



Southern Caregiver Resource Center

Caring for those who care for others

Fact Sheet: **Alzheimer's Disease and** **Caregiving**

Overview

Alzheimer's disease (AD) is a condition that causes abnormal changes in the brain mainly affecting memory and other mental abilities. Alzheimer's is a disease, not a normal part of aging. Loss of memory is the usual first symptom. As the disease progresses, the loss of reasoning ability, language, decision-making ability, judgment and other critical skills make navigating day-to-day living impossible without help from others, most often a family member or friend. Sometimes, but not always, difficult changes in personality and behavior occur.

Alzheimer's disease poses real challenges for both the person diagnosed with AD and those who assume caregiving responsibilities. This does not mean that there will no longer be times of joy, shared laughter, and companionship. AD often develops gradually, offering time to adjust to the diagnosis, to plan ahead, and to spend quality time together.

Nearly 15 million Americans provide unpaid care to a person living with Alzheimer's disease or another dementia (Alzheimer's Association 2011 Facts & Figures). Dr. Alois Alzheimer, a German psychiatrist and neuropathologist, is credited with identifying the first published case of

"presenile dementia" in 1907, a condition that is now called Alzheimer's disease.

Alzheimer's is the most common form of dementia in older adults. The words "Alzheimer's" and "dementia" are often used interchangeably, but they are not the same. "Alzheimer's" is a cause of dementia. "Dementia" is a symptom and is used as a term that means a person is no longer able to function on their own because of a lasting impairment of multiple mental abilities affecting memory, attention, and reasoning. Dementia can be caused by many different medical conditions such as a severe head injury or major stroke. Other common dementias are Lewy body dementia, Frontotemporal dementia, vascular dementia, and Parkinson's disease dementia. (See fact sheet: *Is This Dementia and What Does It Mean?*)

Although the cause and progression of AD are not fully understood, increasing evidence shows that the first changes in the brain happen as much as 15 years before symptoms of dementia are exhibited by the person with AD. Certain kinds of brain scans can detect these changes. However, this work is not yet advanced enough for it to be of practical use in predicting who will later develop Alzheimer's disease.

The prevention of Alzheimer's disease is a popular topic in the media. A number of non-medical, life-style practices are recommended for possible prevention, for a healthy way to manage the disease, and for general age-related well-being. There is evidence, but no documented proof, that mental stimulation (brain games), exercise (like walking, swimming, yoga), social activities, and a healthy diet (fruit, vegetables and foods high in anti-oxidants) may help.

However, there is a great deal of evidence that small strokes are common in people with Alzheimer's disease, which only make AD symptoms worse. Given what we know about stroke prevention, maintaining healthy blood pressure, avoiding diabetes or managing it well, keeping cholesterol down, and not smoking are four key things you can do to lower your risk.

This disease can appear as young as age 30 but is typically diagnosed after age 60. Risk of having the disease increases with age. By age 90, as much as 40% of the population may be affected. The genetics of AD are complex, and knowledge is changing rapidly. Except for a small percent of families where a single gene causes the disease, having a family member with AD increases your risk only moderately. Alzheimer's disease is reported to be the sixth leading cause of death in the U.S.

Symptoms

People with AD may show symptoms of the disease three to five years before diagnosis. This period, when changes are present but the full-blown disease is absent is called "mild cognitive

impairment" or MCI. It is important to understand that not everyone with MCI goes on to develop AD. In fact, as many as 40--50% may never develop the disease. (See fact sheet: *Mild Cognitive Impairment (MCI)*.) Early problems are often seen as normal changes due to aging, and only in retrospect do caregivers see that symptoms have been occurring for several years. Although on average individuals survive four to eight years once diagnosed, living for 20 years is not all that unusual. For ease in understanding the changes that occur as the disease progresses, AD is generally divided into three stages: early, middle and late. However, the development of symptoms in an individual will differ from person to person as will the progression of symptoms.

Diagnosis and Science of Alzheimer's Disease

At present, there is no single test that leads to a diagnosis of AD. The doctor first needs to establish that the memory loss is abnormal and that the pattern of symptoms fits AD. This sometimes requires specialized memory testing. The doctor then needs to rule out other illnesses that can cause the same symptoms. For example, similar symptoms can be caused by depression, malnutrition, vitamin deficiency, thyroid and other metabolic disorders, infections, side effects of medications, drug and alcohol abuse or other conditions. If the symptoms are typical of AD and no other cause is found, the diagnosis is made. In the hands of a skilled doctor, this diagnosis is very accurate.

An evaluation for Alzheimer's disease is often requested by a family member or

friend who notices memory problems or unusual behavior. The doctor typically begins the evaluation by taking a health history and by performing a physical examination as well as evaluating the patient's cognitive abilities (mental processes of perception, memory, judgment, and reasoning). This approach can help the doctor determine whether further testing is needed. A primary care physician may refer a patient for more extensive examination in a designated Alzheimer's diagnostic center or by a neurologist, dementia or geriatric specialist. This examination will likely include a thorough medical evaluation and history, blood tests and brain scans (MRI or PET), followed by extensive neurological and neuropsychological assessments. A dementia evaluation should include interviews with family members or others who have close contact with the person being evaluated.

Rapid scientific progress is being made in identifying "biomarkers" of AD. Biomarkers are abnormal findings in blood or cerebrospinal fluid (CSF) or on brain scans that are markers of AD. There is strong evidence that special tests of the CSF may be useful diagnostically. It is also possible now to see amyloid, a key abnormal protein in AD, in the brain using PET scans. As knowledge advances, these tests may come into clinical use. Even now, however, it is clear that tests are not good enough to diagnose AD on their own. The diagnosis will still depend on a skilled and thorough evaluation.

Treatment After Diagnosis

No one fully understands what causes Alzheimer's disease yet, and there is currently no cure. Considerable

progress has been made by researchers in recent years though including the development of several medications for early-stage AD, which can help improve cognitive functioning for awhile.

Three main drugs, donepezil (Aricept), rivastigmine (Exelon), and galantamine (Reminyl) have proved beneficial in improving memory with limited side effects, usually gastro-intestinal upset. Exelon comes in a patch form, which is helpful for people who have trouble swallowing pills. Unfortunately, these drugs are not effective for everyone, and their effectiveness is limited to the early and middle stages of AD. Another drug, memantine HCl (Namenda), is also prescribed to help delay the progression of AD and is often used in combination with the above drugs. A doctor may also prescribe medications to help reduce agitation, anxiety, and unpredictable behavior as well as to improve sleeping patterns and to treat depression.

New medications are developed and tested regularly. People interested in participating in clinical trials should discuss the pros and cons with their physician and family. Information on clinical drug trials and other research is available from the Alzheimer's Disease Education and Referral Center (ADEAR) and FCA's Research Registry.

Regular care from a physician is important. Major, sudden changes in mental status can be the main symptom of important treatable conditions such as a urinary tract infection (UTI), pneumonia, or even a bone fracture. If the physician knows the patient, he or she can quickly recognize a change in mental status. But if they are presented

with a demented patient that they have not seen in years, it can be extremely difficult to know whether anything has changed, and the proper workup may not be initiated.

Caring for Someone with Alzheimer's Disease

Alzheimer's disease is called a family disease because the chronic stress of watching a loved one slowly decline affects everyone. An effective treatment will address the needs of the entire family. Caregivers must focus on their own needs, take time for their own health, and get support and respite from caregiving regularly to be able to sustain their well-being during this caregiving journey. Emotional and practical support, counseling, resource information, and educational programs about Alzheimer's disease all help a caregiver provide the best possible care for a loved one.

Absolutely the easiest thing for someone to say and the hardest thing to accept is the advice to take care of yourself as a caregiver. As stated by one caregiver, "The care you give to yourself is the care you give to your loved one." It is often hard to see beyond the care tasks that await you each morning.

Through training, caregivers can learn how to manage challenging behaviors, to improve communication skills, and to keep the person with Alzheimer's safe. Research shows that caregivers experience lower stress and better health when they learn skills through caregiver training and participate in a support group(s) (online or in person). Participation in these groups can allow

caregivers to care for their loved one at home longer.

When you're starting out as a family caregiver, it's hard to know where to begin. Perhaps you've only recently realized that a loved one needs assistance and is no longer as self-sufficient as he or she once was. Or, perhaps there has been a sudden change in their health.

Now it is time to take action and to take stock of the people, services and information that will help you provide care. The earlier you get support, the better.

The resources listed at the end of this fact sheet will help you locate local training classes and support groups. (See fact sheets: *Caregiver's Guide to Understanding Dementia Behaviors* and *Dementia, Caregiving and Controlling Frustration*.)

The role of the caregiver changes over time as the needs of the person with AD change. The following table offers a summary of the stages of AD, what kinds of behaviors to expect, caregiving information, and recommendations related to each stage of the disease.

Early-Stage Alzheimer's	Early Stage Caregiving
<ul style="list-style-type: none"> • Trouble remembering recent events or conversations, or the month or day of the week • Asking the same question over and over or repeating stories • Loss of ability to manage finances, or making mistakes in writing checks • Withdrawal from social situations and general apathy, or trouble initiating an activity • Cooking and shopping become more difficult; pans may be left to burn on the stove, and food may be forgotten in the refrigerator • Poor judgment--difficulty making wise decisions; may be easily swayed by others • Tendency to lose things or forget where they are when they are "put away carefully" • May become disoriented in familiar surroundings or get lost easily • Driving ability is compromised; unfamiliar driving routes or driving in an unfamiliar place will prove difficult • Denial that anything is wrong 	<p>During the early stage, both the caregiver and the individual with AD will want to take time to adjust to the diagnosis and to make plans for the future:</p> <ul style="list-style-type: none"> • Learning: The more you know about AD, the easier it will be for you as a caregiver. Learn as much as you can about the early and middle stages of AD, don't worry about the late stage yet. Finding other caregivers to talk to can also be a great way to learn about and make sense of your own experience. One of the most difficult things to learn is to differentiate between the disease and your loved one. Particularly in the early stage, caregivers may find themselves thinking, "He's doing this to spite me!" or "She is just being lazy." In these cases, the behavior that is upsetting to the caregiver is usually a result of the disease process, not an attempt by the person with AD to hurt or frustrate the caregiver. • Emotional Support: A diagnosis of AD can be a heart-wrenching experience for both the person diagnosed and the caregiver. The person with AD may not remember or may not admit to having the disease or ever being told they have Alzheimer's. Trying to convince them otherwise is fruitless and frustrating for the caregiver. The caregiver needs to get appropriate emotional support through counseling, a support group, or other family members. The goal is to establish a system of emotional support that will grow and change with you as your caregiving role and the emotional challenges change. Depression is common in caregivers of people with AD, which should be addressed. • Family Roles: As the disease progresses, it will be harder for the person with AD to fulfill the roles they have typically played in

the family. For example, if he or she was the only driver in the family, it will be important for family members to find alternative means of transportation; e.g., learning how to drive, recruiting volunteer drivers from among family and friends, using public transportation or paratransit. If the person with AD customarily prepared all of the meals, now is the time for the caregiver to begin learning how to cook. If the person with AD was in charge of household finances, someone else will need to assume this role. Focusing on these issues early will allow the person with AD to help the caregiver prepare for the future.

- **Finances:** AD can be a costly disease. It is important to begin mapping out strategies for meeting the increasing financial demands placed on the family as the disease progresses. Financial planning should include reviewing your insurance coverage; e.g., health, disability, and long-term care. Be aware that Medicare does not pay for long-term care or custodial care. Medi-Cal, the safety net for those living on a limited income, does provide coverage for those who qualify. Health insurance counseling is available free to seniors. To locate help in your community, call the Eldercare Locator at website: eldercare.acl.gov.
- **Legal:** Eventually the person with AD will need help making medical decisions and financial decisions and in making all sorts of important personal decisions such as who will provide for their care. Legal documents should be completed as early as possible in the disease process, even prior to a diagnosis. Waiting too long may result in the person no longer being deemed capable of signing legal documents. A Power of Attorney for Finances and Power of Attorney for Healthcare (Advanced Health Care

	<p>Directive) can ensure that the person with AD is cared for by trusted family members or friends. Without these documents, caregivers may have to petition for conservatorship through court proceedings in order to get the right to make decisions on behalf of the person with AD. The family may also lose access to bank accounts if a member is not co-named on the account(s). Clear legal documentation can help prevent someone from attempting to take advantage of or lay claim to financial resources for their personal gain. Free and low-cost legal services are available to seniors. See the resource section of this fact sheet for organizations that can help with legal issues.</p>
<p>Middle-Stage Alzheimer's</p>	<p>Middle-Stage Caregiving</p>
<p>Difficult behaviors emerge often, but not always. Common examples include:</p> <ul style="list-style-type: none"> • Anger, suspicion, overreacting, and paranoia; e.g., believing that family members are stealing money, or a spouse is having an affair. • More repetition of questions or statements. • Wandering or sundowning; i.e., restlessness or agitation in the late afternoon and evenings. • Fear of bathing. • Eating problems, table manners decline. • Involuntary leakage of urine (incontinence) or having urine "accidents." • Hoarding belongings, especially paper. • Inappropriate sexual behavior. 	<p>During the middle stage of AD, the caregiver's role will expand to full time. Keeping the person with AD safe will become a priority. Both the person with AD and the caregiver will need help and support.</p> <ul style="list-style-type: none"> • Dealing With Challenging Behaviors: We often use intuition to help us decide what to do. Unfortunately, dealing with Alzheimer's disease and other dementias is counter-intuitive; i.e., often the right thing to do is exactly opposite of what seems like the right thing to do. (See FCA's article: <i>Ten Real-life Strategies for Dementia Caregiving</i>.) • Emotional Support: People caring for loved ones with AD frequently feel isolated, and feelings of grief and loss surface as the person they are caring for changes. (See fact sheet, <i>Caregiving and Ambiguous Loss</i>.) Getting emotional support from professionals, family, friends, and/or a support group as well as taking periodic breaks from the responsibilities of caregiving is crucial to the mental and physical health of caregivers. Be sure to

<ul style="list-style-type: none"> • Violent behavior - hitting, shouting, arming themselves for protection. • Will go from needing help choosing clothes and remembering to change clothes to needing help getting dressed. • Will progress from needing reminders regarding personal care to needing help bathing, taking medication, brushing teeth, shaving, brushing hair, toileting, etc. • Increased difficulty with verbal expression and comprehension, particularly when trying to name items. • Spatial problems; e.g., having trouble finding their way, sometimes even at home. • Loss of reading, writing, and arithmetic abilities; difficulty following the story line of a television show. • Loss of coordination often leading to shuffling feet or gait problems. • Will need care or supervision, possibly for 24 hours a day. • May lose the ability to recognize family and friends at times. 	<p>Speak to your physician if you feel depressed or anxious.</p> <ul style="list-style-type: none"> • Respite Care: Caregivers need a regular break or "respite" from providing care and assistance. Respite care includes in-home help (another family member, a neighbor, friend, hired caregiver, or volunteer caregiver) and out of home help (adult day care or a short stay in an assisted care facility). The "Family Care Navigator" on caregiver.org can help you locate the Area Agency on Aging, a source for your local community respite resources. (See fact sheet: <i>Caregiving at Home: A Guide to Community Resources</i> to learn about programs that can help ease the demands placed on the caregiver.) • Safety: Creating a safe and comfortable environment is important. An occupational therapist or physical therapist can provide advice and help in making the home safer for both the caregiver and care recipient. Ask your physician, the local Alzheimer's Association, or the Area Agency on Aging for a referral to a professional who is experienced in home modification and assistive devices. For people with AD who are at risk of becoming lost outside of their home, the local police should be advised, and the person should register with the Alzheimer's Association's Safe Return program. • Medical Care: The person with AD will need ongoing medical care both for AD and for any other health problems that might arise. Over time, the caregiver will be depended upon to help provide the status update to medical staff. Make sure there is a release of information noted in the medical chart of the patient so that the physician can speak freely with you. It is important to develop a positive relationship with the physician(s) and other health care professionals. You will need them to
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	<p>understand your role as the caregiver, to listen to your input, and to work with you as a team member in providing appropriate medical care.</p> <ul style="list-style-type: none"> • The stress of caregiving can affect your health. Be sure to take care of yourself by getting regular medical care for yourself. If you need to be hospitalized or need time off from your caregiving duties, emergency respite care can be arranged. A caregiver whose health is seriously affected may need to look at alternative options for a loved one such as a residential facility. • Planning for the Future: Many caregivers wish to keep their loved one at home for as long as possible. However, if more care or a different type of care is needed than what can be provided at home, residential care is often the next best option. Many assisted care facilities have programs specifically designed for individuals with dementia. Hiring in-home help is an alternative to relocating your loved one to a care facility. (For more information about these next steps, see fact sheets: <i>Home Away from Home: Relocating Your Parents</i> and <i>Hiring In-Home Help</i>.)
Late-Stage Alzheimer's	Late-Stage Caregiving
<ul style="list-style-type: none"> • Loss of ability to communicate • Inability to recognize people, places, and objects • Requires full assistance with all personal care activities • Loses ability to walk • Loses ability to smile • Muscles may become contracted • May lose ability to swallow • Seizures may occur 	<ul style="list-style-type: none"> • Placement: Families caring for a loved one with end-stage Alzheimer's should give thoughtful consideration to placement in a skilled nursing facility or dementia care facility where adequate management and supervision can be provided. • Hospice: Hospice services are designed to support individuals at the end of life. Services may include support groups, visiting nurses, pain management, and home care. Hospice services are usually arranged through the treating physician and are usually not available until the physician anticipates that a person has less than six months to live. Several

<ul style="list-style-type: none"> • Weight loss • Majority of time spent sleeping • May exhibit a need to suck on items • Incontinence of both bowel and bladder 	<p>organizations specialize in helping families deal with the challenges involved in end-of-life care. (See fact sheet: <i>Caregiving At Home: A Guide to Community Resources</i> and the advanced illness fact sheets including <i>Holding on and Letting Go</i>. Refer to the resource section at the end of this fact sheet for more information.)</p>
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Again, it's important to remember that the life-changing effects of Alzheimer's disease for both the person diagnosed with AD and those who assume caregiving responsibilities does not mean that there will no longer be times of joy. Although the challenges are real, the often slow progression of the disease offers time for shared laughter, intimacy, and social experiences. You will have opportunities to manage legal and financial issues in advance and adjust to the diagnosis so that you can make the most of your time together.

Resources

Southern Caregiver Resource Center
 3675 Ruffin Road, Suite 230
 San Diego, CA 92123
 (858) 268-4432 | (800) 827-1008 (in CA)
 Fax: (858) 268-7816
 E-mail: scrc@caregivercenter.org
 Web Site: www.caregivercenter.org

Southern Caregiver Resource Center offers free support services to family caregivers of adults with chronic and disabling conditions in San Diego and Imperial counties. Services include information and referral, needs assessments, care planning, family consultation, case management, individual counseling, legal and financial consultation, respite care, education and training, and support groups.

**Family Caregiver Alliance
 National Center on Caregiving**
 (415) 434-3388 | (800) 445-8106
 Web Site: www.caregiver.org
 E-mail: info@caregiver.org

Family Caregiver Alliance (FCA) seeks to improve the quality of life for caregivers through education, services, research and advocacy. Through its National Center on Caregiving, FCA offers information on current social, public policy and caregiving issues and provides assistance in the development of public and private programs for caregivers, as well as a toll-free call center for family caregivers and professionals nationwide.

Alzheimer's Association
www.alz.org

Provides education, support and service for people diagnosed with Alzheimer's disease and related conditions.

Alzheimer's Disease Education and Referral Center (ADEAR)
www.nia.nih.gov/alzheimers

The center provides information about Alzheimer's disease, current research and clinical trials.

Alzheimer's Foundation of America
www.alzfdn.org

The Alzheimer's Foundation of America offers support, respite grants, toll-free phone line for family caregivers who wish to speak with a social worker, online articles, professional education and training, and AFA Teens.

Eldercare Locator
eldercare.acl.gov

The Eldercare Locator helps older adults and their caregivers find local services including health insurance counseling, free and low-cost legal services and information for local Area Agencies on Aging.

Recommended Readings

Fact Sheets

Advanced Illness: Holding On and Letting Go

Caregiver's Guide to Understanding Dementia Behaviors

Caregiving and Ambiguous Loss

Caregiving at Home: A Guide to Community Resources

Dementia, Caregiving, and Controlling Frustration

Dementia: Is This Dementia and What Does It Mean?

Hiring In- Home Help

Home Away from Home: Relocating you Parents

This fact sheet was prepared and updated by Family Caregiver Alliance and reviewed by Bruce R. Reed, PhD, Professor of Neurology, Associate Director, UC Davis Alzheimer's Disease Center. © 2012 Family Caregiver Alliance. All rights reserved.

*Making Choices About Everyday Care
Mild Cognitive Impairment (MCI)*