

Alzheimer's Disease

Caregiver
SUPPORT NETWORK
HOME HEALTH & HOSPICE



GephardtApproved ✓

BEST OF STATE 2008-2011
HEALTHINSIGHT QUALITY AWARD 2006-2011

What is Alzheimer's Disease?

Dr. Alois Alzheimer first described this illness in 1906. It is a syndrome that affects the brain, causing progressive losses in:

- Memory
- Judgment and Thinking Skills
- Communication Abilities
- Physical Function

In Alzheimer's disease (AD), "plaques" and "tangles" form in the brain, interrupting nerve transmission and causing brain cells to die. Its cause and cure have not yet been identified, though intensive research is ongoing.

AD: The Most Common Form of Dementia

Dementia refers to any disorder in which mental functions deteriorate. Alzheimer's disease is the most common type of dementia, accounting for over 60% of all dementia cases. AD is an irreversible dementia.

Other dementias include:

- Vascular Dementia
- Fronto-Temporal Lobe Dementia
- Dementia related to Parkinson's Disease
- Lewy Body Dementia

Risk Factors

Over 5.5 million Americans are currently affected by Alzheimer's disease. It strikes without regard for gender, race, ethnicity, education or socioeconomic level. Age is the greatest risk factor. Chances that adults will develop AD are 1 in 10 over age 65; 1 in 4 over age 74; and 1 in 2 over age 85. Other suspected risk factors include high blood pressure, high cholesterol, diabetes, obesity and previous head injury. Some protective strategies are thought to include regular aerobic exercise averaging about 150 minutes weekly and following a heart-healthy Mediterranean-type diet.

Accurate Diagnosis is Crucial

A diagnosis of AD is made by a physician after in-depth interviews with the patient and the family and a thorough medical examination, which may include MRI, lab work, cognitive testing and depression screening. All other possible conditions with similar symptoms should be ruled out. The **University of Utah's Center for Alzheimer's Care, Imaging & Research** is a diagnostic center. It offers positron emission tomography (PET) imaging, a technique that enables definitive early diagnosis of Alzheimer's, as part of its comprehensive approach. A referral from the person's primary physician is needed to schedule an evaluation.

Resources

The mission of **Caregiver Support Network Home Health & Hospice (CSN)** is to support both patients and family caregivers with in-home care, education, advocacy and resource and referral information. This award-winning, full-service home health, hospice and private duty company is the only agency in Utah that specializes in dementia care.

CSN provides **Allen Cognitive Level Screening**. This validated testing uses non-threatening activities to identify the abilities and limitations of a person with cognitive impairment. It provides caregiver training as well as important guidelines for enhancing safety and function. This testing is performed by a trained clinician and is covered by Medicare.

CSN also provides **Caregiver Coaching**, an individual or family session with a geriatric professional to identify resources and answer specific senior care questions. Establishing a plan and facing challenges with accurate information can reduce the stress of caregiving. Consider scheduling a **Caregiver Coaching** session. It may be covered under a working caregiver's Employee Assistance Program benefit.

Call **Caregiver Support Network** for more information.

801-747-2100 Salt Lake Office

801-547-0060 Davis Office

435-915-3424 Cache Valley Office

The Utah Chapter of the Alzheimer's Association provides support, consultation, education and referral. The Alzheimer's Association sponsors support groups throughout Utah, a 3-day adult day center scholarship program and the Safe Return Program. Go to alz.org or call:

801-265-1944 or 800-272-3900

Local **Area Agencies on Aging** provide programs such as Meals on Wheels, Senior Companion, Family Caregiver Support Program, Senior Health Insurance Information Program, etc. Refer to the government section of the phone book.

Symptoms and Behaviors

SYMPTOMS

Alzheimer's disease is most simply classified in three stages by the severity of its symptoms: Early (mild dementia), Middle (moderate dementia) and Late (severe dementia). Though the length of each stage varies between individuals, most people with AD will exhibit all the major symptoms.

Early Stage

- Short Term Memory Loss
- Mild Confusion and Communication Difficulties
- Impaired Judgment and Loss of Insight
- Personality and Behavior Changes
- Depression
- Difficulty Completing Instrumental Activities of Daily Living like Managing Finances, Meal Preparation, etc.

Middle Stage

- Increased Memory Loss and Confusion
- Moderate Communication Problems
- Increased Confusion to Person, Place, Time and Circumstance
- Poor Judgment
- Difficulty in Completing Basic Activities of Daily Living like Dressing, Showering, Toileting, Eating, etc.
- Increased Behavior Disturbances Like Anxiety, Paranoia and Depression

Late Stage

- Extremely Limited Communication
- Total Dependence in All Activities of Daily Living
- Difficulty Walking
- Difficulty Swallowing



BEHAVIORS

AD presents differently in every person, just as every person is unique. The following behaviors are characteristic of AD, though they may or may not be seen in every individual with AD.

- Repetitive Questioning
- Repetitive Behaviors and Movements
- Obsessive/Compulsive Behaviors
- Anxiety/Irritation
- Disorientation/Time Confusion
- Problems with Hygiene
- Apathy/Loss of Initiative
- Emotional Fluctuations
- Wandering
- Sundowning (Increased Agitation/Confusion in the Late Afternoon/Early Evening)
- Paranoia
- Egocentricity
- Delusions and Hallucinations
- Socially Inappropriate Behaviors
- Aggressive Behaviors

Ten Warning Signs of Alzheimer's Disease

From the National Alzheimer's Association

1. Memory Loss that Disrupts Daily Life
2. Challenges in Planning or Solving Problems
3. Difficulty in Completing Familiar Tasks at Home, at Work or at Leisure
4. Confusion with Time or Place
5. Trouble Understanding Visual Images and Spatial Relationships
6. New Problems with Words in Speaking or Writing
7. Misplacing Things and Losing the Ability to Retrace Steps
8. Decreased or Poor Judgment
9. Withdrawal from Work or Social Activities
10. Changes in Mood and Personality

How does Alzheimer's Disease progress?

AD generally does not run an entirely predictable course. It can progress quickly for a time and then remain stable for a period before additional deterioration occurs. Mental abilities can wax and wane depending on a number of factors. This can be very frustrating for the person and family who have no way of knowing what to expect and when.

However, when abrupt changes are observed, such as significantly increased confusion or agitation, an acute infection like a urinary tract infection should be suspected and ruled out as the cause of the change.

A Comprehensive Approach to Treatment

Alzheimer's disease is best managed with a comprehensive approach that includes the following four components:

- 1) Medications that address the disease process.
- 2) Medications that address its symptoms and behaviors.
- 3) Non-medical support like using appropriate communication techniques and providing meaningful activity and environmental structure.
- 4) Management of any other medical and chronic conditions including vision and hearing loss.

Just like other serious illnesses, early detection and intervention are essential to maximizing treatment options, decision-making, safety and quality of life. Long-term planning and medical, financial and legal decisions should be made while the person can fully participate. Utah has comprehensive Advance Directive forms that should be completed by all adults, but especially those with life-limiting illness. An identification registration program, like Alzheimer's Association's Safe Return, should be enrolled in early because disorientation can begin at any time during the disease.

Alzheimer's Medications

Several prescription medications may help slow the progression of AD. They work by keeping brain cells functioning longer.

Cholinesterase Inhibitors

- Aricept (donepezil HCl)
- Exelon (rivastigmine tartrate)
 - Available in Liquid and Patch Form
- Razadyne (galantamine hydrobromide)

These medications increase the level of the neurotransmitter acetylcholine in the brain to allow improved communication between cells. Their effectiveness for the individual should be evaluated in the first 12 to 16 weeks of treatment.

Research gives these drugs a two- to three-year window of effectiveness. The most common side effects are nausea and intestinal distress which may be helped by taking these medications with a meal or snack containing a fatty food like peanut butter to slow their absorption rate.

Glutamate Inhibitor

- Namenda (memantine HCl)

This medication works on a different aspect of cell function and is usually taken with one of the cholinesterase inhibitors listed above. The goal again is to keep brain cells functioning longer. This medication is usually well tolerated by patients with minimal side effects.

Symptoms and Behaviors

Other prescription medications are used to help alleviate the symptoms and behaviors commonly associated with AD. Since no one size fits all regarding medication, finding the best treatment may take experimentation, monitoring and patience. Some of the medications present serious risks. Discuss these options with your physician.

For Anxiety, Paranoia and Sundowning:

- Lorazepam (Ativan)
- Paroxetine (Paxil)
- Remeron
- Respiradol
- Seroquel

For Mood Stabilization:

- Depakote
- Neurontin

For Depressive Features and Repetitive Behaviors:

- SSRI Anti-Depressants (Prozac, Zoloft, etc.)
- Remeron

Goals of Treatment for Alzheimer's Disease

- Make Life as Manageable as Possible for Individuals, Families and Caregivers
- Reduce Caregiver Stress
- Create an "Enjoyable Now" Atmosphere and Attitude
- Build on Skills that are Present
- Preserve Dignity and Enhance Comfort
- Keep Relationships Healthy and Intact

Non-Medical Support

Using effective communication techniques and providing meaningful activity and appropriate environmental structure are equally important to quality of life as are medications. More information on these techniques can readily be found on the Internet and through the Alzheimer's Association.

Communication Techniques

- Validation
- Reassurance
- Reminiscence
- Reorientation
- Redirection/Distracton
- Do Not Argue or Correct

Meaningful Activity

- Social Interaction
- Purposeful Activity
- Aerobic Activity
- Recreation

Environmental Structure

- Flexibility
- A Familiar Routine
- Smooth Transitions
- Bright Lighting
- Secured Walking Areas
- Comforting Colors and Familiar Objects
- Relaxing and/or Familiar Music
- Adequate Nutrition and Hydration
- Protection from Potential Hazards, Loud Noises, Interruptions, Crowds and Over-stimulation

Late Stage

Treatment decisions in the Late Stage of the disease should be focused on quality of life and comfort. These goals are compatible with palliative care. Ask for education and support from the medical professionals involved in your loved one's care. Hospice is an excellent resource for all comfort care questions.

Questions may arise about whether to continue the medications that target the disease process, like Aricept and Namenda. After a long course, it may be difficult to detect the ongoing benefits of these medications. A geriatric specialist gives the following guidelines to discuss with the person's physician:

- If the medication made a noticeable difference when it was first started, consider continuing it until the later stages of the disease.
- If the person is functioning reasonably well AND exhibits a generally stable and positive mood, consider continuing the medication.
- If any of the above are NOT true, consider discontinuing the medication. Remember, the focus is quality of life.

In the end stage of AD, the person may lose the ability to recognize hunger and thirst, and eventually to chew and swallow. Weight loss and dehydration naturally occur. With the decreased nutrition and mobility of the end stage, the chance of the person developing an infection, such as pneumonia, increases. The question about continuing to treat other chronic diseases like diabetes and high blood pressure may arise. The person's end-of-life care wishes should be spelled out early in their Advance Directives. Hospice services can be invaluable during this stage of the disease. Call **Caregiver Support Network Home Health & Hospice** to discuss the full range of care options available.

Caregiving

*"There are only four kinds of people in this world...
those who have been caregivers,
those who are currently caregivers,
those who will be caregivers and
those who will need caregivers."*

Rosalyn Carter (1993)

Former First Lady Rosalyn Carter aptly describes the universal nature of caregiving. It is integral to the life cycle. Caring for a person with dementia can be extremely challenging, though it can offer many rewards as well.

Research shows this type of caregiving to be most stressful for families. The trials of dealing with new symptoms and behaviors may be combined with the grief caused by witnessing ongoing losses. The behaviors caused by AD may cause caregivers to feel that the person is acting out to spite or hurt them. It is essential to remember that the person has no control over their words and actions. Even with this understanding, these behaviors can still be very difficult to contend with.

Common symptoms of caregiver stress include sleep disruption, exhaustion, irritability, depression and social withdrawal. Unmanaged caregiver stress has been shown to put family members at risk for stress-related illness and even premature death. In fact, research shows that in situations where one spouse is caring for another with AD, the care provider's risk of death increases by 66%. So don't wait — get help before a crisis arises.

Caring for someone with dementia "takes a village." Respite, time out for the caregiver to rest and rejuvenate, is crucial to maintaining both the care of the person and the health of the caregiver in the long term. Attending a support group and learning about the disease, its treatment options and resources in the community have all been shown to reduce caregiver stress. Call **Caregiver Support Network Home Health and Hospice** today for more information. We can help!

*Serving Salt Lake, Davis,
Weber, Morgan, Box Elder and
Cache Counties*

Salt Lake
310 East 4500 South
Suite 200
Murray, Utah 84107
(801) 747-2100
(888) 968-4600 Toll Free
(801) 747-2104 Fax

Davis
275 North 300 West
Suite 401
Kaysville, Utah 84037
(801) 547-0060
(866) 547-0060 Toll Free
(801) 547-0301 Fax

Cache Valley
1047 South 100 West
Suite 170
Logan, Utah 84321
(435) 915-3424
(877) 358-3643 Toll Free
(435) 915-3430 Fax



GephardtApproved

BEST OF STATE 2008-2011

HEALTHINSIGHT QUALITY AWARD 2006-2011

Caregiver
SUPPORT NETWORK
HOME HEALTH & HOSPICE