



FAMILY CAREGIVER ALLIANCE®
National Center on Caregiving

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Dementia: Is this Dementia and What Does it Mean?

Introduction

What does it mean when someone is said to have dementia? For some people, the word conjures up scary images of “crazy” behavior and loss of control. In fact, the word dementia describes a group of symptoms that includes short-term memory loss, confusion, the inability to problem-solve, the inability to complete multi-step activities such as preparing a meal or balancing a checkbook, and, sometimes, personality changes or unusual behavior.

Saying that someone has dementia does not offer information about *why* that person has these symptoms. Compare it to someone who has a fever: the person is ill from the fever, but the high temperature does not explain the cause or why this person is ill.

Does *any* loss of memory signify dementia? Isn't memory loss a normal part of aging? We often hear that because someone is old, memory problems are “just natural” and are to be expected. But we know that *serious memory loss is not a normal part of aging*, and should not be ignored.

On the other hand, families might assume that a loved one's noticeable loss of memory must be caused by Alzheimer's disease. In many instances, Alzheimer's is, in fact, the problem. But other conditions also can cause memory and cognitive problems severe enough to interfere with daily activities. These conditions can affect younger as well as older people. A clear diagnosis is needed.

Certain conditions can cause *reversible dementias*. These include medication interactions, depression, vitamin deficiencies or thyroid abnormalities. It is

important that these conditions be identified early and treated appropriately so that symptoms can be improved.

The irreversible dementias are known as *degenerative dementias*, and Alzheimer's disease is the most common. There are a number of other *degenerative dementias*, however, that may look like Alzheimer's, but have distinct or different features which need special attention and different treatment. Reversible and irreversible dementias are described in more detail below.

Importance of Obtaining a Diagnosis for Dementia

The diagnosis of dementia requires a complete medical and neuropsychological evaluation. The process is first to determine if the person has a cognitive problem and how severe it is. The next step is to determine the cause in order to accurately recommend treatment and allow patients and caregivers to plan for the future.

A medical evaluation for dementia usually includes the following:

- **Review of history or onset of symptoms**—Questions you or your loved one might be asked include: What problems have been identified? In what order did things happen? How long have the symptoms been present? How is this affecting the person's ability to function in daily life? Because the person being evaluated may not be able to recall accurately the sequence of events or may underestimate the problem, a caregiver or someone who knows the individual well needs to accompany the patient and provide this information to the doctor or nurse.
- **Medical history and medications**—This will provide information about conditions that might indicate higher risk for a particular type of dementia or identify medications that may contribute to cognitive problems. Again, it is important that someone who can accurately provide this information be with the individual during the appointment.
- **Neurological exam**—The neurological exam helps identify symptoms that may be present in particular kinds of dementia or other conditions that may increase the risk of cognitive problems, such as a stroke or Parkinson's disease.

- **Laboratory tests to rule out vitamin deficiencies or metabolic conditions**—Although not common, sometimes a simple vitamin deficiency, infection or hormone imbalance can cause cognitive symptoms. These may include thyroid imbalances, Vitamin B12, and syphilis. In addition, some laboratory tests may indicate a condition that puts a person at risk for developing dementia, such as high cholesterol or high blood pressure.
- **Brain Imaging**—A CT scan or MRI is done to evaluate the anatomy of the brain for conditions that might cause cognitive changes, such as a stroke or a brain tumor. The tests also allow the determination of brain size and blood vessel changes which can be monitored over time.
- **Mental status testing (also called cognitive or neuropsychological testing)**—These pencil-and-paper tests evaluate many areas of thinking, including memory, language, problem-solving and judgment. The results are used to compare an individual with others of his or her age, education and ethnicity to determine in what areas the individual has problems and how severe they are.

The process of diagnosing dementia has become more accurate in recent years, and specialists are able to analyze the large amount of data collected and determine if there is a problem, the severity, and, often, the cause of the dementia. Occasionally, there may be a combination of causes or it may take time to monitor the individual to be sure of a diagnosis. Determining whether the cause is a reversible or irreversible condition guides the treatment and care for the affected person and family.

Reversible Dementias

Deteriorating intellectual capacity may be caused by a variety of diseases and disorders in older persons. An illness and/or a reaction to medication may cause a change in mental status. These are sometimes called “pseudodementias.” Detecting the underlying cause of changes through medical evaluation may lead to a determination that the cause is reversible or treatable. Examples of conditions that can cause reversible symptoms of dementia include:

Reactions to medications—Adverse drug reactions are one of the most common reasons older persons experience symptoms that mimic dementia. All medications, prescriptions, over-the-counter pills and herbal remedies should be monitored by a physician to reduce the possibility of side effects.

- **Endocrine abnormalities**—The conditions of low or high thyroid levels, parathyroid disturbances or adrenal abnormalities can cause confusion that mimics dementia.
- **Metabolic disturbances**—Confusion or appetite, sleep and emotional changes can be caused by medical conditions including renal and liver failure, electrolyte imbalances (blood chemistry levels), hypoglycemia (low blood sugar), hypercalcemia (high calcium), and diseases of the liver and pancreas.
- **Emotional Distress**—Depression or major life changes such retirement, divorce or loss of a loved one can affect one's physical and mental health. A physician should be informed about major stressful life events.
- **Vision and Hearing**—Undetected problems of vision or hearing may result in inappropriate responses and be misinterpreted. Hearing and eye exams should be performed.
- **Infections**—Confusion can be a symptom of an infection and needs to be brought to the attention of the physician.
- **Nutritional Deficiencies**—Deficiencies of B vitamins (folate, niacin, riboflavin and thiamine) can produce cognitive impairment.

Degenerative (Irreversible) Dementias

If reversible dementias are ruled out and it is determined that the person has a degenerative or irreversible dementia, it is important that families and medical personnel seek the cause of the problem. This will help ensure that the person affected receives proper medical care, and families can plan their caregiving and find appropriate support and resources.

The following are the most common degenerative dementias:

- **Alzheimer's disease**—Alzheimer's disease is the most common cause of dementia in people over 65, although the disease also occurs in people much younger. Alzheimer's affects approximately 50 percent of those over 85. Presently, researchers cannot definitely say what causes the disease, and there is no cure. Symptoms differ from person to person, but declines in memory, thinking and ability to function gradually progress over of a period of years, ending in a severe loss of function. **Ischemic Vascular Dementia (IVD)**—IVD is the second most common dementia, characterized by an abrupt loss of function or general slowing of cognitive abilities that interferes with what are called "executive functions" such as planning and completing tasks. When symptoms appear suddenly, the

person has usually experienced a stroke. For others, the condition develops slowly with a gradual loss of function and/or thinking.

- **Dementia with Lewy Bodies (DLB)**—Dementia with Lewy Bodies is a progressive degenerative disease that shares symptoms with Alzheimer's and Parkinson's. People affected by this disease have behavioral and memory symptoms which can fluctuate, as well as motor problems which are commonly seen with Parkinson's disease.
- **Frontotemporal Dementia (FTD)**—FTD is a degenerative condition of the front (anterior) part of the brain, which can sometimes be seen on brain scans. The frontal and anterior temporal lobes of the brain control reasoning, personality, movement, speech, language, social graces and some aspects of memory. Symptoms may lead to misdiagnosis as a psychological or emotionally-based problem. FTD frequently occurs after age 40 and usually before age 65. Symptoms appear in two seemingly opposite ways: some individuals are overactive, restless, distracted and disinhibited (showing poor social judgment), while others are apathetic, inert and emotionally blunted.
- **Creutzfeldt-Jakob Disease**—Creutzfeldt-Jakob Disease (CJD or Jakob-Creutzfeldt Disease) is a rapidly progressive, fatal brain disease. It is part of a family of diseases, called transmissible spongiform encephalopathies, that are caused by an agent known as a prion ("pree-on"). This condition can be very difficult to diagnose as it has many different symptoms, including behavioral changes, movement changes, cognitive changes and general changes in well-being such as sleep problems, loss of appetite and headaches.
- **Parkinson's Dementia**—Parkinsonism is the name given to a collection of symptoms and signs consisting of tremor, stiffness, slowness of movement, unsteady gait. Many neurological disorders have features of parkinsonism, including many of the dementias. When parkinsonism occurs without any other neurological abnormalities, and there is no recognizable cause, the disorder is termed Parkinson's disease after the English physician who first described it fully in 1817.
- **Progressive Supranuclear Palsy (PSP)**—People with PSP usually show a group of three symptoms, including the gradual loss of balance and trouble walking, loss of control of voluntary eye movements, and dementia. Although these three features are considered to be the hallmarks of PSP, patients with this disorder also experience other symptoms common to degenerative diseases of the brain, including difficulties with movement, changes in behavior and difficulty with speech and swallowing. In part because it is relatively rare, PSP is frequently misdiagnosed as Parkinson's Disease. However, its treatment response

and clinical symptoms are different, making an accurate diagnosis very important.

- **Normal Pressure Hydrocephalus (NPH)**—Gait instability, urinary incontinence and dementia are the signs and symptoms typically found in patients who have NPH. Considered a rare cause of dementia, it primarily affects persons older than 60 years. The precise incidence of NPH is hard to determine because the condition does not have a formal, agreed-upon definition. Some physicians base the diagnosis strongly on radiographic evidence; another group of health care professionals relies more on clinical indications. Still others use a combination of signs and symptoms that they have found to be reliable. Traditionally, treatment is surgical implantation of a shunt to reduce the pressure caused by the build up of cerebrospinal fluid.
- **Huntington's disease (HD)**—Huntington's disease is a fatal disease typically characterized by involuntary movements (chorea) and cognitive decline (dementia). It is caused by a genetic mutation that can be passed down from generation to generation. HD is an illness with profound neurological and psychiatric features affecting certain structures deep within the brain, particularly the basal ganglia, responsible for such important functions as movement and coordination. Structures responsible for thought, perception and memory are also affected, likely due to connections from the basal ganglia to the frontal lobe of the brain. As a result, patients may experience uncontrolled movements (such as twisting and turning), loss of intellectual abilities, and emotional and behavior disturbances.
- **Mixed Dementias**—At times, two of these conditions can overlap. This is commonly seen in Alzheimer's disease and vascular dementia, and also in Alzheimer's disease and Lewy Body dementia.

Medical Treatment for Dementia

There are no cures for degenerative or irreversible dementias, so medical treatments focus on maximizing the individual's cognitive and functional abilities. Specific treatments for dementia vary depending on the cause of the dementia. For patients with Alzheimer's disease and Lewy Body disease, for example, medications are available to slow the rate of decline and improve memory function. These medications are known as cholinesterase inhibitors and seem to be effective for some patients. For patients with Alzheimer's disease, a newer medication, which prevents the buildup of chemicals thought to contribute to memory loss, has also been developed. Treatment for vascular

dementia includes controlling risk factors such as high blood pressure and high cholesterol. Additional medications are available to manage other symptoms associated with dementia, including sleep disorders, movement problems, depression, or behavioral symptoms such as irritability or agitation. Because treatments vary depending on the cause of dementia, an accurate diagnosis is critical.

Communicating about Dementia with Health Care Providers

Good communication with the primary care provider affects the well-being of the person with dementia as well as the well-being of the caregiver. Communicating your concerns clearly and describing the changes you may have observed will help guide the provider to investigate further. In some cases, you may find yourself “educating” medical staff about your loved one’s symptoms.

It is important that your concerns are taken seriously, and you are treated with respect and dignity. If you are not receiving the attention you need, you should communicate your concerns to the provider and request a referral to a resource in the community that specializes in the evaluation of people experiencing cognitive changes. The goal is to establish a partnership to both maintain the quality of health and to solve problems.

Your Role as a Caregiver

Establishing a good working relationship with the primary care physician helps ensure good care and ongoing support. A comprehensive medical work-up that rules out treatable conditions and provides information on current status offers a foundation for care planning, now and in the future.

An accurate diagnosis begins a process of education for caregivers and families so that needs can be met and resources located and put to use. Irreversible dementia requires a level of care that increases as the disease progresses. Through education and the use of available resources, families can learn new skills to handle shifting care needs.

Many families provide care at home for a person with dementia. While this can be an enriching and very rewarding experience, it can also be stressful. Studies have shown that caring for someone with a brain-impairing disorder can be more stressful than caring for someone with a physical impairment. It is essential that caregivers take the time to care for themselves physically and emotionally.

Support and assistance are very important throughout the months or years you are a caregiver. You will need respite from time to time—a break from caregiving demands. Help from friends, other family members or community agencies is invaluable so that you can continue to provide your loved one with good care without becoming exhausted, frustrated or simply burned out.

Safety-proofing the home, learning behavior management techniques and addressing legal and financial matters are important steps families can take to manage dementia, and resources are available to help. Many caregiver support groups—including some on the Internet—offer emotional and practical support. Caregivers may need to educate themselves about long-term care, and also to reach out in their communities to find the assistance they need. The list of resources below offers more information on where to start looking for help.

Every family is different. Whether care for someone with dementia is provided at home, in an assisted living center, an Alzheimer's special care unit, or in a nursing home depends on family resources and patient needs. While placement in a facility is not uncommon in later stages of dementia, every family approaches the caregiving experience in a way that is best for them.

Research into the causes and treatments for dementia continues at a rapid pace. We all look forward to new developments that some day may postpone, cure or even prevent these debilitating disorders.

Recommended Reading

The Forgetting. Alzheimer's: Portrait of an Epidemic, David Shenk, 2001, Random House, New York, NY.

Alzheimer's Disease: Unraveling the Mystery, Anne Brown Rodgers, 2003, ADEAR (Alzheimer's Disease Education & Referral Center, a service of the National Institute on Aging), Silver Spring, M.D.

Caregiving at Home, William Leahy, M.D., 2005, Hartman Publishing Inc. and William Leahy, M.D., 8529 Indian School Road NE, Albuquerque, NM 87112, (505) 291-1274.

FCA Fact Sheets

Fact Sheets are listed here: <https://caregiver.org/fact-sheets>.

CAREGIVING STRATEGIES

- *Caregiver's Guide to Understanding Dementia Behaviors*
- *Caring for Adults with Cognitive and Memory Impairment*
- *Community Care Options*
- *Taking Care of YOU: Self-Care for Family Caregivers*
- *Legal Issues in Planning for Incapacity*

HEALTH CONDITIONS

- *Alzheimer's Disease*
- *Dementia with Lewy Bodies*
- *Frontotemporal Dementia*
- *Huntington's Disease*
- *Parkinson's Disease*
- *Stroke*

Resources

**Family Caregiver Alliance
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San Francisco, CA 94103
(415) 434-3388
(800) 445-8106 toll free
E-mail: info@caregiver.org
Website: www.caregiver.org

Family Caregiver Alliance (FCA) seeks to improve the quality of life for caregivers through education, services, research, and advocacy.

National Center on Caregiving offers information on current social, public policy and caregiving issues, provides assistance in the development of public and private programs for caregivers, and assists caregivers nationwide in locating resources in their communities.

For San Francisco Bay Area residents, FCA provides direct family support services for caregivers of those with Alzheimer's disease, stroke, ALS, head injury, Parkinson's disease, and other debilitating health conditions that strike adults.

Eldercare Locator

Administration on Aging

Phone: (800) 677-1116

www.eldercare.gov

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

BenefitsCheckUp

www.benefitscheckup.org

Designed by the National Council on Aging, this website enables you to complete a questionnaire to find federal, state, and local programs that you might be eligible for and how to apply.

Disease-Specific Organizations

ADEAR (Alzheimer's Disease Education & Referral Center)

(800) 438-4380

www.nia.nih.gov/alzheimers

Alzheimer's Association

(800) 272-3900

www.alz.org

American Stroke Association

(Division of American Heart Association)

(800) 553-6321

www.strokeassociation.org

Huntington's Disease Society of America

(800) 345-4372

hdsa.org

National Parkinson Foundation

(800) 327-4545

www.parkinson.org

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