have many variants. Sometimes, this difference in a gene can cause a disease directly. More often, a variant plays a role in increasing or decreasing a person's risk of developing a disease or condition. When a genetic variant increases disease risk but does not directly cause a disease, it is called a genetic risk factor. Identifying genetic variants may help researchers find the most effective ways to treat or prevent diseases such as Alzheimer's in an individual. This approach, called precision medicine, takes into account individual variability in genes, environment and lifestyle for each person.

6.a Early-Onset Alzheimer's Disease

Early-onset Alzheimer's disease occurs in people age 30 to 60 and represents less than 5% of all people with Alzheimer's. Most cases are caused by an inherited change in one of three genes, resulting in a type known as early-onset familial Alzheimer's disease, or FAD. For others, the disease appears to develop without any specific, known cause. A child whose biological mother or father carries a genetic mutation for early-onset FAD has a 50/50 chance of inheriting that mutation. If the mutation is in fact inherited, the child has a very strong probability of developing early-onset FAD.

6.b Late-Onset Alzheimer's Disease

Most people with Alzheimer's have the late-onset form of the disease, in which symptoms become apparent in the mid-60s and later. The causes of late-onset Alzheimer's are not yet completely understood, but they likely include a combination of genetic, environmental, and lifestyle factors that affect a person's risk for developing the disease. Researchers have not found a specific gene that directly causes the late-onset form of the disease. However, one genetic risk factor – having one form of the apolipoprotein E (APOE) gene on chromosome 19 – does increase a person's risk.

6.c Genetic Testing

A blood test can identify which APOE alleles a person has, but results cannot predict who will or will not develop Alzheimer's disease. It is unlikely that genetic testing will ever be able to predict the disease with 100% accuracy, researchers believe, because too many other factors may influence its development and progression. Currently, APOE testing is used in research settings to identify study participants who may have an increased risk of developing Alzheimer's. This knowledge helps scientists look for early brain changes in participants and compare the effectiveness of treatments for people with different APOE profiles. Most researchers believe that APOE testing is useful for studying Alzheimer's disease risk in large groups of people but not for determining any one person's risk.

7 Montreal Cognitive Assessment (MoCA)

The MoCA is also a cognitive screening tool with 30 items that indicate level of functioning. The screening evaluates visuospatial/executive functioning (decision making), naming, attention, language, calculation, short term memory, and orientation. The MoCA is used more commonly to evaluate driving ability. The scoring is similar to the MMSE.

2.2 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 HCl) 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.

2.3 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.



Behavioral interventions should be investigated and given a trial before using medications to control symptoms or behaviors. 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:

Get Medical Advice

Be cautious about giving any medication-whether it's an over-the-counter 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 Careful

- Under no circumstances should you change dosages without first consulting your physician.
- 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.

Be Candid and Direct

- Giving medication in a specific way at specific times of the day or evening will help to reduce conflicts.

- 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.
- Some caregivers find it useful to give medications in individual cups or envelopes or to keep a calendar and check off 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. Check with your pharmacist before altering medication.

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 they aren’t picked up and eaten by children or pets.
- Avoid leaving the person alone with medication bottles in the room.
- Be sure to properly discard all old medicines.

Be Prepared for Emergencies

- Write down 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.

Fast Facts

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

- Aricept
- Exelon
- Razadyne

Prescription drugs for treatment of moderate to severe stages include:

- Namenda
- Namzaric

Medications to Treat Alzheimer's Disease

This brief summary does not include all information important for patient use and should not be used as a substitute for professional medical advice.

(National Institute on Aging; Alzheimer's Disease Education and Referral Center)

Aricept® / Donepezil: Mild, moderate and severe Alzheimer's

Potential Side Effects

Nausea, vomiting, diarrhea, muscle cramps, fatigue, weight loss.

For current information about this drug's safety and use, visit:

www.aricept.com/prescribing-and-patient-info

Exelon® / Rivastigmine: Mild to moderate Alzheimer's (patch is also for severe Alzheimer's)

Potential Side Effects

Nausea, vomiting, diarrhea, weight loss, indigestion, muscle weakness.

For current information about this drug's safety and use, visit:

www.fda.gov/Drugs

Click on "Drugs@FDA," search for Exelon, and click on drug-name links to see "Label Information"

Namenda® / Memantine: Moderate to severe Alzheimer's

Potential Side Effects

Dizziness, headache, diarrhea, constipation, confusion

For current information about this drug's safety and use, visit:

www.namenda.com and **www.namendaxr.com**

Click on "Full Prescribing Information" to see the drug label

Namzaric® / Memantine extended-release and Donepezil: Moderate to severe Alzheimer's

Potential Side Effects

Headache, nausea, diarrhea, dizziness

For current information about this drug's safety and use, visit:

www.namzaric.com

Click on "Full Prescribing Information" to see the drug label

Razadyne / Galantamine: Mild to moderate Alzheimer's

Potential Side Effects

Nausea, vomiting, diarrhea, decreased appetite, dizziness, headache

For current information about this drug's safety and use, visit:

www.janssenmd.com/pdf/razadyne/PI-Razadyne-RazadyneER.pdf

to see drug label

2.4 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 loss of memory and cognitive skills.

In the early stages of the disease, people with Alzheimer's may exhibit symptoms such as irritability, anxiety, or depression. As the disease progresses, other symptoms may occur, including sleep disturbances, delusions (firmly believing in things that are not real), hallucinations (seeing, hearing, smelling or feeling things that are not there), pacing, constant movement or restlessness, checking and rechecking door locks or appliances, tearing paper 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.

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.

2.4.1 Behavioral Intervention for Agitation

There are two distinct types of treatments for 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 causes, if possible, 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

A key principle to intervention is redirecting the affected person's attention rather than arguing, disagreeing or being confrontational with the person. Arguing usually increases agitation and does not have positive benefits. As a caregiver, we can understand logic but the person may not be able to logically think through what you are asking them to do.

The most important step a caregiver can take to learn and cope with behavioral symptoms is to attend a support group in your area.

Additional intervention strategies include:

- Increase lighting to reduce confusion during the day
- Decrease lighting to reduce restlessness at night
- Equipping doors and gates with safety locks
- Using labels or notes to cue or remind the person
- Simplifying the environment
- Simplifying tasks and routines
- Allowing adequate rest between stimulating events
- Engaging persons in productive activities (folding clothes, rearranging drawers, or sanding wood blocks)
- Removing guns, power tools, or other implements that may be dangerous

2.4.2 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 medications. Antipsychotic medications now carry a black box warning of increased risk of death for persons with dementia.

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.

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

Potential side effects of these drugs include:

- **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.
- **Increased agitation**
- **Sleep difficulties**
- **Decreased balance/increased risk of falls**
- **Dry mouth**
- **Constipation**
- **Dehydration**

Information to Gather Before Calling a Health Care Provider about a New or Worsening Medical or Behavioral Issue

When talking with a health professional, have a list of the person's current medications and allergies, plus the name and phone numbers of their pharmacy.

Patients Name

Date of Birth (mm/dd/yyyy)

Name of Person Completing Form

Phone Number

Relationship to the Person with Dementia

Today's Date (mm/dd/yyyy)

Time Completed (AM/PM)

Insurance (check all that apply and provide policy numbers)

- Medicare A Medicare B Private Medicare
 Medicaid Veterans Private Insurance

Policy Number and Company if applicable

Describe the problem in detail. Include when it started, what you think might be causing the problem, and any things you have done to help relieve the problem.

Does the person NOW appear normal or back to normal? Yes No Not Sure

If no or not sure, what is different? _____

Vital Signs (Record all that are available)

- Heart Rate (pulse) Beats: _____ Per Minute
 Breathing Rate (respiratory) Breaths: _____ Per Minute
 Temperature Degrees: _____ Fahrenheit Celsius
 Blood Pressure _____ / _____ mmHg

Provide a little background about the person's demetia: (check one)

- Very Early Mild Moderate Severe Very Severe

To the best of your knowledge, what is the diagnosis? _____

Has the person started, stopped, or changed a medication within the last two weeks?

- Don't Know No Yes

If yes, what was the change? _____

If there is anything about the person's medical history that you feel may be especially relevant to this problem. list and describe it here:

Is there anything in particular that you are worried about or want to know?

Yes

No

If yes, please explain: _____

Personal Health Record

Family / Friends to Contact in Emergency

1 _____

Name

Relationship

Home Phone

Mobile Phone

2 _____

Name

Relationship

Home Phone

Mobile Phone

Hospital of Choice: _____

Location: _____

Care Preferences (Check All That Apply)

Do everything, including resuscitation and breathing tube

Has a legal document stating preferences for limiting care (e.g., living will or DNR)

Power of attorney for health care decisions

Name

Phone

Other

Main Medical Problems

1 _____

2 _____

3 _____

4 _____

5 _____

Current Medications

_____/_____/_____
(MM/DD/YYYY)

1 _____

Name

Dose / Times Per Day

2 _____

Name

Dose / Times Per Day

3 _____

Name

Dose / Times Per Day

4 _____

Name

Dose / Times Per Day

Medication Allergies

1 _____

Medication Name

Type of Reaction

2 _____

Medication Name

Type of Reaction

Recent Immunizations (Recommended Frequency)

Flu (every year)

Last Received _____

Pneumonia (once)

Last Received _____

Shingles (once)

Last Received _____

Tetanus (every 10 years)

Last Received _____

3. Newly Diagnosed

3.1 Telling Others About a Diagnosis

A diagnosis of Alzheimer's disease can be difficult, but getting accurate information and support can help you know what to expect and what to do next. Being informed will help you plan for the future as the disease progresses.

When you learn that you have a diagnosis of some type of dementia, you may hesitate to tell others. You may be coming to terms with the diagnosis yourself or fear that others may feel uncomfortable around you. It is true that your relationship with family and friends will change, but it is important to talk to the people in your life about dementia and about the changes you will all experience together.

Talking about your diagnosis is important for helping people understand dementia and learning about how they can continue to be a part of your life. The following suggestions may help:

- Explain that dementia is not a normal part of aging, but a disease of the brain which results in impaired memory, thinking and behavior.
- Share educational information on Alzheimer's disease or other dementia, or invite family and friends to attend Alzheimer/dementia education programs.
- Be honest about how you feel about your diagnosis and allow other family members to do the same.
- Assure friends that although the disease will change your life, you want to continue enjoying their company.
- Let family and friends know when and how you may need their help and support.

3.1.1 Helping Children and Teens

Children often experience a wide range of emotions when a parent or grandparent has Alzheimer's disease. Younger children may be fearful that they will get the disease or that they did something to cause it. Teenagers may become resentful if they must take on more responsibilities or feel embarrassed that their parent or grandparent is "different." College-bound children may be reluctant to leave home.

- Reassure young children that they cannot "catch" the disease from you.
- Be straightforward about personality and behavior changes. For example, you may forget things, such as their names, and say and do things that may embarrass them. Assure them that this is not their fault or intentional, but a result of the disease. Find out what their emotional needs are and find ways to support them, such as meeting with a counselor who specializes in children who have a loved one diagnosed with Alzheimer's or other type of dementia.

- Record your thoughts, feelings and wisdom to "be with them" as they experience important events in their lives (graduations, dating, marriage, births and deaths).



3.2 Coping with Dementia

After receiving a diagnosis, you may experience a range of emotions, including:

- Denial about having dementia
- Fear of losing people important to you
- Loneliness because no one seems to understand what you are going through
- Frustration with not making yourself understood
- Loss of the way you used to see yourself
- Depression or anger about the way your life is changing

The feelings you may be experiencing are normal. But it is important to find ways to deal with those feelings. The following suggestions may help you take care of your emotional needs:

- Write in a journal about your experiences and feelings.
- Join a support group.
- Talk to your physician, who can determine if there is an appropriate treatment.
- See a counselor.
- Talk to a clergy member or other person who can help with your spiritual needs.
- Share your feelings with your friends and family.
- Do the activities you enjoy as long as you are able.
- Dementia will bring significant changes in your day-to-day experiences.

“I’ve absorbed my diagnosis into part of who I am. It’s not as important to me now that I’ve come to terms with it. Getting over that hurdle is the hardest part.” - Jenny

Things you once did easily will become increasingly difficult. The following suggestions may help you cope with changes in your daily life and plan for changes that will occur in the future.

“I’m going to have to make the best of this, and that’s what I’m doing.”
- Elizabeth

3.2.1 Doing Difficult Tasks

You may find familiar activities such as balancing your checkbook, preparing a meal or doing household chores more difficult. Try the following tips:

- Do difficult tasks during the times of the day when you normally feel best.
- Give yourself time to accomplish a task, and don't let others rush you.
- Take a break if something is too difficult.
- Arrange for others to help you with tasks that are too difficult.

3.2.2 Communicating With Others

You may begin to experience difficulty understanding what people are saying or finding the right words to express your thoughts. The following tips are important in communicating:

- Take your time.
- Ask the person to repeat a statement, speak slowly or write down words if you do not understand.
- Find a quiet place if there is too much distracting noise.

3.3 Living Well

Dementia is always changing you. One day you may be able to do something, and the next day you may not. However, you can continue to live independently during the early stages of the disease by making simple adjustments, taking safety precautions and having the support of others.

3.3.1 Get Help with Daily Tasks

Give yourself more time and less hassle by using services that can take care of everyday activities like shopping, cooking, bill paying and housekeeping. You could also ask a friend or relative to help with these tasks.

- Get meals or groceries delivered to your home. Also consider stocking your freezer with microwave meals.
- Use a lawn service to do yard work.
- Ask your bank if they provide services to help pay bills and keep track of your accounts. Or, have bills paid directly from your checking or savings account.
- Hire a cleaning service to vacuum, dust, mop and do laundry.

3.3.2 Use Memory Aids

Labels, lists, notebooks and sticky notes can help you cope with memory loss.

- Label drawers to help you find things.
- Keep important numbers by the phone.
- Post reminders to lock doors or shut windows.
- Have step-by-step instructions on how to work appliances (such as the computer) or complete routine tasks (such as fixing your hair).
- Post a schedule of the things you do every day, such as meal times, exercise, a medication schedule and bed time.
- Have someone call to remind you of meal times, appointments or your medication schedule.
- Keep a book containing important notes, such as phone numbers, people's names, any thoughts or ideas you want to hold on to, appointments, your address and directions to your home.

3.3.3 Dealing with Memory Changes

- Post important phone numbers in large print next to the phone.
- Have someone help you label and store medications in a pill organizer.
- Mark off days on a calendar to keep track of time.
- Label photos with the names of those you see most often.
- Label cupboards and drawers with words or pictures that describe their contents.
- Have someone help you organize closets and drawers to make it easier to find what you need.
- Post reminders to turn off appliances and lock doors.

3.3.4 Keep Track of Appointments and Things

- Put an oven mitt in the middle of the floor to remind you the oven is on.
- Use post-it notes to remind you of important things to do or to remind you how to operate appliances (e.g. steps to warm up food in the microwave).
- Keep a day planner next to the phone to write appointments in.
- Use a weekly dispenser for pills.

3.3.5 Stay Active and Healthy

Continue doing hobbies you enjoy. Whether it's gardening, dancing, painting, volunteering, playing sports or card games, you will benefit from the mental and social stimulation.



Be active! Getting exercise helps people with Alzheimer's feel better and helps keep their muscles, joints, and heart in good shape. For tips, see www.nia.nih.gov/Go4Life.

Eat a well-balanced diet that includes fruits, vegetables, and whole-grain products: www.nia.nih.gov/health/publication/whats-your-plate.

Continue to enjoy visits with family and friends, hobbies, and outings.

3.4 Making A Plan

At some point, it will become too difficult to live independently. Make plans now for your future care so your family can honor your wishes.

Many individuals manage on their own during the earliest stages of Alzheimer's disease, with support and assistance from others. The following suggestions may help if you live by yourself.

- Arrange for someone to help you with housekeeping, meals, transportation and other daily chores.
- Make arrangements for direct deposit of checks, such as your retirement pension or Social Security benefits.
- Make arrangements for help in paying bills. You can give a trusted individual the legal authority to handle money matters.
- Leave a set of house keys with a neighbor you trust.
- Make arrangements for someone to regularly check your smoke alarm.

A Message To Family Members and Friends

Please don't correct me. I know better -- the information just isn't available to me at that moment.

Remember, my feelings are intact and I get hurt easily.

I usually know when the wrong word comes out, and I'm as surprised as you are.

I need people to speak a little slower on the telephone.

Try to ignore off-hand remarks that I wouldn't have made in the past. If you focus on it, it won't prevent it from happening again. It just makes me feel worse.

I may say something that is real to me but may not be factual. I am not lying, even if the information is not correct. Don't argue - it won't solve anything.

If I put my clothes on the chair or the floor, it may be because I can't find them in the closet.

If you can anticipate that I am getting into difficulty, please don't draw attention to it, but try to carefully help me through it so nobody else will be aware of the problem.

At a large gathering, please keep an eye on me because I can get lost or overwhelmed easily! But please don't shadow my every move. Use gentle respect to guide me.

Sometimes you give me the message that you think I am faking these problems. What you don't see is my terrible confusion and my hurt knowing how you feel.

I don't mean to frustrate you. I know you get impatient and tired of telling me things three times in a row. Please be patient.

Ask me what I think or want. Don't assume that you know.

Believe I still love you, even if I am having trouble showing it.

- Have family, friends or a community service program call or visit daily.
- Keep a list of questions and concerns to discuss with them during your time together.
- Keep a list of things for them to check out around the house, such as electrical appliances, mail and food items.

3.4.1 Put Your Affairs in Order

Do some legal, financial, and long-term care planning:

Get information to help you plan:

www.nia.nih.gov/alzheimers/topics/legal-and-financial-planning

- Prepare or update your will, living will, healthcare power of attorney, and financial power of attorney. To find a lawyer, contact your local bar association or the National Academy of Elder Law Attorneys: www.naela.org
- Learn about care you may need in the future and how to pay for it: www.longtermcare.gov
- Explore getting help to pay for medicines, housing, transportation, and more. Visit the National Council on Aging: www.benefitscheckup.org

Do some personal preparation:

- Write a love letter to your children, spouse, and friends sharing precious memories. Save for a future time.
- Write a family history. Some stores sell books with questions that prompt you for details.

3.4.2 Get Regular Medical Care

- Make regular appointments with your primary care doctor or specialist (neurologist, neuropsychiatrist, geriatrician).
- Consider going to a specialized memory disorders clinic. Ask your doctor for a referral if desired.
- Ask about new prescription drugs for dementia (they may help reduce some symptoms).
- Keep a list of things that happen and your responses to any medication so when you have your appointment, you can bring the doctor up-to-date.
- Find out if you are eligible to participate in a Clinical Trial. See the Research section of this book for more information.

3.4.3 If You Are Working

- If you have problems performing your job, consider reducing your hours or switching to a less demanding position.
- Consult your employer's HR department or employee assistance program about family leave, disability benefits, and other employee benefits.
- Find out if you qualify for Social Security disability benefits through "compassionate allowances." Visit www.socialsecurity.gov/compassionateallowances or call 1-800-722-1213.

3.5 Safety

3.5.1 Home

- Make home safety improvements, such as installing grab bars in the bathroom to minimize falls. Use appliances that have an automatic shut-off feature. Write HOT above the hot water tap in the shower or glue a red disk on the tap. Use arrows to indicate ON.

- Get home-safety tips: www.nia.nih.gov/alzheimers/publication/home-safety-people-alzheimers-disease. Ask your doctor to order a home-safety evaluation and recommend a home health care agency to conduct it. Medicare may cover the cost.
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3.5.2 Medicines

- Take your medications as prescribed. Taking your Alzheimer medications can help minimize symptoms. Consider using a pill box to help you organize medications. Ask the pharmacist or a family member to place pills in the pill box for you. Write down the times to take your medicine on a calendar.
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3.5.3 Fraud Protection

- Protect yourself from solicitors and potential fraud. Do things that will limit solicitors calling you on the phone or sending you mail. Get your phone number registered on the “national do not call list.” Consider getting Caller ID so you know who is calling you. Stop unwanted junk mail by taking steps to get off mailing lists.
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3.5.4 Going Out

- Carry your name, address and phone number in every sweater and coat pocket, or buy a bracelet to put this information on.
 - Understand that at some point it may no longer be safe for you to drive.
 - Discuss with your family and physician about how and when you will make decisions about driving.
 - Have a plan to get around. If it is no longer safe for you to drive, there are other ways to get where you need to go. Ask family and friends for a ride.
 - Take taxi cabs or other public transportation. Some communities offer paratransit services for seniors and those with special needs.
 - Talk with your doctor if you become confused, get lost, or need lots of help with directions, or if others worry about your driving.
 - Get a driving evaluation. Ask your doctor for names of driving evaluators, or visit the American Occupational Therapy Association: http://myaota.aota.org/driver_search.
 - Learn about driving safety: www.nia.nih.gov/health/publication/older-drivers.
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3.5.5 If You Live Alone

- Identify someone who can visit you regularly and be an emergency contact. If you are at risk of falling, order an emergency response system. A special pendant or bracelet lets you summon help if you fall and can't reach the phone.
- Consider working with an occupational therapist. This person can teach you ways to stay independent. Ask your doctor for more information.
- Get tips about self-care, preventing falls, staying connected, and more: www.alzms.org/programs/resources
- Stick with familiar places, people, and routines. Simplify your life.

3.6 Advocacy

3.6.1 Be an Advocate for Yourself

One way to help yourself is to be an advocate. If you are concerned about any of the early signs, go to the doctor. If you don't get help, ask to be referred to a specialist. You need to speak up in order to have your needs met.

Being an advocate is to make your needs known and work towards having those needs met. An important basis for being able to speak up for yourself is a strong self-image. This gives you the sense that you have the right to respect, to fair treatment, to consideration from others and to have your needs met.

Over time I came to realize that I was the same person as before, but I now have a disability that I have to work around and I may need help from others in expressing my ideas and getting my needs met.

People with serious memory problems can go through an identity crisis as they come to terms with changes in their abilities. Believing that you are the same person as before is important to having a full life.

3.6.2 Others Help Me Advocate

People who share my goals and help me to do all that I can do for myself are also advocates for me.

What do I want in an Advocate?

- Someone who is caring, understanding, honest, trustworthy, capable and has respect for me.
- Someone who will listen and ask me different times in different ways to make sure they understand.
- Someone who has the ability to understand the issues and to communicate accurately my needs and wishes when and where I can't.

I Can Live Well with Dementia

Source:

Global Dementia Charter - Alzheimer's Disease International

Note:

This Charter outlines the rights that people living with dementia around the world should be able to expect to allow them to live well.

- 1 I should have access to a doctor to check if I have dementia.** I should have access to a memory assessment to check if my dementia worries are true. A diagnosis will allow my family, friends and I to plan for the years ahead and prepare for when my needs will change.
- 2 I should have access to information about dementia so I know how it will affect me.** Dementia will affect me and everyone around me. My family, friends and I should have access to high quality information and advice so we know what to expect as my condition progresses.
- 3 I should be helped to live independently for as long as I can.** I want to be as active as I can, for as long as possible, supported by those around me, in a safe environment.
- 4 I should have a say in the care and support that I am given.** I have a voice and should have a say in the care that I am given, for as long as I can.
- 5 I should have access to high quality care that's right for me.** At all stages of the condition, I should have access to high quality care when I need it, be that in my home, my village, town or community, or in a care home.
- 6 I should be treated as an individual, with those looking after me knowing about my life.** People looking after me should know about my life, family and history so they can provide personalized care that's right for me. My care should be shaped around my personality, preferences and lifestyle.
- 7 I should be respected for who I am.** I should not be discriminated against on any grounds, including age, disability, gender, race, sexual orientation, religious beliefs, social or other status.
- 8 I should have access to medicine and treatment that helps me.** During all stages of dementia, I should have access to medication and treatment that helps me to live well, and these should be regularly assessed by my doctor.
- 9 My end of life wishes should be discussed with me while I can still make decisions.** I should have a say about how I spend my final days, so my end of life care wishes should be discussed with me while I can still make decisions.
- 10 I want my family and friends to have fond memories of me.** I want to have peace of mind that my family and friends will have adequate support to cope with my death and be comforted in their grief, to help them remember me for the person I was.

4. Health Care 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 (or during the early stage) of dementia.

4.1 Capacity for Health Care Decisions

Individuals have a moral and legal right to make their own health care 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 health care decisions requires the individual to have a minimum level of "capacity" to make such decisions. The Mississippi Uniform Health-Care 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 health care. Mississippi law also recognizes that capacity may 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 health care decision even though they have designated an agent in an advance directive as described below.

4.2 Advance Directives

The Mississippi Uniform Health-Care Decisions Act (MCA §41-41-203(d)) defines health care 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." This Act prescribes the "Advance Health Care Directive" (AHCD) as the instrument by which a person with capacity can designate an agent who will be able to make health care decisions for the maker. An adult in Mississippi is entitled to make his or her own medical treatment

and health care decisions, and maintain the privacy of his or her own medical information, unless someone else has legal authority to do so. This includes the right to implement, alter and refuse medical treatment. However, one may lose this capacity through illness or injury, and medical providers may be reluctant to render non-emergency treatment without consent of someone with lawful authority to approve such measures.

Section 1 of the AHCD is the health care power of attorney, in which one or more persons may be listed in the maker's order of choice and designated as agents to make medical and health care treatment decisions for the maker. The maker can select whether the agent may make such decisions without prior determination of the maker's incapacity, or whether one or more doctors must first determine the maker's incapacity before the agent can make decisions for him or her. In Section 2, the maker can state any personal health care decisions, such as about keeping or removing life-support treatments or tube-fed food and liquids in the event of terminal illness, and other choices concerning medical treatment based on the maker's own personal choices. In the optional Section 3, the maker may list the name and contact information for his or her personal physician. Section 4 is an authorization for organ donation if the maker desires.

In light of the stringent privacy regulations under the Health Insurance Portability and Accountability Act (HIPAA) governing the release of personal medical information, it is wise to include specific language in the AHCD that identifies the agent as your "personal representative" who is entitled to request and receive your medical information for HIPAA purposes.

4.3 Health Care Surrogate

Additionally, the Uniform Health-Care 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 health care directive. The surrogate must be within the designated classes of persons authorized to act as surrogate, which are in order of priority:

- 1 Spouse, unless legally separated;
- 2 Adult child;
- 3 Parent;
- 4 Adult brother or sister; or
- 5 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 health care 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 his or her care or payment with a family member or other person, HIPAA privacy rules permit 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.

4.4 Caregiver Act in Mississippi

The Caregiver Act took effect in Mississippi on July 1, 2015. The Caregiver Act is a solution that has three important provisions to assist Mississippi's family caregivers as they take care of their loved ones.

The law requires hospitals to:

- Provide a hospital patient or patient's legal guardian an opportunity to designate a lay caregiver.
- Notify the lay caregiver of the patient's discharge to home or transfer to another licensed facility.
- Attempt to consult with the designated lay caregiver to prepare her or him for the patient's aftercare and issue a discharge plan describing the patient's aftercare needs.

The Caregiver Act was one of the recommendations from the Caregivers Task Force. This task force was formed as a result of the 2014 Caregiving Resolution. The Caregiving Task Force included representatives from ten governmental and non-profit organizations.

4.5 Family Communication about Health Care Values

Personal values and choices about health care 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 health care agent, to the extent he or she 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.)

4.6 Treatment Withdrawal/ Refusal

If there is an identified agent or surrogate, families should be contacted and involved in the decision-making 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 with 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.

5. Hygiene and Personal Care

5.1 Grooming

People with dementia 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

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



When people feel good about how they look, they often feel better. Helping people with dementia brush their teeth, shave, put on makeup, and get dressed can help them feel more like themselves.

The person with dementia may forget how to perform grooming tasks such as combing hair, caring for fingernails, and shaving. He or she may also be afraid of grooming tools such as razors and nail clippers. Helping the person with grooming and dressing will allow him or her 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:

Maintaining Grooming Routines

- If the person has always gone to the beauty shop or barber, continue to take him or her. 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.

Mouth Care

Here are some tips to help the person with dementia care for his or her teeth and mouth:

- Show the person how to brush his or her teeth. Go step by step. Remember to let the person do as much as possible.
- Brush your teeth at the same time.
- Help the person clean his or her dentures.
- Ask the person to rinse his or her mouth with water after each meal and use mouthwash once a day.
- Try a long-handled, angled, or electric toothbrush if you need to brush the person's teeth.
- Take the person to see a dentist. Some dentists specialize in treating people with dementia. Ask the dentist how often the person should be seen.

Other Grooming

Here are some other suggestions for grooming:

- Encourage a woman to wear makeup if she has always used it. If needed, help her put on powder and lipstick. Don't use eye makeup.
- Encourage a man to shave, and help him as needed. Use an electric razor for safety.
- Take the person to the barber or beauty shop. Some barbers or hairstylists may come to your home.
- Keep the person's nails clean and trimmed.

5.2 Dressing

Physical appearance is important to everyone's sense of self-esteem. For the person with dementia, 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 dementia 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 or she recognize his or her clothes?
- Is he or she 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?

Pay Attention to the Feet

- To give the person's feet support, encourage them to wear shoes instead of slippers.
- Slip-on styles with elastic closures on the top of the shoe are best.
- Shoes with crepe soles can help to prevent falls.
- Try slip-on shoes that won't slide off or shoes with Velcro® straps.
- 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.

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.
- Put away some clothes in another room to reduce the number of choices. Seeing many clothes can be overwhelming and upsetting to the person.

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.
- Buy loose-fitting, comfortable clothing, such as sports bras, cotton socks and underwear, and sweat pants and shorts with elastic waistbands.
- Hand the person one thing at a time, or give step-by-step dressing instructions.
- Give the person simple clothing selections so the person can dress independently for as long as possible.
- Avoid girdles, control-top pantyhose, knee-high nylons, high heels, and tight socks.
- Use Velcro® tape or large zipper pulls for clothing instead of shoelaces, buttons or buckles.

5.3 Incontinence

Incontinence, which includes loss of bladder and/or bowel control and bedwetting, is a difficult and very common problem for a person who has dementia.

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 person to get to the bathroom in time? If the answer to any of these is "yes," consult your health care provider.

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.

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.

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, disposable briefs or underwear, or panty liners.

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.
- Be understanding when bathroom accidents occur. Stay calm and reassure the person if he or she is upset.

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, gelatin, or fruit juice.
- Help the person with dementia retain a sense of dignity despite the problems with incontinence. Reassuring and non-judgmental statements will help lessen feelings of embarrassment and frustration.

5.4 Bathing

Keeping the person who has dementia clean can be a challenge for the caregiver. A person who is depressed might have lost his or her 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 dementia 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 dementia, 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 or she 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.

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

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 or herself.
- Keep the bathroom warm, well-lit and comfortable.
- Play soft music if it helps to relax the person.
- 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 or she needs or wants a bath.
- If the individual continues to resist the idea of bathing, distract him or her for a few moments and then try again. Do not argue about the need for a bath or shower.

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 dementia than baths. Reset the water heater to 120 degrees Fahrenheit to prevent burns.
- Never leave the person alone in the bathroom.

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. Be sure mats are light colored and do not look like a dark hole.
- Use only two or three inches of water in the tub and test the temperature in advance to prevent burns.

- 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.

Help the Person Feel in Control

- Involve and coach the person through each step of the process, reminding them of the areas that need to be washed. 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.

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. Distract the person by talking about something else or singing if the person becomes upset.

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.

Get professional help with bathing if it becomes too hard for you to do on your own.

5.5 Eating

Eating healthy foods helps everyone stay well. It's even more important for people with Alzheimer's disease. Here are some tips for healthy eating:

Buying and Preparing Food

When the person with Alzheimer's disease lives with you:

- Buy healthy foods such as vegetables, fruits, and whole-grain products. Be sure to buy foods that the person likes and can eat.
- Give the person choices about what to eat – for example, “Would you like green beans or salad?”
- Buy food that is easy to prepare, such as premade salads and single food portions.

It may be helpful to have someone else make meals or use a service such as Meals on Wheels, which brings meals right to your home. For more information, check your local phone book or visit www.mowaa.org.

When a person with early-stage Alzheimer's disease lives alone, you can buy foods that the person doesn't need to cook. Call to remind him or her to eat.

Maintain Familiar Routines



Change can be difficult for a person with Alzheimer's disease. Maintaining familiar routines and serving favorite foods can make mealtimes easier. They can help the person know what to expect and feel more relaxed. If a home health aide or other professional provides care, family members should tell this caregiver about the person's preferences.

Try these tips:

- View mealtimes as opportunities for social interaction. A warm and happy tone of voice can set the mood.
- Be patient and give the person enough time to finish the meal.
- Respect personal, cultural and religious food preferences, such as eating tortillas instead of bread or avoiding pork.
- If the person has always eaten meals at specific times, continue to serve meals at those times.
- Serve meals in a consistent, familiar place and way whenever possible.
- Avoid new routines, such as serving breakfast to a person who has never routinely eaten breakfast.

As Alzheimer's progresses, familiar routines and food choices may need to be adapted to meet the person's changing needs. For example, a family custom of serving appetizers before dinner can be preserved, but higher-calorie items might be offered to help maintain the person's weight.

Stay Safe

In the early stage of Alzheimer's, people's eating habits usually do not change. When changes do occur, living alone may not be safe anymore. Look for these signs to see if living alone is no longer safe for the person with Alzheimer's:

- The person forgets to eat
- Food has burned because it was left on the stove
- The oven isn't turned off

Other difficulties, such as not sitting down long enough for meals and refusing to eat, can arise in the middle and late stages of the disease. These changes can lead to poor nourishment, dehydration, abnormally low blood pressure and other problems.



Caregivers should monitor the person's weight and eating habits to make sure he or she is not eating too little or too much. Other things to look for include appetite changes, the person's level of physical activity, and problems with chewing or swallowing. Talk with the person's doctor about changes in eating habits.

For more information, visit www.nia.nih.gov/alzheimers/topics/caregiving

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.

6. Making Every Day Count

6.1 Effective Communication

Dementia can be a long term condition. A person can live with Alzheimer's disease for three to twenty years after diagnosis, although the life span of the disease is generally 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 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 or she still requires and benefits from direct communication. The following tips can improve interactions:

6.1.1 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.

6.1.2 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

6.1.3 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.

6.1.4 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?,” “Who am I?” or “Remember when...?”

Like many people in their later years, the person with dementia 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 dementia 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.

6.1.5 Treat the “Patient” as a Person

Try to:

- Appreciate and acknowledge the dementia 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 dementia 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 him!”
- “She kept me up all night again!”

Instead of talking about the person, assume that he or 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.

Dementia affects a person’s ability to think, communicate, and perform the most basic activities of daily living. But like people of all ages, the person with dementia 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.

6.1.6 Communicate Slowly and Calmly

- Speak slowly and in simple sentences. Lower the pitch of your voice.
- Give the person with dementia 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 dementia 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. It’s time to get up now.”
- “Okay, you’re up. Now let’s get dressed.”
- “Okay, why don’t we go downstairs now?”
- “It’s time for breakfast.”

**6.1.7
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 okay.” “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/see the similarity between 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!”



**6.1.8
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.”

Fast Facts: Choosing Your Words

The person with dementia won’t see the similarity between the following statements:

- “Please sit down here.”
- “Why don’t you come here and have a seat?”

6.1.9 Match your Actions and Words

- Be aware of your body language. Even though you might use kind and gentle words, the person with dementia 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 can confuse the person. Use the same words whenever possible.
- Maintain eye contact, smile, and use touch to comfort and reassure.

6.1.10 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 Alzheimer's disease or other types of dementia.
- Keep in mind that the person with dementia wants to contribute to the family's well-being. Instead of assuming that the person can't perform a task, 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 but will feel the enjoyment of being helpful.

6.1.11 Talk About and Name Emotions

- Help the person with dementia label emotions by making such comments as, "You look sad. This must be really frustrating for you," or by emphasizing what they feel, i.e. "You're really feeling angry right now, aren't you? You know, it's okay 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."

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.

6.1.12 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 okay.
- 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.

6.1.13 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.

6.1.14 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.
- Hearing loss can contribute to memory loss. The American Academy of Audiology recommends testing/retesting annually by a licensed Audiologist.
- Use unspoken communication like pointing, gesturing, or touching.
- 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!!

6.2 Planning Daily Activities

While scientists are searching for the causes and cures of Alzheimer's disease and other types of dementia, and conducting tests to identify medications that control symptoms, caregivers can contribute immensely to the quality of life for loved ones with dementia 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 dementia, 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 dementia 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 dementia 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 dementia 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 the brain cells. Participating in daily activities stimulates brain cells.

During the middle stages, a person with dementia 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, cross-stitching, 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, bingo or simple puzzles

Reading Activities

- Discussion of newspaper and magazines articles, or Bible study

Visits

- 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 dementia. 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.



6.2.1 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 noise by shutting windows and doors and by turning off the television.

6.2.2 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.

6.2.3 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

6.2.4 Moment by Moment Activities

An enriched environment promotes natural and spontaneous interaction between the people or persons with dementia and their surroundings. Match the activity with what the person with dementia can do.

- Choose activities that can be fun for everyone.
- Help the person get started.
- Decide if he or she can do the activity alone or needs help.
- Watch to see if the person gets frustrated.
- Make sure he or she feels successful and has fun.
- Let him or her watch if that is more enjoyable.

6.2.5 Self-Care and Daily Housekeeping

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.

The person with dementia can do different activities each day. This keeps the day interesting and fun. Here are some daily activities people with dementia may enjoy:

6.2.6 Plan Events and Activities

Household Chores

Wash dishes, set the table, prepare food, sweep the floor, dust, sort mail and clip coupons, sort socks and fold laundry, sort recycling materials or other things.

Cooking and Baking

Decide what is needed to prepare the dish; measure, mix, and pour; tell someone else how to prepare a recipe; watch others prepare food.

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 – Long-term memories remain intact throughout the early and middle stages of Alzheimer’s disease. 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, photos, 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 or another type of dementia. It can be gently stimulated by providing fragrances that are relevant to the person’s life. The purpose is to stimulate memory-making and provide sensory stimulation, not to identify specific scents.

Memory Box

Help the person make a memory box consisting of objects from his or her past. Any memorabilia from his or her life will be useful. The box will also include items from his or her 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.

Exercise

Take a walk together, watch exercise videos/DVDs or TV programs made for older people, use a stationary bike, use stretching bands, throw a soft ball or balloon back and forth, lift weights or household items such as soup cans.

Music and Dancing

Play music; talk about the music and the singer, ask the person with Alzheimer’s what he or she was doing when the song was popular, sing or dance to well-known songs, attend a concert or musical program.

Pets

Feed, groom, walk, sit and hold a pet.

Gardening

Take care of indoor or outdoor plants, plant flowers and vegetables, water the plants when needed, go to school events, talk about how much the plants are growing.

Visiting with Children

Play a simple board game, read stories or books, visit family members who have small children, walk in the park or around schoolyards, go to school events, talk about fond memories from childhood.

Going Out

Remember to plan outings for the time of day when the person is at his or her best, and keep outings from becoming too long. Go to a favorite restaurant, park, shopping mall, or museum.

6.2.7 Therapeutic Care Approaches

Virtual Dementia Tour™

The Virtual Dementia Tour™ (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. *For more information:* <http://www.secondwind.org>

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® is a registered trademark of ROMPA® Ltd. All Rights Reserved.

Whether you need a relaxing retreat for yourself or have a loved one that 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 more information:* <http://www.snoezelen.info>

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.

For more information: <http://www.montessorifordementia.com.au>

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.

6.3 Visiting

Visiting allows the caregiver and the person with dementia 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 dementia 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 dementia important social outlets. Listed next are tips to assist you in having visitors outside the home and visitors in the home.

6.3.1 Therapeutic Care Approaches

- 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.

6.3.2 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 dementia 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.
- Prepare visitors before the visit. Educate visitors about how the person with dementia 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 or her one-on-one, or by understanding that he or she 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.

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 people to have morning visitors, while others may benefit from late afternoon visits.

6.3.3 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 dementia. Some people on whom you thought you could depend may avoid you, while others will rally to your side.

6.4 Going Out

People in the early stages of Alzheimer's disease may still enjoy going out to places they enjoyed in the past. For example, the person might enjoy going to a favorite restaurant, park, shopping mall, swimming pool, museum, or theater. Keep going on these outings as long as you are comfortable with them.

6.4.1 Plan Ahead

Here are some tips to make outings fun:

- Plan outings for the time of day when the person with dementia is at his or her best.
- Keep outings from becoming too long. Take note of how tired the person gets after a certain amount of time. Bring the person home before he or she becomes overtired.
- Use a business-size card to tell others about the person's disease. Sharing this information with store clerks or restaurant staff can make outings more comfortable for everyone.

6.4.2 Eating Out

Going out to eat can be a welcome change, but it can also be challenging. Planning can help. Before choosing a restaurant, think about its layout, menu, noise level, waiting times, and the helpfulness of the staff.

Ask yourself:

- Does the person with Alzheimer's disease know the restaurant well?
- Is it quiet or noisy most of the time?
- Are tables easy to get to? Do you need to wait before being seated?
- Is the service quick enough to keep the person from getting restless?
- Does the restroom meet the person's needs?
- Are foods the person with Alzheimer's likes on the menu?
- Is the staff understanding and helpful?

Before going to the restaurant, decide if it is a good day to go. If it is, think about the best time to go. Earlier in the day may be best, so the person with dementia is not too tired. Also, the restaurant may be less crowded, and service may be quicker. If you decide to go later, try to get the person to take a nap first. Before you leave home, gather what you need. Helpful items may include utensils, a towel, wipes, or bathroom items.

6.4.3 At the Restaurant

- Tell the waiter or waitress about any special needs, such as extra spoons, bowls, or napkins.
- Ask for a table near the restroom and in a quiet area. Seat the person with his or her back to busy areas.
- Help the person choose a meal, if needed. Suggest food you know the person likes. Read parts of the menu or show the person pictures of the food.
- Limit the number of choices.
- Ask the server to fill glasses half full or leave the drinks for you to serve.
- Order finger food or snacks to hold the attention of the person with dementia.
- Go with the person to the restroom. Go into the stall if the person needs help.

6.5 Adult Day Care and Group Respite

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

6.5.1 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 dementia. 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 or her needs?"

6.5.2 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 dementia.

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 dementia may need more care than the center can provide. Center staff and support groups can help evaluate your needs for future care.

6.5.3 Adult Day Care and Respite - Things You Can Do

Choosing a Center

Adult day centers provide a planned program that includes a variety of health, social and support services in a protective setting during daytime hours. It seems more advantageous for individuals to begin attending an adult day center while they can fully enjoy the activities and company of others. As their abilities and needs change, they are then familiar with the setting and feel comforted and cared for.

We suggest that use of an adult day center begin when a prospective enrollee needs supervision and:

- can no longer structure his or her own daily activities;
- finds it difficult to initiate and focus on an activity, e.g. reading, conversation, watching television;

- is isolated and lonely or desires peer interaction;
- cannot be safely left alone;
- lives with someone who works and is away from the home most of the day;
- is anxious or depressed and needs social and emotional support;
- feels uncertain and anxious when left alone;
- requires attention that leads to your own anxiety, frustration, compromised health and/or depression.

Below are some suggestions for choosing the right adult day center for you or your loved one.

Step 1 – Determine Your Needs

- What specific services are important to the person using the center?
 - A safe, secure environment?
 - Social activities?
 - Assistance with daily living skills – walking, eating, taking medications, bathing?
 - Therapies – physical, speech, occupational, nursing?
 - Health monitoring – blood pressure, blood sugar levels, food/liquid intake, weight?
 - Nutritious meals and/or snacks? Special diet?
 - Exercise programming?
 - Specialized care such as dementia care or traumatic brain injury care?
- What do you, the caregiver need?
 - Occasional free time?
 - Coverage while working?
 - Transportation for your loved one?
 - Assistance in planning care?

Step 2 – Locate An Adult Day Center

- Search centers in NADSA’s database:
<http://www.nadsa.org/consumers/choosing-a-center/>
- Contact your local Area Agency on Aging (800-677-1116)
- Ask at a local senior center or organization serving persons with developmental disabilities (as applicable)
- Use a search engine to locate a center and review center websites

Step 3 – Make An Appointment To Visit The Center(s)

Step 4 – Know What To Ask During Your Visit

(see site visit checklist below)

Step 5 – Check References

- Talk to two or three people who have used the center you are considering. Ask for their opinion.

Step 6 – Try It Out

- Select a day center and give it a try for a few days.
- Keep in mind that it often takes several visits for a new participant to feel comfortable in a new setting and routine. Staff may have suggestions for making the transition easier both at home and at the center.

Step 7 – Take Care Of Yourself

- Relax knowing your loved one is being well cared for. Always feel free to check in with the center and ask questions. They are there to help you!

Site Visit Checklist

- Did you feel welcome?
- Were the center services and activities properly explained?
- Did you witness appropriate and meaningful activities in process?
- Was the facility easily accessible? Clean, odorless and pleasant to visit?
- Were you provided information regarding staffing, programming, and costs?
- Is the facility clean, pleasant and free of odor?
- Is the building and site wheelchair accessible?
- Is the furniture sturdy and comfortable?
- Is there a quiet place for relaxing at the center?
- Did the staff and participants interact with each other, seem cheerful and comfortable?

7. Holiday Hints

Holidays can be meaningful, enriching times for both the person with Alzheimer's disease and his or her family. Maintaining or adapting family rituals and traditions helps all family members feel a sense of belonging and family identity. For a person with Alzheimer's, this link with a familiar past is reassuring.

The tips below can help you and the person with Alzheimer's visit and reconnect with family, friends, and neighbors during holidays.

7.1 Caregiver

- Adjust the 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 versus doing all the cooking yourself. Make menus simple, preferably potluck.
- Consider lunch or brunch to avoid evening confusion.
- Consider inviting 5–6 versus the normal 15–20.
- Keep number of visitors to a minimum at any one time.
- Attend an Alzheimer's / dementia caregiver support group or arrange for respite care.
- Take care of yourself, maintain exercise and healthy eating habits. Relax and enjoy!

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

7.2 Person with Dementia

- Involve the person throughout preparations, i.e.
 - food preparation
 - setting the table
 - folding the towels or laundry
 - doing 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 the 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 a “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.

7.3 Visitors

7.3.1 Preparing Visitors

Explain to guests that the person with dementia does not always remember what is expected and acceptable. Give examples of unusual behaviors that may take place such as incontinence, eating food with fingers, wandering or hallucinations.

- If this is the first visit since the person with dementia became severely impaired, tell guests that the visit may be painful. The memory-impaired person may not remember guests’ names or relationships, but can still enjoy their company.
- Explain that memory loss is the result of the disease and is not intentional.
- Stress that the meaningfulness of the moment together matters more than what the person remembers.

7.3.2 If You are Visiting

In the Home

- Call ahead to schedule a good time for visit.
- Educate yourself about memory loss and Alzheimer’s by attending a support group.
- 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 the caregiver to update you on appearance / behavior before visit.
- Offer to help the caregiver by providing respite, meals, or running errands.
- Have the caregiver offer communication techniques; go with the flow!
- Be emotionally available if the caregiver wants to talk about the situation.

In Long-Term Care

- Limit amount of noise and confusion; may need to meet in a quiet room.
- Visit early in the 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.

7.4 Gift-giving Ideas

7.4.1 Gifts for the Caregiver

-
- Money and/or time
 - Housecleaning – weekly, bi-monthly, 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
 - 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!

7.4.2 Gifts for the Person with Dementia at Home

-
- Sneakers with Velcro®
 - 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
 - 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!

7.4.3 Gifts for the Person in Long-Term Care

-
- Sneakers with Velcro®
 - Easy care clothes – slacks with elastic waist, sweat suits
 - Bird feeder
 - Mobiles
 - Large calendars
 - Purse/wallets with fake credit cards and money
 - Cookies, candy
 - Costume jewelry
 - Personal hygiene items – hairbrush, comb, tissue, lotions
 - Cuddly stuffed toy
 - Pet visits
 - Music from 40's and 50's and favorite church hymns
 - Favorite homemade foods
 - iPod with music playlist of their favorite songs
 - 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!

For more holiday tips, go to www.nia.nih.gov/alzheimer's/topics/caregiving or <http://www.alzfdn.org/EducationandCare/holidays.html>

8. Safety

8.1 Home Safety

Research has shown that with a few physical changes to the environment, people with dementia can maintain a productive and active lifestyle. Dementia 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 dementia 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 dementia. While most people can easily distinguish among many different noises, colors, or patterns in a room, the person with dementia 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 dementia. A familiar, well-organized living area helps both you and the individual. 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 paint to prevent glare.

- Use contrast. A person with dementia might not be able to distinguish between an off-white wall and a beige door or handrail. For this reason, you may want to have light walls and dark doors and handrails.

Pay Attention to Flooring

- Keep floor surfaces uncomplicated. The person might perceive checkerboard tile or dark colored 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 or her path. Some of the newer textured types of vinyl 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.

Orient the Person

- Experiment with labels, pictures, and numbers to help the person understand where he or she 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.
- Label hot-water faucets red and cold-water faucets blue, or write the words “hot” and “cold” near them.
- Put signs near the oven, toaster, and other things that get hot. The sign could say “Stop!” or “Don’t Touch – Very Hot!”
- Put a gate across stairs if the person has balance problems.
- Install grab bars in the tub/shower and beside the toilet.

Wallcoverings Make a Difference

- Use wall hangings made of various textured materials. Many people with dementia 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 long-term care center, 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 dementia 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.
- Be careful about small pets. The person may not see the pet and trip over it.

Installing Locks Out of Sight

- Place deadbolt locks either high or low on exterior doors to make it difficult for the person with dementia 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.

Basic Safety

- 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.
- Place smoke and carbon monoxide detectors in or near the kitchen and in all bedrooms.
- Keep emergency phone numbers and the person's address near all phones.
- Lock up or remove medicines, alcohol, matches and lighters, cleaning and household products, toothpaste, lotions, shampoos, perfumes, soap, etc. (these items may look and smell like food to a person with dementia).
- Make sure cords to electrical outlets are out of the way or tacked to baseboards.
- Clean up spills right away.
- Reset the water heater to 120 degrees Fahrenheit to prevent burns.
- Check foods in the refrigerator often. Throw out any that have gone spoiled.

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.

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.

Lighting

- Cover windows with blinds, shades or sheer draperies to block bright sunlight.
- Avoid using bare light bulbs or clear "decorator" bulbs without shades.
- Check all rooms for adequate lighting. Use nightlights in bathrooms, bedrooms, and hallways.

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
- 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 dispose of 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

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.

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, gasoline and other dangerous items, 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.

- Poisonous plants – contact the National Poison Control Center at 1-800-222-1222 or www.poison.org to find out what houseplants are poisonous.

- Consider the backyard or patio as part of the living environment. Give the person an opportunity to garden, walk, or work outdoors in a safe, supervised area.

For more home safety tips, see “Home Safety for People with Alzheimer’s Disease,” www.nia.nih.gov/alzheimers/publication/home-safety-people-alzheimers-disease.

8.2 Travel Safety

Taking a person with Alzheimer’s disease on an overnight trip is a challenge. Traveling can make the person more worried and confused, so it’s important to think ahead. Here are some tips.

- Talk with the person’s doctor about medicines to calm someone who gets upset while traveling.
- Find someone to help you at the airport, train station, or bus station.
- Keep important documents with you in a safe place. These include health insurance cards, passports, doctors’ names and phone numbers, a list of medicines, and a copy of the person’s medical records.
- Pack items the person enjoys looking at or holding for comfort.
- Travel with another family member or friend.
- Take an extra set of clothing in a carry-on bag. People with memory problems may wander around a place they don’t know well.

In case someone with dementia gets lost:

- Make sure the person wears an ID bracelet or something else that tells others who he or she is.
- Carry a recent photo of the person with you on the trip.

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

After You Arrive

- Allow lots of time for each thing you want to do. Don't plan too many activities.
- Plan rest periods.
- Follow a routine like the one you use at home. For example, try to have the person eat, rest, and go to bed at the same time he or she does at home.
- Keep a well-lighted path to the toilet, and leave the bathroom light on at night. Be prepared to cut your visit short if necessary.

Communicate with others when you're out in public. Some caregivers carry a card that explains why the person with dementia might say or do odd things. For example, the card could read, "My family member has dementia. He or she might say or do things that are unexpected. Thank you for your understanding." Visiting and spending time with family and friends is important to people with Alzheimer's disease. They may not always remember who people are, but they often enjoy the company.

Here are some tips to share with people you plan to visit:

- Be calm and quiet. Don't use a loud voice or talk to the person with Alzheimer's as if he or she were a child.
- Respect the person's personal space, and don't get too close.
- Make eye contact and call the person by name to get his or her attention.
- Remind the person who you are if he or she doesn't seem to know you.
- Don't argue if the person is confused. Respond to the feelings that he or she expresses. Try to distract the person by talking about something different.
- Remember not to take it personally if the person doesn't recognize you, is unkind, or gets angry. He or she is acting out of confusion.
- Have ready some kind of activity, such as a familiar book or photo album to look at. This can help if the person with Alzheimer's is bored or confused and needs to be distracted, but be prepared to skip the activity if it is not needed.

For more information, go to "Caring for a Person with Alzheimer's Disease" at www.nia.nih.gov/alzheimers/publication/caring-person-alzheimers-disease or visit www.nia.nih.gov/alzheimers/topics/caregiving

8.3 Driving

Driving is a complex activity which requires quick reactions, clear sensory abilities, and split-second decision making. For the person with dementia, 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 or she 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 driving tests to determine how well a person sees, judges distance and responds to traffic. A physician who is a dementia care specialist, may administer a cognitive exam called a Trail Making Test to determine whether the person is still capable of driving safely. Ask the person who administers the test to explain the results to you and the person with dementia.

In the Hopkins study, more than **44%** of persons 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. **(PENDING ON TJ)**

- Look for signs of driving problems, here are some signs of unsafe driving:
 - Forgetting how to locate familiar places
 - Having a "fender bender" or accident
 - 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).

Things You Can Do to Prevent Them from Driving

- 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 dementia 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 or she 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, 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 his or 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 his or her driver’s license will discourage driving. The person may not remember that he or she no longer has a license to drive, or even that he or 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.

Helpful Tools

Booklet **At the Crossroads: Family Conversations about Alzheimer's Disease, Dementia & Driving from The Hartford.**

<http://hartfordauto.thehartford.com/UI/Downloads/Crossroads.pdf>

Driving Assessments **Your Road Ahead: A Guide to Comprehensive Driving Evaluations from the Hartford.**

https://www.thehartford.com/sites/the_hartford/files/your-road-ahead-2012.pdf

The MIND Center at University of Mississippi Medical Center

Jackson, Mississippi

(601) 496-MIND (6463)

Covered by Medicare and other payers as part of cognitive assessment visit

North Mississippi Medical Center

Tupelo, MS

(800) THE-DESK

Mississippi Methodist Rehab Center

Jackson, MS

(800) 223-6672

Mississippi State University T.K. Martin Center

(\$185 per hour, usually takes 2-4 hours)

(662) 325-1028

Not Medicare/Medicaid provider

Contract with Vocational Rehab – No charge if client Voc Rehab Case manager can refer them

<http://www.tkmartin.msstate.edu/>

Veteran Services **Assessments conducted through Kinesio Therapy Department**
Must have a physician referral
Veterans only

North MS

VA Medical Center Memphis

(901) 523-8990

Central/South MS

Biloxi VA Gulf Coast Clinic

(850) 912-2000 ext. 32197 or 32571

8.4 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 dementia. Persons with dementia are at serious risk of death or injury if not found quickly. Searching for lost individuals with dementia 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 rare. 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

Things You Can Do to Prevent or Address Wandering

- Make sure the person carries some kind of ID or wears a medical bracelet. If the person gets lost and can't communicate clearly, an ID will let others know about his or her illness. It also shows where the person lives.
- Let neighbors and the local police know that the person with dementia tends to wander. Ask them to alert you immediately if the person is seen alone and on the move.
- Place labels in garments to aid in identification.
- Keep an article of the person's worn, unwashed clothing in a plastic bag to aid in finding him or her with the use of dogs.
- Keep a recent photograph or video recording of the person to help police if he or she becomes lost.
- Keep doors locked. Consider a keyed deadbolt, or add another lock placed up high or down low on the door. If the person can open a lock, you may need to get a new latch or lock.
- Use loosely fitting doorknob covers so that the cover turns instead of the actual knob (due to the potential hazard they could cause if an emergency

exit is needed, locked doors and doorknob covers should be used only when a caregiver is present).

- Place STOP, DO NOT ENTER, or CLOSED signs on doors.
- Divert the attention of the person with dementia away from using the door by placing small scenic posters on the door; placing removable gates, curtains, or brightly colored streamers across the door; or wallpapering the door to match any adjoining walls.
- Install safety devices found in hardware stores to limit how much windows can be opened.
- Install an “announcing system” that chimes when the door opens.
- Secure the yard with fencing and a locked gate.
- Keep shoes, keys, suitcases, coats, hats, and other signs of departure out of sight.
- Do not leave a person with Alzheimer’s who has a history of wandering unattended.

For more tips on home safety, see “Home Safety for People with Alzheimer’s Disease,” www.nia.nih.gov/alzheimers/publication/home-safety-people-alzheimers-disease.

8.5 Alert Systems

If the person with dementia does get lost, there are several programs that can be useful:



Silver Alert

Mississippi’s Silver Alert System is designed to help find missing persons 18 years or older with dementia or other cognitive impairment. This system helps law enforcement to locate that person as quickly as possible.

Criteria for Silver Alert

- The missing adult, age 18 or older, is believed to have dementia or other cognitive impairment.
- The person is believed to be missing and in imminent danger regardless of circumstance.

If a person with dementia becomes lost, the family, legal caregiver or custodian must file a missing person report with the local law enforcement agency where the person became missing with the following information:

- Description of missing person including physical characteristics, clothing and recent photo if available.
- Description of known circumstances under which person became missing including time, place, direction, possible destinations, and if person was walking or in a vehicle.

For more information go to www.dps.state.ms.us/crime-investigation/bureau-of-investigation/silver-alert/

Project Lifesaver

The primary mission of Project Lifesaver is to provide timely response to save lives and reduce potential injury for adults and children who wander due to Alzheimer’s disease, autism, and other related conditions or disorders. Citizens enrolled in Project Lifesaver wear a small personal transmitter around the wrist or ankle that emits an individualized tracking signal. If an enrolled client goes missing, the caregiver notifies their local Project Lifesaver agency, and a trained emergency team responds to the wanderer’s area. Most who wander are found within a few miles from home, and search times have been reduced from hours and days to minutes. Recovery times for Project Lifesaver clients average 30 minutes – 95% less time than standard operations.

Currently, only a few counties in north Mississippi have this program and it is administered through law enforcement agencies in those areas. To learn more, go to <http://www.projectlifesaver.org/>

GPS Tracking Devices

One way to address wandering is to use a life saving location device. Using GPS tracking, these devices allow seniors to be found quickly and safely. To learn more: <https://www.alzheimers.net/8-8-14-location-devices-dementia/>

8.6 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.

8.7 Advanced Preparation

Your planning will be most effective if you begin right now before a crisis looms.

Here are some tips for preparing for potential disasters:

- Talk with family and friends – having a support network during an emergency makes it easier to get help if needed.
- Meet with your professional caregivers – if your loved one is receiving services from a paid professional or agency you need to know what their policy is in the event of a disaster.

- Research where you should go and have an evacuation plan – is a hotel, a friend or family member in a safe area, or a shelter the best alternative for you? Check if there is a special needs shelter in your area.
- Don't forget to plan for your pets – pets can be reassuring and calming for the person with dementia, but you need to know where pets are allowed before you go.
- 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® armbands
 - Easy on/off clothes (a couple of sets)
 - Velcro® 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® bags to hold medications and documents
 - Physician's name, address and phone numbers (including cell phone)

8.8 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.

8.8.1 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.

8.8.2 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.

More information on disaster preparedness is available from:

- 1 National Hurricane Center at www.nhc.noaa.gov.
- 2 The Calm Before the Storm: Family Conversations about Disaster Planning, Caregiving, Alzheimer's Disease and Dementia from the Hartford at www.thehartford.com/lifetime

8.9 Protecting Against Exploitation

8.9.1 Health Care Scams

Question what you see or hear in ads or online. Newspapers, magazines, movies, and radio and TV stations do not always check to make sure the claims in their ads are true or say if a celebrity is being paid to endorse a product. Ask your doctor, nurse, other healthcare provider, or pharmacist about a product before you buy it. Don't let a salesperson talk you into making a snap decision.

Look for red flags in ads or promotional material that:

- Promise a quick or painless cure
- Claim the product is made from a special, secret, or ancient formula
- Offer products and services only by mail or from one company
- Use statements or unproven case histories from so-called satisfied patients
- Claim to be a cure for a wide range of ailments
- Claim to cure a disease (such as arthritis or Alzheimer's disease) that hasn't been cured by medical science
- Promise a no-risk, money-back guarantee
- Offer an additional free gift or a larger amount of the product as a special promotion
- Require advance payment and claim there is a limited supply of the product

If you have questions about a product, talk to your doctor. Getting the facts about healthcare products can help protect you from health scams. For more information, visit www.nia.nih.gov/health/online-health-information-it-reliable

The AARP Fraud Watch Network gives you access to information about how to protect yourself and your family. Non-members and members alike can get their Watchdog Alerts, stay up-to-date on con artists' latest tricks, and find out what to do if you've been victimized. It's free for everyone regardless of age and membership in AARP is not required.

When you sign up, you'll get:

- The latest, breaking scam alerts, delivered right to your inbox
- Prevention tips based on thousands of hours of interviews with con artists and law enforcement
- Access to resources from our network of experts
- Access to a special network of people like you who are sharing their experiences with scams, so you know what to watch out for

For more information, go to <http://www.aarp.org/money/scams-fraud/fraud-watch-network/?intcmp=AE-MON-CONP-SPOT2-SCAMS-FWN>.

8.8.2 Fraud Watch Network

9. Understanding Behavior Changes

Dementia 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 dementia is different, so the behaviors or changes he or she experiences will also be different.

For the person with dementia changes in behavior may be caused by:

- Physical discomfort (illness, medication)
- Anxiety (worry or fear)
- 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)

Dementia causes brain cells to die, so the brain cell communication is less effective over time.

Common personality and behavior changes you may see include:

- Getting upset, worried, and angry more easily
- Acting depressed or not interested in things
- Hiding things or believing other people are hiding things
- Imagining things that aren't there
- Wandering away from home
- Pacing a lot
- Showing unusual sexual behavior
- Hitting you or other people
- Misunderstanding what he or she sees or hears

This changes how a person acts.

You also may notice that the person stops caring about how he or she

In addition to changes in the brain, other things may affect how people with dementia behave:

- Feelings such as sadness, fear, stress, confusion, or anxiety
- Health-related problems, including illness, pain, new medications, or lack of sleep
- Other physical issues like infections, constipation, hunger or thirst, or problems seeing or hearing
- Problems in their surroundings, like too much noise or being in an unfamiliar place

looks, stops bathing, and wants to wear the same clothes every day. If you don't know what is causing the problem, call the doctor. It could be caused by a physical or medical issue.

Caregivers cannot stop dementia-related changes in personality and behavior, but they can learn to cope with them. Here are some tips:

- Keep things simple. Ask or say one thing at a time.
- Have a daily routine, so the person knows when certain things will happen.
- Reassure the person that he or she is safe and you are there to help.
- Focus on his or her feelings rather than words. For example, say, “You seem worried.”
- Don’t argue or try to reason with the person.
- Try not to show your frustration or anger. If you get upset, take deep breaths and count to 10. If it’s safe, leave the room for a few minutes.
- Use humor when you can.
- Give people who pace a lot a safe place to walk.
- Try using music, singing, or dancing to distract the person.
- Ask for help. For instance, say, “Let’s set the table” or “I need help folding the clothes.” Talk with the person’s doctor about problems like hitting, biting, depression, or hallucinations. Medications are available to treat some behavioral symptoms.

9.1 Repetition

A person with Alzheimer’s may do or say something over and over. He or she may repeat a word, question or action. In the span of one hour, a person



with dementia may ask the same question 10 or more 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.

9.1.1 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 or she is feeling, not what he or she 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.

9.2 Hallucinations

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

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.

9.2.1 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 or other type of dementia.

- 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 well-lit 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, a new conversation, looking at photos, or counting coins.

9.3 Aggression or Combativeness

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.

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.

Most of the time, agitation and aggression happen for a reason. When they happen, try to find the cause. If you deal with the causes, the behavior may stop.

For example, the person may have:

- Pain, depression, or stress
- Too little rest or sleep
- Constipation
- Soiled underwear or diaper
- Sudden change in a well-known place, routine, or person
- A feeling of loss—for example, the person may miss the freedom to drive
- Too much noise or confusion or too many people in the room
- Being pushed by others to do something—for example, to bathe or to remember events or people—when dementia has made the activity very hard or impossible
- Feeling lonely and not having enough contact with other people
- Interaction of medicines

Look for early signs of agitation or aggression. If you see the signs, you can deal with the cause before problem behaviors start. Try not to ignore the problem. Doing nothing can make things worse. Deal with combativeness by trying to examine the underlying causes.

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.

9.3.1 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?

9.3.2 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 Combateness Personally

Keep in mind that the person is not necessarily angry at you. Instead, he or she may misunderstand the situation or be frustrated with his or her own disabilities.

Use Distractions

Do not persist in making the person perform a particular task, especially if he or she has repeatedly been unsuccessful. If you see the person getting frustrated with buttoning a shirt, try to distract him or her 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?"

9.4 Suspicious Thoughts

Due to memory loss and confusion, the person with dementia might see things differently. He or she may become suspicious of those around him or her 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.

9.4.1 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 or her opinions. Agree with their assumptions and acknowledge their thoughts.

Offer a Simple Answer

A person with dementia 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 or her 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.

9.5 Sexuality

All human beings need to be touched, caressed and held. For people with dementia and caregivers, this need is especially important. Dementia 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 dementia include the following:

Bold Behavior

The person may forget his or her 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 themselves in public. It may appear the person is trying to harass others, but he or she really does not understand that his or her 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.

9.5.1 Things You Can Do

Respond Carefully to Threats and Accusations

If the person makes accusations or becomes extremely suspicious, do not waste time arguing. Instead, try to distract the person with another activity or reassure him or her with a hug or touch.

Look for a Reason Behind the Behavior

Keep in mind that if the person exposes themselves they may simply need to go to the bathroom. If the person begins to take off their clothes, they 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. Get more information. See "Intimacy, Sexuality, and Alzheimer's Disease: A Resource List," www.nia.nih.gov/alzheimers/intimacy-sexuality-and-alzheimers-disease-resource-list.

9.6 Sundowning

Individuals with diseases such as Alzheimer's disease 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 or her 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.

9.6.1 Things You Can Do

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 night time sleeplessness is a problem.

Cut Back the Noise

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 Health Care Provider

Your physician or nurse practitioner may be able to 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.

9.7 Rummaging and Hiding Things

Someone with Alzheimer's disease may start rummaging or searching through cabinets, drawers, closets, the refrigerator, and other places where things are stored. He or she also may hide items around the house. This behavior can be annoying or even dangerous for the caregiver or family members. If you get angry, try to remember that this behavior is part of the disease process.

In some cases, there might be a logical reason for this behavior. For instance, the person may be looking for something specific, although he or she may not be able to tell you what it is. He or she may be hungry or bored. Try to understand what is causing the behavior so you can fit your response to the cause.

You can take steps that allow the person with Alzheimer's to rummage while protecting your belongings and keeping the person safe. Try these tips:

- Lock up dangerous or toxic products, or place them out of the person's sight and reach.
- Remove spoiled food from the refrigerator and cabinets. Someone with Alzheimer's may look for snacks, but lack the judgment or sense of taste to stay away from spoiled foods.
- Remove valuable items that could be misplaced or hidden by the person, like important papers, checkbooks, charge cards, jewelry, and keys.
- People with Alzheimer's often hide, lose, or throw away mail. If this is a serious problem, consider getting a post office box. If you have a yard with a fence and a locked gate, place your mailbox outside the gate.
- Keep the person with dementia from going into unused rooms. This limits his or her rummaging through and hiding things.

- Search the house to learn where the person often hides things. Once you find these places, check them often, out of sight of the person.
- Keep all trash cans covered or out of sight. People with Alzheimer's may not remember the purpose of the container or may rummage through it.
- Check trash containers before you empty them, in case something has been hidden there or thrown away by accident.

You also can create a special place where the person with Alzheimer's can rummage freely or sort things. This could be a chest of drawers, a bag of objects, or a basket of clothing to fold or unfold. Give the person a personal box, chest, or cupboard to store special objects. You may have to remind him or her where to find his or her personal storage place.

10. Late Stage Alzheimer's and Dementia Care

Despite our best research efforts, Alzheimer's disease and other dementias remain incurable. Caring for a loved one in the final stage of life is very hard and may be even harder when the person has Alzheimer's or another form of dementia. Being prepared for the end of a person's life and knowing what to expect can make this time easier.

The late stage of Alzheimer's may last anywhere from several 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 comfort, quality of life, and dignity and treating the person with compassion.

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.

10.1 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 or dementia 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 while they are still able to ingest food and beverages orally:

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 puree it in a blender.

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 or dementia 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!

10.2 Use of Gastrostomy or Feeding Tubes

The use of artificial nutrition and hydration in patients in the final stages of Alzheimer's and dementia is a controversial and emotional subject.

In the end stages of dementia, patients are typically unable to eat and drink due to a variety of reasons. As a result, family members and health care workers may be drawn to the perceived benefits of providing artificial nutrition and hydration to a patient with severe dementia via a percutaneous

endoscopic gastrostomy (PEG) tube or feeding tube. However, various studies have shown the use of feeding tubes to be ineffective in preventing malnutrition or in preventing the occurrence or increasing the healing of pressure ulcers, preventing aspiration pneumonia, providing comfort, improving functional status, or extending life. For more information: www.nia.nih.gov/health/understanding-healthcare-decisions-end-life

In addition, studies provide convincing evidence that feeding tubes do not improve patient outcomes and there is often increased risk of aspiration leading to pneumonia and increased complications requiring hospitalizations. The decision to use or not use a feeding tube or gastrostomy is best made by the patient early in the disease process, or at end of life by the family with input and guidance from their health care providers.

10.3 Maintaining Healthy Skin And Body

A person in the late stage of the disease can become bedridden 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.

10.4 Maintaining Bladder and Bowel Function

A person with Alzheimer's or dementia 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 or she 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.

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

10.5 Decreasing the Risk of Infections and Pneumonia

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, Pneumonia and Shingles

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. The CDC recommends that people 60 years old and older get a shingles vaccine.

10.6 Recognizing Pain or Illness

Promoting quality of life means keeping those in the late stage of Alzheimer's and dementia 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.

10.7 Staying Connected to the Person with Alzheimer's or Dementia

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.

10.8 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.

10.8.1 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 or she may be able to tap his or her 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 or she 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.

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

10.9 Deciding on Palliative or Hospice Care

Hospice is an end of life approach to care, and so it is not tied to a specific place. It can be offered in two types of settings—at home or in a facility such as a nursing home, hospital, or even in a separate hospice center. Hospice care brings together a team of people with special skills—among them nurses, doctors, social workers, spiritual advisors, and trained volunteers. Everyone works together with the person who is dying, the caregiver, and/or the family to provide the medical, emotional, and spiritual support needed. A member of the hospice team visits regularly and is always available by phone—24 hours a day, 7 days a week.

For a dementia patient to receive hospice, they must meet specific criteria including Functional Assessment Staging (FAST Tool) and at least one medical complication associated with poor prognosis over the prior year. For more information: www.dementiacarecentral.com/aboutdementia/facts/stages

FAST (Functional Assessment Staging)

Must show all of the features of stages 6a - 7c:

- 6a - cannot dress without assistance
- 6b - cannot bathe without assistance
- 6c - cannot toilet without assistance
- 6d - urine incontinence
- 6e - bowel incontinence
- 7a - < 6 intelligible words during average day
- 7b - speech limited to single intelligible word during average day
- 7c - unable to ambulate independently

Medical Conditions Affecting Prognosis:

- Aspiration pneumonia
- Pyelonephritis
- Septicemia
- Multiple stage III-IV Pressure Ulcers
- Recurrent fever after antibiotics
- 10% Weight Loss in past 6 months or serum albumin < 2.5

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. 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.

The hospice team will provide the following services in the patient's care setting:

- 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.

**10.10
How Does
Alzheimer's or
Dementia
Cause Death?**

Alzheimer's or dementia is not usually a direct cause of brain death and does not suddenly cause the entire brain to cease functioning.

Most often, the complications of the debilitating disease are what cause the death of Alzheimer's and dementia patients. These complications include infections, such as infections of bed sores or pressure ulcers that occur when people stay in bed for prolonged periods.

Alzheimer's and dementia patients also may have difficulty swallowing, and they may inhale food which can result in aspiration pneumonia. Pneumonia is listed as the cause of death in as many as two-thirds of patients with dementia. Alzheimer's patients also can develop fatal blood clots – another complication of being bedridden, and damage to brain tissue can even increase the likelihood of serious brain injury.

Families and caregivers of people with Alzheimer's and other dementias face many challenges as they cope with the steady loss of their loved one's mental and physical skills. As the disease moves to its end stages, certain steps can provide measures of comfort, both to the caregiver and to the person with Alzheimer's. Health care professionals can help caregivers fill the last days with love and tenderness even through the wrenching turmoil of letting go.

11. Finding In-Home Care

Seventy percent of America's 5.4 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.

You may choose to find assistance from an elder attorney or geriatric case manager to plan for future care.

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.

11.1 Steps to Finding In-Home Care

11.1.1 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 allow 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.

11.1.2

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 by volunteers or friends. Others, like many types of companion care or sitter services, can be expensive – as much as \$12 to \$22 per hour. If required, nursing care at home can be \$50+ per hour.



Area Agencies on Aging have comprehensive home based services around the state. 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 Area Agencies on Aging.

Medicare

Medicare does not pay for long term care services in the home such as sitter companion services. Nor does Medicare pay for care in nursing homes, assisted-living facilities or personal care homes to persons with conditions such as Alzheimer's disease that need custodial (daily living needs), but not skilled care (requires a health care professional to provide). Instead, benefits cover costs associated with rehabilitation or restoration care after a hospital stay. Medicare will pay for hospice care.

Diagnosing Alzheimer's can be an involved process because there is not a single definitive test. Instead the process consists of ruling out other conditions with similar symptoms which do have definitive tests and mental evaluations with a team of specialists including neurologists, psychiatrists and psychologists. Since this is a diagnostic process, Medicare Part B will cover 80 percent of the cost once an individual has reached their deductible.

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. Medicaid will pay for long term custodial care in a nursing facility based on economic eligibility and the need of the resident.

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 permanent “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 long-term care insurance includes partial coverage for home care. Most insurance companies who offer such a policy have extensive requirements for eligibility. You will need to contact your insurance company to see whether your long-term care policy covers the home care services you need and your primary care provider may have to produce proof of need in the home.

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. Other programs for veterans and their wives who served during war time include Aid and Attendance for in-home care and a VA medical foster home program. You may access these benefits through the Veteran’s administration benefits office or you may ask for assistance from the VFW.

11.2 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:

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.

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.

Home Health Care

For home health 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. Home health care's primary purpose is teaching families and is not a long-term option.

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.

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 for the covered costs of hospice for eligible patients. Contact a hospice service to determine if they meet your needs. Hospice eligibility for Alzheimer's disease sufferers is very specific and will have to be identified by your physician.

Service Agencies for In-Home Care versus 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. Hiring independent workers does require you to pay taxes on their salary, where most agencies are considered independent contractors with no tax liability to the caregiver.

12. 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.

12.1 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, 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?

12.2 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:

12.2.1 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. Some assisted living settings now have memory care units that address the specific needs of persons with dementia.

12.2.2 24-Hour Care with Skilled Nursing Services

Settings referred to as skilled nursing facilities, nursing homes, Alzheimer's special care units, personal care and rehabilitation or health care centers, 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 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 stages 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.

12.2.3 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. 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.

12.3 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.

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

Specifically 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?

12.3.2 What Is the Process for Developing a Care Plan?

Look For:

- 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.
- Available information about Alzheimer's disease (books, posters, brochures, etc.).

Typically, staff will conduct periodic assessments and develop care plans at all residential care settings (except housing only settings). 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 or her as an individual and treats him or her 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 manage behavior challenges?
- What is your policy regarding the use of physical restraints that prevent free movement?
- How is 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.

12.3.3 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.

12.3.4 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.

12.3.5 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 identify the time of day and locate key areas 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.).

**12.3.6
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.

For Your Convenience

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

Rights and Protections in a Nursing Home

Source

<https://www.medicare.gov/what-medicare-covers/part-a/rights-in-nursing-home.html>

As a resident in a Medicare and/or Medicaid-certified nursing home, you have certain rights and protections under federal and state law that help ensure you get the care and services you need.

The nursing home must tell you about these rights and explain them in writing in a language you understand. They must also explain in writing how you should act and what you're responsible for while you're in the nursing home. This must be done before or at the time you're admitted, as well as during your stay. You must acknowledge in writing that you got this information.

At a minimum, federal law specifies that a nursing home must protect and promote the rights of each resident. As a person with Medicare, you have certain guaranteed rights and protections. In addition to these rights, you also have the right to:

1 Be Treated With Respect

You have the right to be treated with dignity and respect, as well as make your own schedule and participate in the activities you choose. You have the right to decide when you go to bed, rise in the morning, and eat your meals.

2 Participate In Activities

You have the right to participate in an activities program designed to meet your needs and the needs of the other residents.

3 Be Free From Discrimination

Nursing homes don't have to accept all applicants, but they must comply with local, state, and federal civil rights laws.

4 Be Free From Abuse And Neglect

You have the right to be free from verbal, sexual, physical, and mental abuse, as well as abuse of your money or property (called "misappropriation of property"). Nursing homes can't keep you apart from everyone else against your will.

If you feel you've been mistreated (abused) or the nursing home isn't meeting your needs (neglect), report this to the nursing home administrator. Depending on your state, the agency that investigates abuse and neglect will be Adult Protective Services and/or the State Survey Agency. The nursing home must investigate and report all suspected

violations and any injuries of unknown origin within 5 working days of the incident to the proper authorities. The Long-Term Care Ombudsman can also help by being your advocate and helping you resolve your concerns.

5 Be Free From Restraints

Nursing homes can't use any physical restraints (like side rails) or chemical restraints (like drugs) to discipline you or for the staff's own convenience.

6 Make Complaints

You have the right to make a complaint to the staff of the nursing home or any other person without fear of being punished. The nursing home must address the issue promptly.

7 Get Proper Medical Care

You have these rights regarding your medical care:

- To be fully informed about your total health status in a language you understand.
- To be fully informed about your medical condition, prescription and over-the-counter drugs, vitamins, and supplements.
- To be involved in the choice of your doctor.
- To participate in the decisions that affect your care.
- To take part in developing your care plan. By law, nursing homes must develop a care plan for each resident. You have the right to take part in this process. Family members can also help with your care plan with your permission.
- To access all your records and reports, including clinical records (medical records and reports) promptly during weekdays. Your legal guardian has the right to look at all your medical records and make important decisions on your behalf.
- To express any complaints (also called "grievances") you have about your care or treatment.
- To create advance directives in accordance with state law.
- To refuse to participate in experimental treatment.
- Have your representative notified. The nursing home must notify your doctor and, if known, your legal representative or an interested family member when:
 - You're injured in an accident and/or need to see a doctor.
 - Your physical, mental, or psychosocial status starts to get worse.
 - You have a life threatening condition.
 - You have medical complications.
 - Your treatment needs to change significantly.
 - The nursing home decides to transfer or discharge you from the nursing home.

- Get information on services and fees. You have the right to be told in writing about all nursing home services and fees (those that are charged and not charged to you) before you move into the nursing home and at any time when services and fees change. In addition:
 - The nursing home can't require a minimum entrance fee if your care is paid for by Medicare or Medicaid.
 - For people seeking admission to the nursing home, the nursing home must tell you (both orally and in writing) and display written information about how to apply for and use Medicare and Medicaid benefits.
 - The nursing home must also provide information on how to get a refund if you paid for an item or service, but because of Medicare and Medicaid eligibility rules, it's now considered covered.
- Manage your money. You have the right to manage your own money or choose someone you trust to do this for you. In addition:
 - If you deposit your money with the nursing home or ask them to hold or account for your money, you must sign a written statement saying you want them to do this.
 - The nursing home must allow you access to your bank accounts, cash, and other financial records.
 - The nursing home must have a system that ensures full accounting for your funds and can't combine your funds with the nursing home's funds.
 - The nursing home must protect your funds from any loss by providing an acceptable protection, like buying a surety bond.
 - If a resident with a fund passes away, the nursing home must return the funds with a final accounting to the person or court handling the resident's estate within 30 days.
- Get proper privacy, property, and living arrangements. You have these rights:
 - Keep and use your personal belongings and property as long as they don't interfere with the rights, health, or safety of others.
 - Have private visits.
 - Make and get private phone calls.
 - Have privacy in sending and getting mail and email.
 - Have the nursing home protect your property from theft.
 - Share a room with your spouse if you both live in the same nursing home (if you both agree to do so).
 - Be notified by the nursing home before your room or your roommate is changed. They should take your preferences into account.
 - Review the nursing home's health and fire safety inspection results.
- Spend time with visitors. You have these rights:
 - Spend private time with visitors.
 - Have visitors at any time, as long as you want to see them, and as long as the visit doesn't interfere with the provision of care and privacy rights of other residents.

- See any person who gives you help with your health, social, legal, or other services at any time. This includes your doctor, a representative from the health department, and your Long-Term Care Ombudsman, among others.
- Get social services. The nursing home must provide you with any needed social services, including:
 - Counseling.
 - Help solving problems with other residents.
 - Help in contacting legal and financial professionals.
 - Discharge planning.
- Leave the nursing home:
 - Leaving for visits:

If your health allows, and your doctor agrees, you can spend time away from the nursing home visiting family or friends during the day or overnight, called a "leave of absence." Talk to the nursing home staff a few days ahead of time so the staff has time to prepare your medicines and write your instructions.
 - Caution:

If your nursing home care is covered by certain health insurance, you may not be able to leave for visits without losing your coverage.
 - Moving out:

Nursing homes may have a policy that requires you to tell them before you plan to leave. If you don't, you may have to pay an extra fee.
- Have protections against unfair transfer or discharge:
 - You can't be sent to another nursing home or made to leave the nursing home, unless any of these are true:
 - It's necessary for the welfare, health, or safety of you or others.
 - Your health has improved to the point that nursing home care is no longer necessary.
 - The nursing home hasn't been paid for services you got.
 - The nursing home closes.
 - You have these rights:
 - You have the right to appeal a transfer or discharge.
 - The nursing home can't make you leave if you're waiting to get Medicaid.
 - Except in emergencies, nursing homes must give a 30-day written notice of their plan and reason to discharge or transfer you.
 - The nursing home has to safely and orderly transfer or discharge you and give you proper notice of bed-hold and readmission requirements.
- Form or participate in resident groups:
 - You have a right to form or participate in a resident group to discuss issues and concerns about the nursing home's policies and operations. Most homes have such groups, often called "resident councils." The home must give you meeting space and must listen to and act upon grievances and recommendations of the group.

- Have your family and friends involved:
 - Family and friends can help make sure you get good quality care. They can visit and get to know the staff and the nursing home's rules. Family members and legal guardians may meet with the families of other residents and may participate in family councils, if one exists. With your permission, family members can help with your care plan. If a family member or friend is your legal guardian, he or she has the right to look at all medical records about you and make important decisions on your behalf.

13. Caring for the Caregiver

Caregivers providing at-home-care for a person with Alzheimer's are a unique group. Over 15 million family and friends provide an estimated 17 billion hours of



unpaid care to those with Alzheimer's and other dementias. More than 62% of caregivers are women, and 23% are age 65 or older. Families may spend up to \$50,000 a year on care needs. Huge pressures are placed on caregivers. Not just the amount of time, but the type of care they provide makes their caregiving so intense.

Caregivers for people with Alzheimer's or other dementias 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 jobs, 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.

13.1 Signs of Caregiver Stress

You probably know all the details about the health of the person for whom you're caring. You're on top of what medications must be taken and when, and you can even spot minor changes in his or her mood and attitude. Are you as aware of what's going on with you?

Probably not. When you're caring for a loved one, it's easy to forget about your own needs, putting you at serious risk of burnout. Here are five signs that you've reached the end of your rope – and suggestions on what you can do about it.

1 You feel furious one minute, sad and helpless the next.

Whatever you call it – second-hand stress or the more serious caregiver burnout – the despairing mix of physical and emotional exhaustion strikes many caregivers at one time or another. As you ride the emotional

rollercoaster of caregiving, you're easily overwhelmed and angry. You can't eat or you eat too much. You're exhausted even after a night's sleep. Your brain is foggy and you no longer care about the things that used to bring you joy.

The fix: Your life has changed in profound ways, so it's natural to feel frustrated and to grieve for what you have lost. But untreated anxiety or depression is serious, and you can't take good care of anyone if you don't take of yourself. First, check in with your doctor to rule out any medical conditions that can trigger symptoms of mental health problems. Let your doctor know that you are a caregiver and might need support to be able to continue in this role. Finally, remind yourself that while you are doing everything you can, you will never do everything – and that's OK too.

2 You catch every bug that comes your way.

Stress doesn't just make you anxious and depressed. It takes a toll on your immune system. If you are getting sick more often and staying sick longer than you used to, your body is trying to tell you something. Listen up.

The fix: Don't let routine checkups slide because you don't think you have the time. See your primary care doctor and your dentist regularly. Ditto for immunizations, mammograms and other recommended screenings. Eating a nutritious diet and getting at least seven hours of sleep a night boosts your body's natural defenses.

3 You're snapping at everyone.

When you feel helpless and overwhelmed, you're more likely to overreact to the things people do, or don't do. Like a toddler having a tantrum, you need a timeout.

The fix: Don't set the bar so high that you can never meet it. Pick up the phone and make a call to a friend. Studies show that simply giving voice to your frustrations and fears dials down tension and eases the isolation that shadows caregivers. Mapping out a daily routine that you try to stick to will also give you a greater sense of control. Prioritize your to-do list, whether it's grocery shopping or taking your loved one to a doctor's appointment. Don't worry about things lower down on the list that don't get done.

4 You know you should exercise, but you just don't have the time.

No one functions well in crisis mode day after day. Caregiving is a marathon, not a sprint. You need to find a way to dial down the tension.

The fix: Force yourself to get moving. Exercise is the best stress reliever. Not only will you feel better right away, the surge of endorphins that exercise triggers lifts your mood, clears your head and helps you sleep better at night. A brisk 30-minute walk or jog on the treadmill, even a 10-minute walk around the block, jump-starts your brain, soothes nerves and powers up your immune system.

5 You can't remember the last time you met a friend for dinner or a movie.

Everyone needs a break from time to time, so why don't you give yourself one? Caregivers – motivated by a mix of love, loyalty and a dash of guilt – rarely do.

The fix: We are not suggesting a two-week Caribbean cruise, though that would be lovely, right? An overnight visit with a college friend, a night at a bed and breakfast, even a few hours to write in your journal, sip a cup of hot tea while you read a book or watch reruns of your favorite sitcom, can be restorative. One caveat: Taking a break doesn't mean running errands or doing chores. It's you time.

6 You're the go-to caregiver. Always.

This may be the hardest job you'll ever have, and it can take time to adjust and come to terms with it. But try going it alone and you'll quickly hit bottom.

The fix: Establish a network of relatives, friends or people in the community you can call on. Schedule a family meeting or video chat about who does what and who pays for it. Let everyone know you will not be available to host holiday meals, organize the church book drive or do any other draining activities that you've normally handled. Keep a to-do list with you and whip it out when others ask if they can help. Your neighbor might be happy to spend a few hours at your house while you go to the gym. A friend can buy groceries when she's at the store.

Meanwhile, join a local or online support group so you can connect with sympathetic ears and glean ideas for coping better. Be aware that there are a wide range of programs and professionals out there who can help make the job easier for you.

13.2 Helping Children Understand Alzheimer's Disease

When a family member has Alzheimer's disease, it affects everyone in the family, including children and grandchildren. Giving children understandable information about Alzheimer's can help them cope with the disease in their family. The type of relationship the child has with the family member and the child's age are important to help determine:

- What information the child receives;
- How the information is presented;
- The child's part, if any, in caring for the person with Alzheimer's disease.

It is important to answer children's questions simply and honestly. For example, you might tell a young child, "Grandma has an illness that makes it hard for her to remember things."

You can help children know that their feelings of sadness and anger are normal. Comfort them. If children express guilt or feel that they may have done something to hurt their grandparent, reassure them that they did not cause the disease.

Do not expect a young child to help care for the person with Alzheimer's disease. Make sure a child of any age has time for his or her own interests and needs, such as playing with friends, going to school activities, or doing homework. Make sure you spend time with your child, so he or she does not feel that all your attention is on the person with Alzheimer's.

Help the child understand your feelings. Be honest about your feelings when you talk with a child, but do not overwhelm him or her.

Many younger children will look to you to see how to act around the person with Alzheimer's. Show children they can still talk with the person, at least in the early stages of the disease. Doing fun things together, with parental supervision depending on the age of the child, can help both the child and the person with Alzheimer's. Here are some things they might do:

- Walk in the neighborhood
- Do simple arts and crafts
- Play music
- Sing
- Look through photo albums
- Read stories out loud

However, in the later stages of disease, the person with Alzheimer's may be completely unresponsive. This may be very hard for a child to understand. Some children might not talk about their negative feelings, but you may see changes in how they act. Problems at school, with friends, or at home can be signs that they are upset. You may want to ask a school counselor or a social worker to help a child understand what is happening and how to cope.

A teenager might find it very hard to accept how the person with Alzheimer's disease has changed. He or she might find the changes upsetting and not want to be around the older person. It is a good idea to talk with teenagers about their concerns and feelings. Do not force them to spend time with the person who has Alzheimer's. This could make things worse.

If the stress of living with someone who has Alzheimer's disease becomes too great for a child, talk to other family members or friends about helping out. Or, find out about, and consider using, respite care options available in your community. Then, both you and your child can get a much-needed break.

For More Information

Alzheimer's Disease Education and Referral Center

P.O. Box 8250

Silver Spring, MD 20907-8250

1-800-438-4380 (toll-free)

www.nia.nih.gov/alzheimers

10 Ways to Deal with Caregiver Stress

Source:

www.aarp.org

1 Put Your Physical Needs First

Eat nutritious meals. Don't give in to stress-driven urges for sweets or overindulge in alcohol. Get enough shut-eye; if you have trouble sleeping at night, try napping during the day. Schedule regular medical checkups. Find time to exercise, even if it means you have to ask someone else to provide care while you work out. If you experience symptoms of depression – extreme sadness, trouble concentrating, apathy, hopelessness, thoughts about death – talk to a medical professional.

2 Connect With Friends. Isolation Increases Stress

Getting together regularly with friends and relatives can keep negative emotions at bay.

3 Ask For Help

Make a list of things you have to do and recruit others to pitch in. Even faraway relatives and friends can manage certain tasks.

4 Call On Community Resources

Consider asking a geriatric care manager to coordinate all aspects of your loved one's care. Other service providers, including home health aides, homemakers and home repair services, can shoulder some of the many responsibilities of caregiving. Volunteers or staff from faith-based organizations or civic groups might visit, cook or help you with driving.

5 Take A Break

You deserve it. Plus, your ailing family member might benefit from someone else's company. Think about respite care by friends, relatives or volunteers. Or try for a weekend or longer vacation by turning to a home health agency, nursing home, assisted living residence or board-and-care home; these facilities sometimes accept short-term residents. Adult day centers, which usually operate five days a week, provide care in a group setting for older people who need supervision.

6 Deal With Your Feelings

Bottling up your emotions takes a toll on your psyche – and even on your physical well-being. Share feelings of frustration with friends and family. Seek support from co-workers who are in a similar situation. Make an appointment with a professional counselor, or join a caregiver support group.

7 Find Time To Relax

Doing something you enjoy, such as reading, walking or listening to music, can recharge your batteries. Some caregivers meditate or use relaxation techniques such as deep breathing or visualizing a positive place. If you're religious, you might find that prayer can be a powerful tool.

8 Get Organized

Simple tools like calendars and to-do lists can help you prioritize your responsibilities. Always tackle the most important tasks first, and don't worry if you can't manage everything.

9 Just Say No

Accept the fact that you simply can't do everything! Resist the urge to take on more activities, projects or financial obligations than you can handle. If someone asks you to do something that will stretch you too thin, explain honestly why you can't – and don't feel guilty.

10 Stay Positive

Do your best to avoid negativity. Hold a family meeting or call an elder care mediator to resolve conflicts with siblings and other relatives. Instead of dwelling on what you can't do, pat yourself on the back for how much you are doing, and focus on the rewards of caring for someone you love.

A Caregivers Bill of Rights

Read the list to yourself every day

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.

Horne, Jo. (1985) Caregiving: Helping an Aged Loved One. AARP Books.

14. Healthy Aging

Getting older can come with a variety of health challenges. But you can take action to maintain good health and reduce your risk of disease and disability. Exercise, good nutrition, regular health screenings, managing any chronic conditions and participating in social activities are just a few ways to promote healthy aging - in particular promoting a healthy brain.

Aging well depends on your genes, your environment and your lifestyle. Making healthy lifestyle choices may help you maintain a healthy body and a healthy brain.

A simple question to ask – What if you could reduce your risk of dementia in a few simple ways? While we can't control some risk factors for Alzheimer's disease or dementia, research suggests that certain lifestyle factors might reduce the risk of cognitive decline.

The following information is designed to promote several aspects of healthy aging, in particular some of those that researchers believe have an impact on cognition. Your doctor or health care provider can provide additional information about taking care of your health and there are a number of resources on the internet and at libraries.

14.1 Brain Health

We all want to stay healthy and independent as we age. In addition to keeping our bodies in good shape, we want to keep our minds healthy too.

Some common age-related changes to memory and learning are:

- Increased difficulty finding words
- More problems in multi-tasking
- Mild decreases in ability to pay attention

Yet as you age you can still learn new things, create new memories and improve vocabulary and language skills.

14.1.1 Possible Risks or Threats to Brain Health

-
- Some medicines, or improper use of them
 - Smoking
 - Excessive use of alcohol
 - Heart disease, high blood pressure, diabetes, and other health problems
 - Traumatic brain injury, depression and stroke
 - Alzheimer's disease
 - Poor diet
 - Insufficient sleep or sleep apnea
 - Lack of physical activity
 - Little social activity and being alone most of the time
 - Hearing Loss

14.1.2 So what can you do to protect brain health?

- Take care of your health
- Eat healthy
- Get moving with physical activity
- Keep your mind active
- Stay connected

14.2 Nutrition

The foods we choose to eat are the foundation of our overall health. Making healthy food choices is a smart thing to do no matter your age. Your body changes through your 60s, 70s, 80s and beyond. Food provides the nutrients that your body needs as you age and can help ward off chronic diseases and obesity.

The National Institute on Aging recommends using the following tips to choose foods for better health at each stage of life:

1 Drink Plenty of Liquids

With age, you may lose some of your sense of thirst. Drink water often. Low-fat or fat-free milk or 100% juice also helps you stay hydrated. Limit beverages that have lots of added sugars or salt. Learn which liquids are better choices.

2 Make Eating a Social Event

Meals are more enjoyable when you eat with others. Invite a friend to join you or take part in a potluck at least twice a week. A senior center or place of worship may offer meals that are shared with others. There are many ways to make mealtimes pleasing.

3 Plan Healthy Meals

Find trusted nutrition information from ChooseMyPlate.gov and the National Institute on Aging. Get advice on what to eat, how much to eat, and which foods to choose, all based on the Dietary Guidelines for Americans. Find sensible, flexible ways to choose and prepare tasty meals so you can eat foods you need.

4 Know How much to Eat

Learn to recognize how much to eat so you can control portion size. When eating out, pack part of your meal to eat later. One restaurant dish might be enough for two meals or more.

5 Vary Your Vegetables

Include a variety of different colored vegetables to brighten your plate. Most vegetables are a low-calorie source of nutrients. Vegetables are also a good source of fiber.

6 Eat for Your Teeth and Gums

Many people find that their teeth and gums change as they age. People with dental problems sometimes find it hard to chew fruits, vegetables, or meats.

Don't miss out on needed nutrients! Eating softer foods can help. Try cooked or canned foods like unsweetened fruit, low-sodium soups, or canned tuna.

7 Use Herbs and Spices

Foods may seem to lose their flavor as you age. If favorite dishes taste different, it may not be the cook! Maybe your sense of smell, sense of taste, or both have changed. Medicines may also change how foods taste. Add flavor to your meals with herbs and spices.

8 Keep Food Safe

Don't take a chance with your health. A food-related illness can be life threatening for an older person. Throw out food that might not be safe. Avoid certain foods that are always risky for an older person, such as unpasteurized dairy foods. Other foods can be harmful to you when they are raw or undercooked, such as eggs, sprouts, fish, shellfish, meat, or poultry.

9 Read the Nutrition Facts Label

Make the right choices when buying food. Pay attention to important nutrients to know as well as calories, fats, sodium, and the rest of the Nutrition Facts label. Ask your doctor if there are ingredients and nutrients you might need to limit or to increase.

10 Ask Your Doctor about Vitamins or Supplements

Food is the best way to get nutrients you need. Should you take vitamins or other pills or powders with herbs and minerals? These are called dietary supplements. Your doctor will know if you need them. More may not be better. Some can interfere with your medicines or affect your medical conditions.



14.3 Physical Health

According to the National Institute on Aging, regular exercise and physical activity are important to the physical and mental health of almost everyone, including older adults. Being physically active can help you continue to do the things you enjoy and stay independent as you age. Regular physical activity over long periods of time can produce long-term health benefits. That's why health experts say that older adults should be active every day to maintain their health. In addition, regular exercise and physical activity can reduce the risk of developing some diseases and disabilities that develop as people grow older. In some cases, exercise is an effective treatment for many chronic conditions. For example, studies show that people with arthritis, heart disease, or diabetes benefit from regular exercise. Exercise also helps people with high blood pressure, balance problems, or difficulty walking.

You don't need to buy special clothes or belong to a gym to become more active. Physical activity can and should be part of your everyday life. Find things you like to do. Go for brisk walks. Ride a bike. Dance. Work around the house. Garden. Climb stairs. Swim. Rake leaves. Try different kinds of activities that keep you moving and strive to achieve 30 minutes of activity daily. Look for new ways to build physical activity into your daily routine.

To get all the benefits of physical activity try to focus on all of these four ways to be active:

- Build up endurance, an activity that makes you breathe hard, because it builds up your energy and “staying power.”
- Focus on strength in order to keep using and build muscles. Strong muscles will help you lift yourself from a chair, walk in the park and help prevent falls.
- Do things to help your balance such as standing on one foot.
- Stretching can improve your flexibility. Moving more freely will make it easier for you to tie your shoes or look over your shoulder when driving.

If you are not used to energetic activity check with your health care provider prior to starting any exercise program. Also, to make sure you are exercising safely it is best to follow a few simple safety tips:

- Start slowly, especially if you haven't been active for a long time. Little by little, build up your activities and how hard you work at them.
- Don't hold your breath during strength exercises. That could cause changes in your blood pressure. It may seem strange at first, but you should breathe out as you lift something and breathe in as you relax.
- Use safety equipment. For example, wear a helmet for bike riding or the right shoes for walking or jogging.
- Unless your doctor has asked you to limit fluids, be sure to drink plenty of fluids when you are doing activities. Many older adults don't feel thirsty even if their body needs fluids.
- Always bend forward from the hips, not the waist. If you keep your back straight, you're probably bending the right way. If your back “humps,” that's probably wrong.
- Warm up your muscles before you stretch. Try walking and light arm pumping first.

Exercise should not hurt or make you feel really tired. You might feel some soreness, a little discomfort, or a bit weary, but you should not feel pain. In fact, in many ways, being active will probably make you feel better.

14.4 Social Activities and Engagement

As people get older, they often find themselves spending more and more time at home alone. The isolation can lead to depression and is not good for your health. If you find yourself spending a lot of time alone, try adding a volunteer or social activity to your routine. The National Institute on Aging recommends the following information related to an active and social lifestyle.

14.4.1 Benefits of an Active Lifestyle

Engaging in social and productive activities you enjoy, like taking an art class or becoming a volunteer in your community or at your place of worship, may help to maintain your well-being.

Research tells us that older people with an active lifestyle:

- Are less likely to develop certain diseases. Participating in hobbies and other social and leisure pursuits may lower risk for developing some health problems, including dementia.
- Have a longer lifespan. One study showed that older adults who reported taking part in social activities (such as playing games, belonging to social groups, or traveling) or meaningful, productive activities (such as having a paid or unpaid job, or gardening) lived longer than people who did not. Researchers are further exploring this connection.
- Are happier and less depressed. Studies suggest that older adults who participate in what they believe are meaningful activities, like volunteering in their communities, say they feel happier and healthier. One study placed older adults from an urban community in their neighborhood public elementary schools to tutor children 15 hours a week. Volunteers reported personal satisfaction from the experience. The researchers found it improved the volunteers' cognitive and physical health, as well as the children's school success. They think it might also have long-term benefits, lowering the older adults' risk of developing disability, dependency, and dementia in later life.
- Are better prepared to cope with loss. Studies suggest that volunteering can help with stress and depression from the death of a spouse. Among people who experienced a loss, those who took part in volunteer activities felt more positive about their own abilities (reported greater self-efficacy).
- May be able to improve their thinking abilities. Another line of research is exploring how participating in creative arts might help people age well. For example, studies have shown that older adults' memory, comprehension, creativity, and problem-solving abilities improved after an intensive, 4-week (8-session) acting course. Other studies are providing new information about ways that creative activities like music or dance can help older adults.

Activities to Consider

Would you like to get more involved in your community or be more socially active? There are plenty of places to look for opportunities, depending on your interests. Here are some ideas:

- Get out and about
- Join a senior center and take part in its events and activities
- Play cards or other games with friends
- Go to the theater, a movie, or a sporting event
- Travel with a group of older adults, such as a retiree group
- Visit friends and family
- Try different restaurants
- Join a group interested in a hobby like knitting, hiking, painting, or wood carving
- Learn something new
- Take a cooking, art, or computer class
- Form or join a book club
- Try yoga, tai chi, or another new physical activity
- Learn (or relearn) how to play a musical instrument
- Become more active in your community
- Serve meals or organize clothing donations at a place for homeless people
- Help an organization send care packages to soldiers stationed overseas
- Care for dogs and cats at an animal shelter
- Volunteer to run errands for people with disabilities
- Join a committee or volunteer for an activity at your place of worship
- Volunteer at a school, library, or hospital
- Help with gardening at a community garden or park
- Organize a park clean-up through your local recreation center or community association
- Sing in a community choral group, or play in a local band or orchestra
- Take part in a local theater troupe
- Get a part-time job

14.5 What is the Chronic Disease Self- Management Program

The Chronic Disease Self-Management Program (CDSMP), developed by Dr. Kate Lorig at Stanford University, is an evidence-based program offered for two and a half hours, once a week, for six weeks. People with different chronic health problems and/or disabilities attend together in community settings such as senior and community centers, churches, libraries, senior housing, retirement communities and physician offices. In Mississippi, this program is known as Motivated to Live a Better Life. The workshops are facilitated by two trained leaders; one or both have a chronic condition. The six-week workshop covers techniques to deal with problems such as: dealing with difficult emotions, depression, positive thinking, pain, making informed

treatment decisions, healthy eating; appropriate exercises for maintaining and improving strength, flexibility and endurance; appropriate use of medications; communicating effectively with family, friends and health professionals; nutrition; and how to evaluate new treatments. It is the process in which the CDSMP is taught that makes it effective. Sessions are highly participative, and mutual support and success build participants' confidence in their ability to manage their health and maintain active and fulfilling lives. CDSMP is currently offered in 46 states and 19 countries. There are three levels of trainers. T-trainers provide training to Master Trainers. Master Trainers can then train Lay Leaders. Trainings are offered as the need for Lay Leaders and Master Trainers are identified.

14.5.1 Assumptions that underlie the CDSMP

People with chronic conditions have similar concerns and problems. People with chronic conditions must deal not only with their disease(s), but also with the impact these have on their lives and emotions.

Lay people with chronic conditions, when given a detailed leaders' manual, can teach the CDSMP as effectively, if not more effectively, than health professionals. The process or way the CDSMP is taught is as important, if not more important, than the workshop's subject matter.

Session One

- Introduction to Workshop
- The Mind-Body Connection / Distraction
- Getting a Good Night's Sleep
- Introduction to Action Plan

Session Three

- Making Decisions
- Pain and Fatigue Management
- Endurance Exercise
- Relaxation: Body Scan
- Action Plans

Session Five:

- Making Healthy Food Choices
- Medication Usage
- Making Informed Treatment Decisions
- Dealing with Depression
- Action Plans

Session Two

- Dealing with Difficult Emotions
- Introduction to Physical Activity and Exercise
- Preventing Falls and improving Balance
- Action Plans

Session Four

- Better Breathing
- Healthy Eating
- Communication Skills
- Problem-Solving
- Action Plans

Session Six:

- Working with your Health Care Professional and Health Care System
- Weight Management
- Looking Back and Planning for the Future

14.5.2 How was the program evaluated?

About 1,000 people with heart disease, lung disease, stroke or arthritis participated in a randomized, controlled test of the program and were followed for up to three years. The Stanford Division of Family and Community Medicine looked for changes in many areas: health status (disability, social / role limitations, pain and physical discomfort, energy/fatigue, shortness of breath, psychological well-being/distress, depression, health distress, self-rated general health); health care utilization (visits to physicians, visits to emergency department, hospital stays, and nights in hospital); self-efficacy (confidence to perform self-management behaviors, manage disease in general and achieve outcomes); and self-management behaviors (exercise, cognitive symptom management, mental stress management / relaxation, use of community resources, communication with physician, and advance directives).

14.5.3 CDSMP Outcomes

CDSMP has undergone extensive evaluation in several countries. The program has been proven effective across socioeconomic and education levels and the health benefits persist over a two-year period even when disability worsens. There is strong evidence that CDSMP has a beneficial affect on physical and emotional outcomes and health-related quality of life. Participant outcomes have been evaluated at four months, six months, one year and two years. All outcomes reported have statistical significance.

Program participants, when compared to non-participants, demonstrated significant improvements in exercise, cognitive symptom management, communication with physicians, self-reported general health, health distress, fatigue, disability and social/role activity limitations. They also spent fewer days in the hospital and had fewer outpatient visits and hospitalizations. These data yield a cost-to-savings ratio of approximately 1:10. Many of these results persisted for as long as three years.

14.5.3 Does the program replace existing programs and treatment?

The Self-Management Workshop will not conflict with existing programs or treatment. It is designed to enhance regular treatment and disease-specific education such as Better Breathers, cardiac rehabilitation or diabetes instruction. In addition, many people have more than one chronic condition. The program is especially helpful for these people, as it gives them the skills to coordinate all they need to manage their health, as well as to help them keep active in their lives.

14.5.3 How was the program developed?

The Division of Family and Community Medicine in the Department of Medicine at Stanford University received a five-year research grant from the federal Agency for Health Care Research and Policy and the State of California Tobacco-Related Research Project. The purpose of the research was to develop and evaluate, through a randomized controlled trial, a community-based self-management program that assists people with chronic illness. The study was completed in 1996. The research project had several investigators: Halsted Holman, MD, Stanford Professor of Medicine; Kate Lorig, DrPH,

Stanford Associate Research Professor of Medicine; David Sobel, MD, Regional Director of Patient Education for the Northern California Kaiser Permanente Medical Care Program; Albert Bandura, PhD, Stanford Professor of Psychology; and Byron Brown, Jr., PhD, Stanford Professor of Health Research and Policy. The Program was written by Dr. Lorig, Virginia González, MPH, and Diana Laurent, MPH, all with the Stanford Patient Education Research Center. Ms. González and Ms. Laurent also served as integral members of the research team. The CDSMP process design was based on the experience of the investigators and others with self-efficacy, people's confidence that they can master a new skill or affect their own health. The content of the workshop was the result of focus groups in which people with chronic health problems discussed which content areas were the most important for them.

For more information on Motivated to Live a Better Life contact the Mississippi State Department of Health-Office of Preventive Health at 601-206-1559.

15. Research

A worldwide quest is currently underway to find new treatments to slow, stop, or even prevent Alzheimer's disease and related dementias. With increased public attention and federal research funding, the trajectory of these diseases can change. Under the leadership of the National Institutes of Health (NIH), the Alzheimer's research community is intensifying its efforts, seeking to identify effective ways to treat or prevent Alzheimer's and related dementias as soon as possible.



A division of the U.S. Department of Health and Human Services, NIH is the largest public funder of biomedical research in the world, investing more than \$30 billion in taxpayer dollars to achieve its mission to enhance health, lengthen life, and reduce illness and disability.

Fighting Alzheimer's disease and related dementias is a priority not just at the NIH and other Federal agencies, but across the Nation and much of the world.

In January 2011, then President Obama signed the National Alzheimer's Project Act (NAPA), which called for an aggressive and coordinated U.S. plan to accelerate Alzheimer's disease research, provide better clinical care, and improve services for people with the disease and their families. The law also established an Advisory Council on Alzheimer's Research, Care, and Services, consisting of some of the Nation's foremost experts. The Advisory Council's first National Plan to Address Alzheimer's Disease in 2012 outlined objectives and set milestones to achieve the ultimate research goal: to find effective interventions to treat and prevent Alzheimer's and related dementias by 2025.

Updated annually, the research component of the National Plan is a collaborative, constantly evolving framework. It outlines the basic, translational, and clinical research needed to understand and conquer Alzheimer's disease and related dementias. It also encourages the American public, which is increasingly aware of the devastation wrought by this disease, to be fully engaged in this critical effort.

As of December 2017, Congress has approved a total of 1.39 billion in federal funding for Alzheimer's research.

This increase has enabled new and innovative research projects including:

- Large-scale research to identify new risk and protective genes
- Development of new human cellular models of Alzheimer's that may enable rapid screening of hundreds of thousands of molecules as potential therapeutic agents
- Establishment of translational centers that will develop and apply cutting-edge approaches to drug discovery and development
- Population studies of trends in the incidence and prevalence of dementia
- Development of novel interventions to support dementia caregivers
- Clinical trials of therapies in people at the highest risk of dementia

15.1 Treatment Pipeline

Currently, there are five FDA-approved Alzheimer's drugs that treat the symptoms of Alzheimer's disease and temporarily help memory and thinking problems in about half of the people who take them. But these medications do not treat the underlying causes of Alzheimer's or related dementias. In contrast, many of the new drugs in development aim to modify the disease process itself, by impacting one or more of the many wide-ranging brain changes that Alzheimer's causes.

These changes offer potential "targets" for new drugs to stop or slow the progress of the disease. Many researchers believe successful treatment will eventually involve a "cocktail" of medications aimed at several targets, similar to current state-of-the-art treatments for many cancers and HIV/AIDS. Over the last 30 years, researchers have made remarkable progress in understanding healthy brain function and what goes wrong in Alzheimer's disease.

Promising target areas for next-generation drug therapies under investigation in current research studies include:

- 1 Beta-amyloid** is the chief component of plaques, one hallmark Alzheimer's brain abnormality. Scientists now have a detailed understanding of how this protein fragment is clipped from its parent compound amyloid precursor protein (APP) by two enzymes – beta-secretase and gamma-secretase. Researchers are developing medications aimed at virtually every point in amyloid processing. This includes blocking activity of beta-secretase enzyme; preventing the beta-amyloid fragments from clumping into plaques; and even using antibodies against beta-amyloid to clear it from the brain.
- 2 Beta-secretase (BACE)** is one of the enzymes that clips APP and makes it possible for beta-amyloid to form. Therapies that interrupt this process may reduce the amount of beta-amyloid in the brain and ultimately intervene in the development of Alzheimer's disease.

- 3 Tau protein** is the chief component of tangles, the other hallmark brain abnormality of Alzheimer's. Tau protein helps maintain the structure of a neuron, including tiny tube-like structures called microtubules that deliver nutrients throughout the neuron. Researchers are investigating mechanisms to prevent tau protein from collapsing and twisting into tangles, a process that destroys microtubules and, ultimately, the neuron itself.
- 4 Inflammation** is another key Alzheimer's brain abnormality. Both beta-amyloid plaques and tau tangles cause an immune response in the brain. Microglia are cells that act as the first form of immune defense in the brain. While microglia help clear beta-amyloid in the brain, they may become overactive in the presence of beta-amyloid and produce compounds that damage nearby cells.
- 5 Insulin resistance** in the brain is another common feature of Alzheimer's disease. For reasons researchers do not completely understand, the brain becomes resistant to the normal effects of insulin, including the conversion of glucose to energy that brain cells can use to fuel cell functioning. Some research suggests that beta-amyloid decreases the body's ability to use insulin. Other research has found reduced levels of insulin in the brain.

15.2 Mississippi's Research Initiatives

Research currently underway in Mississippi is steadily adding to our understanding of the aging brain and we are closing in on more effective ways to prevent and treat Alzheimer's and related diseases.

The MIND Center at University of Mississippi Medical Center

Led by Dr. Thomas Mosley, The Memory Impairment and Neurodegenerative Dementia (MIND) Center is a major research and clinical care initiative at the University of Mississippi Medical Center (UMMC) aimed at elucidating the causes and developing treatments for Alzheimer's disease and related forms of dementia through innovative research. The MIND Center's ARIC Neurocognitive Study (ARIC NCS) is the most comprehensive and long-term study on dementia risk ever undertaken and one of the largest studies in the nation in African Americans to address racial disparities in dementia risk.

The ARIC NCS has been ongoing for over 30 years and is a collaborative effort among five leading academic medical centers including The MIND Center at UMMC, Johns Hopkins University, University of Minnesota, Wake Forest University, and University of North Carolina – Chapel Hill. Partially funded by a competitive research grant from the National Institutes of Health, state appropriations and private support, The MIND Center brings together leading-edge research, state-of-the-art brain imaging and powerful new genetic technologies to accelerate the pace of discovery in the search for treatments to slow or prevent Alzheimer's and other forms of cognitive decline and dementia.

Precise Research Centers

Founded in 2004 by Dr. Joseph Kwentus, Precise Research Centers conducts clinical studies with investigational medications to find better treatments for common disorders like Alzheimer's disease, ADHD, alcohol dependence, bipolar disorder, and depression. Headquartered in Flowood, Precise researches medications in all phases of drug development and has collaborated on clinical trials for many conditions with leading pharmaceutical companies.

University of Southern Mississippi

Dr. Vijay Rangachari is currently conducting research at the University of Southern Mississippi in the field of biological chemistry with a focus on the biophysics of amyloid protein deposits in the brain characteristic of Alzheimer's and Parkinson's disease. His lab is working to identify the mechanisms involved in inflammation-induced amyloid plaque formation, which is thought to occur in conditions such as traumatic brain injury, with an end goal of translating molecular theories into meaningful patient therapies.

The Memory Center at Hattiesburg Clinic

The Memory Center at Hattiesburg Clinic conducts clinical trials that focus on neurological therapeutics, with Alzheimer's disease being an area of special interest and expertise. Led by Dr. Ronald Schwartz, the Memory Center offers the community access to potential new treatments for Alzheimer's. These treatments can only be discovered through the partnership of patient volunteers, research sites, and scientific sponsors.

Mississippi State University

Dr. Deborah Eakin in the Department of Psychology is currently conducting research which examines the stability of metamemory with age, even when memory is impaired.

The unprecedented growth in the number of individuals with Alzheimer's coupled with the tremendous human and societal costs, underscores the urgency of research efforts. In the past, when the investment has been made in research to find ways to prevent and treat major diseases such as breast and prostate cancer, heart disease, stroke, and HIV/AIDS, disease outcomes have been dramatically improved. We must do the same with Alzheimer's and dementia. Mississippi's commitment to Alzheimer's and dementia research is critical to addressing one of the most severe public health challenges facing Mississippi and the nation today.

15.3 Participating in Clinical Trials

Only through clinical research can we gain insights and answers about the safety and effectiveness of drugs and therapies. Groundbreaking scientific advances in the present and the past were possible only because of participation of volunteers, both healthy and those diagnosed with an illness, in clinical research.



Clinical research requires complex and rigorous testing in collaboration with communities that are affected by the disease. As clinical research opens new doors to finding ways to diagnose, prevent, treat, or cure disease and disability, volunteer participation in clinical trials is essential to help us find the answers.

15.4 How to Find a Clinical Trial

There are many ways you can get help to find a clinical trial. You can talk to your doctor or other health care provider or you can search on various websites to find available studies. Caregiver or family support groups sometimes have lists of clinical studies. Also, newspapers may have advertisements for clinical trials at nearby hospitals, clinics or universities.

If you are interested in learning more about clinical research involving older adults, you may want to visit www.NIHSeniorHealth.gov and look at the “Participating in Clinical Trials” topic area or visit one of the websites listed here.

- **ClinicalTrials.gov**

ClinicalTrials.gov is a registry and results database of publicly and privately supported clinical studies of human participants conducted around the world. It is run by the National Library of Medicine at the National Institutes of Health, and is the largest clinical trials database, currently holding registrations from over 230,000 trials from 195 countries in the world.

- **ResearchMatch.org**

ResearchMatch.org is a non-profit effort to link people who are trying to find research studies to researchers who are looking to participate in their studies. It is a free and secure registry that has been developed by major academic institutions across the country who want to involve you in the mission of helping today’s research make a real difference in everyone’s health in the future.

- **AlzMS.org/Research**

AlzMS.org/Research is a resource provided by Alzheimer’s Mississippi which lists current clinical trial opportunities in Mississippi and provides an opportunity for prospective study participants to match with suitable clinical trials within a desired geographical region.

- **UMC.edu/MINDCenter**

Visit the Research Study Opportunities page of the umc.edu/MINDCenter website for information regarding active clinical trials and research studies at The MIND Center, and to identify clinical trials in which you or your loved one may be eligible to participate.

- **TrialMatch.alz.org**

TrialMatch.alz.org is a free, easy-to-use clinical studies matching service sponsored by the Alzheimer's Association that generates customized lists of studies based on user-provided information.

- **MemoryStrings.org**

The memory strings community is a movement powered by *globalalzplatform.org* to encourage and support clinical research.

- **Precise-Research.com/studies/currently-enrolling**

Visit this site to learn more about the studies currently enrolling at Precise Research in Flowood.

- **HattiesburgClinic.com/memory-center-trials**

Visit this site to learn more about the studeis currently enrolling at the Hattiesburg Clinic Memory Center.

Our Nation faces many challenges as we work together to find effective therapies to prevent and treat Alzheimer's disease and related dementias by 2025. But, we are optimistic. With the generous support of study volunteers and their families, dedicated researchers are advancing our understanding of this complex disease day-by-day. The National Institutes of Health, with the participation of all who search for answers, has set its sights on a cure for Alzheimer's.

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17. Information and Referral Services

The material in this book is provided for informational purpose only. We do not claim that the information is an exhaustive compilation of resources. These resources are intended, but not promised or guaranteed to be current or complete. However, honest efforts have been made to provide comprehensive information for the benefit of users.

If you have additions or corrections, please contact one of our partners: Alzheimer's Mississippi, Inc., The MIND Center at UMMC or the Department of Mental Health, Division of Alzheimer's.

17.1 Geriatricians

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. Some physicians however, are board certified in Geriatric Medicine and have additional training in working with diseases of elders.

Bolivar County

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

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

Dr. Scott Nelson
 907 E Sunflower Road
 Cleveland, MS 38732
 (662) 721-1399

DeSoto County

Baptist Memory Care Center
 400 Market Boulevard
 Suite 111
 Collierville, TN 38017
 (901) 227-1234

Forrest County

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

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

Harrison County

Dr. Yashashree L. Bethala
Dr. Bennett W. Cheney
Dr. Regina Clare Mills
Dr. Gholam Reza Motakhaveri
Dr. Marion Jean Wainwright
Biloxi Internal Medicine
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 Suite 101
 Biloxi, MS 39531
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Dr. Scott Gibson
Dr. Kathy Gregg
Dr. Sara Sanders
Dr. Kimberly C. Tarver
Dr. Gwen Windham
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 Pascagoula, MS 39581
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Dr. John Hassell
Dr. Terry Pitts
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 1800 12th Street
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 (601) 703-9223

Dr. Robert Kiehn
 1500 Highway 19N
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 Tupelo, MS 38801
 (662) 377-5930

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Lincoln County

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 427 US 51
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 (601) 833-6011

Neshoba County

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Dr. Ahmand Haidar

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Dr. Roberto Lopez

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17.2 Psychiatrists

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Dr. Peter Kamp

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319 Courthouse Road
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17.3 Neurologists

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Neurology Associates of MS
4105 Hospital Street
Suite 104
Pascagoula, MS 39581
(228) 769-0276

Jones County

Dr. Minipuri Gunavan Singh
Dr. Aremmia D. Tanious

1203 Jefferson Street
Laurel, MS 39440-4354
(601) 649-2863
(601) 518-1111

Lafayette County

Dr. James Parker
Dr. Ethel Rose
Dr. Eric K. Undesser
Dr. Xinhong Zhang

1500 E. Woodrow Wilson Avenue
Routing #127
Jackson, MS 39216
(601) 364-1285
(601) 939-0361

Dr. Malcolm M. Roland

Oxford Neurology
510 Azalea Drive
Oxford, MS 38655
(662) 281-0112

Lauderdale County

Dr. Jimmy V. Wolfe

Anderson Neurology Center
1521 A 22nd Avenue
Meridian, MS 39301
(601) 703-3830

Dr. Paul Bradley

1521 22nd Avenue
Meridian, MS 39301
(601) 703-3830

Dr. Zaineb Daud

Dr. Aamir Hashmat

Meridian Medical Associates
2024 15th Street
Suite 4A
Meridian, MS 39301
(601) 553-2000

Lee County

Dr. Bette Cardner
Dr. W. Thomas Oakes Jr.

Tupelo Neurology Clinic
609 Brunson Drive
Tupelo, MS 38801-4948
(662) 844-7021

Dr. Mark Fletcher
Dr. Justin Graff
Dr. Donna Harrington
Dr. Samuel Newell, Jr.

Dr. Lisa Dabbs
Dr. Corey Mauldin
Dr. Paige Sanders
Neurology Consultants
IMA-Tupelo
845 S. Madison Street
Tupelo, MS 38801
(662) 377-3008

Dr. Thomas Joseph McDonald

North MS Neurosurgical Services
4381 S. Eason Boulevard
Suite 302
Tupelo, MS 38801
(662) 377-5700

Dr. Brian Thomas**Dr. Traci Thomas**

Thomas Neuropsychology
144 S. Thomas Street
Suite 104A
Tupelo, MS 38801
(662) 231-8916
(662) 231-5072

Madison County

Dr. Jigyasa Tewari, MD

Merit Health
161 River Oaks Drive
Canton, MS 39046
(601) 855-4701

Pearl River County

Dr. Michael B. Mitchell

128 Highland Pkwy
#200
Picayune, MS 39466
(601) 358-9630

Pike County

Dr. Joseph William Farina, Jr.

McComb Neurology Center
118 N. Broadway
McComb, MS 39648
(601) 249-2491

Rankin County

Dr. Ruth K. Fredericks**Dr. Larry Parker****Dr. Adele Thiel**

1020 River Oaks Drive
Suite 420
Flowood, MS 39232-9500
(601) 939-0361

Warren County

Dr. Mohammed A. Ahmed

104 McAvley Drive
Vicksburg, MS 39183
(601) 638-7271

Dr. Namita K. Arora

3444 Wisconson Avenue
Vicksburg, MS 39180
(601) 638-0031

Dr. Krishna J. Goli

2100 Hwy 61 N
Vicksburg, MS 39183
(601) 883-3573

17.4 Counseling Services

As a caregiver, if you need to talk to someone who understands what you're going through, join a support group. Call Alzheimer's Mississippi, Inc., The Mind Center at UMMC 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.

2005 Harris Drive
Oxford, MS 38655
(662) 513-9936
mcampell@ifulford.net

B. Heath Gordon, Ph.D.

4500 I-55 North
Highland Village
Suite 234
Jackson, MS 39211
(601) 982-8531 (Tel)
(601) 982-1115 (Fax)
www.heathgordonphd.com

Kristine M. Jacquin, Ph.D.

*Licensed Clinical Psychologist
Assistant Professor of Psychology
Mississippi State University*
P.O. Box 6161
Starkville, MS 39762
(662) 325-1022
kmj8@ra.msstate.edu

W. Criss Lott, Ph.D.

*Clinical Director
St. Dominic Counseling Center*
969 Lakeland Drive
Jackson, MS 39216
(601) 200-3110

Molly Meeks, MS, NCC

Summit Counseling
431 North State Street
Jackson, MS 39201
(601) 949-1949

Sue Ann Meng, LCSW

Kim Tarver, MD
*The MIND Center
University of Mississippi
Medical Center*
2500 N. State Street
Jackson, MS 39216
(601) 984-5642
(601) 984-5610

Katherine Nordal, Ph.D.

The Nordal Clinic, P.A.
1121 Grove Street
Vicksburg, MS 39180
(601) 634-0118

C. Gerald O'Brien, Ph.D.

640 Lakeland East Drive
Suite F
Jackson, MS 39232-9778
(601) 664-6730
drob@netdoor.com

Julie Orr, MA, MCP, LPC

In Home Counseling
P.O. Box 1451
Madison, MS 39110
(601) 813-3112

Jo Ann O'Quin, Ph.D.

*Professor Emerita of Social Work
(662) 236-1879
joannoquin@gmail.com*

Ashley Parker, LCSW

*Geriatric Social Worker
and Consultant
225 Honours Drive
Madison, MS 39110
(601) 613-5078
ashleyparkerswk@gmail.com*

17.5 Sitter Services & Home Health

Regional or State-wide

Covenant Caregivers

(601) 856-5660

www.covenantcaregivers.com

Home Instead

Multiple locations in MS

www.homeinstead.com

Kare-In-Home Hospice

Multiple Locations in MS

(601) 485-5012

www.kareinhome.com

Kindred at Home

(866) 546-3733

www.kindredhealthcare.com

Oxford Healthcare

Locations in Gulfport, Hattiesburg,
Jackson and Magee

(601) 906-7071

Prime Care Nursing

(800) 844-4298

www.pcnursing.com

Sitters, LLC.

Jackson, Oxford and Tupelo

www.sittersllc.com

Sta-Home Health & Hospice

www.sta-home.com

Southern Healthcare

www.southernhealthcare.com

Forrest County

Camellia Healthcare

133 Mayfair Road

Hattiesburg, MS 39402

(601) 268-0408

Forrest General Home Care and Hospice

1414 S. 28th Avenue

Hattiesburg, MS 39402

(800) 844-4663

Visiting Angels

106 Carterville Road

Petal, MS 39465

(601) 336-4144

Hancock County

Mississippi Home Care of Bay St. Louis

12083 and 12085 Highway 603

Bay St. Louis, MS 39520

(228) 466-5870

Harrison County

Camellia Healthcare

11703 Highland Circle

Gulfport, MS 39503

(228) 374-2273

Comfort Keepers

1505 E. Pass Road

Gulfport, MS 39501

(228) 220-3123

Deaconess Home Care of Biloxi

2556 Marcia Court

Suite 102

Biloxi, MS 39531

(228) 388-7707

Deaconess Home Care of Gulfport

15487 Oak Lane

Suite 200A

Gulfport, MS 39503

(228) 539-3636

Kare-In-Home Health Services

10281 Corporate Drive
Gulfport, MS 39503
(228) 604-2155

PRN Home Care Services

P.O. Box 323
Biloxi, MS 39533
(228) 385-2603

Praetorian Health Services

10241 Boney Avenue
Suite A
D'Iberville, MS 39540
(228) 314-1290

Right at Home

6340 Kiln DeLisle Road
Suite A
Pass Christian, MS 39571
(228) 255-9225

Saad Healthcare

10598 D'Iberville Boulevard
D'Iberville, MS 39540
(228) 432-8855

Salus Home Care

13109 Shriner's Boulevard
Suite B
Biloxi, MS 39532
(228) 207-2515

Hinds County

Amada Senior Care

1867 Crane Ridge Drive
Suite 220A
Jackson, MS 39216
(601) 864-3752
www.amadaseniorcare.com/
Jackson

Assisting Angels

(601) 201-6868
(601) 573-4625
www.assistingangelsllc.com

Comfort Keepers

5888 Ridgewood Road
Suite C
Jackson, MS 39211
(601) 206-1234
www.comfortkeepers.com

Mississippi Home Care

1200 North State Street
Suite 200
Jackson, MS 39202
(601) 352-5063

Southern Healthcare

1088 Flynt Drive
Jackson, MS 39232
(601) 933-0037
www.southernhealthcare.com

T&C Sitters, LLC

122 Green Harbor Drive
Jackson, MS 39206
(601) 366-1911
www.tandsittersofms.com
tlsittersllc@comcast.net

Jackson County

**Deaconess Home Care
of Pascagoula**

3425 Pascagoula Street
Suites 2, 3 & 4
Pascagoula, MS 39567
(228) 769-1683

Home Instead Senior Care

1716 Government Street
Suite C
Ocean Springs, MS 39564
(228) 818-6110

Lafayette County

Providence Companion Care

317 Heritage Drive
Oxford, MS
www.providencecompanioncare.com
(662) 234-0100

Lamar County

Comfort Keepers

2111 Oak Grove Road
#A
Hattiesburg, MS 39401
(601) 296-6300

Lee County

Comfort Keepers

499 Gloster Creek Village
Suite H11
Tupelo, MS 38802
(662) 841-8477

Right At Home

2686 MS-145
Suite D
Saltillo, MS 38866
(662) 260-4102

Safe and Sound Home Care

211 Court Street
Tupelo, MS 38801
(855) 463-1222

Visiting Angels

398 E. Main Street
#206
Tupelo, MS 38804
(662) 432-1900

Madison County

Assisting Angels

P.O. Box 667
Madison, MS 39130
(601) 954-1325

Home Care Assistance

1029 Highway 51
Suite F-2
Madison, MS 39110
(601) 790-9175
[www.homecareassistance
madisoncounty.com](http://www.homecareassistance
madisoncounty.com)

**Merry Heart Personal Care
& Sitting, LLC**

501 Cobblestone Court
Suite C
Madison, MS 39110
(601) 421-3393
www.merryheart.com

Southern Homecare

(601) 540-3106
www.southernhomecarems.com

Pearl River County

Mississippi Home Care of Picayune

1701 Highway 43 N
Suite 6
Picayune, MS 39466
(866) 749-9101

Pike County

Compassus

119-D West Presley Boulevard
Suite D
McComb, MS 39648
(601) 250-0884
www.compassus.com

Stone County

Mississippi Home Care of Wiggins

1111 East Frontage Drive
Wiggins, MS 39577
(601) 528-8615
www.homecareassistance.com

17.6 Hospice

Forrest County

Compassus Hospice & Palliative Care

517 W. Scooba Street
Units 20 & 30
Hattiesburg, MS 39401
(601) 329-2952

Deaconess Hospice of Hattiesburg

710 South 28th Avenue
Suite B
Hattiesburg, MS 39402
(601) 261-4010

Forrest General Home Care and Hospice

1414 S. 28th Avenue
Hattiesburg, MS 39402
(800) 844-4663

Hospice Advantage

811 Rebecca Avenue
Hattiesburg, MS 39401
(601) 705-0360

SouthernCare Hattiesburg

4700 Hardy Street
Suite Y
Hattiesburg, MS 39402
(601) 579-9493

St. Joseph Hospice

105 Asbury Circle
Condo C, Suite C-1
Hattiesburg, MS 39402
(601) 261-2515

George County

SouthernCare Lucedale

98 Glen Oaks Drive
Lucedale, MS 39452
(601) 947-9282

Harrison County

Camellia Healthcare

11703 Highland Circle
Gulfport, MS 39503
(228) 374-4434

Canon Hospice

1520 Broad Avenue
Suite 500
Gulfport, MS 39501
(228) 575-6251

Compassus Hospice & Palliative Care

12261 Highway 49
Unit 5
Gulfport, MS 39503
(228) 265-9771

Deaconess Hospice of Biloxi

2556 Marcia Court
Suite 101
Biloxi, MS 39531-2352
(228) 435-2265

Kindred Hospice Biloxi

962 Tommy Munro Drive
Suite D&E
Biloxi, MS 39532
(228) 385-7845

Kare-In-Home Health Services

10281 Corporate Drive
Gulfport, MS 39503
(228) 220-0438

Pinnacle Hospice

10532 Auto Mall Parkway
Suite D
D'Iberville, MS 39540
(228) 207-0390

Saad Healthcare

10598 D'Iberville Boulevard
D'Iberville, MS 39540
(228) 432-8855

Southerncare Biloxi

8195A Woolmarket Road
Biloxi, MS 39532
(228) 396-4756

St. Joseph Hospice

1240 Broad Avenue
Gulfport, MS 39501
(228) 865-7897

Hinds County

**Compassus Hospice
& Palliative Care**

1865 Lakeland Drive
Suite A
Jackson, MS 39216
(601) 956-9755
www.compassus.com

Hospice Advantage

1865 Lakeland Drive
Suite A
Jackson, MS 39216
(601) 956-9755
www.hospiceadvantage.com

Jackson County

We Care Hospice

3725 Main Street
Moss Point, MS 39563
(228) 474-2030

Lamar County

Camellia Healthcare

133 Mayfair Road
Hattiesburg, MS 39402
(601) 264-8692

Lauderdale County

Quality Hospice Care

1413 23rd Avenue
Meridian, MS 39301
(601) 693-0103

Lee County

Camellia Hospice

1413 Main Street
Tupelo, MS 38801
(662) 844-2870

Gentiva Hospice

1140 Main Street
Tupelo, MS 38801
(662) 844-2417

Halcyon Hospice

3289 McCullough Boulevard
Belden, MS 38826
(662) 823-9850

**North MS Medical Center
Inpatient Hospice**

www.nmhs.net
(662) 377-6673

Sanctuary Hospice

5159 Main Street
Tupelo, MS 38801
(662) 844-2111

SouthernCare Hospice Services

408 Council Circle
Suite B
Tupelo, MS 38803
(662) 841-0085
www.southerncarehospice.com

Madison County

Hospice Ministries, Inc.

450 Town Center Boulevard
Ridgeland, MS 39157
(601) 898-1053
www.hospiceministries.org

Neshoba County

Quality Hospice Care

340 Byrd Avenue
Philadelphia, MS 39350
(601) 656-5252

Stone County

Southern Hearts Hospice

713 Hall Street
Wiggins, MS 39577
(601) 928-5300
www.southernheartshospice.com

Union County

HomeCare Hospice

104 West Bankhead Street
New Albany, MS 38652

Warren County

**Compassus Hospice
& Palliative Care**

1650 North Highway 61
Suite C & D
Vicksburg, MS 39183
601-634-8836
www.compassus.com

17.7 Adult Day Care & Group Respite Centers

Adams County

Natchez Multi-Purpose Senior Center/Day Care

800 Washington Street
Natchez, MS 39120
(601) 442-5082

Alcorn County

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 County

It's A Blessing Adult Day Care

902 Louisiana Street
Shelby, MS 38774
(662) 398-5263

Sunny Seniors

*Kay Daugherty
Carolyn Via*
107 South Victoria
Cleveland, MS 38732
(662) 843-0541
(662) 719-9911
(662) 719-7048

Clarke County

Handy Elderly Day Care

P.O. Box 462, 114 2nd Street
Shubuta, MS 39360
(601) 687-1128

Coahoma County

SLA Jones Activity Center Adult Day Care

500 Indiana Avenue
Clarksdale, MS 38614
(662) 627-2720

Forrest County

Pine Belt Mental Health Adult Day Care & Respite

Center Twin Oaks Senior Center
701 West Pine Street
Hattiesburg, MS 39403
(601) 545-5614

Grenada County

GranCare Adult Day Center

361 Thomas Street
Grenada, MS 38901
Ronnie Respass
ronnierespass@yahoo.com
(662) 226-1700

Harrison County

Gulf Shores Adult Day Care

2301 Atkinson Road
Biloxi, MS 39531
(228) 388-1723

Lyman Senior Citizen Activities Center

14592 County Farm Road
Gulfport, MS 39503
(228) 832-2606

Hinds County

Ancor Adult Day Care Center

5451 Robinson Road
Jackson, MS 39204
(601) 373-1628

Baptist Adult Day Health Services

Clinton
652 Highway 80 West
Clinton, MS 39056
(601) 926-1222

Baptist Adult Day Health Services

North Jackson
6250 Old Canton Road
Suite 140
Jackson, MS 39211
(601) 956-7794

Golden Ladies & Gentlemen Adult Day Care

428 W. Northside Drive
Jackson, MS 39206
(769) 216-2756
glgadcfamily@gmail.com
(Private Pay & Medicaid Waiver)

Jones County

Pine Belt Mental Health Adult Day Care

231 South 14th Avenue
Laurel, MS 39440
(601) 649-2933

Lafayette County

Memory Makers Respite Day Program

125B Heritage Drive
Oxford, MS 38655
(662) 234-3332

Lauderdale County

Christa House

1918 24th Avenue
Meridian, MS 39301
(601) 483-5822

Brookdale Meridian

4555 35th Avenue
Meridian, MS 39305
(601) 483-4566
www.brookdale.com

Lawrence County

Lawrence County Personal Home

1134 East Broad Center
Monticello, MS 39654
(601) 587-9226

Lawrence County Senior Center ADC

1447 East Sellers Highway
Monticello, MS 39654
(601) 587-0873

Lee County

The Hannahouse Adult Day Care

217 Franklin Street
Tupelo, MS 38804
(662) 844-5483

Lee County Multi-Purpose Day Care Center

5338 Cliff Gookin Boulevard
Tupelo, MS 38803
(601) 844-9004

Leflore County

Garden Park Adult Day Care

2713 Highway 82 E
Greenwood, MS 38930
(662) 451-9058

Lowndes County

Beautiful Life Adult Day Care

1551 2nd Avenue N
Columbus, MS 39701
(662) 329-1025

Madison County

**Desmond & Puller
Adult Day Care Center, LLC**

525 East Center Street
Canton, MS 39046
(601) 859-7808

Monroe County

First Friends

303 1st Avenue
Amory, MS 38821
(662) 256-1130

Neshoba County

**New Beginnings
Adult Day Care Services**

1120 East Main Street
Philadelphia, MS 39350
(601) 656-0304

Newton County

Footprints Adult Day Care

851 Northside Drive
Newton, MS 39345
(601) 683-4320

Noxubee County

Sunshine Club Elderly Day Services

500 Lawrence Street
Macon, MS 39341-3002
(662) 726-9011

Panola County

Dignity and Mercy Adult Day Care

569 Hwy 6 West
Batesville, MS 38606
(662) 563-1641
dignitymercy@yahoo.com

Perry County

We Care Day Care Adult Day Care

109 Elm Street E
Richton, MS 39476
(601) 788-2599

Rankin County

Peach Tree Village

6100 Old Brandon Road
Brandon, MS 39042
(601) 933-1100

Region 8 Mental Health Services

615 Marquette Road
Brandon, MS 39042
(601) 824-0342
www.region8mhs.org

Sunflower County

Faith & Hope Adult Day Care

141 N. Main Street
Drew, MS 38737
(662) 745-0275

Tishomingo County

Tishomingo County Adult Day Care

P.O. Box 335
Dennis, MS 38838
(662) 438-7187

Union County

Sunshine Inn Assisted Living & Adult Day Care

1645 State Hwy 178
West Myrtle, MS 38650
(662) 988-3401

Washington County

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

Yazoo County

Our Time Adult Day Care Services

112 & 114 4-Lane, Highway 49
Benton, MS 39040
(601) 668-3752
[ourtimeadultdayservices@
yahoo.com](mailto:ourtimeadultdayservices@yahoo.com)

17.8 Nursing Homes (with Alzheimer's Care Units)

A licensed nursing home or licensed personal care home may establish a separate Alzheimer's/Dementia Care Unit for residents suffering from a form of dementia or Alzheimer's Disease. (Source: Miss. Code Ann. §43-11-13)

Amite County

Liberty Community Living Center

323 Industrial Park Drive
Liberty, MS 39645
(601) 657-4255
Accepts Medicaid

Claiborne County

Claiborne County Senior Care

2124 Old Highway 61 South
Port Gibson, MS 39150
(601) 437-8737

Coahoma County

Clarksdale Nursing Center

1120 Ritchie Street
Clarksdale, MS 38614
(662) 627-2591
Accepts Medicaid

Forrest County

Bedford Alzheimer's Care Center

300-B Cahal Street
Hattiesburg, MS 39401
(601) 544-5300
www.bedfordcarecenters.com
Accepts Medicaid

Hattiesburg Health and Rehabilitation

514 Bay Street
Hattiesburg, MS 39401
(601) 544-4230
Accepts Medicaid

Hancock County

Woodland Village

5427-A Gex Road
Diamondhead, MS 39525
(228) 255-4832 x 11 – Kim Garcia
Accepts Medicaid

Hinds County

Willow Creek

49 Willow Creek Lane
Byram, MS 39272
(601) 863-4201
Accepts Medicaid

Holmes County

Holmes County LTC Center

15481 Bowling Green Road
Durant, MS 39063
(662) 653-4106

Lamar County

Lamar Healthcare and Rehab Center

6428 US Highway 11
Lumberton, MS 39455
(601) 794-8566
Accepts Medicaid

Lauderdale County

Poplar Springs Nursing Center

6615 Poplar Springs Loop
Meridian, MS 39305
(601) 483-5256
Accepts Medicaid

Lowndes County

Philwood Suites of Windsor Place

81 Windsor Place
Columbus, MS 39702
(662) 241-5518
Private Pay

Madison County

Madison County Nursing Home

1421 E. Peace Street
Canton, MS 39046
(601) 855-5760
Accepts Medicaid

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
(601) 663-1200
Accepts Medicaid

Bedford Care Center of Newton

1009 S. Main Street
Newton, MS 39345
(601) 683-6601
Accepts Medicaid

Prentiss County

Landmark Nursing and Rehabilitation Center

100 Lauren Drive
Booneville, MS 38829
(662) 720-0972
Accepts Medicaid

Sharkey County

Sharkey-Issaquena Nursing Home

431 West Race Street
Rolling Fork, MS 39159
(662) 873-6218
Accepts Medicaid

Smith County

MS Care Center of Raleigh

309 Magnolia Drive
Raleigh, MS 39153
(601) 782-4244

Stone County

Stone County Nursing & Rehab Center

1436 E. Central Avenue
Wiggins, MS 39577
(601) 928-1889 x13
Accepts Medicaid

Wilkinson County

Wilkinson County Nursing Center

166 South Lafayette Street
Centreville, MS 39631
(601) 645-5253
Accepts Medicaid

17.9 Personal Care Homes & Assisted Living Facilities (with Alzheimer's Care Units)

A licensed nursing home or licensed personal care home may establish a separate Alzheimer's/Dementia Care Unit for residents suffering from a form of dementia or Alzheimer's Disease. (Source: Miss. Code Ann. §43-11-13)

Adams County

Magnolia Village

311 Highland Boulevard
Natchez, MS 39120
(601) 446-5097
Private Pay

DeSoto County:

Olive Grove Terrace

9684 Goodman Road
Olive Branch, MS 38654
(662) 550-4394
Private Pay

Hermitage Gardens of Southaven

108 Clarington Avenue
Southaven, MS 38871
(662) 349-9043
Private Pay

Lifepointe Village at Southaven

2782 Star Landing Road East
Southaven, MS 38672
(662) 429-7672

Forrest County

Brookdale Hattiesburg

107 Fox Chase Drive
Hattiesburg, MS 39401
(601) 271-8480
Private Pay

The Claiborne at Hattiesburg

200 Whispering Pines Boulevard
Hattiesburg, MS 39402
(601) 909-2385

Harrison County

Bay Cove Assisted Living and Memory Care

680 Bay Cove Drive
Biloxi, MS 39532
(228) 702-9972

Brookdale Biloxi

2120 Enterprise Drive
Biloxi, MS 39531
(228) 388-0946
Private Pay

The Cove at Seashore Highlands

12170 Highland Way
Gulfport, Mississippi 39503
(228) 831-7000

Hinds County

Brookdale Clinton

501 E. Northside Drive
Clinton, MS 39056
(228) 233-3787
Private Pay

Riggs Manor

Retirement Community
2300 Seven Springs Road
Raymond, MS 39154
(601) 857-5011

Itawamba County

Countrywood Manor Assisted Living

145 Watson Drive
Mantachie, MS 38855
(662) 282-7808

Lafayette County

The Blake at Oxford

110 Ed Perry Boulevard
Oxford, MS 38655
(662) 234-5050

Hermitage Gardens of Oxford

1488 Belk Avenue
Oxford, MS 38655
(662) 234-8244
Private Pay

Lamar County

Provision Living at Hattiesburg

217 Methodist Boulevard
Hattiesburg, MS 39402
(601) 329-2030

Lauderdale County

Brookdale Meridian

4555-35th Avenue
Meridian, MS 39305
(601) 483-4566
Private Pay

Lee County

Hickory Senior Living

111 East Troy Street
Suite G
Tupelo, MS 38804
(662) 840-3111
www.hickoryseniorliving.com

Lowndes County

The Arrington

234 Windsor Boulevard
Columbus, MS 39702
(662) 241-0001

Madison County

Beau Ridge

650 Highland Colony Parkway
Ridgeland, MS 39157
(601) 707-9883
www.beau-ridge.com
Private Pay

The Blake at Township

608 Steed Road
Ridgeland, MS 39157
(601) 500-7955
www.blakeliving.com
Private Pay
Qualified Veterans

Brookdale Ridgeland

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 and Hughes Center

200 Dominican Drive
Madison, MS 39110
(601) 856-0100
Private Pay

Marshall County

Christopher's Personal Care Home

885 Highway 178E
Holly Springs, MS 38635
(662) 551-1122

Pike County

The Clairborne at McComb

209 Doug Rushing Drive
McComb, MS 39648
(601) 324-5511

Oktober County

The Claiborne at Adelaide

74 Claiborne Way
Starkville, MS 39759
(662) 268-9555

Rankin County

The Blake at Flowood

350 Town Center Way
Flowood, MS 39232
(601) 345-2202

Brookdale Brandon

140 Castlewood Boulevard
Brandon, MS 39042
(601) 919-1208
Private Pay

Peachtree Village

6100 Old Brandon Road
Brandon, MS 39042
(601) 933-1100

Washington County

Valor Manor

1880 Fairgrounds Road
Greenville, MS 38703
(662) 334-4646
Private Pay

17.10 Nursing Homes

Nursing home facilities which do not have a designated Alzheimer's / Dementia Care Unit, but may be appropriate for non-ambulatory patients with Alzheimer's or another form of dementia:

Adams County

Adams County Nursing Center

587 John R. Junkin Drive
Natchez, MS 39120
(601) 446-8426
Accepts Medicaid

Crown Health & Rehab of Natchez

344 Arlington Avenue
Natchez, MS 39120
(601) 443-2344

Glenburney Health Care and Rehabilitation Center

555 John R. Junkin Drive
Natchez, MS 39120
(601) 442-4396

Alcorn County

Cornerstone Rehabilitation and Healthcare Center, LLC

302 Alcorn Drive
Corinth, MS 38834
(662) 286-2286

Dogwood Corinth

1101 Old Highway 45 South
Corinth, MS 38834
(662) 269-4111
Private Pay

Mississippi Care Center of Alcorn County

3701 Joanne Drive
Corinth, MS 38834
(662) 287-8071

Whitfield Nursing Home

2101 E. Proper Street
Corinth, MS 38834
(662) 286-3331

Attala County

Attala County Nursing Center

326 Hwy. 12 West
Kosciusko, MS 39090
(662) 289-1200

State Veterans Home

310 Autumn Ridge Drive
Kosciusko, MS 39090
(662) 289-7044
Qualified Veterans

Benton County

Ashland Health & Rehabilitation

16056 Boundry Drive
Ashland, MS 38603
(662) 224-6196

Bolivar County

Bolivar Medical Center - LTC Facility

901 E. Sunflower Road
Cleveland, MS 38732
(662) 846-2520

Cleveland Nursing & Rehab

4036 Highway 8 East
Cleveland, MS 38732
(662) 843-4014

Delta Rehabilitation and Healthcare Center, LLC

200 Martin Luther King Drive
Cleveland, MS 38732
(662) 843-5347

Oak Grove Retirement Home

209 Oak Circle
Duncan, MS 38740
(662) 395-2576

Shelby Health & Rehabilitation Center

1108 Church Street
Shelby, MS 38774
(662) 398-5117

Calhoun County

Bruce Community Living Center

176 Highway 9 South
Bruce, MS 38915
(662) 412-5100

Calhoun County Nursing Home

152 Burke CC Road
Calhoun City, MS 38916
(662) 628-6611

Carroll County

Vaiden Community Living Center

868 Mulberry Street
Vaiden, MS 39176
(662) 464-7714

Chickasaw County

Floy Dyer Manor

1000 East Madison
Houston, MS 38851
(662) 456-1100

Shearer Richardson Memorial Nursing Home

512 Rockwell Drive
Okolona, MS 38860
(662) 447-3311

Choctaw County

Choctaw Nursing and Rehabilitation Center

311 W. Cherry Street
Ackerman, MS 39735
(662) 285-1946

Clarke County

Lakeside Health and Rehabilitation Center

191 Highway 511 East
Quitman, MS 39355
(601) 776-2141

Clay County

Dugan Memorial Home

804 E. Main Street
West Point, MS 39773
(662) 494-3640

Coahoma County

Greenbough Health and Rehabilitation Center

340 Desoto Avenue
Clarksdale, MS 38614
(662) 627-3486

West Point Community Living Center

1122 N. Eshman Avenue
West Point, MS 39773
(662) 494-6011

Copiah County

Copiah Living Center

806 W. Georgetown Strett
Crystal Springs, MS 39059
(601) 892-1880
www.copiahlivingcenter.com

Pine Crest Guest Home

133 Pine Street
Hazlehurst, MS 39083
(601) 894-1411

Covington County

Arrington Living Center

701 S. Holly Street
Collins, MS 39428
(601) 698-0400

Covington County Nursing Center

1207 South Fir Street
Collins, MS 39428
(601) 765-8262

State Veterans Home - Collins

3261 Highway 49
Collins, MS 39428
(601) 765-0519
Qualified Veterans

DeSoto County

Beverly Healthcare - Southaven

1730 Dorchester Drive
Southaven, MS 38671
(662) 393-0050
Accepts Medicaid

Desoto Healthcare Center

7805 Southcrest Parkway
Southaven, MS 38671
(662) 349-7500

Diversicare of Southaven

1730 Dorchester Drive
Southaven, MS 38671
(662) 393-0050

Landmark of DeSoto

3068 Nail Road West
Horn Lake, MS 38637
(662) 280-1219

Forrest County

Alden Pointe

#2 Courtland Drive
Hattiesburg, MS 39402
(601) 296-9711
Private Pay

Bedford Care Center of Hattiesburg

10 Medical Boulevard
Hattiesburg, MS 39401
(601) 264-3709

Bedford Care Center - Monroe Hall

300 Cahal Street
Hattiesburg, MS 39401
(601) 544-5300

Bedford Care Center of Petal

908 S. George Street
Petal, MS 39465
(601) 544-7441

Franklin County

Meadville Convalescent Home
300 Highway 556
Meadville, MS 39653
(601) 384-5861

George County

George Regional Health & Rehabilitation Center

859 Winter Street
Lucedale, MS 39452
(601) 947-9101

Glen Oaks Nursing Center

55 Suzanne Street
Lucedale, MS 39452
(601) 947-2783

Greene County

Greene Rural Health Center

1017 Jackson Avenue
Leakesville, MS 39451
(601) 394-2371

Leakesville Rehabilitation and Nursing Center

1300 Melody Lane
Leakesville, MS 39451
(601) 394-2331

Grenada County

Grenada Living Center

1950 Grandview Drive
Grenada, MS 38901
(662) 226-9554

Grenada Rehabilitation and Health Care Center, LLC

1966 Hill Drive
Grenada, MS 38901
(662) 226-2442

Hancock County

Dunbar Village

725 Dunbar Avenue
Bay St. Louis, MS 39520
(228) 466-3099

Harrison County

The Boyington Health & Rehabilitation Center

1530 Broad Avenue
Gulfport, MS 39501
(228) 864-6544

Dixie White House Health & Rehabilitation Center

538 Menge Avenue
Pass Christian, MS 39571
(228) 452-4344

Driftwood Nursing Center

1500 Broad Avenue
Gulfport, MS 39501
(228) 868-1314

Greenbriar Nursing Center

4347 West Gay Road
D'Iberville, MS 39540
(228) 392-8484

Gulfport Care Center

11240 Canal Road
Gulfport, MS 39503
(228) 539-9943

Lakeview Nursing Center

16411 Robinson Road
Gulfport, MS 39503
(228) 831-3001

The Pillars Biloxi

22790 Atkinson Road
Biloxi, MS 39531
(228) 388-1805
Accepts Medicaid

Veterans Administration Hospital

Extended Care Unit 23 West
400 Veterans Avenue
Biloxi, MS 39531
(228) 523-5000
Qualified Veterans

Hinds County

Belhaven Senior Care

1004 North Street
Jackson, MS 39202
(601) 355-0763

**Chadwick Nursing
and Rehabilitation**

1900 Chadwick Drive
Jackson, MS
(601) 372-0231

Clinton Healthcare

1251 Pinehaven Road
Clinton, MS 39056
(601) 924-2996

Community Place

1129 Langley Avenue
Jackson, MS 39204
(601) 355-0617
www.communityplace.org

Compere's Nursing Home

865 North Street
Jackson, MS 39202
(601) 948-6531

Cottage Grove Nursing Home

1116 Forest Avenue
Jackson, MS 39206
(601) 366-6461
Accepts Medicaid

Forest Hill Nursing Center

927 Cooper Road
Jackson, MS 39212
(601) 372-0141

**Hinds County Nursing &
Rehabilitation Center**

3454 Albemarle Road
Jackson, MS 39213
(601) 362-5394

**Lakeland Nursing &
Rehabilitation Center**

3680 Lakeland Lane
Jackson, MS 39216
(601) 982-5505

Magnolia Senior Care

3701 Peter Quinn Drive
Jackson, MS 39213
(601) 366-1712

**Manhattan Nursing &
Rehabilitation Center**

4540 Manhattan Road
Jackson, MS 39206
(601) 982-7421

**Pleasant Hills Community
Living Center**

1600 Raymond Road
Jackson, MS 39204
(601) 371-1700

State Veterans Home - Jackson

4607 Lindbergh Drive
Jackson, MS 39209
(601) 353-6142
Qualified Veterans

**Woodlands Rehabilitation and
Healthcare Center, LLC**

102 Woodchase Park Drive
Clinton, MS 39056
(601) 924-7043

Holmes County

UMMC Holmes County LTC

239 Bowling Green
Lexington, MS 39095
(662) 834-1341
Accepts Medicaid

Lexington Manor Senior Care

56 Rockport Road
Lexington, MS 39095
(662) 834-3021

Humphreys County

Humphreys County Nursing Center

500 CCC Road
Belzoni, MS 39038
(662) 247-1821

Itawamba County

Daniel Health Care / The Meadows

1905 South Adams Street
Fulton, MS 38843
(662) 862-2165
Accepts Medicaid

Courtyards Community Living Center

907 E. Walker Street
Fulton, MS 38843
(662) 862-6140

The Meadows

1905 S. Adams Street
Fulton, MS 38843
(662) 862-2165

Jackson County

Ocean Springs Health & Rehabilitation

1199 Ocean Springs Road
Ocean Springs, MS 39564
(228) 875-9363

Plaza Community Living Center

4403 Hospital Street
Pascagoula, MS 39581
(228) 762-8960

River Chase Village

5090 Gautier-VanCleave Road
Gautier, MS 39553
(228) 522-6700
www.riverchasevillagemms.com

Settler's Pointe Personal Care

13625 Wilfred Seymour Road
Ocean Springs, MS 39564
(228) 872-1746

Singing River Nursing & Rehab Center

3401 Main Street
Moss Point, MS 39563
(228) 762-7451
Accepts Medicaid

Sunplex Subacute Center

6520 Sunscope Drive
Ocean Springs, MS 39564
(228) 875-1177

Jasper County

Jasper County Nursing Home

15 South Sixth Street
Bay Springs, MS 39422
(601) 764-2101

Jefferson County

Jefferson County Nursing Home

910 Main Street
Fayette, MS 39069
(601) 786-3888

Jefferson Davis County

Jefferson Davis Extended Care Facility

1320 Winfield Street
Prentiss, MS 39474
(601) 792-1172

Jones County

Care Center of Laurel

935 West Drive
Laurel, MS 39440
(601) 649-8006

Comfort Care Nursing Center

1100 West Drive
Laurel, MS 39440
(601) 422-0022

Jones County Rest Home

683 County Home Road
Ellisville, MS 39437
(601) 477-3334

Laurelwood Community Living Center

1036 West Drive
Laurel, MS 39440
(601) 425-3191

Magnolia Gardens

945 West Drive
Laurel, MS 39440
(601) 518-0597
Private Pay

Kemper County

Mississippi Care Center of DeKalb

205 Willow Avenue
DeKalb, MS 39328
(601) 743-5888

Lafayette County

Brookdale Oxford

100 Azalea Drive
Oxford, MS 38655
(662) 912-3871

Oxford Health & Rehab Center

1301 Belk Boulevard
Oxford, MS 38655
(662) 234-7821

State Veterans Home - Oxford

120 Veterans Drive
Oxford, MS 38655
(662) 236-1218
(662) 236-7641
Qualified Veterans

Lamar County

Merit Health Wesley

5001 Hardy Street
Hattiesburg, MS 39402
(601) 268-8000

Windham House of Hattiesburg

37 Hillcrest Drive
Hattiesburg, MS 39402
(601) 264-0058

Lauderdale County

Bedford Care Center of Marion

6434-A Dale Drive
Marion, MS 39342
(601) 294-3515

Golden Living Center – Meridian

4728 Highway 39 North
Meridian, MS 39301
(601) 482-8151

James T. Champion Nursing Facility

1455 North Lakeland Drive
Meridian, MS 39307
(601) 581-8450

Meridian Community Living Center

517 33rd Street
Meridian, MS 39305
(601) 483-3916

**North Pointe Health
& Rehabilitation**

211 Windmill Road
Meridian, MS 39301
(601) 486-2525

**The Oaks Rehabilitation
& Healthcare Center**

3716 Highway 39 North
Meridian, MS 39301
(601) 482-7164

Queen City Nursing Center

1201 28th Avenue
Meridian, MS 39301
(601) 483-1467

Reginald P. White Nursing Facility

1451 North Lakeland Drive
Meridian, MS 39307
(601) 581-8500

Lawrence County

Lawrence County Living Center

1134 East Broad Street
Monticello, MS 39654
(601) 587-9226
Private Pay, Medicaid Pending

Lawrence County Nursing Center

700 South Jefferson
Monticello, MS 39654
(601) 587-2593

Leake County

Carthage Health & Rehab Center

310 Ellis Street
Carthage, MS 39051
(601) 267-1432

Golden Living Center – Carthage

1101 East Franklin Street
Carthage, MS 39051
(601) 267-4551

Lee County

Cedars Health Center

2800 West Main Street
Tupelo, MS 38801
(662) 844-1441

Diversicare at Tupelo

2273 South Eason Boulevard
Tupelo, MS 38804
(662) 842-2461

**North MS Medical Center /
Baldwyn Nursing Facility**

739 4th Street South
Baldwyn, MS 38824
(662) 365-4091

North MS Medical Center SNF

830 South Gloster
Tupelo, MS 38801
(662) 377-3000

**Tupelo Nursing &
Rehabilitation Center**

1901 Briar Ridge Road
Tupelo, MS 38804
(662) 844-0675

Leflore County

**Crystal Rehabilitation and
Healthcare Center, LLC**

902 Sgt. John A. Pittman Drive
Greenwood, MS 38930
(662) 453-9173

Golden Age Nursing Home

2901 Highway 82 East
Greenwood, MS 38930
(662) 453-6323

**Riverview Nursing &
Rehabilitation Center**

1600 W. Claiborne Avenue Ext.
Greenwood, MS 38930
(662) 453-8140

Lincoln County

Countrybrook Living Center

525 Brookman Drive
Brookhaven, MS 39601
(601) 833-2330

Golden Living Center - Brook Manor

519 Brookman Drive
Brookhaven, MS 39601
(601) 833-2881

Haven Hall Healthcare Center

101 Mills Street
Brookhaven, MS 39601
(601) 833-5608

Silver Cross Health & Rehab

503 Silver Cross Drive
Brookhaven, MS 39601
(601) 833-2361

Lowndes County

Aurora Health and Rehabilitation
310 Emerald Drive
Columbus, MS 39702
(662) 327-8021

**Baptist Memorial Hospital
Golden Triangle
Transitional Care Unit**

2520 5th St. North
Columbus, MS 39701
(662) 244-1500

Trinity Healthcare Center

230 Airline Road
Columbus, MS 39702
(662) 327-9404

Vineyard Court Nursing Center

2002 5th Street North
Columbus, MS 39705
(662) 328-1133

Madison County

The Arbor

600 S. Pear Orchard Road
Ridgeland, MS 39157
(601) 856-2205

Highland Home

638 Highland Colony Parkway
Ridgeland, MS 39157
(601) 853-0415

The Nichols Center

1308 Highway 51 North
Madison, MS 39110
(601) 853-4343

St. Catherine's Village - Siena Center

200 Dominican Drive
Madison, MS 39110
(601) 856-0100

Marion County

Columbia Rehabilitation and Healthcare Center, LLC

1506 North Main Street
Columbia, MS 39429
(601) 736-9557

The Grove

11 Pecan Drive
Columbia, MS 39429
(601) 736-4747

The Myrtles Nursing Center

1018 Alberta Avenue
Columbia, MS 39429
(601) 731-1745

Marshall County

Christopher's House

885 Highway 178 East
Holly Springs, MS 38635
(662) 551-1122
Private Pay
Accepts Medicaid

Great Oaks Rehabilitation and Healthcare Center, LLC

111 Chase Street
Byhalia, MS 38611
(662) 838-3670

Holly Springs Rehabilitation and Healthcare Center, LLC

1315 Highway 4 East
Holly Springs, MS 38635
(662) 252-1141

Monroe County

Care Center of Aberdeen

505 Jackson Street
Aberdeen, MS 39730
(662) 369-6431

River Place Nursing & Rehab Center

1126 Earl Frye Boulevard
Amory, MS 38821
(662) 257-9919

Montgomery County

Winona Manor Healthcare and Rehabilitation Center

627 Middleton Road
Winona, MS 38967
(662) 283-1260

Neshoba County

Choctaw Residential Center

135 Hospital Circle
Philadelphia, MS 39350
(601) 656-2582

Hilltop Manor Health and Rehabilitation Center

101 Kirkland Street
Union, MS 39365
(601) 774-8233

Newton County

Bedford Care Center of Newton

1009 South Main Street
Newton, MS 39345
(601) 683-6601

J. G. Alexander Nursing Center

25112 Highway 15
Union, MS 39365
(601) 774-5065

Noxubee County

Noxubee County Nursing Home

606 N. Jefferson Street
Macon, MS 39341
(662) 726-2097

Oktibbeha County

The Carrington

307 Reed Road
Starkville, MS 39759
(662) 323-2202

**Starkville Manor Health Care and
Rehabilitation Center**

1001 Hospital Road
Starkville, MS 39759
(662) 323-6360

Panola County

Diversicare of Batesville

154 Woodland Road
Batesville, MS 38606
(662) 563-5636

Sardis Community Nursing Home

613 East Lee Street
Sardis, MS 38666
(662) 487-2720

Pearl River County

Bedford Care Center of Picayune

2797 Cooper Road
Picayune, MS 39466
(601) 799-1616

Pearl River County Nursing Home

305 W. Moody Street
Poplarville, MS 39470
(601) 795-4543

**Picayune Rehabilitation and
Healthcare Center, LLC**

1620 Read Road
Picayune, MS 39466
(601) 798-1811

Perry County

Perry County Nursing Center

202 Bay Avenue West
Richton, MS 39476
(601) 788-2490

Pike County

Camellia Estates

1714 White Street
McComb, MS 39648
(601) 250-0066

**Courtyard Rehabilitation
and Healthcare**

501 South Locust Street
McComb, MS 39648
(601) 684-8111

**McComb Nursing &
Rehabilitation Center**

415 Marion Avenue
McComb, MS 39648
(601) 684-8700

Pontotoc County

Pontotoc Health and Rehab Center

278 West Eighth Street
Pontotoc, MS 38863
(662) 489-6411

Pontotoc Nursing Home

176 South Main Street
Pontotoc, MS 38863
(662) 488-7640

Sunshine Health Care

1677 Highway 9 North
Pontotoc, MS 38863
(662) 489-1189

Prentiss County

**Longwood Community
Living Center**

200 Long Street
Booneville, MS 38829
(662) 728-6234

Quitman County

**Quitman County Health and
Rehab Center**

350 Getwell Drive
Marks, MS 38646
(662) 326-3690

Rankin County

Brandon Nursing and Rehabilitation

355 Crossgates Boulevard
Brandon, MS 39042
(601) 825-3192
www.brandonrehabcenter.com

Brandon Court

100 Burnham Road
Brandon, MS 39042
(601) 664-2259

Briar Hill Rest Home

1201 Gunter Road
Florence, MS 39073
(601) 939-6371

Jaquith Nursing Home

Highway 468, Building 78
P.O. Box 207
Whitfield, MS 39193
(601) 351-8015
[www.msh.state.ms.us/JNH/
INDEX.htm](http://www.msh.state.ms.us/JNH/INDEX.htm)
Accepts Medicaid

Methodist Specialty Care Center

1 Layfair Drive
Suite 500
Flowood, MS 39232
(601) 420-7760

Scott County

Lackey Convalescent Home

266 First Avenue
Forest, MS 39074
(601) 469-4151

Mississippi Care Center of Morton

96 Old Highway 80 East
Morton, MS 39117
(601) 732-6361

Simpson County

Bedford Care of Mendenhall

925 West Mangum Avenue
Mendenhall, MS 39114
(601) 847-1311

Hillcrest Nursing Center

1401 First Avenue NE
Magee, MS 39111
(601) 849-0384

Stone County

Azalea Gardens Nursing Center

530 Hall Street
Wiggins, MS 39577
(601) 928-5281

Sunflower County

**Indianola Rehabilitation and
Healthcare Center, LLC**

401 Highway 82 West
Indianola, MS 38751
(662) 887-2682

**Ruleville Nursing &
Rehabilitation Center**

800 Stansel Drive
Ruleville, MS 38771
(662) 756-4361

Walter B. Crook Nursing Facility

840 North Oak Avenue
Ruleville, MS 38771
(662) 756-1609

Tallahatchie County

**Tallahatchie General Hospital
Extended Care Facility**

201 South Market Street
Charleston, MS 38921
(662) 647-5535

Tate County

**Senatobia Convalescent Center
& Rehab**

402 Getwell Drive
Senatobia, MS 38668
(662) 562-5664

Tippah County

Golden Living Center - Ripley

101 Cunningham Drive
Ripley, MS 38663
(662) 837-3011

Rest Haven Health & Rehabilitation

103 Cunningham Drive
Ripley, MS 38663
(662) 837-3062

Tippah County Nursing Home

1005 City Avenue North
Ripley, MS 38663
(662) 837-9221

Tishomingo County

**Tishomingo Community
Living Center**

1410 West Quitman
Iuka, MS 38852
(662) 423-3422

Tishomingo Manor

230 Kaki Avenue
Iuka, MS 38852
(662) 423-9112

Tunica County

**Tunica County Health and
Rehab Center**

1024 Highway 61 South
Tunica, MS 38676
(662) 363-3164

Union County

New Albany Health & Rehab Center

118 South Glenfield Road
New Albany, MS 38652
(662) 534-9506

Sunshine Assisted Living

1645 State Highway 178
West Myrtle, MS 38650
(662) 988-3959

Union County Health & Rehabilitation Center

1111 Bratton Road
New Albany, MS 38652
(662) 539-0502

Walthall County

Billdora Senior Care

314 Enoch Street
Tylertown, MS 39667
(601) 876-2173

Golden Living Center - Tylertown

200 Medical Circle
Tylertown, MS 39667
(601) 876-2107

Warren County

The Bluffs Rehabilitation and Healthcare Center, LLC

2850 Porter's Chapel Road
Vicksburg, MS 39180
(601) 638-9211

Heritage House Nursing Center

3103 Wisconsin Avenue
Vicksburg, MS 39180
Accepts Medicare and Medicaid

Shady Lawn Health & Rehabilitation

60 Shady Lawn Place
Vicksburg, MS 39180
(601) 636-1448

Vicksburg Convalescent Center

1708 Cherry Street
Vicksburg, MS 39180
(601) 638-3632

Washington County

Arbor Walk Healthcare Center

570 North Solomon Street
Greenville, MS 38701
(662) 335-5863

Legacy Manor Nursing & Rehab Center

1935 North Theobald Ext.
Greenville, MS 38704
(662) 334-4501

Mississippi Care Center of Greenville

1221 East Union Street
Greenville, MS 38701
(662) 335-5811

River Heights Healthcare Center

402 Arnold Avenue
Greenville, MS 38701
(662) 332-0318

Washington Care Center

1920 Lisa Drive
Greenville, MS 38703
(662) 335-2897

Wayne County

Pine View Health and Rehabilitation Center

1304 Walnut Street
Waynesboro, MS 39367
(601) 735-9025

Webster County

Diversicare of Eupora

156E Walnut Avenue
Eupora, MS 39744
(662) 258-8293

**Webster Health Services
Nursing Facility**

70 Medical Plaza
Eupora, MS 39744
(662) 258-6221

Winston County

Louisville Healthcare

543 East Main
Louisville, MS 39339
(662) 773-8047

Winston County Nursing Home

562 East Main Street
Louisville, MS 39339
(662) 773-6211

Yalobusha County

Yalobusha County Nursing Home

630 South Main Street
Water Valley, MS 38965
(662) 473-1411

Yazoo County

Martha Coker Greenhouse Homes

2041 Grand Avenue
Yazoo City, MS 39194
(662) 746-4621

**Yazoo City Rehabilitation and
Healthcare Center, LLC**

925 Calhoun Avenue
Yazoo City, MS 39194
(662) 746-7770

17.11 Alzheimer's Geriatric & Psychiatric Units

Adams County

Natchez Regional Medical Center Senior Behavioral Unit

54 Sergeant Prentiss Drive
Natchez, MS 39121
(601) 443-2131

Calhoun County

Calhoun Health Services Senior Care Unit

140 Burke/Calhoun City Road
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)
(662) 456-3700

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

Forrest County

Merit Health

5001 Hardy Street
Hattiesburg, MS 39402
(601) 268-8029
www.wesley.com/merit-health-wesley/senior-behavioral-health.aspx

Franklin County

Franklin County Memorial Hospital Senior Care Unit / Journeys

40 Union Church Road
Meadville, MS 39653
(601) 384-8180
(601) 384-8100

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
(228) 436-1477

**Garden Park Medical Center
Seasons Behavioral Health**

15200 Community Road
Gulfport, MS 39503
(228) 575-7115 (Geriatric/Psychiatric)

Hinds County

Merit Health Central

1850 Chadwick Drive
Jackson, MS 39204
(601) 376-1000

**MS Baptist Medical Center
Senior Health Services**

1225 North State Street
Jackson, MS 39202
(601) 968-1000

St. Dominics Behavioral Health

969 Lakeland Drive
Jackson, MS 39216
(601) 200-3090
(800) 632-5907

Humphreys County

**Humphreys County Memorial
Hospital Senior Care Unit**

500 CCC Road
Belzoni, MS 39038
(662) 247-3831

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
(601) 792-4276

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 Beginnings
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

Monroe County

**Pioneer Community Hospital
of Aberdeen**

400 South Chestnut Street
Aberdeen, MS 39730-3335
(662) 319-2121
(662) 369-2455

Neshoba County

**Neshoba County General Hospital
Senior Life**

1001 Holland Avenue
Philadelphia, MS 39350
(601) 663-1460 (Senior Life Program)

Panola County

**Merit Health
Batesville Behavioral Health**

155 Keating Road
Batesville, MS 38606
(662) 563-5646
(662) 561-4000
(888) 578-0012

Prentiss County

**Baptist Memorial Hospital
Booneville Senior Care**

100 Hospital Street
Booneville, MS 38829
(662) 720-5000

Quitman County

**Quitman County Hospital
Senior Care Unit**

340 Getwell Drive
Marks, MS 38646
(662) 326-8031

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 4th St.
Rolling Fork, MS 39159
(662) 873-4395
(662) 873-4600

Simpson County

Simpson General Hospital Senior Care

1842 Simpson, Highway 149
Mendenhall, MS 39114
(601) 849-7129 (Senior Care)
(601) 847-2221 (Main Line)
(601) 847-9994 (Intensive Outpatient)

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)
(662) 756-2711

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

Merit Health

2100 Highway 61 North
Vicksburg, MS 39183
(800) 843-2131
(601) 883-3288 (Behavioral Health)
(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 St.
Louisville, MS 39339
(662) 779-0173 (Turning Point Unit)

Yazoo County

Kings Daughters Hospital

823 Grand Avenue
Yazoo City, MS 39194
(662) 746-2261

17.12 Mississippi Legal Services

Bailey Law Firm

5100 Wheelis Drive
Suite 215
Memphis, TN 38117
(901) 843-2760
www.thebaileylawfirm.com

Bradley Law Firm

J. Anthony Bradley
3107 E. Corporate Edge Drive
Germantown, TN 38138
(901) 682-2030
(877) 439-2532
www.bradley-law.com

Richard A. Courtney, CELA

R. Scanlon Fraley
Frascoigna Courtney, PLLC
4400 Old Canton Road
Suite 220
Jackson, MS 39211
(601) 987-3000
(866) 353-3752
www.frascourtlaw.com

Terry Cox

Cox Law Firm
149 S. Rowlett
Collierville, TN 38017
www.coxelderlaw.com

Walt Dallas **Estate Planning 123**

130 Riverview Drive
Suite A
Flowood, MS 39232
(601) 209-1601
www.estateplanning123.com

David Dunn **Dunn & Hemphill**

Columbus, MS
(662) 327-4211
www.marketstreetlaw.com

A. M. Edwards, III **Wells, Moore, Simmons,** **Edwards & Wilbanks, PLLC**

4450 Old Canton Road
#200
Jackson, MS 39211
(601) 360-9303
(601) 354-5400
www.wellsmoore.com

Jeramie J. Fortenberry **Fortenberry Legal**

1605 23rd Avenue
Gulfport, MS 39501
(228) 206-4939
www.fortenberrylaw.com

J. Hale Freeland **Freeland Shull, PLLC**

302 Enterprise Drive
Suite A
Oxford, MS 38655
(662) 234-1711
www.freelandshull.com

Pamela Hancock, Attorney **Hancock Law Firm, PLLC.**

855 South Pear Orchard Road
Building 100
Ridgeland, MS 39157
(601) 853-2223
www.hancocklawgroup.com

R. Kelly Kyle **Elizabeth Wynn** **Betty Thomas DeRossette** **KyleWynn + Associates, PLLC.**

406 Orchard Park
Ridgeland, MS 39157
Hernando, MS
Diamondhead, MS
(601) 978-1700
(800) 839-7857
www.kyle-wynn.com

Barry K. Jones
Wise, Carter, Child & Caraway, PA
401 East Capitol Street
Heritage Building
Suite 600
Jackson, MS 39201
(601) 968-5500
www.wisecarter.com

Ginny Kilgore
North MS Rural Legal Services
(662) 234-8731

Lancaster Law Firm
336 N. Green Street
Tupelo, MS 38804
(662) 823-2679
www.lancasterlaw.net

Robert M. Logan
Logan & May, PA
205 E. Church Street
Newton, MS 39345
(601) 683-7888

Dennie Mayhone, Jr.
Mayhone Elder Law, PLLC
2112 Bienville Boulevard
Suite H-2
Ocean Springs, MS 39564
(228) 215-1226
www.southmselderlaw.com

Ronald Morton
Morton Law Firm, PLLC
132 Fairmont Street
Suite A
Clinton, MS 39056
(601) 925-9797
www.mortonelderlaw.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 MS, LLC
5500 Plaza Drive
Suite C
Flowood, MS 39232
(601) 992-1437
www.theelderlawfirm.net

Kathy Brown van Zutphen
AL-MS Coastal Law, LLC
1115 B Cowan Road
Gulfport, MS 39507
(228) 357-5227
www.al-mscoastallaw.com

17.13 Mississippi Resources

Alzheimer's Mississippi
855 S. Pear Orchard Road
Suite 501
Ridgeland, MS 39157
(601) 987-0020
(877) 930-6190 (Toll Free)
(844) 587-9159 (Fax)
www.alzms.org

**Alzheimer's Association
Mississippi Chapter**
207 West Jackson Street
Suite #1
2nd Floor
Ridgeland, MS 39157
(769) 230-0611
www.alz.org/ms/

**American Parkinson
Disease Association**
P. O. Box 4091
Brandon, MS 39047
(866) 678-2431
www.msapda.org

disentangleAD
Provides mini-grants to families
dealing with Alzheimer's Disease
in South Mississippi
www.disentanglead.com

**Mississippi Access to Care
(MAC) Center**
(844) 822-4622
www.mississippiaccesstocare.org

**The MIND Center Clinic
University of Mississippi
Medical Center**
2500 North State Street
Jackson, MS 39216
(601) 496-MIND (Appointments)
(601) 815-4237 (Information)
mindcenter@umc.edu
www.umc.edu/mindcenter

University Physicians
Pavilion
2500 North State Street
Suite F, Pavilion
Jackson, MS 39216

University Physicians
Flowood Family Medicine Center
2466 Flowood Drive
Flowood, MS 39232

University Physicians
Grants Ferry
1010 Lakeland Place
Flowood, MS 39232

UMMC Grenada TeleMIND
960 Avent Drive
Grenada, MS 38901

UMMC Holmes County TeleMIND
239 Bowling Green Road
Lexington, MS 39095

Life Help TeleMIND
2504 Browning Road
Greenwood, MS 38930

MS Department of Mental Health (MSDMH) Offices

Division of Alzheimer's Disease & Other Dementias

1101 Robert E. Lee Building
239 North Lamar Street
Jackson, MS 39201-1311
(601) 359-1288
(877) 210-8513 (Toll Free)
www.dmh.ms.gov

MS Division of Medicaid

(800) 880-5920
(601) 576-4162

MS Social Security Disability

(800) 772-1213

MS Department of Mental Health

(877) 210-8513 (Help Line)

LA/MS Hospice Organization

(888) 546-1500

MS Association of Home Care

(601) 853-7533

MS Health Care Association

(601) 898-8320

MS Independent Nursing Home Association

(601) 364-5174

MS Public Service Commission

www.psc.state.ms.us

MS Southern Senior and Family Resources

(601) 573-7810

When You Need Help

State Ombudsman for Long-Term Care

For help with problems in residential care facilities:
(601) 359-4927

Aging and Adult Protective Services

Adult Protective Services

(844) 437-6282

Aging and Adult Services

(800) 948-3090

Office of the Attorney General Vulnerable Persons Unit

(601) 359-4158

Medicaid Fraud Control Unit

(800) 852-8341

Department of Human Services

(800) 345-6345

Veteran's Affairs

(800) 827-1000 (Benefits)
(877) 222-VETS (Health Care)
(800) 488-8244
(VA Inspector General)
(800) 273-8244 ext.1 (Crisis Line)
www.va.gov

Veteran's Caregiver Support

(855) 260-3274
www.caregiver.va.gov

17.14 Alzheimer's and Dementia Research Centers

**The MIND Center
University of Mississippi
Medical Center (UMMC)**
2500 N. State Street
Jackson, MS 39216
(601) 815-4237
www.umc.edu/mindcenter

**Neurological Research Center
Hattiesburg Clinic
Memory Center**
415 South 28th Avenue
6th Floor
Hattiesburg, MS 39401
(601) 579-5016
[www.hattiesburgclinic.com/
department/memory-center](http://www.hattiesburgclinic.com/department/memory-center)

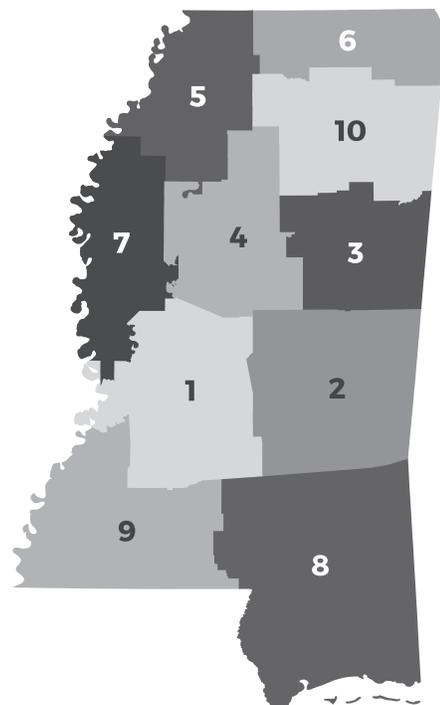
Precise Research
3531 Lakeland Drive
Brentwood Plaza
Suite 1060
Flowood, MS 39232
(601) 420-5810
www.precise-research.com

**Rangachari Labs
University of Southern Mississippi**
118 College Drive
#5043
Hattiesburg, MS 39406
(601) 266-6044
www.sites.usm.edu/rangachari/

17.15 Area Agencies on Aging (AAA)

Area agencies will make referrals for companions, homemaker services, transportation, home delivered meals, congregate mealsites, and Medicaid waivers for adult day care. Call the agency in your area.

- 1 Central MS Area Agency on Aging**
(601) 981-1516 or (800) 995-9925
Copiah, Hinds, Madison, Rankin, Simpson, Warren, Yazoo
- 2 East Central Area Agency on Aging**
(601) 683-2401 or (800) 264-2007
Clark, Jasper, Kemper, Lauderdale, Leake, Neshoba, Newton, Scott, Smith
- 3 Golden Triangle Area Agency on Aging**
(662) 324-4650 or (800) 217-6909
Choctaw, Clay, Lowndes, Noxubee, Oktibbeha, Webster, Winston
- 4 North Central Area Agency on Aging**
(662) 283-2675 or (888) 427-0714
Attala, Carroll, Grenada, Holmes, Leflore, Montgomery
- 5 North Delta Area Agency on Aging**
(662) 561-4100 or (800) 844-2433
Coahoma, Desoto, Panola, Quitman, Tallahatchie, Tate, Tunica
- 6 Northeast MS Area Agency on Aging**
(662) 728-7038 or (800) 745-6961
Alcorn, Benton, Marshall, Prentiss, Tippah, Tishomingo
- 7 South Delta Area Agency on Aging**
(662) 378-3831 or (800) 898-3055
Bolivar, Humphreys, Issaquena, Sharkey, Sunflower, Washington
- 8 Southern MS Area Agency on Aging**
(228) 868-2311 or (800) 444-8014
Covington, Forrest, George, Hancock, Jackson, Jones, Marion, Perry, Wayne, Greene, Harrison, Jefferson Davis, Lamar, Pearl River, Stone
- 9 Southwest MS Area Agency on Aging**
(601) 446-6044 or (800) 338-2049
Adams, Amite, Claiborne, Franklin, Jefferson, Lawrence, Lincoln, Pike, Walthall, Wilkinson
- 10 Three Rivers Area Agency on Aging**
(662) 489-2415 or (877) 489-6911
Calhoun, Chickasaw, Itawamba, Lafayette, Lee, Monroe, Pontotoc, Union



17.16 National Resources

Actavis/Allergan

Rx Assistance

www.allergan.com
(800) 851-0758

Administration on Aging

330 C Street SW
Washington, DC 20201
(202) 619-0724
www.aoa.gov
oainfo@aoa.gov

Alzheimer's Association (National Headquarters)

225 N. Michigan Avenue
17th Floor
Chicago, IL 60601
(800) 272-3900 (24/7 Helpline)
(800) 572-1122
(MedicAlert + Safe Return)
www.alz.org
www.alz.org/safereturn
info@alz.org

Alzheimer's Disease Education and Referral Center (ADEAR)

P.O. Box 8250
Silver Spring, MD 20907-8250
(800) 438-4380
www.nia.nih.gov/Alzheimers
adear@alzheimers.org

Alzheimer's Foundation of America

322 Eighth Avenue, 7th Floor
New York, NY 10001
(866) 232-8484
www.alzfdn.org
info@alzfdn.org

Centers for Medicare & Medicaid Services (CMS)

7500 Security Boulevard
Baltimore, MD 21244-1850
(877) 267-2323
www.cms.gov

Children of Aging Parents

P.O. Box 7250
Penndel, PA 19047
(800) 227-7294
www.caps4caregivers.org
caps4caregivers@aol.com

Cuidando con Cariño Compassionate Care Help Line

(877) 658-8896
www.hispanichealth.org
cuidando@hispanichealth.org

The Eldercare Locator

(800) 677-1116
www.eldercare.gov
eldercarelocator@n4a.org

Family Caregiver Alliance

690 Market Street
Suite 600
San Francisco, CA 94104
(800) 445-8106
www.caregiver.org
info@caregiver.com

Forest Laboratories NAMENDA, MEMANTINE

(877) 262-6363
www.frx.com

Music and Memory

160 First Street
P.O. Box 590
Mineola, New York 11501
www.musicandmemory.org

National Caregiving Foundation

801 North Pitt Street
#116
Alexandria, VA 22314-1765
(800) 930-1357
www.caregivingfoundation.org

National Council on Aging

300 D Street SW
Suite 801
Washington, DC 20024
(202) 479-1200
www.ncoa.org
info@ncoa.org

National Family Caregivers Association (NFCA)

10400 Connecticut Avenue
Suite 500
Kensington, MD 20895-3944
(800) 896-3650
www.thefamilycaregiver.org

National Hospice & Palliative Care Organization

1700 Diagonal Road
Suite 625
Alexandria, VA 22314
(703) 837-1500
(703) 837-1233 (Fax)
(800) 658-8898 (Help Line)
www.caringinfo.org
caringinfo@nhpco.org

National Institute on Aging

31 Center Drive
#5C27
Bethesda, MD 20892
(800) 222-2225
niaic@nia.nih.gov
www.nia.nih.gov

**Novartis
EXELON**

(877) 636-6794
www.novartis.com

**Ortho-McNeil
RAZADYNE**

(800) 526-7736
www.razadyneer.com

**Pfizer
ARICEPT**

(800) 294-8490
www.aricept.com

**Senior Citizens Resources/USA.gov
U.S. General Services
Administration
Office of Citizen Services
and Communications**

1800 F Street NW
Suite G-142
Washington, DC 20405
(800) 333-4636
www.usa.gov/Topics/Seniors.shtml

Today's Caregiver

P.O. Box 21646
Ft Lauderdale, FL 33335
(800) 829-2734
www.caregiver.com
editor@caregiver.com

USAgainstAlz

2 Wisconsin Circle, Suite 700
Chevy Chase, MD, 20815
(202) 349-3803
www.usagainstalzheimers.org

Veterans Benefits

(800) 827-1000
www.vba.va.gov/VBA/

Veteran's Caregiver Support

(855) 260-3274
www.caregiver.va.gov

**The Website for Family
Caregiving Advocacy**

1101 Vermont Ave NW
Suite 101
Washington, DC 20005
www.caregiverscount.com

17.17 Helpful Websites

Alzheimer's Disease

- www.alzms.org
- www.alz.org/ms
- www.alzfdn.org

Brain Games

- www.lumosity.com
- www.brain.com
- www.sharpbrains.com
- www.photographic-memory.org
- www.fitbrains.com
- www.dakim.com
- www.wisernowalz.com
- www.happy-neuron.com

Caregiving - General

- www.nfcacares.org
- www.caregivinghelp.org
- www.agis.com
- www.carepages.com
- www.fullcirclecare.org
- www.nia.nih.gov/hbo
- www.pbs.org/theforgetting
- www.agingcare.com
- www.caring.com
- www.caregiverstress.com
- www.careliving.org

Dementia

- www.dementiaguide.com
- www.lbda.org
- www.hdsa.org
- www.cjdfoundation.org
- www.apdaparkinson.org
- www.hydroassoc.org
- www.ftd-picks.org
- www.nnpdf.org

Hispanic Resources

- www.alz.org/espanol
- www.alz.org/hispanic/grandpa.asp
- www.thehartford.com/alzheimers
- www.alzcast.org
- www.alzinfo.org
- www.healthcentral.com/alzheimers
- www.alzheimersweekly.com
- www.ashbymemorymethod.com
- www.alzbrain.org
- www.memorybridge.org

Hospice

- www.hospicefoundation.org
- www.elderhope.com

Therapeutic Care Approaches

- www.secondwind.org/virtualdementiatour.html
- www.snoezeleninfo.com/main.asp
- www.myersresearch.org
- www.learningtospeakalzheimers.com

Professional Training

- www.elearning.alz.org
- www.hcinteractive.com/professionalcares
- www.alz.org/qualitycare
- www.alzfdn.org

17.18 Suggested Reading

Dignified Life: The Best Friends Approach to Alzheimer's Care

Virginia Bell and D. Troxel
Health Professional Press, 2004

Creating Moments of Joy

Jolene Brackey
Purdue University Press, 2008

Coach Broyles' Playbook for Alzheimer's Caregivers

Frank Broyles
Alzheimer's Association, 2006

Caregiver Survival 101: Strategies to Manage Problematic Behaviors Presented in Individuals with Dementia.

Lisa Byrd, PhD.

Montessori-Based Activities for Persons with Dementia

Cameron Camp

Learning to Speak Alzheimer's

Joanne K. Coste
Mariner Books, 2004

Still Alice

Lisa Genova
iUniverse, Inc., New York, 2007

Ten Thousand Joys and Ten Thousand Sorrows: A Couple's Journey Through Alzheimer's

Olivia Hoblitzelle
Tarcher / Penguin, 2010

The 36-Hour Day

Nancy L. Mace and Peter V. Rabins
4th Edition
Johns Hopkins Press Health Book, 2006

A Guide to the Spiritual Dimension of Care for People with AD and Related Dementia

Eileen Shamy
Colcom Press, 2003

Navigating the Alzheimer's Journey: A Compass for Caregivers

Carol Bowlby Sifton
Health Professional Press, Jan. 2004

What's Happening to Grandpa?

Maria Shriver

Little Brown Books for Young Readers, 2004

Living Your Best with Early Stage: An Essential Guide

Lisa Snyder

Sunrise River Press, 2010

Alzheimer's Disease and Related Illnesses

Beth Spencer and Laurie White

Complete Guide to Alzheimer's-Proofing Your Home

Mark Warner

Revised and Updated, Purdue University Press, 2000

Moving A Relative With Memory Loss: A Family Caregiver's Guide

Beth Spencer and Laurie White

Whisp Publications, 2006

Before I Forget

B. Smith & Dan Gasby

Harmony Books, 2016

17.19 Suggested DVDs

Alzheimer's: Every Minute Counts

www.pbs.org

Alzheimer's Project

HBO Documentary

www.hbo.com/alzheimersproject

Bathing Without Battle: Personal Care of Individuals with Dementia

www.bathwitoutabattle.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

I'll Be Me: Glen Campbell Documentary

www.facebook.com/glencampbelldocumentary

The Forgetting: A Portrait of Alzheimer's, Stories of Love, Courage, and Hope

Twin Cities Public Television

www.shop.bs.org

Learning to Speak Alzheimer's: An Introduction to the Habitation Approach to Care

www.aquariusproductions.com

Saavy Caregiver: A Caregiver's Manual

www.memorylossdvd.com

17.20 GPS Devices

GPS Devices

Great Call

This is like a life alert but detects falls automatically, instead of having to press a button for help. It may be better for dementia patients since they may not remember to press an alert button if they fall.

www.greatcall.com

Safe Wise

This is aimed at parents of children, but would probably be good for older adults too, especially with the bright colors. This site also compares a few different devices that are similar to each other and gives the major pros and cons of each.

www.safewise.com

GPS Bracelets

GPS is used to locate the bracelet: a smartphone app can send a message to the bracelet to track it if the person wearing it is lost. If the person is capable, he/she can pull on the bracelet to send out an SOS signal or can tap a button to send a GPS signal.

www.pfotech.com

Silver Alert

Bill

A link to the bill passed concerning silver alerts if consumers, caregivers, or faculty/staff want to read about it.

billstatus.ls.state.ms.us/documents/2010/pdf/HB/0600-0699/HB0664PS.pdf

US States that have passed Silver Alert Bill

A link to Alzheimer's Foundation of America website listing all of the states, as of 2012, that had passed the silver alert bill. The website lists, by state, the name of the program, who is eligible in that state, and what agency to contact if it is needed.

www.alzfdn.org

Mississippi Department of Public Safety

Mississippi Department of Public Safety webpage on the silver alert.

www.dps.state.ms.us/crime-investigation/bureau-of-investigation/silver-alert/

For more information about wandering or the Silver Alert System, contact Alzheimer's Mississippi at (601) 987-0020 or the state Department of Mental Health at (601) 359-1288.

17.21 Phone Apps

Phone Apps

Keystone Technologies

This website lists all kinds of apps, anything from words with friends and Spotify to medicine and bill reminders.

www.keystone-technologies.com

Sunrise Senior Living

This website lists different apps that are handy for seniors, including medicine and appointment reminders. It also lists if they are free or paid for and what the costs are associated with it.

www.sunriseseniorliving.com

Seniornet

This website is more focused on medical reminders and ways to keep track of things like blood pressure or O2 levels, help for finding your parked car in the big parking lot, magnifying glass for when you lose or can't work reading glasses, medicine reminders, and heart rate trackers. It also tells which phones it works with and prices associated with the app itself.

www.seniornet.org

RxList

Designed for caregivers, who can search based on looks of a pill or by name to find out what it is supposed to look like as well as general facts about the medication.

www.rxlist.com

Drugs.com

This is another possibly less clunky website for identifying pills based on color, size, and/or description.

www.drugs.com

Mississippi Department of Public Safety

Mississippi Department of Public Safety website about renewing driver's licenses, scheduling tests for driver's licenses, or getting state-issued ID cards.

www.dps.state.ms.us

Alzheimer's | MISSISSIPPI

Ridgeland Office

855 S. Pear Orchard Road
Suite 501
Ridgeland, MS 39157
601.987.0020

Gulfport Office

11975 Seaway Road
Suite B114
Gulfport, MS 39503
228.236.7211

Contact Us Today

 facebook.com/alzms
 twitter.com/alzmississippi
877.930.6190 (24/7)
info@alzms.org

Providing care and support services for Mississippians affected by Alzheimer's disease while increasing awareness and advocating for improved treatments and research to find a cure.

Services and Support



Community Education

A variety of quality seminars and presentations for people with early dementia and family caregivers.



24/7 Access – 877.930.6190

Reliable information and support all day, every day.



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.



Support Groups

More than 40 support groups throughout Mississippi.



Professional Training

Quality on-site training for professionals.



Conferences

Convening renowned clinicians, providers, caregivers and professionals to address and train Mississippians.

A cure for Alzheimer's tomorrow.



Care for Alzheimer's today.

The MIND Center at the University of Mississippi Medical Center uses pioneering research, state-of-the-art brain imaging and powerful new genetic technologies in the quest to bring an end to Alzheimer's and other dementias.

The MIND Center Clinic offers outpatient care for people with memory loss and cognitive impairment. We also deliver specialized care, health education and caregiver support statewide, via online technology, through the UMMC Center for Telehealth.

To learn more, visit umc.edu/mindcenter.

To schedule an appointment call, 601.496.MIND (6463).





Mississippi Department of Mental Health

Supporting a Better Tomorrow...One Person at a Time

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