

Section 6

Alzheimer's and Other Dementias



Do Memory Problems Always Mean Alzheimer's Disease?

By the National Institutes of Health

Many people worry about becoming forgetful. They think forgetfulness is the first sign of Alzheimer's disease. But not all people with memory problems have Alzheimer's. Other causes for memory problems can include aging, medical conditions, emotional problems, mild cognitive impairment, or another type of dementia.

Age-Related Changes in Memory

Forgetfulness can be a normal part of aging. As people get older, changes occur in all parts of the body, including the brain. As a result, some people may notice that it takes longer to learn new things, they don't remember information as well as they did, or they lose things like their glasses. These usually are signs of mild forgetfulness, not serious memory problems, like Alzheimer's disease.

Differences Between Normal Aging and Alzheimer's Disease

Normal Aging	Alzheimer's Disease
Making a bad decision once in a while	Making poor judgments and decisions a lot of the time
Missing a monthly payment	Problems taking care of monthly bills
Forgetting which day it is and remembering it later	Losing track of the date or time of year
Sometimes forgetting which word to use	Trouble having a conversation
Losing things from time to time	Misplacing things often and being unable to find them

Memory Loss Related to Medical Conditions

Certain medical conditions can cause serious memory problems. These problems should go away once a person gets treatment. Medical conditions that may cause memory problems include:

- Tumors, blood clots, or infections in the brain
- Some thyroid, kidney, or liver disorders
- Drinking too much alcohol
- Head injury, such as a concussion from a fall or accident
- Medication side effects
- Not eating enough healthy foods, or too few vitamins and minerals in a person's body (like vitamin B12)

A doctor should treat serious medical conditions like these as soon as possible.

Memory Loss Related to Emotional Problems

Emotional problems, such as stress, anxiety, or depression, can make a person more forgetful and can be mistaken for dementia. For instance, someone who has recently retired or who is coping with the death of a spouse, relative, or friend may feel sad, lonely, worried, or bored.

Trying to deal with these life changes leaves some people feeling confused or forgetful. The confusion and forgetfulness caused by emotions usually are temporary and go away when the feelings fade. Emotional problems can be eased by supportive friends and family, but if these feelings last for more than 2 weeks, it is important to get help from a doctor or counselor. Treatment may include counseling, medication, or both. Being active and learning new skills can also help a person feel better and improve his or her memory.

For More Information About Memory Loss

National Institute of Mental Health

1-866-615-6464 (toll-free)

1-866-415-8051 (TTY / toll-free) nimhinfo@nih.gov www.nimh.nih.gov

Eldercare Locator

1-800-677-1116 (toll-free)

<https://eldercare.acl.gov>

Source: National Institutes of Health, Do Memory Problems Always Mean Alzheimer's Disease?; www.nimh.nih.gov.

KNOW^{the} 10 SIGNS

EARLY DETECTION MATTERS

Have you noticed any of these warning signs?

Please list any concerns you have and take this sheet with you to the doctor.

Note: This list is for information only and not a substitute for a consultation with a qualified professional.

____ **1. Memory loss that disrupts daily life.** One of the most common signs of Alzheimer's, especially in the early stages, is forgetting recently learned information. Others include forgetting important dates or events; asking for the same information over and over; relying on memory aides (e.g., reminder notes or electronic devices) or family members for things they used to handle on their own. **What's typical?** Sometimes forgetting names or appointments, but remembering them later.

____ **2. Challenges in planning or solving problems.** Some people may experience changes in their ability to develop and follow a plan or work with numbers. They may have trouble following a familiar recipe or keeping track of monthly bills. They may have difficulty concentrating and take much longer to do things than they did before. **What's typical?** Making occasional errors when balancing a checkbook.

____ **3. Difficulty completing familiar tasks at home, at work or at leisure.** People with Alzheimer's often find it hard to complete daily tasks. Sometimes, people may have trouble driving to a familiar location, managing a budget at work or remembering the rules of a favorite game. **What's typical?** Occasionally needing help to use the settings on a microwave or to record a television show.

____ **4. Confusion with time or place.** People with Alzheimer's can lose track of dates, seasons and the passage of time. They may have trouble understanding something if it is not happening immediately. Sometimes they may forget where they are or how they got there. **What's typical?** Getting confused about the day of the week but figuring it out later.

____ **5. Trouble understanding visual images and spatial relationships.** For some people, having vision problems is a sign of Alzheimer's. They may have difficulty reading, judging distance and determining color or contrast. In terms of perception, they may pass a mirror and think someone else is in the room. They may not recognize their own reflection. **What's typical?** Vision changes related to cataracts.

____ **6. New problems with words in speaking or writing.** People with Alzheimer's may have trouble following or joining a conversation. They may stop in the middle of a conversation and have no idea how to continue or they may repeat themselves. They may struggle with vocabulary, have problems finding the right word or call things by the wrong name (e.g., calling a watch a "hand clock"). **What's typical?** Sometimes having trouble finding the right word.

____ **7. Misplacing things and losing the ability to retrace steps.** A person with Alzheimer's disease may put things in unusual places. They may lose things and be unable to go back over their steps to find them again. Sometimes, they may accuse others of stealing. This may occur more frequently over time. **What's typical?** Misplacing things from time to time, such as a pair of glasses or the remote control.

____ **8. Decreased or poor judgment.** People with Alzheimer's may experience changes in judgment or decision making. For example, they may use poor judgment when dealing with money, giving large amounts to telemarketers. They may pay less attention to grooming or keeping themselves clean. **What's typical?** Making a bad decision once in a while.

____ **9. Withdrawal from work or social activities.** A person with Alzheimer's may start to remove themselves from hobbies, social activities, work projects or sports. They may have trouble keeping up with a favorite sports team or remembering how to complete a favorite hobby. They may also avoid being social because of the changes they have experienced. **What's typical?** Sometimes feeling weary of work, family and social obligations.

____ **10. Changes in mood and personality.** The mood and personalities of people with Alzheimer's can change. They can become confused, suspicious, depressed, fearful or anxious. They may be easily upset at home, at work, with friends or in places where they are out of their comfort zone. **What's typical?** Developing very specific ways of doing things and becoming irritable when a routine is disrupted.

If you have questions about any of these warning signs, the Alzheimer's Association recommends consulting a physician. Early diagnosis provides the best opportunities for treatment, support and future planning.

For more information, go to alz.org/10signs or call 800.272.3900.

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Basics of Alzheimer's disease

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

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

The disease may cause a person to become confused, get lost in familiar places, misplace things or have trouble with language.

It can be easy to explain away unusual behavior as a part of normal aging, especially someone who seems physically healthy. Any concerns about memory loss should be discussed with a doctor.

Alzheimer's disease and other types of dementia

More than 5 million Americans have Alzheimer's disease, which is the most common form of dementia accounting for 60 to 80 percent of all cases. That includes 11 percent of those ages 65 and older and one-third of those 85 and older. The disease also impacts more than 15 million family members, friends and caregivers.

Dementia

Dementia is a general term for the loss of memory and other intellectual abilities that are serious enough to interfere with daily life.

Other types of dementia

- **Vascular dementia** is a decline in thinking skills caused by conditions that block or reduce blood flow to the brain, depriving brain cells of vital oxygen and nutrients. These changes in thinking skills sometimes occur suddenly following strokes that block major brain blood vessels. It is widely considered the second most common cause of dementia after Alzheimer's disease.
- **Mixed dementia** is a condition in which abnormalities characteristic of more than one type of dementia occur simultaneously. Symptoms may vary, depending on the types of brain changes involved and the brain regions affected, and may be similar to or even indistinguishable from those of Alzheimer's or another dementia.
- **Parkinson's disease dementia** is an impairment in thinking and reasoning that eventually affects many people with Parkinson's disease. As brain changes gradually spread, they often begin to affect mental functions, including memory and the ability to pay attention, make sound judgments and plan the steps needed to complete a task.
- **Dementia with Lewy bodies** is a type of progressive dementia that leads to a

decline in thinking, reasoning and independent function due to abnormal microscopic deposits that damage brain cells.

- **Huntington's disease dementia** is a progressive brain disorder caused by a defective gene. It causes changes in the central area of the brain, which affect movement, mood and thinking skills.
- **Creutzfeldt-Jakob disease** is the most common human form of a group of rare, fatal brain disorders known as prion diseases. Misfolded prion protein destroys brain cells, resulting in damage that leads to rapid decline in thinking and reasoning as well as involuntary muscle movements, confusion, difficulty walking and mood changes.
- **Frontotemporal dementia (FTD)** is a group of disorders caused by progressive cell degeneration in the brain's frontal lobes (the areas behind the forehead) or its temporal lobes (the regions behind the ears).
- **Normal pressure hydrocephalus** is a brain disorder in which excess cerebrospinal fluid accumulates in the brain's ventricles, causing thinking and reasoning problems, difficulty walking and loss of bladder control.
- **Down syndrome dementia** develops in people born with extra genetic material from chromosome 21, one of the 23 human chromosomes. As individuals with Down syndrome age, they have a greatly increased risk of developing a type of dementia that's either the same as or very similar to Alzheimer's disease.
- **Korsakoff syndrome** is a chronic memory disorder caused by severe deficiency of thiamine (vitamin B-1). It is most commonly caused by alcohol misuse, but certain other conditions also can cause the syndrome.
- **Posterior cortical atrophy (PCA)** is the gradual and progressive degeneration of the outer layer of the brain (the cortex) located in the back of the head (posterior). It is not known whether PCA is a unique disease or a possible variant form of Alzheimer's disease.

How Alzheimer's disease affects the brain

The changes that take place in the brain begin at the microscopic level long before the first signs of memory loss.

What goes wrong in the brain

The brain has 100 billion nerve cells (neurons) that connect to others to help us function every day. Cells are divided in groups that are involved in thinking, learning, memory, as well as the senses. Operating like tiny factories, cells process and store information and communicate with other cells. Keeping everything running requires coordination as well as large amounts of fuel and oxygen.

Scientists believe Alzheimer's disease prevents parts of a cell's factory from running well. Just like a real factory, backups and breakdowns in one system cause problems in other areas. As damage spreads, cells lose their ability to do their jobs and, eventually, die.

The role of plaques and tangles

The brains of individuals with Alzheimer's have an abundance of plaques and tangles. Plaques are deposits of a protein called beta-amyloid that builds up in the spaces between nerve cells. Tangles are twisted fibers of a protein called tau that builds up inside of cells. Developing some plaques and tangles is normal with age, but those with Alzheimer's tend to develop far more in a predictable pattern in the areas important for memory before spreading to other regions.

Scientists do not know exactly what role plaques and tangles play in Alzheimer's disease. Most experts believe that they disable or block communication among nerve cells and disrupt processes cells need to survive. The destruction and death of nerve cells causes memory failure, personality changes, problems in carrying out daily activities and other symptoms of Alzheimer's disease

Causes and risk factors

While scientists know that Alzheimer's disease involves the failure of nerve cells, why this happens is still unknown. However, they have identified certain risk factors that increase the likelihood of developing Alzheimer's.

Age

The greatest known risk factor for Alzheimer's disease is increasing age. Most individuals with the illness are 65 and older. One in nine people in this age group has Alzheimer's. Nearly one-third of people age 85 and older have Alzheimer's.

Family History

Another risk factor is family history. Research has shown that those who have a parent, brother or sister with Alzheimer's are more likely to develop the disease than individuals who do not. The risk increases if more than one family member has the illness.

Familial Alzheimer's and genetics

Two categories of genes influence whether a person develops a disease: risk genes and deterministic genes. Risk genes increase the likelihood of developing a disease but do not guarantee it will happen. Deterministic genes directly cause a disease, guaranteeing that anyone who inherits one will develop a disorder.

There are several genes that increase the risk of Alzheimer's. APOE-e4 is the first gene identified and is the strongest indicator of Alzheimer's. Other common forms of the APOE gene are APOE-e2 and APOE-e3. Everyone inherits a copy of some form of APOE from each parent. Those who inherit one copy of APOE-e4 have an increased risk of developing Alzheimer's; those who inherit two copies have an even higher risk but not a certainty.

Rare deterministic genes cause Alzheimer's in a few hundred extended families worldwide. These genes are estimated to account for less than 1 percent of cases. Individuals with these genes usually develop symptoms in their 40s or 50s.

Other risk factors

Age, family history and genetics are all risk factors we can't change. Research is beginning to reveal clues about other risk factors that we may be able to influence. There appears to be a strong link between serious head injury and future risk of Alzheimer's. It's important to protect your head by buckling your seat belt, wearing a helmet when participating in sports and proofing your home to avoid falls.

One promising line of research suggests that strategies for overall healthy aging may help keep the brain healthy and may even reduce the risk of developing Alzheimer's. These measures include eating a healthy diet, staying socially active, avoiding tobacco and excess alcohol, and exercising both the body and mind.

Some of the strongest evidence links brain health to heart health. The risk of developing Alzheimer's or vascular dementia appears to be increased by many conditions that damage the heart and blood vessels. These include heart disease, diabetes, stroke, high blood pressure and high cholesterol. Work with your doctor to monitor your heart health and treat any problems that arise.

Studies of donated brain tissue provide additional evidence for the heart-head connection. These studies suggest that plaques and tangles are more likely to cause Alzheimer's symptoms if strokes or damage to the brain's blood vessels are also present.

How to find out if it's Alzheimer's disease

Not everyone experiencing memory loss or other possible Alzheimer's warning signs recognize that they have a problem. Signs of dementia are sometimes more obvious to family members or friends.

The first step in following up on symptoms is finding a doctor that a person feels comfortable with. There is no single type of doctor that specializes in diagnosing and treating memory symptoms or Alzheimer's disease. Many people contact their regular primary care physician about their concerns. Primary care doctors often oversee the diagnostic process themselves.

In some cases, the doctor may refer the individual to a specialist such as a:

- Neurologist who specializes in diseases of the brain and nervous system.
- Psychiatrist who specializes in disorders that affect mood or the way the mind works.
- Psychologist with special training in testing memory and other mental functions.

There is no single test that proves a person has Alzheimer's. The workup is designed to evaluate overall health and identify any conditions that could affect how well the mind is working. When other conditions are ruled out, the doctor can then determine if it is Alzheimer's or another dementia.

Experts estimate that a skilled physician can diagnose Alzheimer's with more than 90 percent accuracy. Physicians can almost always determine that a person has dementia,

but it may sometimes be difficult to determine the exact cause.

Steps to diagnosis include:

Understanding the problem

Be prepared for the doctor to ask:

- What kinds of symptoms have occurred.
- When they began.
- How often they happen.
- If they have gotten worse.

Reviewing medical history

The doctor will interview the person being tested and others close to him or her to gather information about current and past mental and physical illnesses. It is helpful to bring a list of all the medications the person is taking. The doctor will also obtain a history of key medical conditions affecting other family members, especially whether they may have or had Alzheimer's disease or other dementias.

Evaluating mood and mental status

Mental status testing evaluates memory, the ability to solve simple problems and other thinking skills. This testing gives an overall sense of whether a person:

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

The doctor may ask the person his or her address, what year it is or who is serving as president. The individual may also be asked to spell a word backward, draw a clock or copy a design. The doctor will also assess mood and sense of well-being to detect depression or other illnesses that can cause memory loss and confusion.

Physical exam and diagnostic tests

A physician will:

- Evaluate diet and nutrition.
- Check blood pressure, temperature and pulse.
- Listen to the heart and lungs.
- Perform other procedures to assess overall health.

The physician will collect blood and urine samples and may order other laboratory tests. Information from these tests can help identify disorders such as anemia, infection, diabetes, kidney or liver disease, certain vitamin deficiencies, thyroid abnormalities, and problems with the heart, blood vessels or lungs. All of these conditions may cause confused thinking, trouble focusing attention, memory problems or other symptoms similar to dementia.

Neurological exam

A doctor will closely evaluate the person for problems that may signal brain disorders other than Alzheimer's.

The physician will also test:

- Reflexes.
- Coordination.
- Muscle tone and strength.
- Eye movement.
- Speech.
- Sensation.

The doctor is looking for signs of small or large strokes, Parkinson's disease, brain tumors, fluid accumulation on the brain and other illnesses that may impair memory or thinking.

The neurological exam may also include a brain imaging study. The most common types are magnetic resonance imaging (MRI) or computed tomography (CT). MRIs and CTs can reveal tumors, evidence of small or large strokes and damage from severe head trauma or a buildup of fluid. Researchers are studying other imaging techniques so they can better diagnose and track the progress of Alzheimer's.

When the diagnosis is Alzheimer's disease

Once testing is complete, the doctor will make an appointment to review results and share his or her conclusions. A diagnosis of Alzheimer's reflects a doctor's best judgment about the cause of a person's symptoms, based on the testing performed.

You may want to ask the doctor:

- Why the diagnosis is Alzheimer's.
- Where the person may be in the course of the disease.
- What to expect in the future.

Find out if the doctor will manage care going forward and, if not, who will be the primary doctor. The doctor can then schedule the next appointment or provide a referral. Alzheimer's disease is life-changing for both the diagnosed individual and those close to him or her. While there is currently no cure, treatments are available that may help relieve some symptoms. Research has shown that taking full advantage of available treatment, care and support options can improve quality of life.

Consider:

- How to provide increasing levels of care as the disease progresses.
- How the individual and family members will cope with changes in the person's ability to drive, cook and perform other daily activities.
- How to ensure a safe environment.

It is also important to begin making legal and financial plans. A timely diagnosis often allows the person with dementia to participate in this planning. The person can also decide who will make medical and financial decisions on his or her behalf in later stages of the disease.

Stages of the disease

Alzheimer's disease typically progresses slowly in three general stages: mild (early-stage), moderate (middle-stage), and severe (late-stage).

Overview of disease progression

The symptoms of Alzheimer's disease worsen over time, but because Alzheimer's affects people in different ways, the rate at which the disease progresses varies. On average, a person with Alzheimer's lives four to eight years after diagnosis, but can live as long as 20 years, depending on other factors.

Changes in the brain related to Alzheimer's disease begin years before any signs of the disease. This time period, which can last years, is referred to as preclinical Alzheimer's disease.

The following stages - mild, moderate and severe - provide an overall idea of how abilities change once symptoms appear and should be used as a general guide. Be aware that stages may overlap, making it difficult to place a person with Alzheimer's in a specific stage.

Mild Alzheimer's Disease (Early-stage)

In the early stage of Alzheimer's, a person may function independently. He or she may still drive, work and be a part of social activities. Despite this, the person may feel as if he or she is having memory lapses, such as forgetting familiar words or the location of everyday objects.

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

Common difficulties include:

- Problems coming up with the right word or name.
- Trouble remembering names when introduced to new people.
- Having greater difficulty performing tasks in social or work settings.
- Forgetting material that was just read.
- Losing or misplacing a valuable object.
- Increasing trouble with planning or organizing.

Moderate Alzheimer's Disease (Middle-stage)

Moderate Alzheimer's is typically the longest stage and can last for many years. As the disease progresses, the person with Alzheimer's will require a greater level of care.

You may notice the person with Alzheimer's confusing words, getting frustrated or

angry, or acting in unexpected ways, such as refusing to bathe. Damage to nerve cells in the brain can make it difficult to express thoughts and perform routine tasks.

At this point, symptoms will be noticeable to others and may include:

- Forgetfulness of events or about one's own personal history.
- Feeling moody or withdrawn, especially in socially or mentally challenging situations.
- Being unable to recall their address or telephone number or the high school or college from which they graduated.
- Confusion about where they are or what day it is.
- The need for help choosing proper clothing for the season or the occasion.
- Trouble controlling bladder and bowels in some individuals.
- Changes in sleep patterns, such as sleeping during the day and becoming restless at night.
- An increased risk of wandering and becoming lost.
- Personality and behavioral changes, including suspiciousness and delusions or compulsive, repetitive behavior like hand wringing or tissue shredding.

Severe Alzheimer's Disease (Late-stage)

In the final stage of this disease, individuals lose the ability to respond to their environment, to carry on a conversation and, eventually, to control movement. They may still say words or phrases, but communicating pain becomes difficult. As memory and cognitive skills continue to worsen, personality changes may take place and individuals need extensive help with daily activities.

At this stage, individuals may:

- Require full-time, around-the-clock assistance with daily activities and personal care.
- Lose awareness of recent experiences as well as of their surroundings.
- Experience changes in physical abilities, including the ability to walk, sit, and eventually, swallow.
- Have increasing difficulty communicating.
- Become vulnerable to infections, especially pneumonia.

Wandering

Six out of 10 people with Alzheimer's disease will wander and become lost. People can wander or become confused about their location at any stage of the disease. If not found within 24 hours, up to half of those who get lost risk serious injury or death.

The Alzheimer's Association offers services to help ensure safety. Medic Alert® + Alzheimer's Association Safe Return® is a 24-hour emergency response service that provides assistance when a person with dementia becomes lost or has a medical emergency. Another great service is Alzheimer's Association Comfort Zone®, a comprehensive Web-based location management system that allows families to monitor a person with Alzheimer's.

Visit alz.org/safety to learn more.

Treating the symptoms

Currently, there is no cure for Alzheimer's disease and no way to stop the underlying death of brain cells. But drugs and non-drug treatments may help with both cognitive and behavioral symptoms.

A comprehensive care plan for Alzheimer's disease:

- Considers appropriate treatment options.
- Monitors treatment effectiveness as the disease progresses.
- Changes course and explores alternatives as necessary.
- Respects individual and family goals for treatment and tolerance for risk.

Cognitive symptoms

Three types of drugs are currently approved by the FDA to treat cognitive symptoms of Alzheimer's disease.

The first type, cholinesterase (KOH-luh-NES-ter-ays) inhibitors, prevents the breakdown of acetylcholine (a-SEA-til-KOH-lean), a chemical messenger important for memory and learning. By keeping levels of acetylcholine high, these drugs support communication among nerve cells.

Three cholinesterase inhibitors are commonly prescribed:

- Donepezil (Aricept®), approved in 1996 to treat mild-to-moderate Alzheimer's and in 2006 for the severe stage.
- Rivastigmine (Exelon®), approved in 2000 for mild-to-moderate Alzheimer's.
- Galantamine (Razadyne®), approved in 2001 for mild-to-moderate stages.

The second type of drug works by regulating the activity of glutamate, a different messenger chemical involved in information processing:

- Memantine (Namenda®), approved in 2003 for moderate-to-severe stages, is the only currently available drug in this class.

The third type is a combination of cholinesterase inhibitor and a glutamate regulator:

- Donepezil and memantine (Namzaric®), approved in 2014 for moderate-to-severe stages.

The effectiveness of the types of treatments varies from person to person. While they may temporarily help symptoms, they do not slow or stop the brain changes that cause Alzheimer's to become more severe over time.

Behavioral symptoms

Many find behavioral changes like anxiety, agitation, aggression and sleep disturbances to be the most challenging and distressing effect of Alzheimer's disease. These changes

can greatly impact the quality of life for individuals living in both family situations and long-term residential care.

As with cognitive symptoms of Alzheimer's, the chief underlying cause of behavioral and psychiatric symptoms is the progressive damage to brain cells. Other possible causes of behavioral symptoms include:

- **Drug side effects**
Side effects from prescription medications may be at work. Drug interactions may occur when taking multiple medications for several conditions.
- **Medical conditions**
Symptoms of infection or illness, which may be treatable, can affect behavior. Pneumonia or urinary tract infections can bring discomfort. Untreated ear or sinus infections can cause dizziness and pain.
- **Environmental influences**
Situations affecting behavior include moving to a new private residence or residential care facility; misperceived threats; or fear and fatigue from trying to make sense of a confusing world.

There are two types of treatments for behavioral symptoms: non-drug treatments and prescription medications.

Non-drug treatments

Steps to develop non-drug treatments include:

- Identifying the symptom.
- Understanding its cause.
- Changing the caregiving environment to remove challenges or obstacles.

Identifying what has triggered behavior can often help in selecting the best approach. Often the trigger is a change in the person's environment, such as:

- New caregivers.
- Different living arrangements.
- Travel.
- Admission to a hospital.
- Presence of houseguests.
- Being asked to bathe or change clothes.

Because people with Alzheimer's gradually lose the ability to communicate, it is important to regularly monitor their comfort and anticipate their needs.

Prescription medications

Medications can be effective in managing some behavioral symptoms, but they must be used carefully and are most effective when combined with non-drug treatments. Medications should target specific symptoms so that response to treatment can be monitored.

Prescribing any drug for a person with Alzheimer's is medically challenging. Use of drugs for behavioral and psychiatric symptoms should be closely supervised.

Some medications, called atypical antipsychotics, are associated with an increased risk of serious side effects. The benefits and risks of these medications should be carefully weighed when deciding whether they should be used.

Hope for the future

The Alzheimer's Association is the world's largest nonprofit funder of Alzheimer's research. Since 1982, we have awarded over \$340 million to more than 2,250 research investigations worldwide.

When Alois Alzheimer first described the disease in 1906, a person in the United States lived an average of about 50 years. Few people reached the age of greatest risk. As a result, the disease was considered rare and attracted little scientific interest. That attitude changed as the average life span increased and scientists began to realize how often Alzheimer's strikes people in their 70s and 80s. The Centers for Disease Control and Prevention recently estimated an average person's life expectancy to be 78.7 years.

Today, Alzheimer's is at the forefront of biomedical research, with 90 percent of what we know discovered in the last 20 years. Some of the most remarkable progress has shed light on how Alzheimer's affects the brain. Better understanding of its impact may lead to better treatments.

Clinical studies drive progress

Scientists are constantly working to advance research. But without clinical research and the help of human volunteers, we cannot treat, prevent or cure Alzheimer's. Clinical trials test new interventions or drugs to prevent, detect or treat disease for safety and effectiveness. Clinical studies are any type of clinical research involving people. Clinical studies can also look at other aspects of care, such as improving quality of life. Every clinical trial or study contributes valuable knowledge, regardless if favorable results are achieved.

Visit alz.org/TrialMatch to learn more about Alzheimer's Association TrialMatch®, a clinical studies matching service that connects individuals living with Alzheimer's, caregivers, healthy volunteers and physicians with current Alzheimer's-related clinical studies.

New directions in treatment and prevention

One promising target is beta-amyloid. This protein fragment builds up into the plaques considered one hallmark of the disease. Researchers have developed several ways to clear beta-amyloid from the brain or prevent it from clumping together into plaques. Experimental drugs that zero in on beta-amyloid are now being tested.

Many other new approaches to treatment are also under investigation worldwide. We don't yet know which of these strategies may work, but scientists say that with the

necessary funding, the outlook is good for developing treatments that slow or stop Alzheimer's.

While there is no known way to prevent Alzheimer's disease, emerging research suggests that the steps people take to maintain heart health may also reduce the risk of Alzheimer's.

This connection makes sense, because the brain is nourished by one of the body's richest networks of blood vessels, and the heart is responsible for pumping blood through these blood vessels to the brain. It's especially important for people to do everything they can to keep weight, blood pressure, cholesterol and blood sugar within recommended ranges to reduce the risk of heart disease, stroke and diabetes. Eating a low-fat diet rich in fruits and vegetables, exercising regularly, and staying mentally and socially active may all help protect the brain.

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Memory loss and changes in mood and behavior are some signs that you or a family member may have Alzheimer's disease or a related dementia. If you have noticed these signs, it is important to consider a diagnosis for the following reasons:

- Many things can cause dementia which is a decline in intellectual ability severe enough to interfere with a person's daily routine. Dementias related to depression, drug interaction, malnutrition, B-12 deficiency, and thyroid problems may be reversible.
- Other causes of dementia include strokes, Huntington's disease, and Parkinson's disease. Alzheimer's disease is the most common cause of dementia. It is important to identify the actual cause in order for an individual to receive the proper care.
- An individual who may have Alzheimer's disease may be able to maximize the quality of his or her life by receiving an early diagnosis. It may also help to resolve anxiety of wondering "What's wrong with me?"
- An early diagnosis may allow time to plan for the future. Decisions regarding care, living arrangements, financial and legal issues, and other important issues may be addressed while the individual can still participate fully in making informed decisions.
- Alzheimer's disease is known to strike persons in their 40's and 50's. This "early onset" form of Alzheimer's disease presents unique planning issues for the individual and family members.

THE DIAGNOSTIC PROCESS

There is no one diagnostic test that can detect if a person has Alzheimer's disease. Typically, diagnosis is made by creating a detailed medical history of the person and by reviewing the results of several tests. These include a complete physical and neurological examination, a psychiatric assessment and laboratory tests. Once this testing is completed, a diagnosis of "probable" Alzheimer's disease may be made by process of elimination. However, experienced diagnosticians can be 90-95% certain that their diagnosis is accurate. The process may be handled by a family physician or may involve a diagnostic team of medical professionals, including the primary physician, neurologist (a physician specializing in the nervous system), psychiatrist, psychologist and nursing staff.

The diagnostic process generally takes more than one day and is usually performed on an outpatient basis. It may involve going to several different locations or even to a specialized Alzheimer's diagnostic center. The Alzheimer's Association Desert Southwest Chapter can refer you to physicians and/or diagnostic centers in the community.

Steps in getting a diagnosis usually involve the following:

1. Medical History Determination

The person being tested and family members will be interviewed both individually and together to gather background information on the person's daily functioning, current mental and physical conditions, as well as family medical history.

2. Mental Status Evaluation

During the mental status evaluation, the person's sense of time and place, and ability to remember, understand, communicate and do simple calculations are assessed. The person may be asked questions such as, "What year is it? What day of the week is it? Who is the current president?" The person will also be asked to complete mental exercises, such as spelling a word backwards, writing a sentence, or copying a design. When reviewing the test results, the physician will consider the individual's overall performance in relation to his or her education background physical condition and occupation.

3. Physical Examination

During the physical exam, the physician will evaluate the individual's nutritional status, blood pressure, pulse and other factors. The physician will also search for the presence of cardiac, vascular, respiratory, liver, kidney and thyroid diseases. Some of these conditions or the combination may cause dementia-like symptoms in some individuals.

4. Neurological Exam

A physician, usually a neurologist, will evaluate the person's nervous system for problems that may signal brain disorders other than Alzheimer's disease. The physician will search for evidence of previous strokes, Parkinson's disease, hydrocephalus (fluid accumulation in the brain), brain tumors, and other illnesses that impair memory and/or thinking. The physician will learn about the health of the brain by testing coordination, muscle tone and strength, eye movement, speech and sensation. For example, the physician will test reflexes by tapping the knee, check the person's ability to sense feeling in their hands and feet, and listen for slurred speech.

5. Laboratory Tests

A variety of tests will be ordered by the physician to help diagnose Alzheimer's disease by ruling out other disorders. Levels of vitamin B-12 and folic acid are measured, as low levels may be associated with dementia. Since very high or low amounts of the thyroid hormones can cause confusion or dementia, levels of the thyroid hormones are measured through a blood test. A physician may also order an EEG (electroencephalogram) to detect abnormal brain wave activity. This test can detect conditions such as epilepsy, which can sometimes cause prolonged, but mild seizures that leave a person in a confused state.

A CT (computerized tomography) scan, which takes x-ray images of the brain, is also frequently used. The brain is scanned for evidence of tumors, strokes, blood clots and the build up of fluid associated with hydrocephalus. MRI (magnetic resonance imaging) is another brain-imaging technique sometimes used. Other tests may also be recommended but are not usually necessary for the diagnosis. These include PET (positron emission tomography) scans, which shows how different areas of the brain respond when the person is asked to perform different activities, such as reading, listening to music or talking; and SPECT (Single Photon Emission Computed Tomography) scan, which shows blood circulation in the brain.

6. Psychiatric, Psychological and other Evaluations

A psychiatric evaluation can rule out the presence of other illnesses, such as depression, which can result in memory loss similar to dementia of the Alzheimer type. Neuropsychological testing may also be done to test memory, reasoning, writing, vision-motor coordination and ability to express ideas. These tests may take several hours, and may involve interviews with a psychologist, as well as written tests. These tests provide more in-depth information than the mental status evaluation. Nurses, and occupational, rehabilitation or physical therapists may be called upon to look for problems with memory, reasoning, language and judgment affecting the person's daily functioning.

UNDERSTANDING THE DIAGNOSIS

Once testing is completed, the diagnosing physician or other members of the diagnostic team will review the results of the examination, laboratory tests and other consultation to arrive at the diagnosis. If all test results appear to be consistent with Alzheimer's disease, the clinical diagnosis will be "probable Alzheimer's disease", or "dementia of the Alzheimer type." If the symptoms are not typical, but no other cause is found, the diagnosis will be "possible Alzheimer's disease." Although researchers have made enormous progress in diagnostic testing, the only way to prove Alzheimer's disease is through an autopsy. If a cause of dementia other than Alzheimer's disease is diagnosed, call the Alzheimer's Association, Desert Southwest Chapter at (520) 322-6601 to request a free informational brochure about related causes of dementia.

THE FAMILY'S ROLE IN DIAGNOSIS

While some people with Alzheimer's disease may initiate their own diagnosis and care, for most, it will be up to another family member to alert the physician. Here are some tips that will help you get someone to the physician for an initial evaluation:

- Schedule the appointment for the person.
- Help with transportation to the appointment.
- Read this pamphlet as a family, to gain a better understanding of what to expect during the diagnostic process.
- Contact the Alzheimer's Association Desert Southwest Chapter if you have any questions or concerns.
- Offer to accompany the person during the testing process if he or she is still uneasy about investigating possible Alzheimer's disease.

On the day of the appointment, bring along items such as glasses, hearing aids, devices that help the person walk, a list of all medications the person is taking, and other personal items that might help during diagnostic testing. Be sure the physician has all medical records, insurance and social security information.

PREPARING FOR DIAGNOSTIC TESTS

Once the initial appointment has been made to evaluate a person, the diagnostic team will need certain information to make an accurate diagnosis. Following are questions that you may want to ask regarding the diagnostic process. It may be helpful to start writing down events that occur and any changes in the person's abilities, behavior and personality that cause you to suspect Alzheimer's disease.

Questions You May Be Asked:

- What symptoms have you noticed?
 - Do you have difficulty performing simple tasks?
 - Is there recent memory loss that affects job skills?
 - Have you noticed poor or decreased judgment?
 - Are there other things you've noticed?
- When did symptoms first appear?
- How have the symptoms changed over time?
- Does the individual suffer from other medical conditions?
- Have other family members been diagnosed with Alzheimer's disease?

Questions to Ask Before Diagnosis Testing:

- Which test will be performed?
- Will any of the tests involve pain or discomfort for the individual?
- How long will the test take?
- How long will it take to learn the results of the test?

Questions To Ask If the Diagnosis is Probable Alzheimer's disease:

- What does the diagnosis mean?
- What symptoms can be anticipated next?
- How will they change over time?
- What level of care will be required now and in the future?
- What medical treatment is available?
- What are the risks and effectiveness?
- What changes should be made in the home to make it safer?
- What resources and support services are available in our community?
- Are experimental drug trails available?

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The Alzheimer's Association Desert Southwest Chapter provides programs and services to tens of thousands of families including Helpline – a 24/7 assistance line, MedicAlert®+Safe Return®, Family Care Consultation, Support Groups, Education, Early Stage Programming and Legislative Advocacy. Please, contact us for any more information or assistance, 24 hours a day, seven days a week, at 800.272.3900 or online at www.alz.org/dsw.

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Stages of Alzheimer's Disease

Each individual's experience with Alzheimer's disease is unique. However, there are some changes that are more common or expected. This chart overviews some the more typical changes caregivers may see throughout the disease.

Symptoms: <ul style="list-style-type: none"> Moderate memory loss with increased loss of recent events Difficulty performing familiar tasks Problems with language Some difficulty with time and place Poor or decreased judgment Difficulty with problem solving Changes in personality, mood behavior Anxiety & depression about symptoms Loss of initiative Usually independent in daily living activities 	Symptoms: <ul style="list-style-type: none"> Increasing memory loss, confusion or shorter attention span Problems recognizing friends/family Disorientation to time, place & situation More impaired judgment & problem solving skills Difficulty organizing thoughts, actions and thinking logically Personality and behavioral changes May be suspicious, irritable, restless Loss of impulse control May see or hear things not present May develop problems with bathing or receiving physical care from others Becoming more dependent on others for assistance with physical care and home chores 	Symptoms: <ul style="list-style-type: none"> Severe memory loss Minimal or no speech Increased feeding and/or swallowing problems Knows only self NO judgment or problems solving skills Unable to control bladder or bowels May place items in mouth May not be able to walk or need maximum amount of assistance to walk May be prone to infection or skin break down May have seizures Dependent for all care needs 	Symptoms: <ul style="list-style-type: none"> Generally has most of late stages symptoms and any of the following symptoms to meet hospice eligibility: <ul style="list-style-type: none"> (aspiration) pneumonia Bladder infection General infection Bed sores Fever after treating with antibiotics Weight loss and inability to maintain sufficient fluids
Examples: <ul style="list-style-type: none"> Forgets things more often and becomes more forgetful as disease progresses Paying bills/writing checks becomes more difficult and contains errors Loses things Arrives at wrong time or place and constantly rechecks calendar Word finding and language skills become more impaired Difficulty starting or completing activities Routine chores become more difficult and take longer to complete Gets lost or confused especially in new environment Gets lost driving 	Examples: <ul style="list-style-type: none"> Memory loss becomes more severe May ask questions over and over Difficulty with personal care such as bathing, dressing or personal hygiene Difficulty shopping, preparing meals, caring for home & managing finances Can't find the right words Problems with numbers Suspicious – may accuse spouse of hiding things or infidelity Loss of impulse control, sloppy manners, may undress at inappropriate times Sleep disturbance at night – may wake up and wander 	Examples: <ul style="list-style-type: none"> Looks into mirror or talks to own image Speaks very little or makes no sense May scream, groan or make grunting sounds (this may indicate pain) May hold food in mouth or forget to chew or swallow May start to sleep more 	Examples: <ul style="list-style-type: none"> Bed bound or wheelchair bound Frequent infections or fever Unexplained weight loss Not able to swallow or begins to choke Person's previously stated views about death and dying are recognized and honored by caregiver(s)
Care Needs: Individuals can generally live alone but may need supervision for driving, taking medications, oversight of finances, and/or housekeeping/lawn care chores	Care Needs: Needs 24-hour supervision, structure and routine. May respond to verbal reminders to initiate and/or complete daily living skills	Care Needs: Needs 24-hour supervision and total assistance with all care needs. Depending on symptoms, Hospice evaluation can be initiated	Care Needs: Needs 24-hour supervision and total assistance for all care needs. Person should qualify for Hospice program

Telling Others About an Alzheimer Diagnosis

When you learn that someone you care about has Alzheimer's, you may hesitate to tell the person that he or she has the disease. You may also have a hard time deciding whether to tell family and friends. Once you are emotionally ready to discuss the diagnosis, how will you break the news? Here are some suggestions for talking about the disease with others.

Respect the person's right to know

- You may want to protect the person by withholding information. But your loved one is an adult with the right to know the truth. It can be a relief to hear the diagnosis, especially if the person had suspected he or she had Alzheimer's disease.
- In many cases, people who are diagnosed early are able to participate in important decisions about their healthcare and legal and financial planning.
- While there is no current cure for Alzheimer's, life will not stop with the diagnosis. There are treatments and services that can make life better for everyone.

Plan how to tell the person

- Talk with doctors, social workers and others who work with people who have Alzheimer's to plan an approach for discussing the diagnosis.
- Consider a "family conference" to tell the person about the diagnosis. He or she may not remember the discussion, but may remember that people cared enough to come together. You may need to have more than one meeting to cover the details.
- Shape the discussion to fit the person's emotional state, medical condition and ability to remember and make decisions.
- Pick the best time to talk about the diagnosis. People with Alzheimer's may be more receptive to new information at different times of the day.
- Don't provide too much information at once. Listen carefully to the person. They often signal the amount of information they can deal with through their question and reactions. Later, you can explain the symptoms of Alzheimer's and talk about planning for the future and getting support.

Help the person accept the diagnosis

- The person may not understand the meaning of the diagnosis or may deny it. Accept such reactions and avoid further explanations.
- If they respond well, try providing additional information.
- The person with Alzheimer's may forget the initial discussion but not the emotion involved. If telling them upsets them, hearing additional details may trigger the same reaction later.

- Reassure your loved one. Express your commitment to help and give support. Let the person know that you will do all you can to keep your lives fulfilling.
- Be open to the person's need to talk about the diagnosis and his or her emotions.
- Look for nonverbal signs of sadness, anger or anxiety. Respond with love and reassurance.
- Encourage the person to join a support group for individuals with memory loss. Your local Alzheimer's Association can help you locate a group. To find an Association near you, please call 1.800.272.3900 or go to www.alz.org.

Telling family and friends

An Alzheimer diagnosis doesn't only affect the person receiving it. The lives of family members and friends may also drastically change.

- Be honest with family and friends about the person's diagnosis. Explain that Alzheimer's is a brain disease, not a psychological or emotional disorder.
- Share educational materials from the Alzheimer's Association. The more that people learn about the disease, the more comfortable they may feel around the person.
- Invite family to support groups sponsored by your local Alzheimer's Association.
- Realize that some people may drift out of your life, as they may feel uncomfortable around the person or may not want to help provide care.
- Alzheimer's disease can also impact children and teens. Just as with any family member, be honest about the person's diagnosis with the young people in your life. Encourage them to ask questions.

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

Updated September 2007

Alzheimer's disease or a related disorder can cause a person to act in different or unpredictable ways. Some individuals become anxious or aggressive; others repeat certain questions or gestures. These changes can lead to frustration and tension, particularly between the demented person and their caregivers (family, friends and for professionals).

It is important to remember that the person is not acting this way on purpose. Changes in behavior can be caused by:

- Physical discomfort (illness, medication)
- Over stimulation (loud noises, a 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)

Whatever the case, be sure to identify the special challenge and consider possible solutions.

First, identify and examine the behavior.

- What is the undesirable behavior? Is it harmful to the individual or others?
- What happened just before the behavior occurred? Did something "trigger" the behavior?
- What happened immediately after the behavior occurred? How did you react?
- Try to answer the following questions: What, where, when, why, and how?

Next, explore potential solutions.

- What are the needs of the person with dementia? Are they being met?
- Can adapting the environment help reduce the difficult behavior?
- How can you change your reaction, or approach to the behavior? Are you responding in a calm and supportive way?

And finally, try different responses in the future.

- Did your new response help?
- Do you need to explore other potential causes and solutions? If so, what can you do differently?

UNDERSTANDING AND RESPONDING TO CHALLENGES

Each person with Alzheimer's disease or a related disorder is not the same, so the behaviors or changes experienced are also different. Therefore, families and caregivers respond to difficult situations in different ways. Next, we will identify some of the most common challenging behaviors and explore possible ways to respond to them.

REPETITIVE ACTION OR CONVERSATIONS

Persons with Alzheimer's or a related disorder may do or say something over and over again. They may repeat a word, question or activity. In most cases, they are probably looking for comfort, security and familiarity.

They may also pace or undo what has just been finished. These actions are often harmless for the person with Alzheimer's disease or a related disorder, but can be stressful for the caregiver and others.

Here are some ways to respond to repetitive behaviors:

- **Look for a reason behind the repetition.** Try to find out if there is a specific cause for the behavior and eliminate it.
- **Respond to the emotion, not the behavior.** Rather than focusing on what they are doing, think about how they are feeling.
- **Turn the action or behavior into an activity.** If they are rubbing a hand across the table, give them a cloth and ask them to help with dusting.
- **Stay calm and be patient.** Reassure them with a calm voice and gentle touch.
- **Answer them.** Give them the answer they're looking for, even if you have to repeat several times.
- **Engage them in an activity.** They may simply be bored and need something to do. Provide structure and engage them in a pleasant activity.
- **Use memory aids.** If they ask the same questions over again, remind them with notes, clocks, calendars, or photographs.
- **Accept the behavior and work with it.** If it isn't harmful, let it be and try to find ways to work with it.
- **Consult a physician.** Repetitive behaviors may be a side effect from medication. Talk with the affected person's physician.

AGGRESSIVE BEHAVIORS

Aggressive behaviors may be verbal (shouting, name-calling) or physical, (hitting, pushing). These behaviors can occur suddenly without an apparent reason, or result from a frustrating situation. Whatever the case, it is important to try to understand what's causing the person to become angry or upset.

Here are some potential ways to respond:

- **Try to identify the immediate cause.** Think about what happened right before the reaction that may have "triggered" the behavior.

- **Focus on the feelings, not the facts.** Try not to concentrate on specific details; rather, consider emotions. Look for the feelings behind the words.
- **Don't get angry and upset.** Be positive and reassuring and speak slowly with a soft tone.
- **Limit distractions.** Examine the environment and make adaptations to avoid similar situations in the future.
- **Try a relaxing activity.** Use music, massage or exercise to help soothe the person.
- **Change focus to another activity.** The immediate situation or activity may have unintentionally caused the aggressive response. Try something different.

SUSPICIOUS THOUGHTS

Due to memory loss and confusion, persons with Alzheimer's disease may see things differently. They may become suspicious of those around them and accuse them of theft, infidelity or other improper behavior. At times, they may also misinterpret what they see and hear.

If this happens:

- **Don't take offense.** Listen to what's troubling them and try to understand their reality. Then be reassuring and let them know you care.
- **Don't argue or try to convince.** Allow them to express their opinions. Agree with their assumptions and acknowledge their thoughts.
- **Offer a simple answer.** Share your thoughts with them, but don't overwhelm them with lengthy explanations or reasons.
- **Switch his/her attention to another activity.** Try to engage them in an activity or ask them to help with a chore.
- **Duplicate items if lost.** If they're looking for a specific item, have several available. For example, if someone's always looking for a wallet, purchase two of the same kind.

RECOGNITION DIFFICULTIES

At times, person with Alzheimer's disease or a related disorder may not recognize familiar people, places, or things. They may forget relationships, call family members by other names and become confused about where they live. They may also forget the purpose of common items, such as a pen or a fork. These situations can be extremely difficult for caregivers to handle and require much patience and understanding.

Caregivers should:

- **Stay calm.** Although being called by a different name or not being recognized may be quite painful, try not to make your hurt apparent.
- **Reply with a brief explanation.** Don't overwhelm the person with lengthy statements and reasons. Instead, clarify with a simple explanation.
- **Show photos and other reminders.** Use photographs and other items to remind the person of important relationships and places.

- **Offer corrections as a suggestion.** Avoid explanations that sound like scolding. Try, “I thought it was a spoon” or “I think he is your grandson, Peter.”
- **Try not to take it personally.** Remember, Alzheimer’s disease or other related disorder causes the affected individual to forget. But your support and understanding will always be appreciated.

ANXIOUS OR AGITATED FEELINGS

Persons with Alzheimer’s or other related disorder may feel anxious or agitated at times. They may become restless and need to move around or pace. They may become upset in certain places or focused on specific details. They may also be over-reliant on the caregiver for attention or direction.

If the persons with Alzheimer’s disease or a related disorder becomes anxious or agitated:

- **Listen to their frustration.** Find out what may be causing their anxiety and try to understand.
- **Reassure them.** Use calming phrases and let them know you’re there for them.
- **Involve them in activities.** Try using art, music, or touch to help them relax.
- **Modify the environment.** Decrease noise and distractions or move to another place.
- **Find outlets for their energy.** They may be looking for something to do. Take a walk, play ball or go for a ride whenever possible.

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April 2015

DON'T

Don't reason.
Don't argue.
Don't confront.

Don't remind them they forget.
Don't question recent memory.
Don't take it personally!



Ooops! You must be kidding.
You mean I can't reason???
Or argue??? Or remind???

DO

Give short, one-sentence explanations.
Repeat instructions or sentences *exactly* the same way.
Allow plenty of time for comprehension.
Eliminate "but" from your vocabulary; substitute "nevertheless".

Agree with them or distract them to a different subject or activity.
Accept the blame when something's wrong (even if it's fantasy).
Leave the room, if necessary, to avoid confrontations.

Respond to the feelings rather than the words.
Be patient and cheerful and reassuring. Go with the flow.
Elevate your lever of generosity and graciousness.



*Hmmm.....accept blame?
This is gonna be tough!*

REMEMBER

They are not crazy or lazy. They are saying normal things, and doing normal things, for an AD patient. If they were doing things, or saying things, to deliberately aggravate you, they would have a different diagnosis.

Some days they'll seem normal, but they're *not*. Their reality is now different than yours and *you cannot change them*. You can't control the disease. You can only control your reaction to it.

Their disability is memory loss. They cannot remember and can't remember that they cannot remember. They'll ask the same question over and over *believing it's the first time they've asked*.

They do not hide things; they *protect* things by putting them in a safe place and then forgetting they've done so. Do not take 'stealing' accusations personally.

They are scared all the time. Each patient reacts differently to fear. They may become passive, uncooperative, hostile, angry, agitated, verbally abusive, or physically combative. They may even do them all at different times, or alternate between them. Anxiety may compel them to *shadow you* (follow everywhere). They can't remember your reassurances. Keep saying them.

Call the Helpline if you need suggestions on handling challenging situations...in Prescott 928-771-9257 or 800-272-3900

"Once dementia is diagnosed, the patient is excused 100% of the time."

-- Adapted from, *Alzheimer's: A Handbook for the Caretaker*
by Eileen H. Driscoll, R.N., Branden Publishing Company, 1994

Don't reason

PWD: "What doctor's appointment? There's nothing wrong with me."

Don't: (reason) "You've been seeing the doctor every three months for the last two years. It's written on the calendar and I told you about it yesterday and this morning."

DO: (short explanation) "It's just a regular check-up."
(accept blame) "I'm sorry if I forgot to tell you."

Don't ask questions of recent memory.

PWD: "Hello, Susie. I see you've brought a friend with you."

Don't: (question memory) "Hi, Mom. You remember Eric, don't you?What did you do today?"

Do: (short explanation) "Hi, Mom. You look wonderful! This is Eric. We work together."

Don't argue.

PWD: "I didn't write this check for \$500. Someone at the bank is forging my signature."

Don't: (argue) "What? Don't be silly! The bank wouldn't be forging your signature."

DO: (respond to feelings) "That's a scary thought."
(reassure) "I'll make sure they don't do that."
(distract) "Would you help me fold the towels?"

Don't take it personally!

PWD: "Who are you? Where is my husband?"

Don't: (take it personally) "What do you mean—who's your husband? I am!"

Do: (go with the flow, reassure) "He'll be here for dinner."
(distract) "How about some milk and cookies? Would you like chocolate or oatmeal?"

Don't confront

PWD: "Nobody's going to make decisions for *me*. You can go now...and don't come back!"

Don't (confront) "I'm not going anywhere and you can't remember enough to make your own decisions."

DO: (accept blame or respond to feelings) "I'm sorry this is a tough time."
(reassure) "I love you and we're going to get through this together."
(distract) "You know what? Don has a new job. He's really excited about it."

Do repeat exactly.

PWD: "I'm going to the store for a newspaper."

Don't: (repeat differently) "Please put your shoes on." "You'll need to put your shoes on."

DO: (repeat exactly) "Please put your shoes on." "Please put your shoes on."

Don't remind them they forget.

PWD: "Joe hasn't called for a long time. I hope he's okay."

Don't: (remind) "Joe called yesterday and you talked to him for 15 minutes."

DO: (reassure) "You really like talking to Joe, don't you?"
(distract) "Let's call him when we get back from our walk"

Do eliminate 'but', substitute 'nevertheless'.

PWD: "I'm not eating this. I hate chicken."

Don't: (say 'but') "I know chicken's not your favorite food, but it's what we're having for dinner."

DO: (say 'nevertheless') "I know chicken's not your favorite food, (smile) *nevertheless* I'd appreciate it if you'd eat a little bit."

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- ☐ **Register with SAFE RETURN.** Be sure to include a current photo with your application.
- ☐ Make neighbors aware of your loved one's diagnosis so that if they notice your loved one wandering they will quickly alert you.
- ☐ Be attentive around your loved one; always be looking for new potential hazards in the environment.
- ☐ Find a good "handyman" that is dependable and can help you at short notice.
- ☐ Lock up or dispose of toxic materials such as cleaning fluids, insecticides, and medicines so that they are not accidentally ingested by your loved one who has memory problems.
- ☐ Learn to disable the car. A person with memory loss should never drive; they can easily get lost and cannot react quickly enough or appropriately to road hazards. Do not risk the life of your loved one or other innocent people on the road.
- ☐ Place locks on the top of doors, out of sight line. Installing doorbells will alert the caregiver if the door opens or closes.
- ☐ Cover or remove mirrors-especially in the bathroom. A person with memory loss may interpret their reflection as a stranger in the home and could lead to an accident.
- ☐ Remove unnecessary rugs to prevent falls or secure rugs (and other easily movable furniture) with a non-slip type backing.
- ☐ Remove unnecessary furniture to keep walkways clear but try not to rearrange furniture unless absolutely necessary.
- ☐ Keep decoration simple with plain walls and carpets and eliminate clutter.
- ☐ Remove poisonous plants (like oleander) so they are not mistakenly eaten.
- ☐ Place a lock on the thermostat and water heater so that a person with dementia cannot adjust them. Be aware that to prevent burns water should be no hotter than 120° F.
- ☐ Install a fire extinguisher in the kitchen.
- ☐ Remove knobs from the stove so that the person with memory loss cannot switch it on. Install child safety latches on the inside of cabinets where cleaning products are kept.
- ☐ Place non-slip mats in showers and tubs.
- ☐ Install grab-bars by the toilet, shower, and bath. Towel rails are NOT a substitute.
- ☐ Learn the Heimlich maneuver.
- ☐ Install night-lights, especially between bedrooms and bathrooms.
- ☐ Install pool safety devices including gate locks.
- ☐ Post important numbers by the telephone: police, fire, family, and friends.
- ☐ Keep a recent photo of your loved one available. Have a plan for your loved one in case you, the caregiver, are unable to provide care.

Call the Alzheimer's Association Desert Southwest Chapter for literature and tips to create a safe home for persons with memory loss, at 800.272.3900 or online at www.alz.org/dsw.

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Alzheimer's Caregiving Tips

Wandering

Many people with Alzheimer's disease wander away from their home or caregiver. As the caregiver, you need to know how to limit wandering and prevent the person from becoming lost. This will help keep the person safe and give you greater peace of mind.

First Steps

Try to follow these steps *before* the person with Alzheimer's disease wanders:

- 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.
- Consider enrolling the person in the MedicAlert® + Alzheimer's Association Safe Return® Program (see www.alz.org or call 1-888-572-8566 to find the program in your area).
- Let neighbors and the local police know that the person with Alzheimer's 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.



Tips to Prevent Wandering

Here are some tips to help prevent the person with Alzheimer's from wandering away from home:

- 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.*
- Place STOP, DO NOT ENTER, or CLOSED signs on doors.
- Divert the attention of the person with Alzheimer's disease 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.

* 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.



For more caregiving tips and other resources:

- **Read** "Caring for a Person with Alzheimer's Disease": www.nia.nih.gov/alzheimers/publication/caring-person-alzheimers-disease
- **Visit** www.nia.nih.gov/alzheimers/topics/caregiving
- **Call** the ADEAR Center toll-free: 1-800-438-4380

The Alzheimer's Disease Education and Referral (ADEAR) Center is a service of the National Institute on Aging, part of the National Institutes of Health. The Center offers information and publications for families, caregivers, and professionals about Alzheimer's disease and age-related cognitive changes.



July 2012

Dental Care (for Dementia)

By the Family Caregiver Alliance

Dental hygiene is important for overall health. Poor dental hygiene may lead to heart disease, gingivitis, stroke, osteoporosis, and respiratory disease. In addition to causing bad breath, inadequate dental hygiene can also affect one's ability to eat, chew, and talk. Certain medications can cause "dry mouth." Dry mouth makes it more difficult to eat and swallow, produce saliva, and causes tongue irritation.

Brushing teeth is a complicated process with many steps. Although most of us do it automatically, if someone is having memory problems, some of the steps might be forgotten. Supervision or assistance is often necessary.

- Talking someone through the steps or modeling the steps yourself at the same time might help the affected person be more successful. Give the person the toothbrush with toothpaste already on it and put your hand over theirs to start the up-and-down brushing movement to help get started. It may be easier to stand behind the person while doing this.
- The bathroom is not the only choice for brushing teeth. A basin on a table or the kitchen sink might work better. It also doesn't have to be the last thing at night before bed or the first thing in the morning. Find a time when both you and the person for whom you are caring are calm and have time to devote to the task.
- A toothbrush with a large handle can be easier to hold onto and maneuver. Put the handle through a tennis ball to give the person something larger to grasp. Another option is an electric toothbrush, which may prove easier to use.
- Although fluoride toothpaste is the best, if the person is likely to swallow the fluoride toothpaste, rather than spit it out, try brushing just with water or baking soda toothpaste.
- Never force someone to open their mouth, and do not pry their lips apart. Take a break and try later if there is a problem or resistance. If the toothbrush is too invasive or if the bristles are too rough on your loved one's delicate gums, try using a Q-tip or gauze wrapped around your finger. If dental care at home is proving to be very difficult or extremely unpleasant for you both, make an appointment to see a dentist every two months for regular dental care.
- It might be easier, if you are doing the brushing, to sit the person on a chair and to brush their teeth from behind. Flossing is also easier from this position.
- Flossing may be more important than brushing. Use a floss holder, Flexi-Picks, or Stim-u-dent, or use a tiny brush that can fit between teeth to clean the gums as well as the teeth.
- Anti-plaque mouthwash can be helpful in preventing gum disease—but ONLY if it won't be swallowed. This can be a substitute for brushing, if necessary. Some mouthwashes can also help with dry mouth, as can artificial saliva products. Talk with your dentist about alternatives if swallowing mouthwash is an issue.

- Dentures need to be taken out daily, brushed, and rinsed. While they are out, try to brush the person's gums and the roof of their mouth with a soft bristled toothbrush. Gum shrinkage can cause dentures to fit improperly, leading to pain, trouble eating, and infection. Have them checked regularly by your dentist.
- Possible signs of dental problems include someone rubbing or touching their cheek or jaw, moaning or shouting out, head rolling or nodding, and flinching, especially when washing their face or being shaved. Restlessness, poor sleep, increased irritation or aggression, and refusal or reluctance to put in dentures when previously there was not a problem are other signs of dental issues.
- Find a dentist who understands dementia who will work with you and your loved one.
- Apples can help clean teeth while being chewed. Avoid hard candy, and be sure to drink plenty of water.

Source: Family Caregiver Alliance, Dental Care (for Dementia), www.caregiver.org.

CarePRO: Care Partners Reaching Out



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- ◆ Do you provide an average of 4 hours of care or supervision per day for that individual?
- ◆ Do you find caring for your loved one increasingly demanding of your time and energy?

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- About dementia and its impact
- How to manage your frustration, irritation, and stress
- How to communicate with your loved one
- How to take better care of your own health

**For more information, please call:
Alzheimer's Association
520-322-6601
1-800-272-3900 (outside of Pima County)**