

Dementia: The Disease, New Hope For Treatment And Caring For A Loved One With AD by Diane Walker, R.N., M.S.

Dementia is general category of brain disorders that can affect a person's ability to think, speak, reason, remember and move (1). The diagnosis and its manifestations have a profound impact on millions of adults and their family members. This article presents a general overview of the diagnosis, current treatment options, caregiving strategies for individuals with Alzheimer's disease and available resources.

Overview - More than four and a half million older Americans are diagnosed with some stage of dementia. Although much of the literature has focused on Alzheimer's disease, which accounts for approximately 50% of dementia diagnoses, there are other causes, some of which are more treatable than Alzheimer's disease.

Dementia usually develops in adults sixty-five (65) years or older, affecting about 10% of older adults. The number of individuals affected increases to about 50% of adults 85 years of age or older. The number of people affected by dementia is rising as the general population ages, and estimates are the number of people affected will quadruple by 2050. (1,2). Chronic, untreatable forms of dementia progress through a series of stages characteristically described as mild to severe with increasing loss of function. The progression may take from three to twenty years depending on the form of the illness.

Dementia can have devastating financial ramifications, not only for the affected person, but also for the nineteen million family members customarily providing most of the care, and for the society that loses the formerly contributing members now caring for or suffering with the diagnosis. Alzheimer's Disease alone costs the US approximately \$100 billion per year for care and treatment and costs businesses \$33 billion a year in lost worker productivity and benefit expenses. (2) It is estimated that the lifetime cost per person with Alzheimer's disease is \$174,000.

Causes & Potential Risk Factors - The cause(s) of dementia are not well known yet and the rate of progression varies with the type of disease the individual manifests. We do know that a healthy brain has about 100 billion nerve cells that generate electrical signals. These signals are relayed from nerve cell to nerve cell. Chemicals called neurotransmitters help the signals move easily between the nerve cells. The transmission of electric impulses results in our ability to think, remember and feel. (3) Persons with dementia develop an inability to transmit electrical signals between nerve cells over time and the number of functioning nerve cells progressively diminishes.

The three most common types of dementia are Alzheimer's disease (AD), Lewy body dementia and vascular dementia. AD accounts for approximately 60% of dementia diagnoses. In AD the nerve cells in certain locations of the brain actually begin to die over time. The amount of neurotransmitters produced by fewer nerve cells is subsequently diminished and progressive symptoms of brain malfunction develop. The brain tissue of adults with AD contains abnormal clumps and irregular knots of cells called plaques and tangles. It is believed that deposits of plaque form between the nerve cells and cause them to die. Research is being conducted to determine if genetic mutations of certain proteins in the brain cause the development of these plaques and tangles. Profound inflammation has also been found in the brain tissue of some individuals with AD, but the role this plays in the disease is unknown. (1)

Lewy body dementia is characterized by microscopic protein deposits found in deteriorating nerve cells. These deposits are also associated with the tremor and rigidity seen in Parkinson's disease. If the deposits are widespread in the brain, the individual begins to manifest the signs and symptoms of AD over time. The deposits can also cause hallucinations and significant fluctuations in alertness. (1)

Vascular dementia results from either extensive narrowing of the arteries that supply blood to the brain due to plaque buildup, or from multiple small blockages of blood to areas of the brain caused by clots which are called "mini-strokes". In this form of dementia, the appearance of symptoms can be either very abrupt or mimic the slow progression found in AD. (1)

Dementia can also result from head trauma, endocrine disorders, long-term effects of alcohol, infectious diseases, nutritional deficiencies, immunologic disorders and other degenerative diseases. The risk factors for AD, in particular, may include age, heredity, environmental exposure, level of mental activity, head injury, certain hormone replacement therapies, high blood pressure and high cholesterol.

Women are more at risk for developing the disease because they live longer than men. There is a slightly higher risk of developing AD if a parent, sister or brother has the disease. Researchers are currently investigating the environment as a contributing factor in AD, but significant environmental links have not yet been identified. Some studies suggest that higher education and remaining mentally active throughout life, especially later in life, may reduce the risk of developing AD. Women using a combination of estrogen and progesterone replacement therapies appear to double their risk of developing AD. (3)

Certain disorders, like delirium and depression, may mimic the symptoms of dementia but are treatable. (1) Depression also sometimes accompanies the early stages of dementia when the individual realizes the severity and prognosis of the condition. Delirium, unlike dementia, results in a severe but short-term state of confusion and can be associated with dehydration, fevers and drug reactions.

Screening and Diagnosis - One of the foremost impediments to getting early treatment for Alzheimer's disease is the assumption that forgetfulness is a normal part of the aging process. Spouses, children and friends who observe the following early warning signs of AD in a loved one need to encourage the person to be screened and evaluated by a clinician (adapted from the Alzheimer's Association): recent memory loss that affects job skills; difficulty performing familiar tasks (cooking, laundry, changing bed linens); problems with language (forgets common phrases or simple words in conversation); disorientation to time and place (forgets the way home); poor or decreased judgment; problems with abstract thinking (how to balance a checkbook); misplacing things; changes in mood or behavior (rapid mood swings); changes in personality (suspicious or fearful), and loss of initiative.

The signs and symptoms of the progression of dementia have been grouped into three generally accepted stages (4). **Mild:** memory loss, language problems, mood swings, diminished judgment and personality changes. **Moderate:** behavioral and personality changes, noticeably diminished capability in demanding situations, long-term memory affected, wandering, agitation, aggression, confusion and progressive loss of functional ability to complete Activities of Daily Living (ADLs). **Severe:** gait and motor disturbances, incontinence, and inability to perform ADLs.

Several studies to rule out other diseases and conditions that can cause these symptoms include: a thorough medical history, basic medical tests, a mental status examination, neuropsychologic testing, and brain scans. These tests help rule out other organic illnesses that can cause or contribute to the symptoms being exhibited.

Treatment – Although there isn't a cure for AD at this time, considerable progress has been made in the area of treatment. A number of medications designed to slow the progression of the disease in the mild and moderate stages have been approved for use and are currently available. These drugs are called cholinesterase inhibitors. These drugs include Aricept, Exelon and Reminyl. These drugs help to maintain the activity of the neurons important for memory formation by blocking an enzyme that breaks down the neurotransmitter acetylcholine. Recently a drug (Memantine) that is not a cholinesterase inhibitor has been found to slow deterioration in Alzheimer's disease. Memantine modifies the activity of one of the major neurotransmitters (glutamate) in the cerebral cortex. It protects the neurons against the toxic effects of excess glutamate—which can destroy nerve cells—without preventing the transmitter from performing normal functions. In controlled studies, Memantine has delayed the need for nursing home placements in people with moderate to severe Alzheimer's disease. Research into the causes of the disease and developing a cure are in progress at centers all over the world. The most controversial research involves the use of stem cells.

It is well documented that people who care for those with early Alzheimer's disease wait an average of three years to seek help after noticing symptoms. Seeking medical help early is important because more than ever, early detection and diagnosis are becoming increasingly accurate. Knowing something about Alzheimer's disease can help families arrange their affairs, plan for long-term care, provide advanced directives for the later stages of the illness, and decide whether to take one of the drugs that may slow the progress of the disease.

Caring for a Person With AD - Caring for a person with AD can be deeply challenging and at the same time, deeply rewarding. Perhaps the first important responsibility for any Caregiver is to consider the implications of long-term caregiving. Caregivers need to ensure family and community resources are in

place to support their primary caregiving activities and provide respite periodically. In addition, planning for the financial costs associated with caregiving and potential nursing home placement should be done early in the course of the disease. It's possible that the care-recipient can help with the planning if it is done early at the time of diagnosis.

Caregiving for a person with AD is a fulltime job. Some of the challenges Caregivers encounter include: safety, personal care and dressing, eating, restlessness, communication breakdown, agitation and aggression, insomnia, boredom and inactivity, hallucinations and delusions, incontinence and wandering. Additional helpful information can be obtained from other AD Caregivers in support groups sponsored by the Alzheimer's Association, on-line chat rooms, and special events targeted to meet the needs of the AD community.

In general, the type of environment and its milieu has a significant impact on the functional ability of person with dementia. The environment must be safe, structured, familiar and repetitive (ritualistic), warm, unrushed, and quiet. These qualities are even more important as the disease progresses and the world becomes less familiar and more frightening.

To provide safety in the home, the Caregiver may want to imagine they live with a small child. Many of the same protections apply: cupboards with cleaning fluids, poisons, drugs, alcohol, razors, knives and guns, need to be locked; access to hair dryers and stoves must be supervised; and jewelry and other valuables including cash needs to be kept in a safe place. There is a brochure on falls prevention in the resource section of *GRISWOLDS SPECIAL CARE*'s website that has useful information about how to prevent a fall. If the care recipient wanders, the doors and windows may need to be locked or alarmed, especially at night so the Caregiver can sleep. Furniture should also be kept in the same place so the environment is familiar. (3,6,7)

Several issues with food and nutrition can develop over time. In the early stages of AD, the person may need to be reminded to eat or to eat what they just prepared. If the person still enjoys cooking, select parts of the meal for them to prepare with you that they can complete safely like washing the vegetables. This is an important time to create a quiet, calm atmosphere because distractions and noise can interfere with the care recipient's appetite and willingness to eat. If they have trouble remembering how to eat, you can offer cups with lids, straws, and a bowl and spoon rather than a plate, knife and fork. At this stage, watch chewing and swallowing carefully to avoid aspiration. You may want to consider substituting finger foods when the use of utensils causes frustration or their purpose is forgotten. For example, you may want to prepare cheese cubes; rolled slices, meatballs, or cubes of meat; fruit sections; precooked vegetables such as broccoli, carrots, and string beans; boiled fingerling potatoes, french fries; fish sticks; chicken "nuggets" and drumsticks; small sandwiches; wontons; dumplings; rolls or crackers; hard boiled eggs; pizza; cookies; melon balls; ice cream cones and creamsicles. Many liquids like milk, fruit drinks and soups can be frozen into ice cubes on a stick. Offer only one or two choices at time to lessen confusion. It may be appropriate to offer several small meals a day particular if eating is an enjoyable, fun activity. Consider using it as a distraction when one is needed. The goal is to ensure the care recipient receives enough nutrition and liquids through out the day. (4,5)

Boredom and inactivity may be signs of depression in the early stages of the disease. Persons with dementia should be encouraged to continue doing what they love to do with their leisure time. Also consult with the care recipient's physician to get clearance for care recipient to do physical activity and exercise. Participation in community groups, volunteer agencies and civic associations, and adult day care can help the person feel a sense of worth and dignity in the early stages of the illness. Boredom and inactivity can also lead to insomnia. A balance of rest and activity throughout the day is important and encourages sleep at night. If the care recipient is getting enough rest, consult with his/her physician about side effects to medications. It is also beneficial to establish a "strict" nighttime ritual for ending the day. Make sure the bedroom is far enough away from the household activities so that it is quiet and peaceful. (4,6)

In the mild to moderate stages of AD, the care recipient should be encouraged to participate in their activities of daily living as much as possible. The steps should be broken down into small tasks, taken one at a time and completed more slowly. If a bath or a shower is comfortable, encourage the

person to bathe with supervision. In the later stages of the disease, bathing can cause a great deal of anxiety for some individuals. Older adults do not need to bathe every day so sponge baths a few times a week may be adequate for personal hygiene if the person becomes afraid of water and bathing. There are also “water-less” bathing/skin care products on the OTC market now that may provoke less anxiety for some individuals. In addition to bathing, the Caregiver will also need to remind the person to brush their teeth often and perform nail care regularly. (4,6)

Offer the care recipient limited choices in clothing to wear and encourage him/her to do as much as possible when dressing. Again, perform the tasks slowly, in small steps. You may want to have only one season of clothes to pick from in the closet. Introduce clothing items with Velcro early in the progression of the disease. They are easier to open and close and cause less frustration than buttons, zippers and laces. Some individuals may want to wear the same clothes every day so try buying a few of the same items so they can be exchanged and washed without notice. In the later stages of the disease, leisure outfits and sweats may be more suitable to wear. (5)

Restlessness, agitation and aggressive behaviors are difficult for most Caregivers to handle at first. The Caregiver’s reaction to these behaviors is very important to avoid escalating them. The behaviors can be signs of side effects to medications or illness and should be discussed with a physician. Sometimes the care recipient is restless because they have an unmet need such as an urge to go to the bathroom, or they feel cold, hungry or scared. Slowly ask the caregiver about each need, one at a time and allow time for an answer. Sudden changes in the environment like noise, sources of frustration or anything unfamiliar may cause the care recipient to be agitated or afraid. The Caregiver should make a note of the trigger to plan to avoid it in the future. Acknowledge the care recipient’s feelings and attempt to interrupt the behavior by eliminating the irritant, use a soothing distraction to change the care recipient’s focus, or begin a familiar activity. It’s very important to remain calm and not to argue with the care recipient at these times. If you can, try leaving the room to let the person calm down. If you are concerned for your safety, make sure s/he is safe from self-harm and go to a near-by location where you can call for help and still keep an eye on the person.

Wandering is another behavior many individuals with AD exhibit that can cause the Caregiver a great deal of concern. Approximately 60% of individuals with AD will wander at some point. Initially there are two principle concerns: safety and identification. Many people simply want to walk or pace. They may be looking for something, think they are going somewhere or are just pacing. Providing a safe, enclosed area where they can walk will greatly diminish concern about this behavior. A fenced in, landscaped backyard is a wonderful environment for the care recipient to walk around, providing many soothing sights and sounds. It’s important that the door to the house is clearly visible and has a direct path leading to it.

Sometimes individuals simply leave the house unaccompanied and unnoticed. They can also be going on an errand or to church and forget the way home. Identification is necessary to protect the person from disappearing. The National Alzheimer’s Association has created the national *Safe Return for Wanderers™* that has been almost 100% successful in returning thousands of people with AD to their loved ones. The individual is given a bracelet to wear with their personal identification data encoded for use by the police. Family members should contact the local chapter for more information about enrolling in this lifesaving program. Caregivers can also give their loved one a card to be carried in their wallet or purse that states they are memory impaired and includes a home phone number. It is also advisable to notify the police a family member has AD and to provide pictures of them to help with identification if the person leaves home alone. In selected cases it may be necessary to lock the doors at night or to alarm an area of the house to notify you that the care recipient is attempting to leave the area. Sometimes you can reduce wandering by simply leaving the hall to the bathroom well lighted and by providing some periods of vigorous exercise during the day. If the care recipient becomes restless at night, you may want to establish a relaxing “return to bed” ritual that includes a glass of milk and soothing music. (4,5,6)

Sundowning is a name for restlessness that regularly occurs late in the day, particularly after dark. It can be caused by inadequate rest throughout the day resulting in fatigue or fear of being left alone. Complex, taxing activities are better scheduled earlier in the day for most individuals. Try initiating a

comfortable, soothing activity at sunset like dinner, quiet music, or an activity that the person enjoys. Make certain the area is well-lighted. Invite the person to spend time doing an enjoyable routine task. Regardless of the cause of the agitation, identifying the triggers of agitation and aggression is the best strategy to avoid these episodes. (4,5)

Individuals may experience hallucinations and delusions in the later stages of the disease. Hallucinations are an unreal sight, smell, taste, or feeling. A delusion is a fixed false belief that the individual is unwilling to change or relinquish. (4,5,6) Again, these may symptoms of illness and should be discussed with a physician. While hallucinations are not grounded in fact, a delusion may be and should be verified to be false. Remember that the thoughts and visions are very real to the person and that arguing with them will generally escalate the behavior into agitation and may precipitate an episode of aggression. Reassurance can be helpful. Acknowledge what the person sees and thinks, clarify that you don't see or hear it but will care for the person. Sometimes the delusion is about people who have died or have abandoned the individual. Reinforcing reality, saying things like, "they haven't been to visit you in 20 years," or "they couldn't steal from you if they are dead!" won't help the individual either. You can acknowledge the content of the hallucination or delusion and switch the subject using a distraction. For example, "Margaret is a wonderful person. Let's look at some pictures of her over here." Or, "Let's turn the lights on so we can see each other. You are so special to me." Sometimes mirrors can trigger delusions and agitation because the person thinks they are seeing a stranger. Covering or removing the mirror may eliminate the trigger for the care recipient.

Incontinence is the leading cause of institutionalization/nursing home placement in the United States and it's a very common experience as the disease progresses. Incontinence is also very upsetting to the care recipient and a calm, understanding response can help wounded pride and self-esteem. Because it can also be a sign of illness, it should be discussed with a physician. Initially the best strategy is to prevent the occurrence of incontinence by regular toileting. Routine toileting every three hours can prevent many accidents from happening. The avoidance of caffeine and excessive liquids late in the day can also prevent incontinence during the night. As the disease progresses, the use of adult briefs, commodes and washable bed pads should be encouraged. Always leave the bathroom door open and the area dimly lit at night. If trips out of the house are planned, know where the nearest bathrooms are and take along a change of clothes in the event of an accident. It can be helpful to log incidents to determine if patterns or triggers exist. Incontinence is also very damaging to the skin. Extra personal care and the use of protective lotions are necessary. If frequent incidents of incontinence at night are exhausting to the Caregiver, consider the use of home care workers to allow for normal sleep and relaxation. Obtaining help can extend the time the care recipient lives at home. (4,5,6)

Resources – Family caregivers who intend to care for their loved one at home for as long as possible need a great deal of support if they want to avoid personal burnout, depression, medical illness and the premature institutionalization of their care recipient. Here is list of available resources that can be contacted directly by family and professional caregivers for assistance or for referral to the appropriate local network of services:

- ❑ National Alzheimer's Association – 800-272-3900; www.alz.org to reach the Alzheimer's Disease Education and Referral Center and the 24 Hr. Help line at 800-272-3900
- ❑ Safe Return Program – 888-572-8566
- ❑ National Family Caregivers Association – 301-942-6430 and www.nfcares.org
- ❑ National Institute on Aging Information Center- 800-222-2225 and www.nih.gov/nia
- ❑ National Institute of Mental Health
- ❑ The Mayo Clinic at www.mayoclinic.com
- ❑ Administration On Aging Nat'l Family Caregiver Support Program at 202-619-0724 and www.aoa.gov/prof/aoaprogram/caregiver and www.aoa.gov/prof/aoaprogram/caregiver/careprof/state_by_state/state_contact.asp
- ❑ WHYY Public Television, Wider Horizons at 215-351-1200 and <http://whyy.org>

Caregivers of individuals with AD can contact the Alzheimer's Association at 1-800-272-3900 to get the listing of support groups in their community. They can also contact their local churches and local mental health referral networks. Many communities also have help lines listed in the phone book. These resources can be invaluable in the first days after diagnosis of a loved one and throughout the course of the disease as the AD person's behaviors become more difficult to manage.

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