



Home Care for the Dementia/Alzheimer's Patient

What is Dementia?

Dementia is the decline in intellectual or cognitive functioning because of brain disease or damage beyond what is expected from normal aging. It is not an actual disease itself, but rather, **refers to a group of symptoms and behaviors** caused by permanent damage or death of the brain's nerve cells.

The loss of intellectual abilities such as thinking, remembering, and reasoning are the symptoms often associated with dementia.

However, there are many other signs that *may* point toward dementia. These include: confusion, altered speech, changes in sleep cycles, behavioral problems (e.g., restlessness, wandering, aggression), depression, poor personal hygiene, suspiciousness, emotional outbursts, as well as poor judgment and mood or personality changes.

Not all dementia is the same. It is important to obtain a proper diagnosis or cause of the dementia because treatment and caregiving will vary somewhat based on this.

And no matter what the cause, it is a condition that can be devastating to individuals and their families when it's diagnosed, and often leaves the family wondering what to do next.

As with all healthcare issues, becoming educated about dementia is a smart and important first step.

Causes of Dementia

While **Alzheimer's disease accounts for 70% to 80% of all cases**, other disorders can also cause dementia including:

- Pick's disease
- Some forms of Parkinson's disease
- Huntington's disease
- Traumatic Brain Injury (e.g., from a fall, motor vehicle accident, multiple concussions, etc.)
- Some brain tumors
- Some forms of chemotherapy used to treat brain tumors
- Exposure to chemicals or environmental toxins
- Stroke
- Prolonged exposure to anesthesia

Currently, doctors can successfully diagnose the underlying cause of dementia symptoms in about 90% of cases by use of specific blood tests (to rule out other causes of dementia) as well as neuro-psychological, mental health evaluations, and in some cases, brain scans.

Note: An Alzheimer's diagnosis can only be confirmed with true accuracy through a post-mortem examination of the brain tissue.

Cognitive Deterioration Scale

The *Cognitive Deterioration Scale* is a diagnostic tool that geriatric doctors and psychologists use to evaluate and test individuals for degenerative dementia.

For example, an elderly individual may start with a diagnosis of normal-aged forgetfulness (stage 2) one year, but the next year they may progress to a diagnosis of mild cognitive impairment (stage 3). It's not Alzheimer's disease, but neither is it 'normal' aging.

Stage 1: Normal

Stage 2: Normal Aged Forgetfulness

Stage 3: Mild Cognitive Impairment

Stage 4: Mild AD

Stage 5: Moderate AD

Stage 6: Moderately Severe AD

Stage 7: Severe AD

Alzheimer's Disease

Alzheimer's disease is a form of dementia related to the ongoing deterioration of the brain. An individual's ability to function normally degenerates to the point of total incapacity and ultimately, death.

Alzheimer's usually starts in the area of the brain involved with learning.

As it progresses in the brain, the symptoms become increasingly worse—the individual is disoriented, their behavior changes, they grow more and more confused about time, place, people, and events, and they struggle to speak, swallow, and walk. Twenty-four hour care is often required.

The Demographics of Alzheimer's Disease

Currently, approximately 5 million Americans are affected by Alzheimer's disease.

It is the sixth leading cause of death in the United States and, in view of the average American's life expectancy, that number will very likely triple by the year 2050.

Worldwide, more than 35 million people suffer from some form of dementia and it is projected that this number will double every 20 years.

Approximately 90% of all Alzheimer's cases occur in people 65 and older. This is known as **late onset** and it is most often diagnosed in 50% of individuals age 85 and older.

The other type of Alzheimer's disease is known as **early onset** because it is diagnosed in roughly 5% to 10% of individuals (those with a genetic predisposition) at a much younger age—in their 30s, 40s, and 50s.

Stages of Alzheimer's Disease

Alzheimer's disease has three stages and while some individuals can and do live longer, a typical life expectancy after diagnosis is 8 years. The three stages are as follows:

- **Early-stage (Mild)** – At this point in the disease process the individual can continue to function independently. Memory loss, especially difficulty remembering newly-learned information, is the most common early sign of Alzheimer's.
- **Mid-stage (Moderate)** – In this stage, the individual shows more physical and mental decline. Personality changes continue to evolve, activities of daily living become more challenging and physical health deteriorates, requiring increased dependency on caregivers.
- **Late-stage (Severe)** – The individual's physical and mental health has declined to such a point that they are totally dependent on others for all their needs.

Of course, there are variations in each of these stages, specific to each individual.

**Common Signs, Symptoms and Behaviors
Associated with Alzheimer's Disease**

Memory loss that disrupts daily life	Forgetting names of close friends and family
Poor judgment	Wearing the wrong clothing for the season, e.g., wearing summer clothes in the winter or putting street clothes on over nightclothes; giving large amounts of money to telemarketers
Difficulty with or unable to complete everyday tasks	Cannot plan or prepare meals; difficulty writing the correct date or correct amount on a check
Language problems	Forgets words for everyday objects like dog, cup, car, purse
Confusion with time and place	Getting lost in the grocery store or taking hours to shop or perform basic tasks
Changes in mood or personality	May be anxious, suspicious, confused or easily upset
Problems with understanding visual images or spatial relationships	Difficulty reading, judging distances or colors
Withdrawal from social activities or work	No longer participates in hobbies, sports or social events with friends and family

Current Research

To date, the FDA has approved five drugs to treat the symptoms of Alzheimer's disease. These drugs may temporarily help improve memory and other cognitive functions, but only in approximately 50% of the people who use them—and, they cannot treat or cure what actually causes Alzheimer's disease.

However, substantial progress has been made in learning what goes wrong in the brain when an individual develops Alzheimer's disease. Areas targeted for future drug development based on current research findings include the following:

- **Beta-amyloid**—this is a protein that makes up the disabling *plaque* in the brain of an individual with Alzheimer's disease. New medicines are being developed that will block this protein from forming, prevent it from forming into plaque, or that use antibodies to clear beta-amyloid from the brain.
- **Tau protein**—this is the main source of *tangles*, an abnormality formed in the brain of an individual with Alzheimer's disease. Research is currently focused on developing a medicine to prevent tau protein molecules from forming into tangles.
- **Inflammation**—this is a brain abnormality that occurs with Alzheimer's disease. Researchers are working to understand the role it plays in causing abnormalities in the brain, with a goal of developing anti-inflammatory medicines just for the brain.
- **Insulin resistance and how brain cells process insulin**—this may have a direct relationship to Alzheimer's disease. Scientists are currently evaluating the role insulin plays in healthy brain function. This may lead to new medicines that support cell function and prevent the changes in the brain caused by Alzheimer's disease.

Use of Brain Imaging and Biomarkers

While researchers work to develop drugs to treat Alzheimer's disease, there are several ongoing clinical trials that use brain imaging studies and involve the clinical testing of spinal fluid and blood.

The hope is that this technology will provide clues to new ways to diagnose and treat Alzheimer's disease at the earliest possible (and therefore most treatable) time—before any symptoms appear.

Identification of biomarkers is also being researched as a way to track an individual's response to treatment.

Gaining new Knowledge from Families with Genetic Indications for Alzheimer's Disease

This research and testing specifically involves those individuals with familial (genetic) predisposition that strongly indicates they will develop Alzheimer's disease.

Researchers are currently testing drugs that could be given *before* any symptoms of the disease appear. These drugs focus on stopping the production of beta-amyloid protein in the brain.

When is Home Care a Viable Option for those with Dementia?

Because there are multiple causes and types of dementia, there are also multiple types of treatment regimens and caregiving approaches.

For example, individuals who suffer from only mild cognitive impairment may need only a few hours of caregiving a week to help with specific activities of daily living, such as assistance when going to the doctor or dentist, performing chores around the house that must be done on a certain day, etc.

For others, such as those with dementia due to a traumatic brain injury, more complex care may be needed to assist with home-based rehabilitation activities, vocational (re)training, or similar activities as part of a formal rehabilitation/care plan.

And for those individuals with Alzheimer's disease, many can remain at home while their disease is in the early and middle stages, with continuous assistance with the activities of daily living from family caregivers, home care agencies, and other community-based resources. However, at some point in the disease process they may need advanced, full-time care in a setting outside their home.

Depending on the type and cause of the dementia, sometimes a residential nursing facility is the answer. A candid discussion with the family doctor once the diagnosis has been made is a good place to start formulating a care plan.

This may also be the time to be certain that financial and legal arrangements are in place to protect the individual and his/her family.

For example, who will make healthcare and/or financial decisions when or if the individual is no longer able to do so? How will their care needs be met? Are the individual's wishes for care written down somewhere for family and caregivers?

Speaking to a lawyer about power of attorney and health care proxy designations for healthcare and personal finances is important at this time.

Family Caregivers and Burnout

Currently, **some 11 million family members care for dementia-afflicted relatives** at home.

For the family caregiver, it can be a particularly stressful, demanding care regimen. This type of caregiving puts him/her at risk for *caregiver burnout*, a condition of near-complete physical and emotional exhaustion, brought on by the cumulative stress of providing ongoing care for an extended length of time.

However, there are resources that family caregivers can use to help make caregiving responsibilities less burdensome and overwhelming:

1. **Use a qualified home care agency to provide care.** Services include assistance with bathing, dressing, preparing meals, eating, housecleaning, laundry, etc.

Additionally, medication management, medical equipment, physical therapy, companionship, and skilled nursing services may be available to care for the individual and support the family caregiver.

The home care team will ensure the individual in their care has a comprehensive service plan/plan of care that meets their clinical, social, and safety needs.

2. Determine if an **adult day care center** in the individual's community is an option. Depending on the type of dementia or disease stage, these centers can serve as safe venues for social activities and a change of scenery for individuals with dementia or Alzheimer's disease.

3. Arrange **respite care**. In addition to professional care provided by a home care agency, other family members and friends could visit with or care for the individual as respite time for the family caregiver. Some community organizations also may offer respite services. The family doctor, a geriatric care manager or the local Area Agency on Aging should be able to identify resources that can provide this support.

Practical Tips for Care of an Individual with Dementia/Alzheimer's at Home

Learning that a loved one has a diagnosis of dementia or Alzheimer's disease can be a shock—even if there were behavioral indications.

We know family caregivers assume a sizeable responsibility for the loved one in their care, and we also know that can be very stressful.

Depending on the cause or type of dementia, in addition to using the services of a qualified home care agency, arranging visits to adult daycare, and using respite care, here are some practical tips that may help family caregivers:

- Create a daily routine and stick to it. Routines and consistency help provide structure for the individual's activities of daily living.
- Try to keep the individual's home environment calm, quiet, and safe.
- Write a daily 'things to do' list (using simple language) for the individual to refer to every day.
- Instead of three big meals offer smaller, more frequent nutritious meals.

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- Assist the individual with their personal care in order to maintain good hygiene. But when helping them bathe, let them do as much as possible on their own, reminding them of next steps in the process as needed. Using the same personal care products every time may help them remember their purpose.
- Be sure the individual gets enough rest and if necessary, monitor their sleep time.
- Be supportive of the individual's feelings, interests, and activities whenever possible. Encourage them to continue any pastimes, hobbies or exercise programs they enjoy and simplify them as needed.

Safety Precautions in the Home for an Individual with Dementia/Alzheimer's Disease

Safety is always paramount when caring for someone who is vulnerable. A professional home care agency will implement (and maintain) safety precautions as part of the service plan/plan of care.

However, depending on the type and severity of the dementia, there are things family members can do to protect and support the individual at home:

Inside of the Home

- Write down the home address and emergency phone numbers and keep this information near all phones
- Install smoke and carbon monoxide alarms near bedrooms; change the batteries once a year
- Place locks on all outside doors and windows, as well as the garage, shed, and basement doors
- Keep a spare house key in a secure and convenient place outside the home

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- Childproof all electrical outlets that are not used
- Install handrails on all stairways
- Remove throw rugs; use non-skid products on hardwood floors to prevent slips and falls

In the Kitchen

- Childproof all latches on kitchen cabinets
- If possible, install childproof knobs on the stove or remove them entirely
- Do not store any flammable materials in the kitchen
- Install a nightlight
- Do not display any artificial fruits, vegetables, flowers or similar items
- Make sure the kitchen sink has a drain trap

In the Bedroom

- Take the lock off the door
- Install a nightlight
- Consider using a baby monitor to listen for any unusual sounds or calls for help
- Avoid the use of space heaters, electric blankets or mattress pads

In the Bathroom

- Take the lock off the door
- In the tub/shower, install non-skid mats and grab bars; add a shower chair/stool and a handheld showerhead
- If needed, use an extended toilet seat and install grab bars next to the toilet
- Ensure there are drain traps in the sink(s)

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- Centralize and lock all medications in a cabinet; be sure all old/unused medication is disposed of properly
- Lock up any bathroom cleaning products
- Install a nightlight

In the Living Room

- Clear electrical cords from all walkways
- Remove throw rugs
- Place decals at eye level on glass doors, picture windows, and furniture with large glass panels
- Secure remote controls for the television, DVD player, and stereo system

In the Laundry Room

- Lock the laundry room, if possible, and secure all laundry products (soap, bleach, etc.).
- Childproof the controls/knobs/dials on the washer and dryer or remove them entirely
- Keep the doors to the washer and dryer closed and latched (if possible)

In the Basement

- Lock the basement door, if possible
- If there is a freezer in the basement, childproof it or install a lock on it
- Keep all tools and equipment in a locked cabinet

Outside of the Home

- Put bright reflecting tape on the edges of all steps into the home

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- If there is a swimming pool, fountain, or pond on the premises, prevent access to it without direct supervision
- Install automatic sensor lights at entrances to the house and garage
- Install locks on the garage/shed door and any other entrances (e.g., side door)
- Lock up any tools, machines, sports and yard equipment, toxic and flammable materials (paint, gasoline, fertilizer, etc.)
- Lock up the car(s) and the car keys; try to keep them out of sight of the individual

When is a Nursing Home or Residential Facility the Best Choice?

As mentioned earlier, the individual's status, based on the direct observations/concerns of family members as well as professional and family caregivers, and the family physician will all factor into the decision to move the individual out of their home and into a care facility.

Plan Ahead for Transitioning to a Care Facility

The best way to plan is by having a talk with the individual in advance about the type of living arrangements they would want if they need 24/7 supervision.

Sometimes it is hard to know when to discuss a possible move. Usually this depends on the individual's ability to understand what is being discussed.

Nevertheless, whether the individual is in the earliest or latest stage of the disease process, they need to know where they will be moved and why this is necessary.

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A family meeting can help clarify the issues and considerations that affect this decision, such as:

- Are the individual's clinical symptoms such that they require care virtually 24 hours a day to meet their needs? The physician will play a key a role in determining the individual's status or what stage of the disease process they are in (e.g., early, middle, late stage) and can recommend the best course of action.
- Is the family no longer able to provide the care the individual requires? Does the home care agency recommend moving the individual to a care facility?
- Are there financial/legal questions or concerns related to moving the individual out of their home and into a full-time care in a facility?

There may be many issues to address when discussing and planning such a move, and it will require the full cooperation, candor, and participation by the family, the individual (if possible), the caregivers, and the healthcare provider(s).

Continuing to Play a Role in the Caregiving Process

Even after a loved one moves to a care facility, the family caregiver still has a role in their life and an interest in the individual's health and well-being.

Make regular visits, talk with the staff, and participate in all meetings about their care.

This is the time to reminisce, to share happy memories and more good times with them as often as possible.

Additional Resources

Here is a list of resources to learn more about dementia and Alzheimer's disease. Your local community may also have organizations that provide information and support to individuals with dementia or Alzheimer's disease and their families.

- **Alzheimer's Association** (www.alz.org)
- **Alzheimer's Foundation** (www.alzfdn.org)
- **Aging Care** (www.agingcare.com)
- **Third Age** (www.thirdage.com)

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www.arcadiahomecare.com