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FACT SHEET: Alzheimer's Disease

Definition

Alzheimer's disease (AD) is an incurable neurological disease in which changes in the nerve cells of the brain result in the death of a large number of cells. This destruction of brain cells eventually leads to serious mental deterioration, dementia, and death.

Facts

According to the U.S. Congress Office of Technology Assessment, there are an estimated 4 million to 6.8 million persons nationwide with dementia. Up to 500,000 Alzheimer's patients may reside in California.

Alzheimer's disease most commonly strikes individuals who are over 65; however, it can also afflict people much younger. An estimated 11 percent of all Americans over 65 and 25-50 percent of those over 85 have the disease. Alzheimer's accounts for more than half of the number of persons described as having dementia; people with Alzheimer's fill more than half the beds in skilled nursing facilities.

The mid-range medical and social service costs for one person with Alzheimer's are estimated to be more than \$47,500 over the course of the disease. The average annual direct and indirect costs for all Americans with Alzheimer's have been estimated at \$82.7 billion (1994 dollars).

Symptoms

During the first two to four years, people with Alzheimer's disease generally experience loss of memory for recent events, and disorientation. Later, the person will often have problems with progressive memory loss, judgment,

concentration and speech. Loss of physical abilities, similar to that seen in Parkinson's disease, occurs in a small proportion of affected people. At this point, the person may forget to take a bath and will have problems with once-routine chores.

In time, the person's family and/or caregiver will probably have to provide full-time supervision because the confused person may tend to wander off, engage in meaningless and often socially unacceptable behavior, and lose the ability to perform basic self-care activities.

People with Alzheimer's may also suffer sleeplessness, "sundowning" (confusion or agitation in the evening hours), and perseveration (repetition of the same ideas, words, movements, or thoughts). Final stage disease progression includes severe problems with eating, communication, and control of bodily functions.

Diagnosis of Alzheimer's Disease

The diagnosis of Alzheimer's disease can only be made after other diseases with similar symptoms such as brain tumors, strokes, and infections can be ruled out. It must also be differentiated from the occasional forgetfulness that occurs during normal aging and from depression and malnutrition, which can produce early Alzheimer's-like memory loss. Ideally, this diagnosis is made after a thorough medical evaluation followed by extensive neurological and neuropsychological assessments. This examination may be performed at designated Alzheimer's evaluation centers or by skilled medical specialists. A definitive diagnosis can be made only by an autopsy.

Over the past few years, many different methods have been developed and tested for diagnosing Alzheimer's disease in people with memory loss and dementia. These tests include an eye-drop test, genetic tests, spinal fluid tests, various types of neuropsychologic or cognitive tests, and brain imaging tests. While many of these tests are promising and may provide physicians with additional information useful in diagnosis, none has replaced the "gold standard" of a careful, thorough, clinical evaluation performed by an expert. In some cases, these tests have been studied in only a small number of individuals and often are compared to the standard of a clinical diagnosis. At this point, there is still no accurate diagnostic laboratory test for Alzheimer's disease.

Imaging Research

Research using brain imaging has led to more knowledge regarding Alzheimer's disease in three main areas: Brain structure and anatomy, diagnosis, and the physiology of the disease and its relationship to symptoms and behavior.

Brain imaging has been used by clinicians and researchers for many years to look at differences in brain structure and anatomy in people with Alzheimer's disease. It has long been known that shrinking of the brain, or atrophy, accompanies Alzheimer's disease. This finding alone has not been helpful in diagnosing Alzheimer's disease because brain atrophy is also associated with normal aging. CT and MRI scans are helpful diagnostically, however, in that they are able to rule out other conditions such as brain tumors or major strokes, which might account for certain symptoms of dementia.

More recent developments in brain imaging are scans which allow researchers to actually see how the living brain is functioning by looking at blood flow, oxygen and glucose metabolism and specific neuro-transmitter systems. Studies regarding brain blood flow and metabolism may help determine which parts of the brain are most affected at different stages of the illness and may help explain certain behaviors and symptoms which arise. In addition, high resolution MRI

scans may show atrophy in the memory centers of the brain. These sorts of scans may at times be useful in helping to support the diagnosis of AD.

Treatment After Diagnosis

New drugs for the treatment of AD are now available. These drugs increase the brain levels of acetylcholine, a chemical involved in memory functions. The first of the drugs approved, Tacrine, requires frequent blood tests for monitoring. More recently, Donepezil (Aricept) was also approved by the FDA. A number of similar drugs are being tested. These drugs do not cure Alzheimer's or stop its progression, but may provide some symptomatic benefit. It is important to discuss this potential drug treatment with your physician and to have realistic expectations.

Other compounds include Vitamin E, estrogen (a hormone), and non-steroidal anti-inflammatory medications like ibuprofen, all of which are aimed at treating different possible causes of the disease. In addition, current experimental drug trials are looking at the treatment of agitated behaviors using both pharmacological and behavioral approaches. Many drug companies are involved in designing and testing drugs for the possible treatment of AD. None of these drugs has yet been shown to be effective, with the possible exception of Vitamin E.

Alzheimer's disease is often called a family disease—the chronic stress of watching a loved one slowly decline affects everyone. Comprehensive treatment must therefore address the needs of the entire family. This would include emotional support, counseling, and educational programs about Alzheimer's disease for individuals and family members as they strive to provide a safe and comfortable environment at home. *Respite care*, the use of a companion, homemaker, or aide at home or in a special Alzheimer's day care program, may be needed to allow the caregiver time away from his/her 24-hour responsibilities.

The person with Alzheimer's will need good medical follow-up throughout the course of the disease. If he/she experiences delusions or great psychological stress, careful use of drugs to treat these symptoms may be indicated.

Comprehensive counseling should include suggesting that the patient and the family obtain early legal consultation concerning how they can responsibly provide for and make treatment plans for the affected family member who can no longer care for him/herself. The life span of someone with Alzheimer's can range from under five to more than twenty years.

Families caring for a loved one with end-stage Alzheimer's should give thoughtful consideration to placement in a skilled nursing facility where adequate management and supervision can be provided.

New Research Findings

New developments in genetic research into Alzheimer's disease have recently come to light. For a number of years, investigators have known that there is a genetic connection in some cases of Alzheimer's disease, namely an abnormality on Chromosome 21 which results in Down's Syndrome. In such cases, children with Down's Syndrome who live into their 30's and 40's show Alzheimer changes in their brains. Chromosome 21 carries the gene for amyloid precursor protein (APP). This large protein is broken down into beta amyloid which is thought to be the source of senile plaques in the brains of people with Alzheimer's disease. It has been shown that mutations of the APP gene can lead to the development of Alzheimer's disease at a young age, typically in a person's fifties. This is a very rare genetic defect affecting a small number of families.

Other genetic developments include the discovery on Chromosome 14 of the specific gene responsible for the cases of familial early onset AD. This gene encodes a protein called S182 and mutations of this protein can cause AD early in middle age, usually between the ages of 30 and 55. While this is not a very common

cause of AD, it may account for the majority of familial early onset AD.

Most recently, a gene located on Chromosome 1 was identified and linked to the type of AD found in people descended from Germans who lived in Russia near the Volga River. In some Volga German families, AD is inherited with an age of onset between 50 and 70. This gene and the protein it produces share a number of similarities with the Chromosome 14 gene. Again, this is a very rare mutation.

A fourth gene, located on Chromosome 19, codes for a protein called APOE. This protein has three forms: Of the three forms of the protein, APOE4 has the strongest connection with the development of Alzheimer's disease, especially in those families with a high rate of disease in the family. Even in cases of Alzheimer's disease in which there is no clear familial tendency, APOE4 was present in more than half of the cases.

APOE4 is important because it is the first discovery of a potential mechanism for the development of Alzheimer's disease. The APOE4 protein binds to amyloid, and if a drug could be developed which blocks this binding process, it might be a useful treatment.

The presence of two copies of the APOE4 gene confers a high risk of developing the illness in families with genetically transmitted late-onset Alzheimer's disease and a higher risk of getting the disease for non-familial cases. How much it increases the risk cannot yet be established in individual cases, as the risk depends on family history, ethnicity, and other factors that interact with APOE4 but which are poorly understood at this time. The APOE4 gene is considered a *susceptibility* gene, not a disease gene, since not all persons who have the gene get the disease and some people may get the disease without having the gene. It is not a diagnostic test for Alzheimer's disease. It is a risk factor in somewhat the same way that high cholesterol is a risk for heart disease.

With news of these discoveries, many families are asking whether or not they can be tested for

their risk of developing AD. A test to assess the APOE4 gene is available. It cannot be used to predict who will develop late-onset AD for anyone not yet showing symptoms of the disease. Apart from its technical aspects, which are not simple, the issue of genetic testing raises complex personal, social, legal and ethical issues. At this time, routine testing for Alzheimer's disease genes is not recommended. The APOE4 gene is only a risk factor and it is not possible to state the exact degree of risk it confers. Routine testing for these genes on Chromosomes 21, 14 and 1 is not available but even if it were, it would only account for a small number of people with AD. Having a negative test for these genes does not exclude the possibility of having AD. There are still only limited treatment options for this illness, so test results must be placed in the context of accurate information and careful communication and counseling.

Recommended Readings

The 36 Hour Day, Nancy Mace and Peter Rabins, 1999 edition, The Johns Hopkins University Press, 2715 N. Charles Street, Baltimore, MD, 21218-4319 (800) 537-5487.

The Complete Guide to Alzheimer's Proofing Your Home, 1998, Mark L. Warner, Purdue University Press, 1207 South Campus Courts-E, West Lafayette, IN 47907-1207, (800) 933-9637.

The Best Friends Approach to Alzheimer's Care, Virginia Bell and David Troxel, 1997, Health Professions Press, P.O. Box 10624, Baltimore, MD, 21285-0624, (888) 337-8808.

Alzheimer's: A Love Story, Ann Davidson, 1997, Carol Publishing, 120 Enterprise Avenue, Seacaucus, NJ, 07094, (201) 866-0490.

Interventions for Alzheimer's Disease: A Caregiver's Complete Reference, Ruth Tappen, 1997, Health Professions Press, P.O. Box 10624, Baltimore, MD 21285-0624, (888) 337-8808.

Alzheimer's Disease: Cause(s), Diagnosis, Treatment and Care, Zaven S. Khachaturian and Teresa S. Redebaugh (eds.), 1996, CRC Press, LLC, 2000 Corporate Blvd. NW, Boca Raton, FL 33431, (561) 994-0555.

Early Identification of Alzheimer's Diseases and Related Dementias: Quick Reference Guide for Clinicians, No. 19, Paul T. Costa, 1996, U.S. Department of Health and Human Services, Agency for Health Care Policy and Research (AHCPR Publication No. 97-0703). Available from: AHCPR Publications Clearinghouse, P.O. Box 8547, Silver Spring, MD 20907, (800) 358-9295.

Credits

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Ernst, R.L., and Hay, J.W., 1994, The U.S. Economic and Social Costs of Alzheimer's Disease Revisited, *American Journal of Public Health* 84(8):1261-1264.

Evans, D.A., et al., 1990, Estimated Prevalence of Alzheimer's Disease in the United States, *Milbank Quarterly*, 68(2):267-289.

Gunnarsson, L.G., and Lundberg, C., 1995, Cautiousness in Testing for Alzheimer's Disease, *American Journal of Alzheimer's Disease*, July/August: 37-38.

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Office of Technology Assessment, U.S. Congress, 1990, *Confused Minds, Burdened Families*, U.S. Government Printing Office, Washington, DC.

Resources

Alzheimer's Disease Education and Referral Center (ADEAR) P.O. Box 8250
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(301) 495-3311
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www.alzheimers.org/adear

Alzheimer's Association
919 North Michigan Ave., Ste. 1000
Chicago, IL 60611-1676
(312) 335-8700
(800) 272-3900
www.alz.org

This office will provide information about regional chapter offices across the nation. Local chapters may give referrals for doctors, nursing homes, support groups and adult day care programs. Alzheimer's Association chapters also send out newsletters and information about recent research

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