

Alzheimer Disease

HOW TO RECEIVE CREDIT

- Read the enclosed course.
- Complete the questions at the end of the course.
- Return your completed Evaluation to NetCE by mail or fax, or complete online at www.NetCE.com. (If you are a physician, behavioral health professional or Florida nurse, please return the included Answer Sheet/Evaluation.) Your postmark or facsimile date will be used as your completion date.
- Receive your Certificate(s) of Completion by mail, fax, or email.

Faculty

Joan Needham, MSED, RNC, was a graduate of Copley Memorial Hospital School of Nursing. She earned a baccalaureate degree in nursing from the College of Saint Francis in 1977 and a Master's degree in adult education from Northern Illinois University in 1981. She was certified in gerontological nursing by the American Nurses Association and worked in nursing education at various colleges in Illinois for many years. Regrettably, Ms. Needham passed away in 2010.

John M. Leonard, MD, Professor of Medicine Emeritus, Vanderbilt University School of Medicine, completed his postgraduate clinical training at the Yale and Vanderbilt University Medical Centers before joining the Vanderbilt faculty in 1974. He is a clinician-educator and for many years served as director of residency training and student educational programs for the Vanderbilt University Department of Medicine. Over a career span of 40 years, Dr. Leonard conducted an active practice of general internal medicine and an inpatient consulting practice of infectious diseases.

Faculty Disclosure

Contributing faculty, Joan Needham, MSED, RNC, has disclosed no relevant financial relationship with any product manufacturer or service provider mentioned.

Contributing faculty, John M. Leonard, MD, has disclosed no relevant financial relationship with any product manufacturer or service provider mentioned.

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The division planners and director have disclosed no relevant financial relationship with any product manufacturer or service provider mentioned.

Audience

This course is designed for clinicians who come in contact with patients with Alzheimer disease in hospitals, long-term care facilities, home health care, and the office.

Accreditations & Approvals



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This activity has been designated for 15 Lifelong Learning (Part II) credits for the American Board of Pathology Continuing Certification Program.

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NetCE designates this continuing education activity for 15 ANCC contact hours.



This activity was planned by and for the healthcare team, and learners will receive 15 Interprofessional Continuing Education (IPCE) credits for learning and change.

NetCE designates this continuing education activity for 18 hours for Alabama nurses.

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Social workers completing this intermediate-to-advanced course receive 15 Clinical continuing education credits.

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About the Sponsor

The purpose of NetCE is to provide challenging curricula to assist healthcare professionals to raise their levels of expertise while fulfilling their continuing education requirements, thereby improving the quality of healthcare.

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Disclosure Statement

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Course Objective

In order to increase and maintain a reasonable quality of life for patients with Alzheimer disease throughout the course of the disease, caregivers must have a thorough knowledge and understanding of the disease. The purpose of this course is to provide clinicians with the skills to care for patients with Alzheimer disease in any setting as part of the interdisciplinary team.

Learning Objectives

Upon completion of this course, you should be able to:

1. Outline the characteristics and impact of Alzheimer disease.
2. Summarize the pathophysiologic changes in the brain related to dementia and Alzheimer disease.
3. Describe the different types of memory.
4. List the clinical manifestations of Alzheimer disease in relation to stage of disease.
5. Identify the goals and components of the diagnostic workup, including assistance in diagnosing non-English-proficient patients.
6. Discuss the planning issues facing the family after the diagnosis is made.
7. Identify components of a therapeutic environment and devise a strategy for managing patients with Alzheimer disease.
8. Describe the appropriate pharmacologic and non-pharmacologic treatment modalities available for Alzheimer disease.
9. Discuss components of care in working with patients with Alzheimer disease, including rehabilitation and management of coexisting illnesses.
10. Describe interventions for impaired communication.
11. Identify and develop safeguards for issues of sexuality and intimacy that may occur in patients with Alzheimer disease.
12. Apply interventions for maintaining and enhancing nutrition for individuals with Alzheimer disease.
13. Describe successful approaches and skillfully apply interventions for managing specific behaviors common to patients with Alzheimer disease.
14. Compare the techniques used for reminiscing, reality orientation, and validation therapy.
15. Describe and facilitate the care required by those with end-stage Alzheimer disease.
16. Describe and utilize effective interventions for providing support to family caregivers of patients with Alzheimer disease.



Sections marked with this symbol include evidence-based practice recommendations. The level of evidence and/or strength of recommendation, as provided by the evidence-based source, are also included so you may determine the validity or relevance of the information. These sections may be used in conjunction with the course material for better application to your daily practice.

INTRODUCTION

The number of adults 65 years of age and older in the United States has increased by 38% in the last decade and is anticipated to nearly double (to 94.7 million) by 2060 [2]. According to the U.S. Census Bureau data for 2021, 35% of adults older than 65 years of age report at least one disability [10].

Among common causes of disability in the elderly is dementia, the prevalence of which approximately doubles every 10 years after 60 years of age. The Pittsburgh Cardiovascular Health Study-Cognition Study followed 532 individuals from 1998 (mean age: 79 years) to 2013 (mean age: 93 years) for death and dementia. Of the 160 subjects who were alive in 2013, all but 19 (or 88%) were found to have developed some degree of cognitive impairment or dementia [6].

Dementia is also encountered among younger adults. In an epidemiologic survey conducted in the United Kingdom focusing on the prevalence and causes of dementia in adults younger than 65 years of age, the prevalence of dementia in those 30 to 64 years of age was 54 per 100,000 [169]. The commonly reported causes were Alzheimer disease (AD) (34%), vascular disease (18%), and alcohol-associated encephalopathy (10%).

It is estimated that about 6.7 million people in the United States have AD, the most common form of dementia [4]. Approximately 1 in 9 persons 65 years of age or older have AD, and the prevalence increases with age, occurring in 5% of people 65 to 74 years of age, 13.1% of people 75 to 84 years of age, and 33.3% of people 85 years of age and older. Annual payments related to caring for and treating patients with AD and other forms of dementia total approximately \$345 billion, and an estimated 18 billion hours of informal (unpaid) care, valued at \$339.5 billion, were provided in 2022 [4]. Unpaid caregivers include children, partners/spouses, extended family, friends, and others in the community. The number of people with AD is expected to double (to 13.8 million) by 2060, primarily due to increases in longevity and the aged population. The first wave of baby boomers will reach 85 years of age in 2031.

Although the disease was identified and named in the early part of the 20th century, little was known about AD until more recently. Now, there is much that can be done to increase and maintain a reasonable quality of life throughout the course of the disease. To accomplish this, caregivers must have a thorough knowledge and understanding of the disease. Successful management involves the “use of self” and application of behavioral interventions.

This course contains a significant amount of information that pertains to necessary care by the entire healthcare team. In order to support the purpose and unity of the interdisciplinary team, the course includes an appendix with specific nursing and caregiver interventions (**Appendix 1**) as well as information about special care facilities (**Appendix 2**).

The term “caregiver” is used throughout the text and refers to any person interacting with the patient with AD, including professional healthcare providers, nursing assistants, other members of the interdisciplinary team, or family members. Professional caregivers should accept the family as contributing members of the healthcare team.

OVERVIEW

AD was first identified and named in 1906 by Dr. Alois Alzheimer, a German neuropathologist [1]. He had been treating a middle-aged woman who exhibited symptoms of memory loss and disorientation. Five years later, the patient died after suffering hallucinations and symptoms of dementia. The manifestations and course of the disease were so unusual that Dr. Alzheimer was unable to classify the disease into any existing category. Postmortem examination of the brain revealed microscopic and macroscopic lesions and distortions, including neuritic plaques and neurofibrillary tangles.

Although it has been more than a century since the disease was identified, it has been only within the last four decades that it has received recognition. In the past, symptoms were attributed to the

“senility” of old age and these individuals were cared for at home. The problems of dementia were gradually recognized as an issue associated with the older population, but the nature of the disease and how to treat it were still a mystery. In the 1970s, researchers determined that people with AD had a neurochemical deficiency. This enabled them to study the disease in more detail and separate patients with AD from those with dementia of normal aging.

Clinicians and researchers began meeting with family members of patients with AD, leading to the founding of the Alzheimer’s Disease and Related Disorders Association, now the Alzheimer’s Association [15]. This group has been responsible for advancing research, public awareness, education, family support, and public policy changes [15]. Healthcare professionals now know that while there is a strong and as yet incompletely understood relationship between aging and AD, they are not the same condition [5]. The disease is recognized as a family, social, and economic problem.

AD is characterized by insidious, severe, and progressive cognitive impairment that is irreversible and eventually fatal. AD accounts for roughly 60% to 80% of all dementias in the United States [4]. It proceeds relentlessly, gradually destroying all cognitive functions. While the number of adults with AD doubles for every five years after 65 years of age, the disease is also seen (less frequently) in younger people [1].

There are two types of AD: familial and sporadic. Familial AD follows an autosomal dominant inheritance pattern, while sporadic AD has no known inheritance factor. Familial AD can be further classified as early-onset, when it occurs in individuals younger than 60 years of age, or late-onset, when it affects individuals older than 60 years of age [18]. Early-onset type occurs in only 4% to 5% of cases, generally affects people 30 to 60 years of age, and is considered hereditary [4; 18; 65]. There are roughly 200,000 people in the United States with early-onset AD [4; 65].

IMPACT OF ALZHEIMER DISEASE

The impact of AD has been compared to tossing a pebble into a quiet pool—the ripple of the initial toss is just the beginning of the process. In that manner, a diagnosis of AD affects the patient first, moving on to touch family members and other caregivers. The disease has wide-reaching consequences personally, sociologically, and economically.

Demographic Impact

According to the Centers for Disease Control and Prevention (CDC), approximately 121,500 patients with AD died in 2019, making it the fifth leading cause of death in adults 65 years of age or older [4]. Using mortality data provided by the National Vital Statistics System, a CDC analysis showed that the age-adjusted AD death rate per 100,000 population increased from 16.5 in 1999 to 25.4 in 2014 [172]. Rates were higher among women compared with men and among non-Hispanic White individuals compared with other racial/ethnic populations [172]. However, the findings in this report, which are derived from death certificates that list AD as the underlying cause of death, may underestimate the actual number of Alzheimer deaths in the United States. Other organizations approximate the annual number of deaths directly caused or attributable to AD at 500,000 to 700,000; it is thought that the true number lies somewhere between the death certificate data and these higher numbers. Between 2000 and 2019, the annual number of deaths from AD more than doubled, increasing 145%, while the number of deaths from heart disease decreased 7.3% [4]. The AD death rate in 2023 was 37 per 100,000 population.

Approximately 1 million new cases of AD develop each year [4]. As the aging population increases, so will these numbers. Barring effective new treatments, there will be an estimated 13.8 to 16 million patients with AD in 2060 [4].

Economic Impact

As noted, the economic impact of AD is staggering. In 2023, the national cost of caring for persons with AD and other dementias is expected to reach \$345 billion [4]. Projected costs for 2050 are nearly \$1 trillion annually (in 2022 dollars). Of the \$345 billion annual direct and indirect costs of care, [4]:

- Medicare and Medicaid are expected to cover \$222 billion, or 64%.
 - Medicare coverage for hospital and physicians' services accounts for \$157 billion.
 - Medicaid costs associated with long-term nursing home care accounts for \$65 billion.
- Out-of-pocket costs account for \$87 billion.
- Other related costs (e.g., private insurance, managed care organizations, and uncompensated care) account for \$37 billion.

With the help of family and friends, individuals with dementia often live at home. However, as the disease progresses, more care is needed. Depending on the severity of the disease progression, home care workers may be hired or the individual may be placed in a nursing home or assisted living residence. The only federal program that covers long-term nursing home care is Medicaid; however, in order to receive these benefits, the individual must be considered low income and have low assets [4]. Typically, income and assets dwindle and most individuals eventually qualify for Medicaid. Long-term care or private insurance may cover long-term nursing home care, but only if the policies are purchased before the onset of disease. These types of policies are only offered by a few insurers, have very high premiums, and are unaffordable for most. (Private insurance funding accounts for only 4% of total residential facility care costs.) The vast majority of nursing home residents with AD and other dementias depend on Medicaid to pay for their care [4]. However, even with Medicare coverage, families incur high out-of-pocket expenses as a result of premiums, deductibles, co-payments, and other healthcare costs not covered by Medicare [4].

AD sufferers often have comorbidities, including hypertension, congestive heart disease or failure, osteoarthritis, diabetes, peripheral vascular disease, chronic obstructive pulmonary disease, thyroid disease, and stroke. The cost of care for Medicare beneficiaries who suffer from AD and a comorbid condition is significantly higher, sometimes more than double the cost of care for Medicare beneficiaries without AD [4]. Hospitalization is also more likely for these patients than for those with the same condition but without AD.

Impact on Family and Significant Others

Patients are not the only ones affected by AD. More than 11 million family members, friends, and neighbors provide unpaid care for patients with AD that, by one estimate, totals \$239,000 per patient annually [4]. Nearly half of all informal care is for patients with dementia. Interventions that assist caregivers to cope and prevent caregiver burnout are as essential as interventions for the patient.

The patient with AD endures a continuing loss of mental acuity while the family witnesses the slow deterioration of their loved one. There are devastating mental, emotional, and physical changes that result in total dependence, and the need for care continues until death. In the earlier stages, the patient may wander and get lost or get up frequently during the night. The sense of self is slipping away, but the patient is helpless to do anything about it. Familiar routine tasks become monumental chores, causing frustration and humiliation when they cannot be completed. In the later stages, maximum assistance with all activities of daily living is required.

Family members experience the same roller coaster ride of emotions as they too become frustrated, resentful, and often fatigued as they try to provide for the needs of their loved one. Marriages suffer as adult children, sometimes with children of their own, try to care for aging parents, or as one aging spouse feels responsible to meet every need of his or her increasingly dependent partner. Role reversals are common within a marriage or between parent and child. Caregivers have to take on the responsibil-

ities previously assumed by the patients in addition to providing routine care. Caregivers must be strong, considerate, and able to anticipate problems. The support and care of friends may gradually subside as the situation continues for years.

THE PHYSIOLOGY OF ALZHEIMER DISEASE

ANATOMY AND PHYSIOLOGY ASSOCIATED WITH DEMENTIA

With the help of motor and sensory nerves, the brain integrates, regulates, initiates, and controls the functions of the whole body. These processes rely on successful chemical and electrical interactions. Thinking, remembering, and learning do not occur in one single place within the brain. These processes are shared by many structures, especially the cerebral cortex, which directs the most intricate and complicated functions of the brain.

To review, the longitudinal fissure divides the cerebrum into two hemispheres. The central and lateral fissures divide each hemisphere into four lobes: the frontal lobe, parietal lobe, temporal lobe, and occipital lobe. The frontal lobe is responsible for voluntary motor activity and higher intellectual functions involving conscious thought, such as planning, judgment, decision making, and problem solving. This lobe is the organizer and classifier of information. Damage to the frontal lobe results in inhibition of information processing. One section controls discrete body movements, while the centers for speech and smell are found in others. Lesions in the frontal region are linked to impulsiveness and hyperactivity. The Broca area governs verbal language skills and is located in the left frontal lobe.

The parietal lobe processes sensory input related to taste, position sense, touch, shape, and consistency of objects. The synthesis of auditory, visual, and somatic input into thought and memory is accomplished by the temporal lobe. Wernicke's area, which is responsible for the comprehension of written and verbal language, is located in the left temporal lobe.

The temporal lobe contains auditory receptive areas. Impaired memory for verbal material is linked to damage of the left temporal lobe and the inability to remember nonverbal material (e.g., faces) is associated with damage to the right temporal lobe. The reception and processing of visual information passing through the optic nerves is controlled by the occipital lobe.

All dementias can be categorized as one of two patterns of brain deterioration: cortical or subcortical. Cortical types of dementia are characterized by marked memory disturbances. AD is a result of cortical disruption but eventually affects all lobes to some degree [64]. Magnetic resonance imaging (MRI) has shown that the disease apparently occurs in different areas of the brain as it progresses [73]. Subcortical disorders often have associated motor disabilities.

The entire brain is involved in the process of memory. It is believed that the hippocampus (located deep in the brain above the brain stem) and the amygdala (situated under the temporal lobe) are critical to the formation, storage, and retrieval of memory. These structures are an integral part of the limbic system.

The hippocampus, connected by afferent pathways to sensory areas of the cortex, is responsible for the acquisition and temporary storage of declarative memory. Declarative memory enables individuals to organize their world. For example, one learns the route to work and after traveling the route a few times is able to get there even though there may be a detour. The hippocampus maintains the directory for all of these memories so when they are needed they can be retrieved. Individuals with bilateral loss of the hippocampus can only register incoming stimuli until the next stimulus arrives. Memories cannot be called up when needed, such as during learning experiences. Some believe the hippocampus helps associate affective characteristics of various sensory signals, thus helping to control the kinds of information a person will or will not remember.

The amygdala receives input directly and indirectly from the sensory system. All endocrine, visceral motor, and somatic motor effectors are influenced by the output of the amygdala. The sexual and emotional aspects of human behavior are also controlled by the limbic system.

Parkinson disease and Huntington disease are examples of dementias related to diseases that begin primarily with subcortical dysfunction. Subcortical structures include the basal ganglia, thalamus, and brain stem. Motor coordination, vital functions, and central nervous system arousal, timing, and sequential activity are controlled by the subcortical structures. Movement disorders (e.g., tremors, rigidity, chorea) are a prominent and early manifestation of subcortical dementias. In cortical diseases such as AD, impaired motor function occurs late in the course of the illness [14].

The neurons form the foundation of a complex communication system. They are attached to, and surrounded by, a myriad of dendrites, which serve to accept incoming information from the adjacent nerve cells. The nerve axon terminates in the synaptic knob, which contains a multitude of small vesicles. These vesicles, or sacs, are the storage containers for the chemical neurotransmitters that will allow the individual neuron to communicate with other nerve cells across the synaptic cleft. The neurotransmitters combine with the adjacent dendrite, causing a reaction, such as depolarization. They can also be reabsorbed by the emitting neuron or be degraded while in the synaptic cleft.

Until recently, it was believed that the human body formed its full complement of neurons before and for a short time after birth; it could not create new ones after this period. However, researchers, including those at the Institute of Neurology in Sweden and at the Salk Institute, have found that the human brain retains the ability to generate new neurons throughout life [8]. These findings may have an enormous impact on future approaches to the prevention and treatment of neurologic disorders, including AD.

There are several chemical neurotransmitters active in the brain, including dopamine, serotonin, norepinephrine, gamma-amino butyric acid (GABA), and acetylcholine; each has a fairly specific group of actions. Associated neurologic syndromes may be related to a deficit or overabundance of a particular neurotransmitter. An example is dopamine's effects on movement, learning, and emotion and abnormalities in its concentration or action leading to pathologic conditions such as Parkinson disease.

The neurotransmitter that features most prominently in AD is acetylcholine. Dysfunction and reduction of nicotinic acetylcholine receptors is linked to adverse cognitive and neurodegenerative effects [143]. As will be discussed later, the drugs that increase the cerebral levels of acetylcholine, such as the cholinesterase inhibitors, have been shown to provide some improvement in the cognition and function of people with AD [74].

PATHOPHYSIOLOGY OF ALZHEIMER DISEASE

Symptoms seen in individuals with AD are partially the result of damage to the hippocampus and the cerebral cortex, reflected in memory loss, impaired cognition, and atypical behaviors. The damage seen in AD is caused by changes in three major processes. The first process is based on the communication between neurons. Successful communication depends on reliable neuronal functions and the production of neurotransmitters. Any disruption of this process interferes with the normal function of cell-to-cell communication. The second process is cellular metabolism. Sufficient blood circulation is required to supply the cells with oxygen and nutrients such as glucose. The third process is the repair of injured neurons. Neurons have the capacity to live more than 100 years, and as such, they must continuously maintain and adapt themselves in order to survive. If this process slows or stops for any reason, the cell cannot function properly.

The presence of neurofibrillary tangles and amyloid plaques are the structural hallmarks of AD. Beta-amyloid and tau are two proteins involved in the formation of these abnormal structures. A form of tau, A68, is the major component of these tangles. In healthy neurons, the internal structures (called microtubules) are formed like long parallel tracks with crosspieces that carry nutrients from the body of the cells to the ends of the axons. In AD, the structure has disintegrated; crosspieces formed from tau are twisted like two threads wound around each other. Amyloid plaques, made up of beta-amyloid mixed with dendritic debris from surrounding cells, are found in areas of the brain associated with memory. Knowledge of how beta-amyloid causes neuron death and forms plaques is incomplete, but it is known that the normally soluble amyloid becomes insoluble when the apolipoprotein E4 susceptibility gene (*APOE4*) protein latches onto the beta-amyloid.

It is well known that nicotinamide adenine dinucleotide phosphate oxidases (NADPH oxidases) are chief signaling enzymes for the production of excessive reactive oxygen species (ROS) throughout several body systems. One example is atherosclerosis, a condition whereby NADPH oxidases elicit excessive ROS production, which in turn activates an enzyme that causes macrophages to adhere to arterial walls [46]. Several studies have shown that glial NADPH oxidases, activated by beta-amyloid, causes an excessive amount of ROS to accumulate in the brain [50]. Direct neuronal death from extracellular oxidative damage occurs when there is an overabundance of ROS [3; 47]. Additionally, excesses of intracellular ROS activate several pro-inflammatory and neurotoxic cytokines (e.g., interleukin-1 β , prostaglandin E2, and tumor necrosis factor- α) [47]. It is possible that ROS activates polymerizing enzymes (as with atherosclerosis), ultimately aiding the formation of amyloid plaques.

Individuals with more advanced AD also show decreased activity of the enzyme choline acetyltransferase in their brains. This enzyme is involved in the production of acetylcholine, and a significant drop in acetylcholine is linked to memory impairment [128]. Dysfunction and reduction in nicotinic acetylcholine receptors are linked to adverse cognitive and neurodegenerative effects [143].

Genetic Factors

Genes are comprised of four nucleotides in a wide variety of combinations, each of which directs the manufacture of a different protein. Even slight changes in a gene's DNA sequence can produce a faulty protein, which can lead to cell breakdown and eventually disease.

In addition to age and a positive family history of dementia, there are genetic risk factors for AD. Early-onset AD is an autosomal dominantly inherited disorder associated with gene mutations that alter production, assembly, and/or clearance of amyloid beta protein in the brain. Three well-characterized genotypes are mutations that encode for amyloid precursor protein (APP), presenilin-1, and presenilin-2 [12]. APP is a protein from which beta-amyloid, the chief component of plaques seen in the brains of patients with AD, is formed [4; 8]. Mutations of the presenilin 1, presenilin 2, and APP genes leading to AD occur principally on chromosomes 1, 14, and 21 [127; 155].

Genetic predisposition to late-onset AD has been linked to the APOE gene. Every person inherits one of three alleles of the APOE gene from each parent: e2, e3, or e4 in some combination (pairs). APOE3 is the most common allele found in the general population, with 50% to 60% of individuals having one or two copies. The APOE4 allele, either single (heterozygous) or as a pair (homozygous), is found in 5% to 35% of the population and is associated with an increased risk for AD compared with those individuals carrying APOE3 or APOE2 alleles [4; 127]. Carrying one copy of the APOE4 allele confers a 3- to 4-fold increased risk; inheriting two copies of APOE4 allele confers an 8- to 12-fold increased

risk of developing AD [4; 13]. There is evidence that the APOE2 allele may be protective against AD or at least help the maintenance of cognition with age [12; 78; 127].

Although it is possible to determine the APOE gene profile in connection with a strong family history of AD, carrying the e4 allele does not mean that an individual is certain to develop AD. The pathogenesis of AD is complex and other factors come into play, such as age, gender, race, lifestyle (e.g., engagement in regular physical exercise), and vascular disease.

Using data from multiple genome-wide association studies, researchers have identified other genes that may increase an individual's risk of late-onset AD, including bridging integrator 1 (*BIN1*), clustering gene (*CLU*), phosphatidylinositol binding clathrin assembly protein (*PICALM*), and complement receptor 1 (*CR1*) [127]. These studies have been made possible by the completion of the Human Genome Project in 2003 and the International HapMap Project in 2005. Research into the relationship between these genes and AD is in its infancy.

Nongenetic Factors

Although it is generally known what changes occur in the brain of people with AD, it is still not clear why these events occur in certain individuals. There are nongenetic factors related to AD, and research is being conducted to investigate these factors and to develop new theories about the processes involved in triggering the onset of the disease.

An area of investigation concerns a theory of aging that pertains to certain types of molecules, specifically free radicals that are a product of normal metabolism. These substances assist healthy cells in some functions (including signaling and homeostasis), but as discussed, an overabundance of free radicals can injure cells. The oxidative damage due to free radicals may contribute to the development of AD. Because brain cells have a high rate of metabolism and a long life span, they are vulnerable to oxidative stress.

Another area of investigation concerns the possible role of inflammation in the pathogenesis of plaque formation within the brain. Activation of the immune system leads to production of gene products that promote inflammation (i.e., inflammatory mediators). Various compounds involved in the inflammatory process have been found in the plaques of patients with AD [8]. One study has shown indirect evidence that use of nonsteroidal anti-inflammatory drugs (NSAIDs), particularly ibuprofen, may have a protective effect against AD [69].

Chronic conditions that lead to cerebrovascular disease, such as hypertension, diabetes, and obesity, appear to influence susceptibility for developing AD. Of interest is the impact of oxygen and glucose deprivation on neuronal function, amyloid accumulation, and other pathophysiologic features of AD. It has been suggested that limited degrees of brain ischemia may not be sufficient to cause dementia but may play a role in augmenting the pathologic changes and lowering the threshold for clinical expression of AD [8].

Most major vascular risk factors, including hypertension, diabetes, smoking, obesity, and hypercholesterolemia, particularly when present in midlife, have been associated with increased risk of dementia and AD later in life [4]. Less clear is whether these risk factors directly promote the neurodegenerative features (i.e., amyloid deposition) specific for AD or merely augment cognitive decline indirectly as a byproduct of enhanced atherosclerotic cerebrovascular disease. A prospective cohort study of 326 middle-aged community-based participants without dementia, followed for 20 years, found that the presence of two or more vascular risk factors was significantly associated with elevated brain amyloid deposition later in life [173]. In this study, the mean age of participants was 52 years at the time of vascular risk assessment in 1987–1989, and 76 years at the time of brain imaging (PET scan) in 2011–2013.

Vascular risk factors at baseline included body mass index ≥ 30 , current smoking, hypertension, diabetes, and hypercholesterolemia. The risk of amyloid deposition in late life correlated with the number of vascular risk factors present in midlife. Thirty-one percent of individuals with no risk factors in midlife had elevated brain amyloid deposition, compared with 61% of individuals with at least two vascular risk factors. The authors postulated that some aspect of subclinical cerebrovascular disease might increase the propensity for amyloid deposition in the brain or that vascular disease at the arteriolar level might result in reduced clearance of amyloid from the brain [173].

In a prospective analysis of 223 older adults in the Harvard Aging Brain Study, vascular risk was associated with cognitive decline and beta-amyloid deposition in the brain during a 3.7-year period of observation [174]. The rapidity of cognitive decline correlated with the magnitude of the vascular risk score and the burden of beta-amyloid. The interaction of the vascular risk score and amyloid burden with time was significant, suggesting a synergistic effect. These results highlight the importance of addressing vascular risk factors in midlife as part of a strategy to delay cognitive decline in older adults.

Researchers have also studied the role of circulating sex hormone levels in the development of AD. Some data show a correlation between decreased levels of circulating testosterone and AD in men [90]. Depletion of testosterone levels in the brain is a normal consequence of male aging. Because levels of the hormone decrease prior to the development of AD, it is not believed to be a consequence of the disease but rather a possible contributor to its development [92]. The mechanism by which the depletion may affect or cause AD has not been established. However, it has been hypothesized that low testosterone levels may increase brain levels of beta-amyloid [92]. There are also some preliminary studies examining the ability of estrogen to prevent the hyperphosphorylation of tau and, by extension, AD [96]. More research regarding the role of sex hormones in the development of AD is necessary before definitive recommendations may be made.

The prevalence AD is higher among women than men [4]. Two-thirds of AD diagnosed in the United States are in women, a difference that cannot be accounted for by longer lifespan. At the cellular level, this difference appears to be driven by how well the aging brain is able to adapt to gradual loss of estrogen-controlled glucose utilization for energy needs. Studies have shown that estrogenic control of brain glucose metabolism is dismantled during perimenopause, resulting in a hypometabolic state and shift to free fatty acids as the source of energy for cellular mitochondrial function. The risk of developing neurodegenerative disease later in life may be influenced by how well the aging brain adapts to this transition in cellular metabolism [175]. In some women, the hypometabolic state that follows decline in estrogen-controlled glucose utilization by the brain may lead to loss of white matter, beta-amyloid deposition, and disruption of synaptic plasticity [176]. Metabolic studies in the mouse AD model and human cells indicate that brain adaptation to an alternate free fatty acid energy source occurs more readily in men than women [177].

The biologic sex difference in the risk of late-onset AD has been investigated clinically by means of a carefully designed protocol that included laboratory, neuropsychological, and multimodality imaging to assess brain biomarkers [178]. In total, 121 adults (85 women and 36 men) 40 to 65 years of age with normal cognition were enrolled. After adjusting for modality-specific confounders, the female group showed higher beta-amyloid deposition, lower brain glucose metabolism, and lower MRI gray and white matter volumes compared with the male group. Among participants in the female group, menopausal status was the predictor most consistently and strongly associated with the observed brain biomarker differences, followed by hormone therapy, hysterectomy status, and thyroid

disease. These results indicate that sex differences in the development of the AD endophenotype are closely linked to hormonal factors associated with menopause. The authors concluded that the pre-clinical phase of AD may be early in the female aging process and coincides with the endocrine transition of perimenopause, emphasizing that the window of opportunity for preventive measures in women is early in the endocrine aging process [176; 178].

Comorbid Factors

A possible connection between herpes simplex virus-1 (HSV1) and AD has been explored. Researchers have found that the virus is able to enter the brain in later life as the immune system weakens, causing inflammation, oxidative damage, and increases in beta-amyloid and tau, especially in individuals with the *APOE4* allele [147]. HSV1 is found in a high proportion of the brains of elderly individuals with and without AD, but certain individuals, such as those with the *APOE4* allele, will suffer greater viral damage [147]. Interestingly, the *APOE4* allele is also a risk factor for symptomatic, HSV1 reactivation (i.e., “cold sores”). It should be noted that while the presence and activation of HSV1 in the brain is apparently common in the elderly, herpes simplex encephalitis, a serious brain disease, is an exceedingly rare, separate condition.

Researchers at Brown University and Rhode Island Hospital have proposed that AD is a neuro-endocrine disorder “associated with brain-specific perturbations in insulin and insulin growth factor (IGF) signaling mechanisms;” essentially, they hypothesize that AD is a distinct type of diabetes, termed “type 3 diabetes” [148]. Animal experiments have demonstrated that many of the hallmark signs of AD can be reproduced by artificially reducing insulin and IGF levels, but additional research with human subjects is necessary before a link can be definitively proven [61; 149].

**MODIFIABLE RISK
FACTORS ASSOCIATED
WITH ALZHEIMER DISEASE**

As noted, the risk of AD increases with age, doubling every five years after age 65. Other well-established risk factors include family history of dementia and Down syndrome [129; 130]. There is also growing evidence that people suffering head trauma involving loss of consciousness have a higher risk of developing AD [19]. Additionally, some studies have linked hypertension to a heightened risk for AD [93; 94]. As a result of these findings, it was hypothesized that antihypertensive medications may reduce the risk of dementia or AD. A study of more than 5,000 men and women older than 65 years of age found that those taking blood pressure lowering medications had a significantly lower risk of AD [95]. Cellular changes associated with vascular disease are also implicated in AD pathophysiology [150]. Life-time epigenetic changes (i.e., environmental factors that cause interactions with an individual's genetic makeup), even those that occur in the womb, can make an individual more susceptible to AD later in life [127].

Possible Environmental Risk Factors

Aluminum, a metal associated with chronic toxicity, was linked with AD in early studies. High concentrations of aluminum have been found in the brains of some individuals with AD, but the exact nature of the correlation, if any, is unknown [96]. The accumulation of aluminum may be responsible for the changes within the brain, or it might be secondary to the cause(s) of AD. Some research suggests that exposure to aluminum in municipal drinking water (used as a clearing agent during treatment) possesses greater potential for chronic toxicity than exposure from other sources, such as aluminum cookware, and that high intake of aluminum from tap water may be a risk factor for AD [144; 145].

Other researchers speculate that fluoride ingestion (at exposure levels experienced by regular drinking water consumption in fluoridated municipalities and toothpaste use) greatly enhances aluminum's neurodegenerative effects [146]. Higher levels of silicon intake are thought to protect against aluminum toxicity. Research into the possible role of aluminum in the development of AD is ongoing.

In addition to aluminum, other transition metals (e.g., copper, zinc, iron) are implicated as causative factors for AD [144; 151]. Oxidative stress, induced from either excesses or deficiencies of these metals, is theorized as being pathogenic. Iron overload, copper depletion, and zinc overload/depletion have been found in AD brains by various research groups. However, these findings were called into question by a 2011 meta-analysis that discovered citation bias towards irreproducible research, especially regarding iron overload [151]. Concrete evidence for transition metal pathogenesis is currently lacking.

While scholars agree that there may be several environmental factors for AD, no exposures, including pesticides, general air pollutants, lead, and other toxins, have been definitively linked to AD. Taking proactive steps to prevent oxidative damage, improve vascular health, and create a healthier lifestyle overall, seems to be the best defense against many environmental risks.

Possible Lifestyle Risk Factors

The lack of conclusive evidence for environmental causes of AD extends to various nutritional factors [79; 127]. However, a relationship between AD and certain deficiencies has been suggested. Low vitamin E intake, or low intake of all tocopherols from food sources, has been associated with an increased risk of AD in some studies [37; 38; 41]. Oxidative damage, a major component of AD progression, is greatly reduced in individuals with adequate dietary vitamin E/tocopherol intake, and although other antioxidants and antioxidant cofactors are thought to have a protective effect, consistent data regarding the efficacy of vitamin C, flavonoids, and carotenoids,

for example, is lacking. Research so far has shown that vitamin E supplementation does not offer protection equivalent to dietary intake of vitamin E, although it has been suggested that supplementation levels used in studies were too low or that the supplements (usually containing only α -tocopherol) did not replicate the full range of tocopherols available in foods [41]. The Academy of Nutrition and Dietetics' food and nutrition guideline for patients with AD recommends against supplementation with any antioxidants, mainly because of the risk of side effects and lack of efficacy in randomized controlled trials and reviews, even at levels above the recommended daily allowance [35].

Low vitamin B12, B6, and folate levels are also suspected of increasing AD risk, but the association is unproven. These vitamins are cofactors for the methylation of homocysteine, and high levels of homocysteine are thought to contribute to cognitive decline [41]. Supplementation with B12, B6, and folate has been associated with a protective effect in some studies [41].

Fat composition is also suspect. High saturated or trans fat intake and low polyunsaturated and monounsaturated fat intake can cause hypercholesterolemia, a risk factor for AD [153]. Omega-3 fatty acids (especially docosahexaenoic acid, or DHA) are protective against inflammation, oxidative damage, and synaptic loss. Individuals consuming one fish meal per week are better protected against dementia than those eating fish less often [153]. There is consistently strong evidence regarding the protective effect of omega-3 fatty acids for the prevention of AD [41].

A meta-analysis of 16 prospective studies examining the association between physical activity and dementia, AD, and Parkinson disease showed that brisk physical activity is inversely associated with risk of dementia [170]. Further evidence of the neuroprotective effects of exercise is provided by a meta-analysis indicating that aerobic exercise in midlife is associated with a significant reduction in risk for later mild cognitive impairment [171].

Possible Cognitive Risk Factors

There is increasing evidence that individuals who do not engage in regular mental, social, and physical activities (and possibly a combination of all three) are at heightened risk for AD [153]. Social activities and interactions provide opportunities for exercise, which maintains vascular health, and intellectual stimulation and problem solving, which maintain cognition. Individuals with large social networks perform better on tests of cognition despite having similar amounts of brain lesions as individuals with few social contacts. It is not known which specific component of leisure, work, and/or mental activities in late life prevent or delay AD; however, researchers have noted a protective effect when greater mental complexity is required throughout life at work and if cognitive/social/physical activities are maintained during mid-life [153].

An analysis of data from two longitudinal studies of health and aging demonstrated the potential impact of a healthy lifestyle on lowering the risk of AD [179]. In this study, a cohort of 2,765 participants older than 65 years of age were selected on the basis of available lifestyle data at baseline and periodic assessment for AD. A healthy lifestyle score was defined in relation to five factors: nonsmoking, light-to-moderate alcohol consumption, high-quality diet intervention, ≥ 150 minutes/week moderate- or vigorous-intensity physical activity, and engagement in late-life cognitive activities, giving an overall score ranging 0 to 5. During a median follow-up of 5.8 to 6.0 years, 608 (22%) of the participants developed incident AD. Compared with participants with 0 to 1 healthy lifestyle score, the risk of AD was 37% lower in those with 2 to 3 healthy lifestyle factors and 60% lower in those with 4 or 5 healthy factors.

THE ROLE OF MEMORY

AD is characterized by progressive deterioration of the domains of cognition, including memory, higher integrative function, and rational behavior. Cognition involves the host of mental skills and processes that are acquired over a lifetime that provide humans with the ability to learn, think, remember, make judgments, use logic and reason, and have insight. Memory is a major antecedent for developing mastery in these intellectual functions. Memory deficits are an early and progressive sign of AD. In order to understand the behaviors of individuals with AD, it is necessary to understand the significance of memory, the process of remembering and recall, and the various types of memory.

Memory is dynamic, developing in stages and constantly changing. Memory and learning are not separate functions. Both depend on the storage of data that can be retrieved at a later date. The ability to remember simplifies life, allowing minimum energy to be expended on routine activities. For example, arising in the morning and completing the activities of daily living requires little conscious thought. The tasks are performed by rote. However, the person with memory deficits may be unable to recognize the bedroom, unable to find the bathroom, and unaware that teeth must be brushed or where the items are that are used to complete these tasks.

Remembering and Recall

The acquisition of a memory depends on several mechanisms. Information is received from the environment, and the senses perceive it, interpret it, and respond to it. There are three stages involved in this process.

Information is acquired during the first stage; the information is taken in through the senses, perceived, and understood. If the information is visual, it enters the brain through electrical impulses coming from the retina, traveling through the optic nerve and into the cerebral cortex. A limited amount of this information is retained in short-term memory.

Like a clipboard on a computer, the contents of short-term memory are constantly being lost and replaced with other information unless the contents are restored through repetition. For example, when a telephone number is looked up, it is usually remembered long enough to complete the call. This information will soon be forgotten if it is not used again for several days or weeks. However, if the number is dialed every day or several times per week for several weeks, it becomes firmly entrenched in the brain as long-term memory for the duration of use. There is a limited storage capacity for short-term memory.

The second stage of memory is retention. Important information is placed in long-term memory, where the storage involves associations with words, images, or other experiences. This information can be recalled days, weeks, or years later. For a memory to be retained, it must be transferred from short-term to long-term memory. Physical changes take place in the brain to facilitate this transfer.

Retrieval of information occurs in the third stage. Information is stored at an unconscious level and is later recalled, bringing it into the conscious mind. The accuracy and availability of the memory depends on how well the information was processed in stage two (retention). Some memories are easily recalled, others seem temporarily unavailable, and some seem to disappear from the mind completely.

Types of Memory

There are many types of memory. How the information is used depends on how the memory was formulated. Episodic memory pertains to remembering specific events associated with a particular time and place. Episodic memory requires no effort at learning. Remembering the details of a child's birth, one's wedding, or perhaps a catastrophic event are other examples of episodic memory.

Semantic memory requires the conscious involvement of the learner. The knowledge is not associated with a particular time or place but is learned at some point in time. Skills such as using a telephone book, balancing a bank statement, cooking from a recipe, and reading a road map are examples of semantic type memories.

TEN WARNING SIGNS OF ALZHEIMER DISEASE

Normal Aging Events	Possibly Alzheimer Disease
Temporarily forgetting someone's name	Not being able to remember the person later
Forgetting the carrots on the stove until the meal is over	Forgetting a meal was ever prepared
Unable to find the right word, but using a fit substitute	Uttering incomprehensible sentences
Forgetting for a moment where you are going	Getting lost on your own street
Talking on phone, temporarily forgetting to watch a child	Forgetting there is a child
Having trouble balancing the checkbook	Not knowing what the numbers mean
Misplacing a wristwatch until steps are retraced	Putting a wristwatch in a sugar bowl
Having a bad day	Having rapid mood shifts
Gradual changes in personality with age	Drastic changes in personality
Tiring of housework, but eventually getting back to it	Not knowing or caring that housework needs to be done
Source: [121]	Table 1

Implicit memory is information learned without the conscious involvement of the individual. It is established through early and frequent repetition. Reciting the Pledge of Allegiance and singing "Happy Birthday" are the result of implicit memory. Social customs and manners, such as saying please and thank you, develop through implicit memory.

Motor memory is required for tasks utilizing motor skills, such as riding a bicycle, jumping rope, and dancing. Once learned, these skills are rarely lost even if not used for some time.

Affective memory refers to feelings and emotions. Listening to a song may evoke memories of a person, place, or event. The aroma of a certain perfume may bring to mind a specific person. Cooking odors may elicit the memory of family holiday meals. Meeting a person for the first time may bring forth feelings of dislike until one realizes that the person resembles someone from the past.

Semantic memory is the first type affected in the person with AD [131]. The individual may notice that tasks that were once simple to perform are causing increasing frustration. Motor memory is eventually lost as activities requiring fine and gross motor skills become more and more difficult to access. Implicit memory often remains intact as long as the individual can communicate. Anyone

who has worked with those with advanced AD has experienced the surprise of hearing a person in the later stages singing a favorite hymn during church service or an old song during a sing-a-long. There is some evidence that affective memory remains intact far into the disease.


NORMAL AGING, MILD COGNITIVE IMPAIRMENT, AND ALZHEIMER DISEASE

As individuals age, they may notice changes in memory and may express concern that they are developing AD. Age-associated memory impairment, a common and normal process relating to structural and functional brain changes, should not be confused with the memory loss associated with a dementia. Age-associated memory impairment, also called benign senescent forgetfulness, may accompany aging, but unlike AD, it does not include other cognitive impairments. Other factors, such as cardiovascular disease, metabolic disorders, head trauma, alcohol or substance abuse, and side effects of certain medications, can also cause an apparent decline of short-term memory. The Alzheimer's Association lists signs that distinguish normal aging events from those due to AD (*Table 1*).

MILD COGNITIVE IMPAIRMENT

Mild cognitive impairment (MCI) is a spectrum of mild but persistent memory loss that lies between normal age-related memory loss and diagnosed AD. The memory deficits are beyond those expected for the person’s age, and the individual persistently forgets meaningful information that he or she wants to remember. However, other cognitive functions may be normal, there is little loss of ability to work or function in typical daily activities, and there are no other clinical signs of dementia. Multi-step tasks such as shopping, making dinner, and paying bills may take longer than usual and more errors may be made, but overall, little or no assistance is required [154].

Many individuals with MCI have a high probability of developing AD. Those who are likely to progress to AD will have difficulty learning and retaining new information [154]. Testing for biomarkers while making a diagnosis can identify people at risk for or who are progressing to AD but is only recommended for use in research settings. Biomarker testing standards and cut-points are not yet defined; however, low cerebrospinal fluid (CSF) beta-amyloid levels combined with high CSF tau is considered a positive for MCI due to AD [154]. Positron emission tomography (PET) amyloid imaging has also proven valuable for predicting progression to AD in research.



EVIDENCE-BASED
PRACTICE
RECOMMENDATION

The Society of Nuclear Medicine and Molecular Imaging and the Alzheimer’s Association state that amyloid imaging is appropriate in certain patients satisfying core clinical criteria for possible Alzheimer disease because of unclear clinical presentation, either an atypical clinical course or an etiologically mixed presentation.

(<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3733252>. Last accessed August 17, 2023.)

Strength of Recommendation: B (established as probably useful based on good evidence)

PROGRESSION OF ALZHEIMER DISEASE

The onset of AD is slow and insidious; impaired memory is usually the initial symptom, followed later by deficits in other cognitive domains. Symptoms may be present for several months before the family realizes the severity of the problem. In some situations, a spouse may shelter and cover for the patient so even children and friends are unaware. In other cases, it is the death of the healthy spouse that causes other family members to recognize the changes that have occurred in the living partner. After the diagnosis of AD, most patients will survive for 4 to 6 years; however, this number can vary from 3 to 20 years [156].

The early stages are especially challenging for patients with AD, as they realize that they are slipping away and are unable to do anything about it; each stage brings with it additional mental, emotional, or physical losses. Inevitably, nearly all patients develop amnesia (memory impairment), aphasia (language impairment), agnosia (inability to identify common objects), apraxia (inability to use objects, despite knowing their function), and visuospatial deficit and may exhibit apathy, depression, or psychosis. Afflicted individuals will become dependent on caregivers for meeting even the most basic physical needs. The model of the progressive cognitive and functional decline in AD as “childhood development in reverse” (i.e., from the functional capacity of a child to that of an infant) is one that is easy for nonmedical family members and caregivers to understand [6].

The disease progresses continuously, and it is useful to remember that staging of AD is an artificial construct meant to assist in diagnosis and management. Presentation of the disease is widely varied in patients, with symptoms and deficits affecting every individual differently or not at all. The Alzheimer’s Association presents a useful framework for staging, with various benchmarks in cognitive decline, based on the Global Deterioration Scale (GDS) [156]:

Stage 1: Preclinical Stage (Normal Function)

During an interview, no memory problems are evident, and no memory problems are identified by the patient. There may be measurable biomarkers indicating changes; however, no diagnostic criteria have been developed for use by clinicians. This stage exists as a placeholder for future biomarker diagnostics.

Stage 2: Early Stage (Very Mild Cognitive Decline)

Patient complains of memory lapses (e.g., forgetting familiar words and names, the location of keys, eye-glasses, or other everyday objects). These problems are not evident during a medical examination or readily apparent to friends, family, or co-workers. Patients in this stage may be experiencing normal age-related decline or early signs of AD.

Stage 3: Early Stage (Mild Cognitive Impairment Due to AD)

During a detailed medical interview or in clinical testing, problems with memory or concentration may be measurable or discernible. Patients, friends, family, or co-workers begin to notice deficiencies. Common difficulties include:

- Word- or name-finding problems (noticeable to family or close associates)
- Impaired ability to remember names when introduced to new people
- Performance issues in social and work settings (noticeable to others)
- Reading a passage and retaining little material
- Losing or misplacing important objects
- Decline in ability to plan or organize

Early-stage AD or MCI can be diagnosed in some, but not all, individuals with these symptoms.

Stage 4: Early Stage (Moderate Cognitive Decline Due to Mild or Early-Stage AD)

At this stage, the patient interview detects clear-cut deficiencies in the following areas:

- Reduced memory of personal history
- Decreased ability to remember recent events
- Impaired ability to perform challenging mental arithmetic (e.g., counting backward from 100 by serial 7s)
- Decreased capacity to perform complex tasks (e.g., shopping, planning dinner for guests, paying bills and/or managing finances)
- The patient may seem subdued and withdrawn, especially in socially or mentally challenging situations (identified by an acquaintance)

Stage 5: Middle Stage (Moderately Severe Cognitive Decline; Moderate or Mid-Stage AD)

Major gaps in memory and deficits in cognitive function are observed by an acquaintance and are apparent during an assessment. Some assistance with day-to-day activities becomes essential. At this stage, individuals may:

- Be unable, during a medical interview, to recall important details (e.g., their current address, their telephone number, or the name of the college or high school from which they graduated)
- Become confused about where they are or about the date, day of the week, or season
- Have trouble with less challenging mental arithmetic (e.g., counting backward from 40 by 4s or from 20 by 2s)
- Need help choosing proper clothing for the season or the occasion
- Usually retain substantial knowledge about themselves and know their own name and the names of their spouse or children
- Usually require no assistance with eating or using the toilet

Stage 6: Middle Stage
(Severe Cognitive Decline;
Moderately Severe or Mid-Stage AD)

Memory difficulties have significantly worsened, and noticeable personality changes may have emerged. Family members or caregivers relate that the affected individual needs extensive help with daily activities. At this stage, individuals may:

- Lose most awareness of recent experiences and events as well as of their surroundings
- Recollect their personal history imperfectly, although they generally recall their own name
- Occasionally forget the name of their spouse or primary caregiver but generally can distinguish familiar from unfamiliar faces
- Need help getting dressed properly, as without supervision, the individual may make such errors as putting pajamas over daytime clothes, socks over shoes, or shoes on wrong feet
- Experience disruption of their normal sleep/waking cycle
- Need help with handling details of toileting (e.g., flushing toilet, wiping, and disposing of tissue properly).
- Have increasing episodes of urinary or fecal incontinence
- Experience significant personality changes and behavioral symptoms, including suspiciousness and delusions (e.g., believing that their caregiver is an impostor); hallucinations (seeing or hearing things that are not really there); or compulsive, repetitive behaviors, such as hand wringing or tissue shredding
- Tend to wander and become lost

Stage 7: Late Stage (Very Severe Cognitive Decline; Severe or Late-Stage AD)

During an intensive interview, the patient may only be able to speak a few words. This is the final stage of the disease. Individuals lose the ability to respond to their environment, the ability to speak,

and, ultimately, the ability to control movement. At this last stage, individuals will:

- Frequently lose their capacity for recognizable speech, although words or phrases may occasionally be uttered
- Need help with eating and toileting, as there is general incontinence
- Lose the ability to walk without assistance, then the ability to sit without support, the ability to smile, and the ability to hold their head up. Reflexes become abnormal and muscles grow rigid. Swallowing is impaired.

DIAGNOSIS

Dementia is a general term encompassing many conditions, characterized by a decline in an individual's usual level of intellectual functioning severe enough to interfere with daily tasks, activities, work, and social and family relationships [17; 22; 155]. A dementia may be the result of chronic or infectious disease, malignancy, or head trauma, or it may be substance induced. Dementia may be progressive, static, or remitting depending upon the underlying pathology. Cognitive or behavioral symptoms and signs are the major manifestations in patients with dementia.

Other medical conditions present similar clinical manifestations as AD dementia (e.g., dementia with Lewy bodies, primary progressive aphasia, vascular dementia, behavior variant frontotemporal degeneration) [155]. Some of these conditions may be reversible with treatment. A patient suspected of having AD or any dementia should be given a complete workup by practitioners who are experienced in the diagnosis and treatment of dementias. An individual who has personal knowledge of the patient, particularly over an extended period of time, should be available to answer questions that assist in establishing a diagnosis. Knowing the type of dementia is critical in establishing a treatment plan and prognosis (*Table 2*).

OVERVIEW OF MAJOR FORMS OF DEMENTIA

Disease	Features	Major Clinical Manifestations	Course
Alzheimer disease	Involvement of higher brain structures, neurofibrillary tangles, amyloid plaques Accounts for 60% to 80% of all dementias	Memory and other cognitive deficits Visuospatial impairment Wandering Aphasia	Onset: 60 to 80 years of age May progress over 3 to 20 years
Mild cognitive impairment	Cognitive deficits greater than expected for patient's age	Cognitive decline No interference with activities of daily living	May or may not progress into dementia
Multi-infarct or vascular dementia	Multiple cerebral infarctions May be related to cardiovascular disease and/or diabetes	Dependent on location of infarct Cognitive impairment Emotional lability Dysarthria, dysphasia	Onset: 60 to 75 years of age Outcome depends on occurrence of infarcts
Dementia with Lewy bodies	Accumulated bits of synuclein protein Rarely familial	Cognitive impairment Parkinsonian symptoms REM sleep disorder Hallucinations Apathy	Symptoms fluctuate Progressive over approximately 8 years
Parkinson disease	Deficiency of dopamine	Movement disorders Dysarthria, dysphasia, bradykinesia Late cognitive dysfunction	Onset: ≥ 50 years of age Progression varies
Frontotemporal dementia (Pick disease, primary progressive aphasia, semantic dementia)	Abnormal accumulation of protein in certain neurons Rare Predominately genetic	Cognitive impairment Depression, apathy Wandering Disorientation Lack of inhibition	Onset: 35 to 75 years of age May progress over 2 to 10 years
Creutzfeldt-Jakob disease	Prion protein abnormalities Spongiform changes in brain Rare	Cognitive impairment Myoclonus Extrapyramidal movements	Onset: ≤ 60 years of age Rapidly progressive
Normal pressure hydrocephalus	Increase of CSF in cerebral ventricles Possible causes are subarachnoid hemorrhage, infection, trauma, tumor, or post-surgical complications Rare	Cognitive impairment Difficulty with gait Incontinence	Progression depends on cause
Huntington disease	Autosomal dominant order	Cognitive impairment Choreiform movements Dysarthria, dysphasia, bruxism	Early-onset: < 20 years of age Late-onset: Middle age
Wernicke-Korsakoff syndrome	Severe thiamine deficiency Associated with alcoholism, AIDS, cancer, and hyperthyroidism	Confusion Permanent memory gaps Motor and coordination difficulty	Progression may be halted with treatment, but existing damage is irreversible
Gerstmann Sträussler Scheinker disease	Prions suggested Spongiform changes in brain Extremely rare Usually familial	Cerebellar ataxia Cognitive impairment	Onset: 35 to 55 years of age May progress over 2 to 10 years
HIV-associated dementia or AIDS dementia complex	HIV infection	Cognitive impairment Motor dysfunction paraparesis Depression	Progression varies
Neurosyphilis	Spirochete Sexually transmitted disease Rare Occurs with delayed treatment	Cognitive impairment Tremors, ataxia Dysarthria	General paresis may occur 20 to 30 years after primary infection
Traumatic brain injury	Consequence of head trauma	Memory impairment Behavioral symptoms with or without motor and/or sensory deficits	Nonprogressive Repeated injuries can lead to progressive dementia

Source: [113; 114; 115; 116; 117; 118; 120; 156]

Table 2

The symptoms of all-cause dementia include [155]:

- Uncharacteristic changes in mood or personality: Apathy, social withdrawal, socially unacceptable actions (disinhibition), loss of interest in usual activities, agitation, obsessive or compulsive behaviors
- Difficulty with communication: Speech may become impaired due to problems accessing words. Reading and writing may be affected.
- Impaired visuospatial ability: Inability to recognize, find, or understand objects (or faces) despite good vision. Difficulty knowing what to do with tools, eating utensils, or articles of clothing.
- Poor decision making, reasoning, or task planning: Self-preservation instinct seemingly becomes lost, difficulty managing finances or performing other complex tasks
- Impaired learning ability: Repeating questions or conversations, forgetting where objects were left, forgetting to keep appointments

At least two of the above domains should be identified to make a diagnosis of all-cause dementia [155]. Patients with dementia due to AD will present with additional characteristics. Although amnesic presentation is the most common syndrome in AD, memory loss is not always the primary cognitive deficit in AD dementia. Core clinical criteria of probable AD dementia include [155]:

- Onset that is insidious (i.e., over months or years) rather than sudden (i.e., over hours or days)
- Independently verified history of declining cognition
- Additional cognitive deficits that are either amnesic (e.g., impaired learning capacity/short-term memory) or nonamnesic. Nonamnesic presentation includes language impairment (e.g., word-finding); visuospatial impairment (e.g., object agnosia, simultanagnosia, alexia, impaired face recognition); and executive impairment (e.g., reasoning, problem solving, judgment).

- Differential diagnosis of AD

A diagnosis of probable AD can be made based on the medical history, physical examination, diagnostic studies, caregiver interviews, and objective cognitive assessment including either neuropsychological testing or a “bedside” mental status examination [155]. The observation of signs and symptoms during cognitive assessment (with the ruling out of other disease processes) can support the diagnosis even in the absence of pathology reports. The earlier the diagnosis is made, the greater the benefit in managing the clinical course of the illness.

As discussed, the stage of memory impairment between normal aging and very early dementia (i.e., MCI due to AD) gives some insight into the possible etiology and treatment of AD. MCI due to AD must be differentiated from MCI due to other causes by applying the various diagnostic criteria. Specific etiologies should be ruled out (e.g., traumatic, vascular, pharmacologic, neurodegenerative), and a diagnosis of probable AD dementia should not be made when evidence of concomitant disease, trauma, or depression is found [154; 155]. Again, a detailed patient history should be obtained including family history of AD and information about changes in cognition from the patient, family members, caretakers, or clinicians. Certain genetic factors should also be taken into account. In addition, neuroimaging procedures can assist in the diagnosis [76].

The goals of the diagnostic process are to:

- Make a specific diagnosis
- Determine the type of dementia, the extent of the impairment, or the stage of the disease
- Avoid labeling a person with a diagnosis of dementia or AD when it does not exist
- Avoid implementing the wrong treatment as a result of misdiagnosis
- Identify any systemic or psychiatric illness
- Define the practical and psychosocial needs of the patient, the family, and the primary caregivers
- Plan for the future

DISTINGUISHING DEMENTIA, DELIRIUM, AND DEPRESSION	
Condition	Clinical Presentation
Dementia	Gradual onset, irreversible, chronic, progressive, long duration Shortened attention span Impaired memory Difficulty with abstraction, problems with word finding, confabulates Struggles to remain independent
Delirium	Acute or subacute onset, reversible or alleviated with prompt appropriate treatment Short duration (hours to one month) Sensorium clouded Impaired, fluctuating attention span Impaired recent and immediate memory Thinking is disorganized, distorted, speech incoherent Associated with trauma, disease, infection, and/or chemical intoxication
Depression	Variable onset, often abrupt, reversible with treatment Weeks to several years' duration Sensorium clear Attention span normal but easily distracted Selective memory impairment Intact thinking but expresses hopelessness, helplessness Often coincides with major life changes
Source: [25]	

Table 3

As AD progresses, various mood and behavioral disorders may become prominent in many patients and may require intervention and treatment with appropriate medications. Some of these manifestations should lead to reconsideration of the diagnosis of AD. For example, hallucinations in the presence of evolving extrapyramidal symptoms should lead to consideration of Lewy body disease, whereas development of significant personality alterations in the presence of mild dementia should raise the question of Pick disease. The most common pathologic behaviors in patients with AD are apathy (70%), agitation (60%), motor abnormalities (40%), nighttime behavioral disturbances (30%), delusions (25%), disinhibited behaviors (20%), hallucinations (10%), and euphoria (2%) [6].

DISTINGUISHING DEMENTIA FROM DELIRIUM AND DEPRESSION

Remembering the “3 Ds” (dementia, delirium, and depression) during the assessment process can help the practitioner identify the cause of the impairment. Deficits in cognition, memory, or physical

function can also result from delirium and depression. Any two or all three of these conditions can be present at the same time.

Delirium

Delirium is defined as “an acute change in cognition and a disturbance of consciousness, usually resulting from an underlying medical condition or from medication or drug withdrawal” [83]. Delirium may be related to an acute or chronic medical condition or may be substance induced. While delirium is often a forerunner of underlying disease, delirium may also have a psychosocial/environmental cause associated with the death of loved ones, sensory deprivation, or overstimulation and changes in the degree of personal control [24]. The incidence is highest among the elderly and is often misdiagnosed or missed entirely. In individuals with pre-existing dementia, it may be mistakenly assumed that the signs and symptoms are evidence of natural disease progression (**Table 3**). Knowing the patient’s history of onset and type of disease progression is helpful in identifying delirium [83].

CRITERIA FOR MAJOR DEPRESSIVE EPISODE	
Five or more of these symptoms have been present during the same two-week period and represent a change from previous functioning. The symptoms must be present most of the day, nearly every day. At least one of the symptoms is either depressed mood or loss of interest or pleasure. <ul style="list-style-type: none">• Depressed mood• Markedly diminished interest or pleasure in all or almost all activities• 5% or greater change in weight when not dieting or decrease or increase in appetite• Insomnia or hypersomnia• Psychomotor agitation or retardation• Fatigue or loss of energy• Feelings of worthlessness or excessive or inappropriate guilt• Diminished ability to think or concentrate• Recurrent thoughts of death, suicidal ideation, or specific plan of suicide attempt	
Source: [7; 20]	Table 4

Pneumonia and urinary tract infections are common causes of delirium in the older population. Elderly people do not always present the typical signs of inflammatory response, such as elevated temperature and physical pain or discomfort. Confusion may be the only sign that an infection is present. The confusion generally dissipates with appropriate treatment.

Some medications may also be a cause of delirium, including [9]:

- Diuretics
- Steroidal anti-inflammatory agents
- Opioid analgesics
- Antidepressants
- Antipsychotic agents
- Cardiac medications
- Antihypertensive agents
- H2-blocking agents
- Anticholinergic agents

Depression

The diagnosis of depression may be difficult to make in people with multiple medical conditions. Depression is present in 25% of individuals diagnosed with AD [133]. Left undiagnosed and untreated, depression results in an earlier onset of behavioral disturbances, cognitive deficits, and mental suffer-

ing. Depression may also be responsible for earlier admission into a long-term care facility. Depression is often recurrent and thus may be a potentially chronic illness [26]. The fifth revised edition of the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-5-TR) criteria for major depression are summarized in **Table 4**.

Misdiagnosing dementia as depression may result in an exacerbation of the disease, because antidepressants with anticholinergic properties may worsen the confusion and memory impairment. In people with coexisting AD and depression, failure to identify and treat the depression may cause additional physical and emotional discomfort. The clinical interview is the foundation for evaluating and diagnosing depression in older adults. Self-report questionnaires can assist in screening for depression. The 30-item Geriatric Depression Scale (GDS-30) and the Center for Epidemiological Studies Depression Scale Revised (CESD-R) have proven to be reliable and valid.

It has been noted that “memory difficulty, agitation, disrupted sleep-wake cycle, and personality changes (e.g., apathy, increased dependence) are classic symptoms of AD that may be mistaken for depressive signs of poor concentration, decreased interest, changes in psychomotor activity, sleep disturbance, and fatigue” [16].

Dementia

The DSM-5-TR requires the following signs to be present before a diagnosis of major neurocognitive disorder (commonly referred to as dementia) is made [20]:

- Evidence of significant cognitive decline from a previous level of performance in one or more cognitive domains (i.e., complex attention, executive function, learning and memory, language, perceptual-motor, or social cognition) based on both:
 - Concern of an individual, a knowledgeable informant, or the clinician that there has been a significant decline in cognitive function
 - A substantiated impairment in cognitive performance, preferably documented by standardized neuropsychological testing or, in its absence, another quantified clinical assessment
- Cognitive deficits interfere with independence in everyday activities.

Dementia is not diagnosed if the symptoms occur only during the course of delirium or another mental disorder. Delirium may be superimposed on a pre-existing dementia, in which case both diagnoses are given. A specific diagnosis of AD is considered only when all other etiologies for the dementia have been ruled out.

DIAGNOSTIC EVALUATION

History

A complete and thorough medical history is imperative to making an accurate diagnosis. The family history may identify genetic or familial illness. Testing for impaired vision and hearing should be included. People with hearing impairments often deny the problem and will answer questions inappropriately, thus appearing confused. Visually impaired people may have problems controlling their environment and may also appear disoriented. Determine the onset and progression of the disease—whether abrupt or gradual. Identify whether the manifestations fluctuate, are gradually worsening, or if there is a stair-step progression.

The aging process causes diminished liver and kidney function. This loss may interfere with the absorption and metabolism of medications. Adverse effects of drugs such as cimetidine, digoxin, and diazepam are often noted through behavioral changes. A thorough assessment of the medication regimen should be included in the history. It is necessary to question the patient or family regarding the use of:

- All prescription medications
- Over-the-counter medications
- Eye drops, eardrops, and topical medications
- Medications prescribed for someone else
- Herbal and nutritional supplement preparations
- Alcohol
- Other chemical substances

Nutritional and hydration status can also affect cognition. Dehydration may be attributed to the fact that thirst is not sharply experienced by the elderly. Fear of incontinence also hinders the consumption of adequate fluids. Nutritional disorders, such as anemia, hypoglycemia, hyperglycemia, hypoproteinemia, and vitamin deficiencies, often present clinical manifestations similar to AD. Caretakers should be instructed to keep a food diary for three days so dietary intake can be evaluated. Poor nutrition is not uncommon among elder adults and may be related to economic factors, health problems that diminish appetite, living alone and having no motivation to cook, or functional deficits that affect the ability to purchase or prepare food. An informant should supplement the clinical history, and clinicians should use any of the informant-based questionnaires when possible [159].

Functional Assessment

A functional assessment, to investigate the ability to complete activities of daily living, should be included in the diagnostic evaluation [159]. These activities include bathing, dressing, eating, and mobility within the home [2]. Instrumental activities of daily living include preparing meals, shopping, managing money, using the telephone, completing housework, and taking medications. Various tools

are available that measure the person's ability to perform instrumental activities (e.g., Cognitive Performance Test, Executive Function Performance Test, Kitchen Task Assessment) [23]. These tests are also useful in determining whether or not someone can live independently or the degree of assistance that is required. Activities to consider include [23]:

- Food preparation: Shopping, making coffee, preparing and cleaning up after a meal, using/turning off the stove
- Financial ability: Writing checks, paying bills, balancing a bank statement, keeping tax records, handling business affairs and documents
- Mobility: Ability to drive or arrange for and use public transportation
- Current events: Understanding television, books, magazines, and newspapers
- Appointments: Remembering family occasions, holidays, and medications
- Recreation: Engaging in hobbies, playing cards, and games of skill

Physical and Neurologic Examination

Full neurologic and physical exams are required [159]. The neurologic exam consists of testing speech, sensation, coordination, muscle strength, eye movement, and reflexes [157]. Other etiologies associated with neurologic dysfunction (e.g., Parkinson disease, stroke, hypothyroidism, vitamin B12 deficiency, tumors) should be ruled out.

There are many physical disorders that can cause a decrease in the cognitive function of elderly persons. Some may be elicited or suggested by a complete physical examination. The physical examination should determine if fever is present, because many infectious processes (e.g., urinary tract infections) are known to have cognitive and/or psychological manifestations in the elderly. The assessment of cardiac status should include observation of the pulse rate and rhythm, cardiac auscultation, and blood pressure measurements while the patient is sitting and standing. The thyroid gland should be

palpated to note enlargement or the presence of nodules. Pulmonary auscultation is performed to listen for rales and rhonchi and to observe the patient's ease of breathing. Examination of the abdomen for masses and organomegaly can be accomplished easily, as can an assessment of renal pain by palpating and percussing the appropriate regions of the body. Listening for bruits over the carotid arteries and palpation of all major pulses are necessary to help evaluate vascular status. Electrocardiogram and chest x-ray may be useful.

Laboratory Tests

All comorbid conditions must also be identified. The following tests are generally considered mandatory at the initial evaluation, both to rule out other etiologies and to establish a diagnosis of dementia [159]:

- Complete blood cell count
- Blood sedimentation rate
- Blood chemistries including electrolytes, calcium, and blood glucose level
- Urine analysis with culture (and sensitivity if indicated)
- Liver function studies
- Kidney function studies
- Thyroid stimulating hormone
- Vitamin B12 and folate levels
- Syphilis, human immunodeficiency virus (HIV), and *Borrelia* serology (in individual cases)

CSF testing with routine cell count, protein, glucose, and protein electrophoresis may be included for patients with atypical presentation or who are suspected of having chronic meningitis or certain other neurologic diseases (e.g., Creutzfeldt-Jakob disease) [159]. In patients with rapidly progressive dementia, CSF 14-3-3 or total tau measurement is recommended to identify Creutzfeldt-Jakob disease. Electroencephalography may also be useful with atypical presentations or when Creutzfeldt-Jakob disease or transient epileptic amnesia is suspected [159].

In 2022, the U.S. Food and Drug Administration (FDA) permitted marketing of the first in vitro diagnostic test to detect amyloid plaques associated with AD [187]. The Lumipulse G β -Amyloid Ratio (1-42/1-40) test is intended to be used in patients 55 years of age and older presenting with cognitive impairment who are being evaluated for AD and other causes of cognitive decline. The test measures the ratio of beta amyloid 1-42 and 1-40 concentrations in CSF. The specificity is roughly equivalent to PET scan results. This test is not intended to be used as a standalone diagnostic assay or for screening; further, false-positive results are possible [187].

Mental Status and Neuropsychological Testing

Mental status examinations alone are not definitive for establishing a diagnosis of AD; however, they are central to the diagnostic process and provide important information for developing a more complete clinical picture. Additionally, assessment offers a baseline for monitoring the progression of the disease and can be used to reassess mental status in people who have delirium or depression upon initial evaluation. All behavioral and psychological symptoms should be assessed and documented. Delayed recall tests are particularly useful [159].

There are several mental status examinations that can be used, including the Mini-Mental State Examination, the Blessed Information-Memory-Concentration Test, the Blessed Orientation-Memory-Concentration Test, the Short Test of Mental Status, and the Mini-Cog. One study found that compared with the more commonly used Mini-Mental State Examination, the Short Test of Mental Status was slightly more sensitive in identifying individuals with cognitive impairment and was significantly better at documenting MCI due to AD and predicting progression to AD [158]. When administering and interpreting any of these tests, one must be sure to consider the presence of sensory impairments, physical disabilities, and the age, educational level, and cultural influences of the individual being studied [82].

Neuropsychological testing may be appropriate when the mental status test is abnormal but the functional test is normal; when a family member expresses concern or dementia is suspected and results of mental status tests are within the normal range; when the patient has an advanced academic degree; or when the patient's occupation indicates high premorbid intelligence [16]. Preferably, a specialist in neuropsychology should be employed.

When mental status test results indicate cognitive impairment, the results of neuropsychological testing must be considered with the results of other assessments and the patient's history when any of the following circumstances apply:

- Low level of formal education
- Evidence of long-term low intelligence (more than 10 years)
- Inadequate command of English for the test
- Minority racial or ethnic background
- Impairment in only one cognitive area on mental status tests
- No evidence of cognitive impairment for more than six months
- No evidence of functional impairments

Communication with patients regarding personal and family history is a necessary step in identifying dementia and obtaining an accurate diagnosis. When there is an obvious disconnect in the communication process between the practitioner and patient due to the patient's lack of proficiency in the English language, an interpreter is required.

Neuroimaging

Brain imaging should be included in the evaluation of patients suspected of having AD. The imaging modality of choice is MRI, which is able to assess with considerable accuracy the integrity of intracerebral structures as well as the size of the hippocampus [76]. It has been found that the volume of the hippocampus is diminished in patients with AD, compared with non-affected individuals, and that persons with some degree of atrophy are more liable to develop AD. MRI is also sensitive

for detecting cerebral atrophy, vascular disease, and other structural abnormalities that may indicate contributing factors or an alternative diagnosis for dementia. Non-contrast computed tomography (CT) can also help in the diagnosis by identifying structural changes, such as infarcts or mass lesions, that may be the cause of cognitive changes [159; 160].

Single photon emission tomography (SPECT) and PET are noninvasive imaging techniques that provide information about cerebral function and regional cerebral blood flow. Cerebral glucose metabolism can be studied with PET using fluorodeoxyglucose [160]. The ability to image the regional metabolism of the brain and locate areas of diminished function has been of particular importance in advancing the ability to diagnose AD. These techniques help to differentiate AD from other causes of dementia but should not be used as the primary imaging measure [8; 80; 81; 85; 159]. One of the benefits of these tests is the ability to help identify people in the early stages of AD or those with MCI who may benefit from treatments that are now being offered or may soon be developed.

While advances in several imaging techniques are being explored, one study has examined the use of PET in conjunction with a radioactive tracer. This tracer, known as Pittsburgh Compound B, adheres to amyloid clumps in the brain, which are then easily detected by PET scans. Due to the rapid loss of radioactivity in the tracer compound, other tracing elements were compared. AD subjects retained the tracers, while control subjects had a rapid loss of the compounds. It has been found that AD, MCI, and healthy control groups are strongly distinguished using Pittsburgh Compound B PET, and are even more clearly distinguished when combined with the results of fluorodeoxyglucose PET [160].

A novel tracer compound, 18F-AV-45, is currently being researched as an alternative to Pittsburgh Compound B [88]. In several small-scale studies, it has shown a high affinity for beta-amyloid plaque binding in AD brains and stained areas match reliably with postmortem exams.

CRITERIA FOR THE DIAGNOSIS OF AD DEMENTIA

AD should be suspected in the older adult patient who presents with insidious onset and progression of impaired memory combined with other cognitive deficits that interfere with the ability to function at work or in activities of daily life. The diagnosis of AD dementia is based on careful, often repeated, clinical evaluation, as discussed. Laboratory testing and brain imaging studies are of greatest value in excluding other diagnoses.

A working group of the National Institute on Aging and the Alzheimer's Association has established clinical criteria guidance for the diagnosis of probable AD dementia [155]. In summary, the guidelines define AD as a syndrome of dementia characterized by a progressive decline in ability to function and perform usual activities, not explained by delirium or psychiatric disorder, accompanied by cognitive impairment as ascertained by medical history from the patient and a knowledgeable observer, and supported by bedside mental status examination or neuropsychological testing. Cognitive impairment should be evident in at least two of the following domains [155]:

- Ability to acquire and remember new information
- Reasoning and handling of complex tasks
- Visuospatial recognition and abilities
- Language functions
- Personality, behavior, or comportsment
- Additional core criteria include [155]:
- Insidious onset and clear-cut history of worsening
- Prominent cognitive deficits defined as either amnesic (impaired learning and recall of recent information), or nonamnesic (language or word-finding deficits, visual-cognitive deficits, or impairment of reasoning, judgment, or problem-solving)
- Absence of evidence for significant cerebrovascular disease, other defined neurologic disorders, or use of medication that could impact cognition

AFTER THE DIAGNOSIS OF ALZHEIMER DISEASE

A complete diagnostic workup for AD is lengthy and costly and may take as long as a year or more to achieve firm confidence in the diagnosis. After the diagnosis is made, the family and patient may need considerable guidance and counseling. Family members often wonder whether they should tell their loved one of the diagnosis. While it is devastating to learn that one has AD, it is frequently more stressful to be aware of the signs and symptoms and yet have no answer for the problem. The family and the patient should agree before the diagnosis is made so appropriate actions are taken. Not knowing always presents the risk of the person finding out accidentally. Open and honest communications are usually the best, but some families have their own reasons for choosing a different path. Families often look to healthcare professionals for guidance, and it is important to respect their decisions; however, physicians are advised to disclose the diagnosis to their patient [160].

Planning for the Future

Patients and family members should be encouraged to make long-term plans after a diagnosis of AD. When the diagnosis is made early in the course of the disease, the patient can and should fully participate. Decisions can be given some thought if they are made before a crisis occurs. The patient and family must be aware of the need for advance planning as a mechanism for protecting the individual's self-determination. The Patient Self-Determination Act (PSDA), legislated in 1990, is legally recognized in all states. The PSDA recognizes advance directives (the durable power of attorney and in some states, the living will) as legal documents providing direction when the patient is unable to make decisions. In some states, do not resuscitate (DNR) must be also written in the medical orders for those in healthcare facilities even if the advance directives contain this statement. Various states require that DNR orders must also be posted by or on the patient's bed. In

the absence of advance directives, it may be necessary to initiate guardianship when the patient becomes incompetent. After a competency hearing, the judge decides incompetency based on the criteria of that state. The judge assigns a guardian to oversee the patient and his or her estate. Guardianship can protect a vulnerable person, but the process may be lengthy and complicated [28].

In the absence of directives or in controversial situations with institutionalized individuals, the facility's bioethics committee may be required to intervene. The bioethics committee can assist healthcare providers to develop guidelines for decision making.

The family or caretaker(s) may wish to consult with an attorney or financial advisor. This is especially important if the patient is financially responsible for a spouse or dependents. The family and patient may wish to establish a trust or appoint a durable power of attorney. The care of a person with AD is expensive and can bankrupt an individual and impoverish his or her dependents. Most individuals will eventually require the services of a long-term care facility. It is a rare family that has the time, energy, and emotional strength to provide continuing care throughout the course of the illness. The cost and method of payment for such services must be considered. Knowledge about using appropriate community services can delay the need for placement of the affected person in a long-term care facility.

PRESCRIBING A THERAPEUTIC ENVIRONMENT FOR THE HOME OR CARE FACILITY

SAFETY ISSUES

The environment affects the behavior of people with AD. In addition to cognitive impairment related to the disease process, patients are also dealing with the usual changes of aging. This combination of factors places the patient at risk for injury. There are several risk factors associated with expected aging changes.

Sensory and perceptual alterations that diminish the ability to respond to environmental warning stimuli such as odors (e.g., fire, natural gas, spoiled food), sounds (e.g., sirens, alarms, telephone, doorbell), and visual cues (e.g., red lights, signs) are impaired. Musculoskeletal, neurologic, and sensory changes affect mobility and balance. There is a shift in the center of gravity and decreased range of motion of the hips and knees, causing a stiffer, shuffling gait. The righting response (the ability to catch oneself when starting to fall) is also diminished. Osteoporosis is common, especially in women, with approximately 40 million Americans at serious risk of osteoporosis-related fractures [138].

Persons with AD cannot rationalize cause and effect because they are unable to predict potential outcomes of their actions or to evaluate the risks involved. A person with AD may go outside during the middle of a winter night clad only in pajamas. The combination of wandering and impaired memory can be especially perilous. Patients may get lost, becoming dehydrated and ill from exposure. They may suffer thermal injuries related to fires caused by the careless use of smoking materials or inappropriate use of the stove. Loss of impulse control and hyperorality can lead to medication overdose or the ingestion of poisonous substances, such as household chemicals. Lacerations are a risk related to the use of knives and scissors. In the later stages, patients with AD often have difficulty swallowing, causing them to aspirate. Driving a car is hazardous and often presents a problem to the family when the individual is incapable of safely maneuvering a vehicle in traffic. Patients with AD require an environment that will promote health and safety while maximizing independence.

The Use of Physical and Chemical Restraints

It may be tempting for a busy and harried staff or family caregiver to rely on the use of medications or physical restraints in an effort to reduce the problems associated with wandering or agitated patients; however, there are serious ethical issues related to the use of restraints. Healthcare facilities traditionally relied on restraints to protect those in their care

and to avoid liability for injury. In 1989, the U.S. Senate Special Committee on Aging sponsored the national symposium “Untie the Elderly: Quality Care Without Restraints.” A statement by Alan R. Hunt, Esq., addresses the issue of liability [30]:

Healthcare institutions may abandon the use of physical restraints without incurring a significant risk of being sued for malpractice. There are few precedents supporting successful malpractice claims against long-term care facilities based upon a failure to restrain. In fact, the striking conclusion from an examination of cases involving restraints both in nursing homes and hospitals is that the use of restraint has produced more successful lawsuits than nonuse.

It is clear that to be restrained severely diminishes quality of life. This is in addition to the harmful effects of both physical and chemical restraints. The improper application of physical restraints may impede circulation, inhibit breathing, and predispose the patient to muscle atrophy, pressure ulcers, and incontinence [139; 140]. The use of restraints increases disorientation and anxiety in many confused individuals. Restraints have not been proven to prevent falling and injury but have been shown to increase the risk of injury and death [140]. It is recommended that restraints only be used for medical emergencies [139].

A physical restraint is defined by the federal government as “any manual method or physical or mechanical device, material, or equipment attached or adjacent to the client’s body that the individual cannot remove easily which restricts freedom of movement or normal access to one’s body” [29]. To address concerns regarding the costs associated with eliminating restraints, an analysis of nearly 12,000 nursing home residents was completed in 1993, and the data showed that eliminating the use of restraints was less costly than continued use [136]. Nursing homes across the country have made significant progress in this endeavor [140]. The use of restraints in U.S. nursing homes has declined from 40% in the 1980s to 16% in the 2000s [140].

Chemical restraints are used short-term (6 to 12 weeks) in some cases for those who show anger and aggression symptoms, while other patients receive long-term treatment with psychotropic medications in an attempt to permanently alter these behaviors. There is growing evidence that long-term use of atypical antipsychotic drugs, in particular, is not beneficial and is associated with serious side effects, including increased falls, tardive dyskinesia, cerebral cell apoptosis, accelerated cognitive decline, stroke, and even death [161; 162; 163]. One small-scale study found that the three-year survival rate of patients with AD previously on a short-course of an atypical antipsychotic was double that of patients being continually administered the active medication [163].

It is beneficial to have a discussion involving the family, patient, and the facility regarding the use of restraints. The nonuse of restraints is a decision based on a consideration of independence and mobility versus the risk of incidents. The family should be informed of the interventions that will be implemented to maintain safety. The family should report any accident the patient has had while in their care. Families that include patients with AD at home should inform their neighbors and the local police department of the situation so they may help if necessary.

In a care facility, knowledgeable staff can plan a therapeutic physical environment that is safe, warm, and comfortable. Maintaining such an environment will diminish disruptive behaviors, thus reducing or eliminating the need for physical and chemical restraints [139; 162]. Caregivers are elements of the environment and must be prepared to participate in the effort to create the appropriate milieu. The entire staff can be educated in the rationale for a restraint-free environment and how to implement interventions to prevent falls. Staff input in identifying and meeting the needs of all inpatients is encouraged. Employees from all departments should be aware of which people are at risk for falls. All employees must share responsibility for monitoring those at risk as they move about the building.

Reducing Risks of Injury

The physical environment should be evaluated for potential dangers. This is especially important when the patient is at home. A safe environment allows the patient freedom to move about, maximizing independence as long as possible. There are several ways to reduce the risk of trauma and injury related to poisoning, thermal injuries, lacerations, and falls. Remove or lock up:

- Knives, scissors, and other sharp objects
- Household cleaning supplies, bleach, detergents, spot removers, cleaning fluids, paints, paint thinner, insecticides, and any other chemicals
- All medications, including prescription and over-the-counter items
- Aerosol cans
- Small appliances like toasters or irons
- Power tools
- Weapons and anything that may be used as a weapon
- Fragile, breakable, or valuable items
- Smoking materials—provide constant supervision if the patient smokes, and be sure there is an adequate number of working smoke alarms

Place guards over:

- Electrical outlets
- Thermostats
- Stove knobs

Reduce the risk for falls:

- Keep pathways cleared and halls well lit.
- Avoid highly polished floors.
- Remove throw rugs and extension cords.
- Place furniture around the edge of the room to provide open walkways.
- Check stair railings and stair treads or carpet for security.
- Remove unstable or lightweight chairs.

- Remove wheels on beds, chairs, and tables. Use wheelchairs for transport rather than continued seating. Keep the bed in lowest position. Avoid moving furniture in the patient's immediate environment. Set up strategically placed seating areas around the facility that are attractive and inviting so people can sit down when fatigued. Provide safe, attractive outdoor areas for walking and visiting. An area such as an enclosed courtyard offers freedom to wander.

Reduce risks associated with wandering behavior:

- Control access to the outdoors by using double locks or safety locks on doors and windows.
- Install warning bells or buzzers on doors.
- Control access to swimming pools, ponds, lakes, or other natural hazards.
- Provide fenced areas, if possible, to allow freedom of movement.

Devices used to prevent patients from leaving the building that allow for freedom of movement:

- Door locks with keypads (subject to state regulations)
- Security bands worn by patients that will trigger a warning sound when they exit the building
- Bed guards that trigger a warning sound when the patient leaves the bed
- Television monitoring systems.
- Register the patient in the Safe Return Program (1-800-625-3780).

Those with memory deficits should be provided with identification bracelets such as MedicAlert. Have recent snapshots of patients available and always know what they are wearing.

Attend to Physiologic and Psychosocial Needs

Unmet needs can cause the patient with AD to become agitated and anxious. Patients may be unaware of the source of discomfort or be unable to respond to the cues resulting from unmet needs. A routine should be established that will avoid problems resulting from thirst, hunger, lack of sleep and rest, inadequate exercise, and irregular elimination patterns. It is necessary to correct underlying physiologic problems such as infections, dehydration, urinary retention, fecal impaction, hypoxia, or blood sugar imbalance. The staff should be aware if the patient has taken a laxative or is on diuretics and monitor the reaction to other drugs affecting behavior. In addition, they should: provide measures to relieve fear and anxiety; avoid situations that can trigger emotional outbursts; correct sensory deficits with glasses and hearing aids; plan varied activities appropriate for each person's abilities and interests; and give positive reinforcement at every opportunity.

Providing Safe and Appropriate Clothing

Clothing, grooming, and personal appearance can affect the self-esteem of patients even though they are disoriented. Poorly fitting attire can cause falls. It is important that patients wear clothing that is familiar and comfortable. Women who have always worn dresses or men who wore dress shirts and ties every day may react negatively to being dressed in jogging suits. Patients should be provided with well-fitting shoes with nonslip soles; shufflers, especially, need nonslip shoes that glide well on the floor. Shoelaces should be avoided when possible. Socks, nylons, and pants must fit properly. Prevent patients from ambulating in a long robe. In general, it helps to maintain a neat, attractive appearance.

Controlling Environmental Stimuli

Avoiding an overstimulating environment helps to prevent agitation, as does minimizing noise and commotion. Television can be disorienting to those who cannot distinguish between television and reality. Lowering the volume on telephones and communication systems may diminish patient agitation.

Older people in general require increased illumination, so bright, diffused lighting without glare is helpful. People with AD may become frightened by shadows produced by inconsistent light sources. Non-glare glass should be used on all pictures and artwork. Drawing the blinds or drapes at sundown helps to prevent reflections from the glass at night.

The area of care should present an inviting environment with judicious decorating, such as artwork that is familiar and objective (e.g., still life, landscape, seascape). Abstract patterns may further confuse or dazzle the disoriented person. Avoid patterns on floors and walls. Patients with AD may try to “pick” flowers off the wallpaper or may try to walk around or jump over “holes” in the floor created by different colors in the pattern. Mirrors may frighten some who are no longer able to recognize themselves; others find comfort in the reflection.

Orientation clues for those who are able to utilize the information are also useful. These include items such as clocks and calendars with large numbers, activity boards, reminders of special events, and seasonal and holiday decorations. Redundant cueing with pictures, words, and colors are helpful. A picture with the name of the person on the door may help him or her find the right room. This idea may also be used for bathrooms.

Areas of small, comfortable seating groups draw the people in and encourage them to reach out and touch objects. Placing safe, familiar objects around may promote reminiscence. A patient may be happy using a manual carpet sweeper or browsing through a catalog of old objects.

THE INTERPROFESSIONAL HEALTHCARE TEAM

Nursing management of patients with AD supplies the support and coordinates the contributions of the interdisciplinary team. The membership of the team is dictated by the needs of the individual and family and by the setting in which the services are rendered. Education provides caregivers at all levels with the knowledge and skills that are needed to increase the

patient’s quality of life. Often, the nursing assistant or housekeeper spends more time with the patient than the professional staff. Nursing assistants are quite often the direct caregivers in skilled nursing facilities. Supervisors can enhance the assistants’ performance by knowing their capabilities, interests, and past work experiences. Many of them have special talents for working with patients with AD and should be included in the care planning process. This creates an atmosphere of trust and communication by listening and acting upon their observations and suggestions. They should know they are valued team members. Physicians, nurses, and supervisors should use any opportunities to teach nursing assistants.

The nurse is usually the liaison who coordinates services to meet the psychological, social, spiritual, and economic needs of the patient and family. The nurse collaborates and consults with other team members in the assessment and identification of patient/family problems. Conferences attended by team members are useful strategies for planning interdisciplinary interventions for the resolution of problems and goal setting.

Patients and their families are vital members of the team and should be invited to participate in planning and caregiving to the extent they wish to be involved. This process helps build a trusting relationship between patients, their family, and their caregivers. Family members have often cared for the relative for several years. They can share their ideas and provide valuable information. Knowing the patients’ history, characteristics, interests, and philosophies helps the team to individualize their care. Caregivers should be encouraged to engage in counseling and support activities and should be assessed for distress and burnout [160].

The interdisciplinary team should be focused on outcomes. For patients with AD, outcomes are related to the management of behaviors, maximizing independence by maintaining abilities for as long as possible, and preventing complications.

MANAGEMENT OF ALZHEIMER DISEASE

There are no treatments that can cure or reverse the effects of AD. However, AD is not a condition for which nothing can be done. Patients and families can be helped with interventions designed to diminish the manifestations of the disease. The disease and its progression are evaluated by the behaviors exhibited by the individual. Care planning is directed toward the management of the identified behaviors. Although there are many common features, each person is unique and requires distinctive approaches based on an assessment that identifies the specific problems of each individual.

In the preclinical stage, the goal of management for susceptible patients is to prevent and/or delay the onset of the disease. Maintaining a healthy diet and lifestyle, with goals including reduction of oxidative stress and blood pressure and improving circulation, may help in preventing dementia or slowing the rate of disease progression [164]. Dietary, exercise, and pharmacologic treatment guidelines for lowering the risk of obesity, diabetes, cardiovascular disease, and particularly hypertension should be followed, as comorbidities complicate AD treatment and exacerbate the disease process. As noted, there is some evidence that certain nutrients, especially omega-3 fatty acids, can reduce the risk of dementia [79]. Engagement in cognitive activities is also highly recommended.

Management of diagnosed AD consists of pharmacologic and nonpharmacologic therapies. Some pharmacologic agents have shown modest benefits in alleviating problems with cognition and behavior in research settings, though these benefits are often not realized in clinical use [72; 79]. These agents include several cholinesterase inhibitors (ChEIs) and memantine, an *N*-methyl-*D*-aspartate (NMDA) receptor antagonist [89; 90]. The most common adverse effects of ChEIs are nausea, vomiting, and diarrhea, with the most serious being cardiac arrhythmia and other cardiovascular and neurologic effects [79].

Memantine produces fewer adverse effects, and the dropout rate is similar to placebo. Other medications, such as antipsychotic agents and antidepressants, are occasionally necessary, but these agents can cause many unacceptable side effects [89].

Medications for AD may provide temporary improvement in cognition for a subset of patients; however, at present there is no pharmacologic agent or other treatment modality capable of substantially altering the progression of disease. Thus, nonpharmacologic interventions, including social, environmental, and behavioral measures, are the most important elements of a management strategy for patients with AD [71].

PHARMACOLOGIC THERAPIES

ChEIs and memantine are the primary available modes of pharmacologic AD treatment. ChEIs prevent or delay the breakdown of acetylcholine in the brain, a neurotransmitter important for learning and memory. This has been shown to produce a small but measurable temporary improvement in cognitive function and behavioral symptoms in some patients with mild-to-moderate and moderate-to-severe disease [89]. A study published in 2009 showed that while most mild patients with AD respond only minimally to ChEIs, a small cohort respond substantially to treatment [165]. Because these agents do not produce a dramatic result, families and caregivers must be informed of realistic expectations [6].

Donepezil, rivastigmine, and galantamine are ChEIs that have been approved by the FDA for the treatment of AD [86; 89; 90]. Tacrine was the first ChEI to be approved; however, the drug is no longer available due to its more severe side effects, including possible hepatic dysfunction [79; 90]. Rivastigmine and galantamine have been approved for mild-to-moderate AD, while donepezil has been approved for all stages [90].

Although these drugs act in generally the same manner, it is occasionally necessary to switch from one to another in order to continue the beneficial results seen by increasing the level of acetylcholine in the brain. In a study published in 2003, Gauthier et al. showed that patients who had begun to show the loss of effect of donepezil obtained an improved result when switched to rivastigmine [85].

Memantine is the first NMDA receptor antagonist approved by the FDA for use in patients with moderate-to-severe AD [63]. This drug has several mechanisms of action, but it is thought that modulation of the activity of glutamate, a substance involved in information processing, storage, and retrieval, accounts for the therapeutic benefit in AD [4; 84]. Memantine reduces neuronal excitotoxicity by modulating the tonic (i.e., mild, continuous, chronic) activation of NMDA receptors, which should be acting in a phasic manner (i.e., reacting to stimulus) [63]. There is some evidence that beta-amyloid toxicity is also reduced by high doses of memantine [32]. Other neuroprotective drugs have been unsuccessful in clinical trials due to intolerable side effects and inefficacy [95]. Memantine is available in a combination formulation with donepezil [192].



EVIDENCE-BASED
PRACTICE
RECOMMENDATION

The European Academy of Neurology suggests that the use of a combination of cholinesterase inhibitor (ChEI) plus memantine rather than ChEI alone may provide useful benefits in patients with moderate-to-severe Alzheimer disease.

(<https://onlinelibrary.wiley.com/doi/full/10.1111/ene.12707>. Last accessed August 17, 2023.)

Level of Evidence: Expert Opinion/Consensus Statement

In 2021, the FDA granted accelerated approval to aducanumab for the treatment of Alzheimer disease [184]. It is the first new treatment approved for Alzheimer disease since 2003 and is the first therapy that targets the fundamental pathophysiology of the disease. Approval of aducanumab was based on evidence showing a significant reduction

of beta amyloid plaque in those receiving the drug (compared with placebo) [184]. Because it was granted accelerated approval, the manufacturer has not yet linked the reduction in beta amyloid plaque to improvements in patient health or disease progression [185]. Preliminary studies have been conflicting, and the FDA's decision to grant accelerated approval to aducanumab was controversial, with many experts calling for additional research to prove efficacy and questioning whether the approval gives false hope to patients and families [186].

In 2023, the FDA granted accelerated approval to lecanemab for the treatment of AD [189]. Like aducanumab, lecanemab is an anti-amyloid monoclonal antibody, and the presence of amyloid beta pathology should be confirmed prior to treatment initiation. Lecanemab is an intravenous infusion given every two weeks at an infusion center, but subcutaneous delivery is being studied in trials [91].

Medications such as antidepressants and anti-anxiety agents may be appropriate for some people to alleviate symptoms of concomitant depression and anxiety. A 2011 meta-analysis found that the selective serotonin reuptake inhibitors sertraline and citalopram were more effective than placebo at controlling agitation in patients with dementia and may be better tolerated than antipsychotics [168]. Selective serotonin reuptake inhibitors are recommended over tricyclic antidepressants when use of an antidepressant is indicated [159].

Also in 2023, the FDA approved brexpiprazole to treat agitation symptoms associated with AD dementia [191]. Brexpiprazole is a second-generation atypical antipsychotic originally approved for major depressive disorder and schizophrenia and has been used off-label for agitation in AD patients [192]. The recommended starting dosage is 0.5 mg once daily for the first week; then 1 mg once daily during week two; and then increased to the recommended targeted dose of 2 mg once daily. The dose can be titrated to a maximum recommended daily dosage of 3 mg once daily, based on tolerability and clinical response.

Experimental or Alternative Medication Treatments

There is conflicting evidence regarding the clinical benefit of other therapies, including B vitamins, testosterone, ginkgo biloba, selegiline, and statins. Vitamin E, estrogen, and NSAIDs are generally regarded as being non-effective [79; 159].

B vitamin and folic acid supplementation have been studied in an attempt to reduce homocysteine levels in patients with AD. Improvements in cognition remain unproven, although homocysteine levels were found to diminish with consumption of vitamin combinations [87; 98; 99].

The use of hormone therapy has been debated in relation to developing AD. Estrogen replacement therapy for women has been studied and is considered generally ineffective [79]. Testosterone therapy for men, however, has shown mixed effects on cognition, with some research studies showing improved cognition [58; 60]. Part of this benefit may be the result of improvements in cardiovascular risk factors, and it is important to note that testosterone replacement is associated with increased risks of benign prostatic hypertrophy, liver toxicity, and erythrocytosis.

Ginkgo biloba is an herbal product with an unclear mechanism of action, but it may have antioxidant and anti-inflammatory effects, positively influence neurotransmitter levels, and have a protective effect on the energy metabolism of nerve cells when oxygen and glucose levels are low [97]. A certain extract of ginkgo (EGb 761) was shown in one study to produce a slight improvement in cognitive scores in patients with AD [6; 87]. However, another study found no marked improvement in patients with AD who received a daily dose of 120 mg of high-purity ginkgo biloba for six months [100]. Although ginkgo biloba would be a cost-effective treatment modality if effective, more research is needed to support its efficacy [97; 100]. As of 2014, it is not recommended [159].

Selegiline is a monoamine oxidase type B inhibitor that possesses some anticholinergic properties [79]. A meta-analysis of 17 well-designed trials found that a 10 mg per day dose was associated with a four- to six-week improvement in cognition; however, no benefit was seen after six weeks. There is currently not enough evidence to support its use [79].

The use of statins has been shown to decrease the incidence of AD but not to improve the cognitive abilities of the elderly [87]. Poor vascular health is a risk factor for AD; however, it is unknown whether it is the cholesterol-lowering properties of these agents that results in the supposed effectiveness or whether it is due to the pleiotropic functions of statins [166]. There is currently not enough evidence to support their use [159].

For some time, it was believed that vitamin E could prevent or slow the progression of AD, due to a protective effect on neurons through a reduction of oxidative stress [6; 87]. However, research has not supported this use. A 2008 meta-analysis found no evidence of vitamin E effectively preventing or treatment AD or MCI, and no guidelines support its use for AD prevention or treatment [55].

NSAIDs have been studied for both treatment and prevention of AD due to their anti-inflammatory qualities. Twin studies have shown that NSAIDs used continuously for more than two years during a person's lifetime can delay the onset or reduce the likelihood of developing AD [132]. Although certain NSAIDs have been shown in epidemiologic studies to reduce the risk of AD, they have not been proven effective as a form of treatment [101; 102].

Pharmacologic Research

Because the accumulation of amyloid plaques and tau tangles in the brain are the key structural features of AD, drugs that decrease the amount of amyloid and tau present in the blood stream and/or CSF have been a significant area of research [90; 104; 105; 106; 107; 108; 109; 110]. Despite the efficacy of various agents in clearing aggregated plaques, certain research has shown that the course of the disease is not significantly altered by their elimination [54].

Because plaques are considered a sign of later stages of the disease, serious neural pathology is believed to occur as the result of other disease processes or amyloid-induced toxicity [53]. Preliminary studies of a monoclonal beta-amyloid antibody, gantenerumab, have found a reduced deposition of beta-amyloid in treatment-group participants' brains on PET scans versus controls [51; 90]. Trials assessing the efficacy of gantenerumab for prevention of AD in genetically susceptible individuals and treatment of existing AD are being conducted. A 2022 study involving nearly 1,800 adults with AD found that the experimental drug lecanemab reduced markers of amyloid in early disease and resulted in moderately less decline on measures of cognition and function than placebo after 18 months [188]. However, lecanemab was associated with infusion-related reactions in 26.4% of the participants and amyloid-related imaging abnormalities with edema or effusions in 12.6%.

The results of large-scale randomized clinical trials to assess the efficacy of monoclonal antibody therapy for AD have not proved promising. Solanezumab is a humanized monoclonal antibody that binds to the mid-domain of the beta-amyloid peptide. It was designed to increase clearance of soluble beta-amyloid peptides from the brain before deposition of the toxic fibrillary form of the protein [180]. In a double-blind, placebo-controlled phase 3 trial, 2,194 patients with mild AD were assigned to receive intravenous solanezumab or placebo every 4 weeks for 76 weeks. The primary outcome was change from baseline to week 80 in the cognitive subscale of the AD Assessment Scale. Results showed that compared with placebo, solanezumab had no significant effect on cognitive decline [180].

Another humanized monoclonal antibody, donanemab, has been studied, most recently in a double-blind, placebo-controlled phase 3 trial, with results published in July 2023 [190]. This antibody is directed against "insoluble, modified, N-terminal truncated form of β -amyloid present only in brain amyloid plaques," and was shown to significantly slow clinical disease progression at 76 weeks. The trial had several limitations, but a study extension and other trials are planned with the hope of confirming the positive outcome seen with donanemab.

Disruption of the GABAergic and glutamatergic systems is associated with the behavioral and psychological symptoms of AD [63; 92; 94]. Evidence for a link between various mood disorders (including depression) and the heightened risk of developing dementia, related to disruption of GABA and l-glutamic acid levels in the central nervous system, is being sought [167]. While memantine has shown promise in regulating the glutamatergic system, it is hoped that future neuroprotective/neuromodulatory agents may be able to inhibit toxicity well before symptoms of AD. More research is clearly needed regarding the role of regulating the GABAergic and glutamatergic systems in AD treatment [93; 167].

Antipsychotic and Antidepressant Medications

Depending upon the disease stage, 25% to 50% of patients with AD experience concomitant psychotic symptoms [70]. Although antipsychotics have been used in the management of AD, none have been approved specifically for this use. In 2005, the FDA warned the healthcare community regarding the increased risk of mortality in elderly patients receiving atypical antipsychotic medications for dementia-related psychosis. In 2008, the FDA added this warning to typical antipsychotic medications as well [135]. In addition to the increased risk of mortality and other serious side effects, antipsychotics diminish the patient's response to stimuli and may be considered a form of chemical restraint when the sedative properties of the drug are used to facilitate patient management [89]. Even with short-term use, antipsychotic medications are associated with many adverse effects in this population, including [134; 137]:

- Increased mortality rates
- Cerebrovascular events
- Tardive dyskinesia
- Neuroleptic malignant syndrome
- Hyperlipidemia
- Weight gain
- Diabetes
- Sedation
- Parkinsonism
- Decreased cognition

- Akathisia
- Hypotension
- Peripheral anticholinergic effects

A clinical need for the use of antipsychotic medications must be established. Psychotic behavioral disturbances, including agitation, hallucinations, delusions and paranoia, and physical and verbal aggressive behavior, may justify their use [49]. Wandering, impaired memory, depression, insomnia, and anxiety do not warrant their use unless patients present a danger to themselves or to others. Evidence suggests no single drug is more effective than any other, and when a drug is effective, it requires relatively low doses [134]. Greater clinical improvement has not been noted with higher doses [67]. The goal of the therapy is to find the dose at which the identified behaviors are eradicated without causing sedation [66]. Before antipsychotic medications are prescribed [66; 152]:

- Consider that changes in behavior may be caused by a medical problem other than the dementia
- An assessment should be completed to rule out other treatable causes, including the medication itself.
- A specific treatment target should be established and documented.

Because age may alter the absorption, distribution, metabolism, and elimination of many medications, elderly individuals may be more sensitive to their effects [134]. The combination of drugs may also contribute to disorientation and confusion, and administration of multiple drugs increases the risk for adverse, interactional side effects. Ongoing evaluation is required to determine the effectiveness of these agents over time and to assess the need for their continued administration [152]. The APA recommends several actions regarding the use of antipsychotic medications [193]:

- After four weeks, if it is determined that no clinically significant response is achieved, the drug should be tapered and withdrawn.

- Within several (less than four) months of positive response to an antipsychotic, a discussion regarding dose tapering and withdrawal should be initiated.
- If a positive response has been achieved, tapering and withdrawal should be attempted within four months of initiation, unless the patient has had a recurrence of agitation during previous treatments.

NONPHARMACOLOGIC THERAPIES

According to the Alzheimer's Association, nonpharmacologic modes of treatment for AD have been used in the effort to maintain or improve cognitive function, enhance quality of life, and improve the ability to perform activities of daily living [4]. For some patients, this approach is also an effective adjunct to medication prescribed for control of behavioral symptoms such as depression, sleep disturbance, agitation, and depression. The modes of treatment most often studied are supervised physical activity and exercise program, cognitive stimulation, and cognitive training (e.g., computerized memory training, cognitive-behavioral therapy). Clinical reports and meta-analyses published since 2010 have shown mixed results; the impact on cognitive function in patients with mild AD has been difficult to demonstrate, or modest in degree and of uncertain duration [4]. A 2019 Cochrane systematic review found that cognitive training for persons with mild-to-moderate AD is probably associated with small-to-moderate positive effects on global cognition and verbal semantic fluency, and these benefits appear to be maintained for at least a few months [181].

An AD study group in Denmark has investigated the effect of moderate- or high-intensity exercise on cardiorespiratory fitness, as measured by peak oxygen uptake, and the association between this parameter and changes in cognition and neuropsychiatric symptoms in patients with AD. Their results show that cardiorespiratory fitness can be improved in community-dwelling patients with mild AD, and that this improvement has a positive effect on mental speed, attention, and neuropsychiatric symptoms [182].

COMPONENTS OF CARE

The care of people with AD is based on supportive and comfort measures, restorative care, prevention of complications, and management of coexisting illnesses. The 2018 Alzheimer Association Care Practice Recommendations emphasize a philosophy of person-centered care built around the needs of the individual and contingent upon knowing the person through an interpersonal relationship. Practice recommendations for person-centered care include [183]:

- Know the person living with dementia as a unique and complete person, including his/her values, beliefs, interests, and abilities—both past and present.
- Recognize and accept the person's reality, seeing the world from the perspective of the individual living with dementia
- Identify and support ongoing opportunities for meaningful engagement. Support interests and preferences, allow for choice and success—even when dementia is severe, the person can experience joy, comfort, and meaning.
- Build and nurture authentic caring relationships. This involves concentrating on the interaction rather than the task—"doing with" rather than "doing for."
- Create and maintain a supportive community for individuals, families, and staff.
- Evaluate care practices regularly and make appropriate changes.

SUPPORT AND COMFORT MEASURES

The concept of palliative care encompasses both symptom control and maximization of physical and emotional comfort. Behavioral symptoms are rarely the result of the disease alone but are often precipitated by the environment or the approach of the caregivers [33]. For the patient with AD, palliative care is centered on the alleviation of agitation and

anxiety, the prevention of catastrophic reactions, and the management of delusions and hallucinations. Comfort may be extended in a number of ways. Members of the interdisciplinary team work together to develop interventions that will facilitate the individual patient's physical and emotional comfort.

Preservation of Dignity and Quality of Life

The concept of dignity is subjective and may have different meanings for each person. It is beneficial to have an understanding of what the patient was like before the illness. Remember that several aspects of individuality must be met:

- The identity of the person: How does he or she wish to be addressed? Is there a title, such as Doctor, that is appropriate?
- Respect for privacy: A person who has always disrobed in private may react negatively to being undressed by a stranger.
- The appearance of the patient: Attending to grooming and personal hygiene can improve a patient's self-esteem.
- The patient is an adult: Even though cognitive deficits exist, the patient has experienced the joys and challenges of several decades of living. To treat patients as children is inappropriate and demeaning. Using words and touch so they feel valued as individuals is beneficial. People with AD still have a need to make contributions and to feel that they have some control over their lives. They are more content when they are encouraged to remain active and involved, using their remaining strengths and abilities.
- Physical and psychological comfort: People with AD have the same basic needs that healthy individuals have. Unmet needs will be reflected in the patient's behavior. The behavior will not change as long as the need remains unmet. Meeting physical needs can prevent discomfort related to hunger, thirst, restlessness, constipation, or the desire to void.

- When people do not feel safe they become anxious: If patients feel threatened they may strike out verbally or physically. Persons with AD may feel unsafe much of the time because they do not understand the environment and what is going on around them.
- People with AD also need to love and be loved: They have positive and negative feelings. They should be touched, be hugged, and have eye contact with care-givers. Care providers should converse with them on their level without being condescending, compliment them on their appearance, and provide quiet, private areas for visits. Spouses should know that it is acceptable to express affection.
- It is useful to plan activities compatible to the abilities of each individual so they can experience a feeling of success.
- Listen to the patient. What is expressed may not sound rational to others, but it does to them.

Family and staff should consider the wishes of the patient before initiating a treatment that may prove to be more harmful than beneficial. For example, starting an IV for feeding or administering antibiotics for an infection may not be in the best interests of the patient if he or she must be restrained to prevent dislodging of the needle. Acknowledge the individual's autonomy. When a patient is too demented to make decisions, the family must consider what their loved one would have wanted rather than what they themselves want.

Be honest with patients with AD while being optimistic when answering questions. Let them know that although the disease is progressive and there is no cure, there are still treatment options. Honesty from caregivers often encourages patients to consider the future and to make decisions about what they want as their condition worsens.

RESTORATIVE/REHABILITATIVE CARE

Restorative care is based on the premise that quality of life is dependent on autonomous need fulfillment and self-determination. It is concerned with maintaining an individual's sense of dignity and self-worth. The concepts of restorative care are based on a philosophy that is directed towards maintaining functional levels in activities of daily living and preventing complications [34]. Unfortunately, caregivers can become focused primarily on behavioral stability, especially if patients are easily agitated and uncooperative [103]. In many cases, this leads to the patient remaining sedentary because caregivers believe it is easier and/or faster to complete tasks themselves rather than assisting the patient with the task.

Aggressive rehabilitation techniques are usually not appropriate for the management of AD. However, rehabilitation specialists may serve as consultants and provide suggestions for interventions that will delay the onset of self-care deficits. Conflict about the appropriateness of rehabilitation may arise between members of the healthcare team when a secondary problem occurs. For example, if a patient with AD fractures a hip, there may be reluctance to provide physical therapy after surgery. The attitude may be "Why rehabilitate? The person has AD." The diagnosis of dementia should not be an obstacle to appropriate treatment. In this case, if the patient was ambulatory before the fracture, physical therapy should be considered. The potential for achievement is partially dependent on the degree of cognitive impairment.

MAINTAINING AND ASSESSING FUNCTIONAL LEVELS

The manifestations related to AD have a profound effect on the ability to perform activities of daily living. The rate at which those skills are lost varies from person to person. The degree to which function diminishes depends on the complexity of the task. After a skill is lost, it generally cannot be regained. Interventions are based on maintaining a skill for as long as possible. Basic self-care activities can usually be managed through the first two stages

of the disease with varying degrees of assistance. The ability to complete instrumental activities of daily living, such as financial planning and driving, disappears early in the process. Disability associated with self-care deficits can be exacerbated by many factors other than the disease. Other illnesses, medication toxicity, increased fatigue, sensory deprivation, and inadequate support from the environment and caregivers can hasten the onset of functional loss.

Completing a functional assessment of those with AD serves several purposes. The selected tool can identify existing self-care deficits at the time of admission, allowing the care team to establish appropriate goals and interventions. Assessment data can be used to determine placement of patients in programs fitting their capabilities. Their strengths can be identified and utilized to delay the onset of deficits. Using a form that records how many minutes a caregiver spends assisting the patient with each activity (e.g., bathing, dressing, grooming, walking to activities/meals, walking for recreation, assisting with exercise, leading an exercise class, helping with class activities) can help ensure that time is devoted to maintaining functional skills [103].

PREVENTING COMPLICATIONS

AD predisposes patients to a number of complications. In the early stages of the disease, risk is highest for injury and trauma related to wandering; inability to recognize sensory cues for danger; impaired judgment; impulsiveness; memory deficits; altered nutrition related to shortened attention span, apraxia, and agnosia; and excessive energy expenditures due to wandering. In the later stages, there is increased risk for incontinence, pressure ulcers related to impaired mobility, and possibly undernutrition and aspiration related to impaired swallowing.

Each individual should be evaluated for these risks, with appropriate interventions implemented as needed. Validated assessment tools may be used upon admission to determine the risk for pressure ulcers and altered nutrition so preventive measures can be undertaken. These also serve as a baseline for future assessments. A speech pathologist can evaluate for aspiration risk and give the nursing staff ideas for successful intervention.

MANAGING COEXISTING ILLNESS

Many elderly people have multiple medical diagnoses, and those with AD are no exception. Patients may have coexisting chronic illnesses, such as diabetes, cardiovascular disease, osteoarthritis, or depression. Complications associated with these disorders may not be readily apparent. Manifestations of hypoglycemia or digitalis toxicity may be mistakenly attributed to progression of the disease. Patients with AD and with pain related to osteoarthritis may not be able to verbally communicate their discomfort to caregivers. Increased agitation, confusion, and body language may be the only clues. Ongoing monitoring and evaluation is therefore required in order to identify potential or existing problems.

Individuals with AD may also suffer from an acute illness. Elderly people, in general, do not always present with the typical signs and symptoms associated with acute illnesses. As noted, changes in behavior are often the only manifestation of the onset of complications related to coexisting disorders or acute illness such as infections. It is recommended to investigate any sudden or recent change, including:

- Changes in appetite
- Increased confusion
- Changes in sleep pattern
- Falling by someone who is normally a steady walker
- Change in elimination patterns
- Elevated temperature
- Increased restlessness
- Agitation and anxiety

There are four urgent problems to rule out when behavior changes are noted: constipation, pneumonia, urinary tract infection, and medication toxicity. If the evidence is inconclusive, further investigation is warranted.

GENERAL MANAGEMENT TECHNIQUES

General management techniques are based on consistency, focusing on the individual's abilities, task breakdown, cueing, and the use of distraction.

Consistency

Consistent caregivers should be familiar with:

- The patient's strengths and disabilities
- How to approach the patient to avoid triggering catastrophic reactions
- The patient's usual behavior and responses
- When the patient is exhibiting unusual behavior
- The safety risks applicable to the specific patient
- How to maintain a consistent routine and environment

Task Breakdown

Each activity of daily living requires a number of steps that must be completed in sequence in order to accomplish that particular task. The functional assessment identifies the steps of an activity of daily living that the individual can and cannot perform. Using this information, an approach can be developed that allows patients with AD the opportunity to perform the steps that they are capable of performing. For example, a patient may be able to brush his or her teeth if all the needed items are set out. It is possible for well-intentioned caregivers to enforce dependency by overhelping. When a patient begins to have problems completing a task, this approach may prevent premature deterioration.

Cueing

Cueing is a process of giving hints or clues to facilitate independence. Verbal cues require the use of simple instructions given with each step of a task. For example, a caregiver may say, "Please put on your shirt" while handing the shirt to the individual. After the shirt is on, the caregiver may say, "Please button your shirt." Demonstrating the action by buttoning the first button provides an additional cue. Redundant cueing uses several methods, such as colors, words, and pictures to communicate information. A facility may have all bathroom doors painted the same color with the word bathroom on the door and a picture of a toilet.

Distraction

Brief attention span and memory deficits can be helped by the use of distraction techniques. Looking through a picture book may distract the patient who complains of not having dinner immediately after eating. If a patient with AD has his or her hands full while shopping, it will be difficult or impossible for the patient to pick up unnecessary items from the shelves.

COMMUNICATING WITH PATIENTS WITH AD

Communication provides a means for utilizing information and facilitates social interaction. The brain integrates and processes information that is received through the senses. Messages are sent by means of speaking, writing, or gesturing. Messages are constantly sent and received without conscious awareness. Body language may send a more accurate message than words in some instances.

COMMUNICATION PROBLEMS

Communication becomes impaired as AD progresses. The left brain functions of language, reasoning, and calculation are diminished while the right brain functions of feeling and intuition increase. Aphasia is a major manifestation of AD, and both receptive and expressive aphasia eventually occur. Aphasia is a language impairment involving all modalities, including speaking, reading, writing, and arithmetic.

Letters, numbers, signs, and gestures are utilized for language. To use language, one must know what the symbols mean before the information can be interpreted and understood. Speech is a motor act involving movement of the muscles of respiration as well as the lips, tongue, jaw, palate, and larynx. Advanced patients with AD have problems concentrating on what is being said, comprehending what was said, and formulating a response. They will have a flat affect and difficulty in expressing emotions. This does not mean that there is an absence of feeling.

In the first stage of AD, patients' vocabulary shrinks and they have difficulty with word finding. Word substitution may be used, as they use a word with similar meaning in place of the forgotten word. For example, "pencil" may be used for pen or "truck" for car. Patients may try to describe an object that they cannot name (e.g., "that thing I write with" or "what we ride in"). Pseudowords or inappropriate words may be used to fill the gap. Patients may make a "word salad," as several unrelated words are tossed together to compensate for lost words. Speech may be repetitious because they cannot remember what they have already said. There is occasional logorrhea (the rapid flow of speech, often incoherent). During the early stages, individuals can comprehend most messages when they are received but quickly forget the message due to memory deficits [36].

As the disease progresses, there is decreasing ability to comprehend both written and oral language. Persons with AD may be able to understand one or two words but are unable to comprehend an entire sentence or complete thoughts. Simple commands can be understood and followed. They are unable to abstract and all messages are interpreted as literal. The person who is instructed to "hop into bed" will attempt to do just that. For someone with AD, a "wet floor" sign on a freshly mopped floor may be a command to urinate on the floor. Patients will begin to confabulate, or invent fictitious details about past events, in order to disguise the inability to remember. Confabulation is the result of memory deficits but also affects communication. Social phrases such as "please," "thank you," and "how are you" may be retained for a surprisingly long time [36].

Eventually, patients with advanced AD become mute because they are unable to use language in either written or oral form. Perseveration may be evident, as patients repeat the same word over and over. Although there is no verbal exchange between the patient and caregivers, communication does take place. It is helpful for caregivers to remember that patients often understand more than we think they do, but they are unable to verbally express this understanding. Those with AD can "read" the people around them and will respond accordingly.

In spite of the words used, the body language, facial expression, and "touch" of the caregiver may send conflicting messages. Patients are very sensitive to the emotional climate and environment.

In the early stage, patients may make statements that seem to make no sense to caregivers. Frequently, these expressions represent their experiential history being given in a fragmented and illogical sequence. Asking key questions about the statement helps develop a sense of trust between caregiver and patient. For example, Patient C frequently made comments about her students. She was happy and content when a caregiver followed up on her comments. By asking questions, such as, "What subject did you teach?" or "Can you tell me about some of your students?" the interest expressed by the caregiver acknowledged and validated Patient C's worth. When caregivers discredit a statement by correcting the patient or pointing out that it is untrue, alienation and distrust occur. In the last stage, patients have little ability to communicate. Excessive mumbling, striking out, or resisting care may be the only avenue left by which to express mental or physical discomfort.

SUGGESTIONS FOR IMPROVING COMMUNICATION

Use of effective techniques can facilitate the communication process and will avoid physician, caregiver, and patient frustration. All healthcare staff should understand and utilize these techniques.

The patient should always be acknowledged as an adult person, with the same feelings and emotional needs as any adult. Communication should be on an adult level, avoiding the use of jargon, demeaning expressions, or baby talk. It is important to be positive, confident, and hopeful and give praise for small achievements and successes in a respectful manner. It is best to identify and respond to feelings rather than facts. For example, if the patient with AD says, "I'm going Christmas shopping" in the middle of April, one can respond by asking follow-up questions, such as, "What kind of gifts did your children like?" Identify and acknowledge emotions and comments, such as, "This must be really frustrating to you" or "It's okay to feel angry."

The caregiver should tell patients what is being done and prepare them for what is happening by saying “I’m going to move your wheelchair over by the table,” or “I will walk with you to the dining room.”

Time has little meaning. Saying, “Your son will be here after lunch” is preferable to saying, “Your son will be here at 1 p.m.” Asking questions requiring yes/no answers as opposed to open-ended responses is preferable. Instead of asking, “What do you want to wear today?” one could ask, “Do you want to wear the green dress or the blue dress?” as both dresses are held up.

It helps to make sure patients can see and hear the speaker. Placing oneself at eye level, identifying yourself, and calling the patient by name when beginning conversations may also be beneficial. Use eye contact and place yourself at the patient’s level. Use facial expressions and touch, point to, or show items as cues to augment verbal communication.

Eliminate all environmental distractions. Turn off the radio and television. Take patients to a quiet place, if necessary. Limit the number of people conversing at one time. Patients cannot keep track of the topic and who said what.

Processing messages also takes longer. Give patients time to hear you and to formulate a response. If they become stuck, help them find the right word through association. Provide the right word if you know what is meant.

Resist attempts to use logic or to reason with patients with advanced AD. Cognitive deficits associated with AD have undone their ability to be logical and reasonable. Phrases such as, “I just told you that” or “this is the last time I am going to tell you” are humiliating and frustrating. Remember that they are easily distracted. If a patient repeatedly says he or she has to go to the bank, for example, distract the patient by looking at pictures with him or her or asking for assistance with a simple task.

Be aware of the impact of body language. Studies have found that throughout the course of dementia, people remain responsive to nonverbal emotional messages. They react positively to a warm smile, friendly tone of voice, and gentle touch. They may become anxious when approached by a stern face, impatient tone, or a too firm grasp of the wrist. Anxiety leads to agitation and possibly catastrophic reactions. Words and actions must match. Words may be caring and kind, but the person will pick up on tension reflected in facial expressions, body movements, and tone of voice.

Be aware that there are differences in the learned meanings of words and that cultural backgrounds can alter interpretations. Dinner for one individual may be the noon meal and for another the evening meal. Carbonated beverages are called “soda” in some parts of the country and “pop” in another section. In Britain, a face cloth is called a “terry” and gasoline is called “petrol.” Be selective in the use of healthcare terms that have ambiguous sounds, such as, “I’m going to take your vitals now” or “It’s time to go to therapy.”

Avoid giving choices for situations in which a choice may not be reasonable. For example, asking, “Do you want to take a bath now?” implies a choice. If the bath really needs to be given now, say, “It’s time to take a bath now. I will help you.”

Touch the person gently on the arm or hand if necessary to get his or her attention. Speak slowly and softly in a low, calm voice. Stay about an arm’s length away. Use short, specific, familiar words and simple sentences. Give only one direction at a time. For example, hand the patient a washcloth and say, “Please wash your face.”

Avoid asking questions that patients may not be able to answer. In the early stages, patients will be embarrassed and frustrated with yet another reminder that their abilities are diminishing.

Listen carefully. If you do not understand, say so. Never assume that comments are the result of confusion or delusions. The patient may be reliving experiences from years ago. Listen to stories even if you have heard them several times before.

Remember that “white lies” are permissible. The physical safety and emotional feelings of the individual are priorities. When someone says, “I’m waiting for my husband to come for supper,” responding with, “Don’t you remember your husband died five years ago?” is cruel and unnecessary. Respond with a question: “What did your husband like for supper?”

Humor is always beneficial when used at the appropriate time. People with AD enjoy the camaraderie that evolves when people laugh together. However, teasing, sarcasm, or laughing at someone with AD is never appropriate.

COMMUNICATING WITH TOUCH

When used judiciously, touch is very effective when working with people who have AD. The need to touch and be touched may increase with age as other senses such as vision and hearing tend to become diminished. “Skin hunger” may occur when there is lack of human physical contact with others, and researchers have compared lack of touch to malnutrition [40]. All forms of touch convey a message that is either positive or negative. Touch can be therapeutic and give the most pleasure of all senses. The significance of touch is often overlooked in this age of technology. Touching can build one’s self-esteem when it implies acceptance of the person, and it can prevent feelings of rejection and loneliness. Touch can be functional or affectionate. Touch can be comforting and soothing. Gently rubbing the temples or giving a back massage has a calming influence. Caregivers use functional touch when they give a bath, take a pulse, or perform other nursing duties. Holding a hand or giving a hug reflects affection and caring. Touch can say, “I care about you.” It builds trust and a feeling of security. Caregivers also “touch” with their voices, eyes, and facial expressions. Nonphysical touch occurs when you enter someone’s personal space. The response of the individual depends on the situation. Patients may respond with verbal or physical violence if they are agitated or experiencing a catastrophic reaction.

Touching may not be appropriate for all people. Be sure the patient sees you first. If a patient is startled by your presence, he or she may react by striking out. Know the person—some people just do not like to be touched. Others may associate all touching as a prelude to sexual activity. Someone who has been physically abused may connect touching with pain and respond accordingly.

COMPANIONSHIP, INTIMACY, SEXUALITY, AND COMMUNICATION

For reasons that are not yet understood, changes in sexual behavior may become apparent in people with AD. Psychological reactions, such as depression and anxiety, that affect the general population, may also result in sexual dysfunction in the person with AD. Structural changes in the brain and nervous system may also account for sexual dysfunction. Coping with memory deficits may be so stressful that there is little energy or desire left for sexual activity.

The impaired partner may not remember the spouse as a sexual partner. The healthy spouse may be too physically and emotionally fatigued to be interested in sex [39]. In some cases, spousal caregivers find it difficult to view their partners as sexual beings when they must provide for all their physical needs. Healthy partners may feel that it is not proper to expect the spouse with AD to participate in sexual activity. People with AD and their partners are often reluctant to discuss sexual matters. Support and counseling, especially for the healthy person, may be needed in order to cope with the changes brought about by the disease. Sexual intercourse is only one aspect of sexuality. Many couples find renewed meaning in companionship and intimacy. They often experience fulfillment in keeping the commitment to “love for better or worse, in sickness and in health” [39].

Sexuality raises additional issues among residents of long-term care facilities. Staff members are concerned about legal issues, patient's rights, and the family. In some situations, staff members have received little education about sexuality and may react to incidents involving sexuality inappropriately. Sexual functions are closely linked with physical and psychological well-being; ideally, a sexual assessment would be completed for every resident and used in planning care [39]. In the residential setting, a patient may initiate a relationship with another resident. When one or both patients are married, the reaction of the healthy spouse is a legitimate concern for staff members. Assessment and care planning regarding sexual activity is necessary to determine whether both parties are aware of the relationship, if either party is being exploited or exploiting the other party, and if both parties are aware of any risks that may be inherent in the relationship.

In the early stages of AD, the patient may be capable of making decisions regarding sexuality. The staff may need to adapt a viewpoint that asks, "What would we do if this person was living in the community?" For example, a staff member may not approve of homosexuality, or an affair between two married people, but that person does not assume responsibility for forcing those values on the involved parties.

Partners of residents should be given privacy when they visit. Remind staff members not to enter a room with a closed door. Assure the partner that it is acceptable behavior to be intimate if this is the desire of both people.

Interventions may be required when sexual behaviors are carried out in public. The behaviors may not necessarily be rooted in sexual feelings. The person who disrobes at inappropriate times or in unsuitable settings may be feeling uncomfortable because clothing is too tight or too warm. The patient does not realize that clothes should not be removed in public. Exposure may also mean the patient has to go to the bathroom or wants to go to bed. Different clothing may avoid future situations. It may be necessary to dress patients in dresses that zip up the back or in pull-on pants without a zipper so they cannot be easily removed.

Patients who wander at night may crawl into bed with other residents. The person who has slept with a spouse for half a century may be looking for the comfort derived from sleeping with another person in the same bed. Lead them from the room and try to distract them with another activity.

Patients with AD may become jealous and suspicious, accusing their spouse of having an affair. Arguing or trying to convince them otherwise will only escalate the level of anxiety; it is better to patiently distract them with another activity.

Masturbation is not an uncommon behavior for people residing in long-term care facilities. It is an acceptable and therapeutic method for relieving sexual tension. Patients who masturbate in public areas should be taken to their room and provided with privacy. Staff members must observe their right to privacy. Residents may make sexual advances to staff members. Calmly removing their hand or giving them something to hold while care is being rendered may resolve the situation.

MAINTAINING NUTRITIONAL STATUS

Healthy elderly people require 1,500–2,000 calories per day to maintain nutritional status. The person in the middle stages of AD may require an additional 600 or more calories per day to prevent weight loss due to constant walking or pacing. Fluid requirements are 30 mL/kg of body weight [42].

Several studies have linked AD to nutritional deficiencies. Persons with AD tend to have decreased body weight and different fat composition, neither of which is explained by dietary intake, activity, or malabsorption. Several studies report that men and women with AD have vitamin deficiencies. A diet high in nutrients and vitamins has been shown to be of benefit [43]. As with other elderly shut-ins who receive insufficient sunlight, patients with AD are prone to vitamin D deficiency; periodic assessment of serum vitamin D, and supplementation when levels are low, is an important component of follow-up care.

IDENTIFYING ALTERED NUTRITION AND DEHYDRATION

The nutritional and fluid intake of people with AD must be closely monitored. Patients should be weighed at least monthly. Weight loss is considered significant if:

- There is a 5% weight loss in one month; weight loss greater than 5% is considered severe
- There is a 7.5% weight loss over a three-month period; anything greater is considered severe
- There is a 10% weight loss over a six-month period; anything greater is considered a severe weight loss

The Nutrition Screening Initiative has identified the following warning signs of people at risk for unintended weight loss [44]:

- Needs help to eat or drink
- Eats less than half of meals/snacks served
- Has mouth pain
- Has dentures that do not fit correctly
- Has a hard time chewing or swallowing
- Has sadness, crying spells, or withdrawal from others
- Is confused, wanders, or paces
- Has diabetes, chronic obstructive pulmonary disease, cancer, HIV, or other chronic disease



EVIDENCE-BASED
PRACTICE
RECOMMENDATION

According to the Hartford Institute for Geriatric Nursing, the Edinburgh Feeding Evaluation in Dementia scale (EdFED) is a valid and reliable observational instrument that nurses can use to identify eating and feeding difficulties and determine the level of assistance needed.

(<https://hign.org/consultgeri/try-this-series/eating-and-feeding-issues-older-adults-dementia-part-i-assessment>. Last accessed August 17, 2023.)

Level of Evidence: Expert Opinion/Consensus Statement

Undernutrition may be identified by pale, scaling skin with dark areas on the cheeks and under the eyes. The tongue may be swollen and discolored and covered with lesions. Spongy, bleeding gums and dental cavities are other signs. Lack of subcutaneous fat and weak, atrophied muscles may also be noted. Disorientation is common with undernutrition. Signs of dehydration include dry oral mucous membranes, orthostatic hypotension, increases in pulse and respiration, decrease in blood pressure, disorientation, and diminished skin turgor [44].

NUTRITION AND EATING PATTERNS IN PATIENTS WITH AD

There are many factors that interfere with food consumption and absorption among the population with AD. The person who lives alone may lack the cognitive resources to shop for, plan, and cook a nourishing meal. A loss of coordination may make it difficult to pick up utensils and to get food and drink to the mouth. Spilling food may embarrass the person in the early stages of AD. In the later stages, loss of oral control and hyperorality may make it difficult to get adequate nourishment.

Factors that may hinder proper eating and nutrition in patients with AD may be assessed by considering the “A’s of Alzheimer’s” [122]:

- **Aphasia:** Difficulty articulating preferences orally
- **Apraxia:** Difficulty maneuvering food utensils, difficulty chewing and swallowing food
- **Agnosia:** Difficulty recognizing utensils and food
- **Amnesia:** May not remember eating or distinguishing the need to eat
- **Anorexia:** Decreased appetite (psychological cause possible)

Cognitive deficits related to short attention span, disorientation, and memory loss all contribute to the inability to complete a meal. Food may be hidden or thrown away. The patient may be unaware of or unable to respond to hunger and thirst sensations.

Sensory-perceptual deficits interfere with eating skills. Those who have agnosia are not able to identify eating utensils and may try to comb their hair with the fork. The patient with apraxia may know what the fork is and how to use it but be unable to pick it up and bring food to the mouth. Some may persevere during eating, chewing the same mouthful of food over and over. Others may tire of eating or lose interest before the meal is completed.

Poor positioning also impedes the eating process. The table may be too high and the food too far away. Poor oral hygiene can predispose the patient to problems that cause loss of appetite, difficulty in chewing, and pain from oral lesions. In the later stages, dysphagia obstructs nutritional intake. The late-stage patient is unable to feed him or herself and may refuse to eat. Decisions should be made regarding aggressive nutrition and dehydration measures.

Food texture must be adapted to the diminishing skills. Barring other medical conditions, the patient can be placed on a regular diet, avoiding tough, stringy meats and foods that are difficult to chew, such as caramels. A mechanically soft diet with ground or chopped foods may become necessary. Eventually, a pureed diet is usually required. Commercial thickeners added to fluids facilitate swallowing.



EVIDENCE-BASED
PRACTICE
RECOMMENDATION

The European Society for Clinical Nutrition and Metabolism (ESPEN) recommends encouraging adequate food intake and providing adequate support. Simple nursing actions like placing patients or residents at a dining table, providing emotional support, supervision, verbal prompting, encouragement and assistance at mealtimes may promote self-feeding and enhance the feeding process.

(https://www.espen.info/wp/wordpress/wp-content/uploads/2015/11/ESPEN_GL_Dementia_ClinNutr2015.pdf. Last accessed August 17, 2023.)


Level of Evidence: Very low

ASSESSING THE ACTIVITIES OF DAILY LIVING

Activities of daily living are skills learned in childhood that are completed without conscious thought throughout adulthood. Physical and cognitive disabilities can interfere with the mastery required for these skills. The adaptation of the environment and simplification of the task can enable one to function with minimal assistance throughout the first stages of the disease. The diminishing abilities are often the impetus for admission to a long-term care facility. Instrumental activities of daily living are lost early in the course of AD because proficiency in judgment and problem-solving skills are required. As previously noted, money management, use of a telephone, driving, and household management are examples of instrumental activities of daily living.

INDEPENDENCE AND LETTING GO

Adults take their independence for granted. Caring for oneself, running a household, and managing money are tasks that are carried out daily. People in the initial stages of AD are no different. The individual may still go to work every day, drive a car, pay the bills, and balance the checkbook. As the disease progresses, the person's capabilities are gradually lost, resulting in total dependence. This stage is particularly difficult for both the individual and family because the patient with AD is aware that his or her abilities are ebbing away. The patient often experiences difficulty with financial planning and driving, activities that are important to independence. However, it is difficult for family members to suggest that it may be time to retire from a job or to give up driving.



According to the American Academy of Neurology, the Clinical Dementia Rating (CDR) scale is established as useful for identifying patients with dementia at increased risk for unsafe driving. A patient's self-rating of "safe" driving ability is established as not useful for identifying patients at increased risk for unsafe driving.

(<https://n.neurology.org/content/74/16/1316>. Last accessed August 17, 2023.)

Level of Evidence: A

of recommending driving cessation in patients with AD when necessary. As some states have reporting laws, physicians should be aware of their own state's reporting laws. This situation is difficult, especially in the case of the patient who refuses to give up driving. There are several issues that physicians are faced with, including [124]:

- Patient reaction
- Family or caregiver reaction
- Patient confidentiality
- Patient safety
- Public safety
- Third-party liability

Healthcare professionals should work with each patients' caregiver and family to explore all options, including taking away the car keys, disabling the car, or selling the car.

Employment, Termination, or Retirement

It is wise for patients with AD to inform their employers of the diagnosis. It may be possible to switch to a simpler job or one with fewer responsibilities as ability declines; retirement may also be an option. The family can investigate the availability of counseling through an employee assistance program or a social service agency. The family also must determine whether or not any benefits, like a pension or health insurance, will be available to the worker if employment is to be terminated. They should also contact the local Social Security office to find out whether the patient is eligible for benefits.

ETIOLOGIES OF SELF-CARE DEFICITS

A functional assessment will identify which tasks or which steps in the task the affected individual cannot complete. It is useful to monitor patients while they are attempting an activity of daily living to gather data upon which to formulate an appropriate intervention. The etiology for a self-care deficit cannot usually be reversed. However, an understanding of the etiology will result in setting reasonable goals.

Money Management

Determine whether the patient still writes checks with legible handwriting, adds and subtracts in order to balance a monthly statement, handles cash (i.e., paying for purchases and receiving change), or comprehends the routine of paying taxes. Does the patient have an awareness of the family's overall financial status?

As the patient begins to lose the ability to handle financial matters, family members must gradually assume responsibility for these tasks. Patients may make accusations that someone is stealing from them. Allow them to keep small sums of money in their pockets. Consultation with an attorney may be needed to assure fairness to the patient and to the family.

Driving

Losing a driver's license causes a considerable loss of independence. According to the Alzheimer's Association position statement on driving safety, a diagnosis of AD alone should not be considered grounds to revoke a patient's driving privileges [123]. Other factors must be present and considered, such as the degree of cognitive decline, comorbidities, and prescription of medications that may affect driving abilities [123; 124]. Formal assessments, such as an on-the-road driving test, should be considered when appropriate [123]. Physicians carry the responsibility

Memory Loss

Patients with AD do not remember that they have to take a shower, brush their teeth, and shave. They may forget how to find the bathroom, how to turn the water on, or where their toothbrush is when they get there. Knowledge of how to get toothpaste onto the brush or how to use the razor may also be lost.

Shortened Attention Span

Even with reminders, patients often cannot attend to a task long enough to complete it. For example, they may start shaving or brushing their teeth and quit before they are finished.

Sensory-Perceptual Deficits:

Agnosia and Apraxia

Patients with AD may also have a figure-ground deficit, which means that when a number of items are laid out (e.g., toothbrush, toothpaste, razor), they are unable to distinguish one from another. The individual who perseverates may wash the same side of his or her face over and over, unable to move on to another part of the body. Sequencing deficits (the inability to complete the required steps in the correct order) are common in AD. For example, when dressing, patients may put underwear on top of outer clothing or try to put a sock on over a shoe.

Some individuals may suffer excess disability. This is defined as disability beyond that expected by the disease process itself. Treating the excess disability is a priority for people with AD. The condition may be caused by medication toxicity from drugs such as digoxin or phenytoin; other diseases, such as arthritis, cardiac disease, or coexisting mental illness; increased level of fatigue or stress; and vision or hearing impairments. Caregivers may unwittingly contribute to or hasten the onset of dependence by decreasing their expectations. Caregivers can over help because of their desire to spare their loved one. It can be due to impatience with the decreasing abilities, a lack of understanding of the disease, or because it is “just easier” to do it themselves [103].

INTERVENTIONS FOR DELAYING THE LOSS OF FUNCTIONAL SKILLS

Although the changes resulting from AD cannot be reversed, abilities in activities of daily living may be maintained for a longer time if the patient receives personal and environmental support. However, caregivers must remember that once a skill is lost, it is likely lost forever.

A plan must be developed for care that includes specific interventions and goals based on the functional assessment. Appropriate communication techniques must be considered and included. Physicians and other healthcare providers may be involved in the development of the overall plan.

All caregivers must be aware of the care plan to ensure that a consistent approach is used. Lack of consistency or differing expectations of caregivers may impede success. It helps if all caregivers understand the ramifications of the self-care deficits, maintain the patient’s dignity, and have all activities of daily living performed in privacy.

Identify strengths and focus on remaining abilities. It may be that the patient can no longer cut the meat on his or her plate, but if the patient is still able to butter the bread, he or she should not only be allowed but encouraged to do this.

Patients should not be expected to perform an activity of daily living when they are fatigued or agitated. Caregivers should let it go for the time being, and attempt it later, when both parties are rested or calmed down.

Tasks should be broken into their separate components (**Table 5**). Interventions should be based on the steps of the task that the patient is unable to perform.

Include the use of cues in the care plan and be aware of how and when to use verbal or nonverbal cues, demonstration, hand-over-hand techniques, or physical guidance. Verbal cues consist of brief, simple instructions to the patient, such as “Please drink your milk” while presenting the glass of milk. Nonverbal cues consist of touching or pointing. It is often helpful to touch the person’s hand and point

STEPS OF ACTIVITIES OF DAILY LIVING	
Activity	Steps
Bathing	Gets to tub/sink/shower Gathers items needed for task Regulates water Washes/rinses upper body Dries body
Dressing/ undressing	Obtains/selects clothing Puts on/takes off slipover top Puts on/takes off cardigan top Manages buttons, snaps, ties, zippers Puts on/takes off skirt/pants Buckles belt Puts on shoes/socks
Eating	Gets to table Uses spoon, fork, knife appropriately Opens, pours Brings food to mouth Chews, swallows Uses napkin
Toileting	Gets to commode/toilet Manipulates clothing Sits on toilet Cleans self Gets clothing in place Washes hands
Mobility	Gets self to side of bed Maintains upright position Comes to standing position Places self in position to sit in chair Locks wheelchair brakes Turns body to sit Lowers self into chair Propels wheelchair Repositions self in chair Raises self from chair Places self in position to sit on edge of bed Walks alone/with assistance Uses assistive device(s)
Source: [34] Table 5	

to the milk. To demonstrate, pick up the glass of milk and raise it to your mouth. To use hand-over-hand techniques, place the glass of milk in the patient's hand and place your hand on the glass as well. Then raise the glass of milk to the patient's mouth. Handing the milk provides physical guidance. A combination of cues may be utilized for an activity.

Simplify tasks whenever possible. For example, it is easier to fasten shoes with a Velcro closure than it is to lace and tie.

It is important to remember that disruptive behavior during personal care may be triggered by:

- Misinterpretation of environmental cues
- Intrusion of the caregiver into the patient's personal space and territory
- Poor communication between caregiver and patient
- Feelings of poor self-esteem due to increasing dependence
- Feelings of insecurity
- Changes in routine, environment, or personnel
- Physical discomfort

MANAGING PATIENT BEHAVIOR

Managing behavior is the greatest challenge associated with the care of people with AD. To meet the challenge successfully, caregivers must be educated about the disease process and its influence on behavior. Physicians who may deal with patients with AD should especially be knowledgeable in this area.

ALTERING CAREGIVER PERCEPTIONS

All behavior has a reason, although the cause may not be immediately known. Behavior is a response to the environment, caregivers, or internal stimuli. Problems may develop when the expectations of the caregiver do not match the abilities of the patient. The patient has a need for supervision and assistance because of increasing functional disability. The management of behavior is directed toward adapting the environment and approaches to the needs of the individual. Caregivers cannot cure the disease or teach patients to remember. They cannot resolve behavioral issues by using logic, by trying to reason with the person, or by coaxing or using flattery. Caregivers should have a healthy sense of humor and be flexible, creative, and patient.

The medical model of care is no longer effective for patients with late-stage AD. Rigid routines that require vital signs to be taken at 8 a.m., showers/baths to be completed by 11 a.m., and all residents in bed by 8 p.m. are unnecessary and unworkable. Creativity allows the caregiver to acknowledge that sleeping in a bed wearing nightclothes is not necessarily the “norm” for all patients with AD. Behavioral management is successful when caregivers can enter the patient’s reality and utilize techniques that show respect for adult feelings rather than dwelling on childlike behavior. The behavior of a cognitively impaired person is logical within his or her own frame of reference. A knowledge of history is helpful, as it facilitates understanding of the person who is reliving the 1940s, 1950s, or 1960s. An awareness of the patient’s personal history is essential because it helps to know where the individual is “coming from” when he or she relives the past.

Avoid the use of labels in describing behavior. Words such as “uncooperative” are subjective and usually mean that the patient will not complete the desired task when it is asked. When staff members use such labels, the tone is set for all future contacts with the patient. Caregivers may assume that the patient will be difficult and thus elicit the poor behavior that is expected.

STRESSORS AFFECTING PATIENTS WITH AD

Stress affects patients with AD just as it would any other person. The stress is intensified because patients lack control over themselves and their environment. There are many causes for stress, for example, unmet physical needs such as hunger, thirst, constipation, fatigue, and immobility. These can elicit a negative response from the patient. When anxiety and agitation are displayed, patients may be experiencing discomfort related to pain, nausea, or infections. In the early stages of AD, patients often feel anxiety associated with the diagnosis and manifestations of the disease. They know they are “slipping away” and that they are unable to do anything about it. Patients with AD also have the same emotional needs as anyone else. Family and friends may withdraw as the illness progresses, leaving the

patient to feel rejected and isolated. Patients may be deprived of intimacy and physical closeness with a partner. The environment may produce a number of stresses related to sensory overload, for example, too many changes in caregivers and a lack of personal and environmental space. Cognitive impairment may cause patients to misperceive the environment or to suffer delusions and hallucinations.

PROMOTING POSITIVE BEHAVIORS

Caregivers should make every effort to meet the patient’s physical, safety, and emotional needs and to identify and treat health problems. The goal is to arrange an environment that is calm, safe, and serene but provides adequate sensory stimuli. Caregivers should be taught how to communicate effectively with those in their care. They should try to promote the individual’s feeling of security by establishing flexible routines. Security can be enhanced by having the same people take care of the patient. They should focus on the individual patient’s strengths and avoid emphasis on skills that have been lost. Caregivers use nonverbal, indirect, and creative encouragement to bolster the patient’s sense of self.

SUGGESTED MANAGEMENT SKILLS FOR CAREGIVERS

The problem-solving approach can help to control annoying behaviors. When bad behaviors are identified and evaluated, interventions can be established. If the intervention is successful, it is permanently written into the care plan to avoid future similar problems. If the intervention does not have a positive effect on the behavior, further evaluation is needed. Did it fail because of misidentification of the problem or because someone did not understand or follow through with consistency?

Identifying and Evaluating Behaviors

When a behavior is disturbing to caregivers, the specific actions of the patient must be identified. Using subjective descriptions such as “He became violent” or “She is aggressive” provide no clues as to a possible cause or how to intervene. The statement “Mr. J said he didn’t want a shower and bit me when I attempted to take him to the shower room,” provides a starting point for problem resolution.

The next step is to evaluate the behavior by further investigation. In this situation, the problem may be directly related to the shower or it may be due to other factors. To determine triggers for problem behaviors, the following questions may be helpful:

- What events occurred just prior to the incident? Did the patient feel embarrassed because he or she was incontinent and needed to be changed?
- What was the environment like? Were there too many people around; too much noise and commotion?
- Does the behavior arise from a specific issue (every time a shower is attempted) or does it happen to only one staff member?
- Does the behavior affect only one resident and one staff member?
- Is the behavior symbolic of an unrecognized problem? For example, flushing dentures down the toilet may be the only way the person knows how to communicate that the dentures are uncomfortable to wear.

With this information in hand, interventions can be developed.

There are clear-cut solutions to resolving problems caused by unmet needs or an upsetting environment. Other situations may require more deliberation. It may be helpful to discuss the problem with other staff members. Is the interaction between a patient and a particular staff member especially positive? Remember that it may be a housekeeper, a volunteer, or other individual who has the most substantial relationship with the individual. Try to identify the reasons and share this information so these approaches can be used consistently. Before establishing interventions, determine whether the safety or health of the patient or other individuals is at risk as a result of the behavior and whether the problem is truly a patient problem or a staff problem. In some cases, actions are only troubling to the

staff and are not hindering the safety or health of anyone. For example, a patient with dementia who is masturbating in the privacy of his or her room is not a problem except to those members of the staff who consider it delinquent behavior.

Redirecting Behaviors

Redirecting behaviors uses distraction techniques and patients' memory deficits, and short attention spans help to ensure the success of distraction. Used correctly, it avoids confrontation and the risk of catastrophic reactions.

The Use of "Self"

The effective use of one's self as a therapeutic medium is the greatest intervention of all. Caregivers who are successful realize that the responses of the patient are frequently related to the approach of the caregiver. The most successful are those who are willing to "listen" to the patient's unspoken messages and use this information in their interactions. When a disturbing behavior occurs, they view it as a challenge for which they can find a solution rather than placing the responsibility for the behavior on the patient. They learn as much as they can about patients and their pasts through their contacts with the patients' families and others who know them.

As an example, Patient D was agitated one morning and repeatedly called out, saying, "I have to go outside." Because it was a beautiful spring morning, a nursing assistant wheeled Patient D to a window where he could view the trees and the blooming spring flowers. Patient D became more agitated and began pounding the table. Another nursing assistant who knew him suggested that he was upset because for several years he had been a gardener for a public park. The spring was his busiest time; sitting by the window reminded him that he had to get outside to "get his chores done." The nursing assistant also knew that he enjoyed ball games and moved him to the TV where he could watch his favorite team playing.

Caregivers with the therapeutic touch have the ability to go where the patient is at the present time. They can sing Christmas carols in the middle of July if that makes the patient happy. They know when hugs are appropriate and sense when a hand massage is in order. Most importantly, those who make use of “self” truly enjoy working with the patients and are proud of their accomplishments.

SPECIFIC BEHAVIORAL INTERVENTIONS FOR PATIENTS WITH AD

Following the general guidelines provided in the previous section can help in preventing disturbing behaviors. However, disruptive behaviors may occur even in the best of circumstances. Most people with AD do not have simple, uncomplicated dementia. As noted, it is estimated that at least 25% of individuals also have concomitant depression and another 25% have concomitant psychosis [70; 133]. A small number of patients with AD may also have frontal lobe syndrome, which is characterized by responsive aggression [141]. Aggressive behavior may become increasingly physical if the caregiver does not understand the individual's inability to cope with the situation. Psychotic behavioral disturbances include agitation, delusions and hallucinations, and aggressive behavior [49].

In severe cases of potential danger, pharmacologic treatment may be required for disruptive psychotic behaviors along with the implementation of behavioral strategies. As noted, before starting pharmacologic management, assess all disruptive behaviors to rule out causes such as unmet physical needs, physical discomfort, acute medical problems, excessive environmental stimuli, or caregiver improprieties. The bizarre behaviors exhibited by persons with AD may be the only remaining methods by which they can communicate with the world. Vocal and motor activities often viewed as combative, hostile, agitated, or aggressive by members of the staff may be the person's only way of telling caregivers something is not right.

Shadowing

Shadowing occurs when the patient follows or “hovers” around the caregiver and may persist in talking or asking questions. Safety is not usually a concern related to shadowing. However, it can become irritating and annoying to the caregiver, particularly when it involves a family member at home. Remember that the caregiver represents security to the patient. The shadowing may be accompanied by agitated behavior that should be addressed. An assessment of the behavior will help determine if the behavior happens at a specific time of day or if it is triggered by certain people or environments.

Interventions for Shadowing

If certain people or environments trigger shadowing, then adjustments or avoidance is necessary. If the behavior happens at a certain time of day, an activity may be planned to keep the person occupied, such as dusting or winding a ball of yarn. The Alzheimer's Association suggests, “gum therapy” or “cereal therapy” if the person can safely chew and swallow. Chewing is another form of distraction and redirection of energies.

Wandering

Wandering is defined as ambulation that may appear aimless but often has a purpose. There are many unproven theories for wandering. The patient with AD may be looking for something or someone, or it may be a way of coping with stress or of alleviating feelings of loneliness and isolation. The perception of the caregiver, the type of wandering pattern, and the environment help determine whether wandering is considered a problem. Purposeful wandering occurs when the individual has intent for the movement. He or she may be walking to escape boredom or to exercise. Purposeful wanderers are usually predictable and consistently walk the same route. They do not attempt to leave the building, and they are “safe” wanderers. This type of wandering should be considered normal unless the pattern changes. When mobility skills begin to diminish, falling may become a problem. Aimless wandering is characterized by purposeless movement by a

disoriented person who may enter other rooms or take another's belongings. The escapist usually has a destination, planning on "going home" or to some other familiar place.



The Hartford Institute for Geriatric Nursing asserts that best practice in care of older adults with dementia involves: 1) identifying risk for wandering, including interviews with caregivers, 2) providing appropriate supervision, 3) reducing environmental triggers for wandering, and 4) using individualized nursing interventions to address the causes of wandering behavior.

(<https://hign.org/consultgeri/try-this-series/wandering-hospitalized-older-adult>. Last accessed August 17, 2023.)

Level of Evidence: Expert Opinion/Consensus Statement

An example is Patient W, who was very determined to leave the facility so he could visit his sister. When all the staff was busy, he managed to get the nurse's car keys from the counter in the nurse's station. He knew which car was hers and drove away from the premises. He was missed about 15 minutes later. When a search of the grounds and building proved fruitless and when the nurse noted her car missing, the police were notified. Following the staff's advice, the police found Patient W at his sister's house. He had driven 65 miles on an interstate highway without incident.

The most dangerous type of wandering is done by the critical wanderer. This individual tries to leave the premises but is unaware of the hazards involved. He or she may wander into the middle of a busy highway or into a pond of water without any comprehension of cause and effect.

Not all people with AD will wander. Those who may not have wandered at home may do so in the long-term care facility. The first two weeks after admission are critical. The staff should monitor the individual for specific behaviors. The goal is not necessarily to stop the wandering but to ensure the safety of the individual and to avoid intrusion on others.

Interventions for Wandering

- Create a safe environment so the patient can wander without incident.
- Make sure the patient has an identification band or bracelet on at all times. In a long-term care facility, provide a list of wanderers to all staff members.
- Always know what the patient is wearing. Place his or her name in all pieces of outer clothing.
- Install gates on stairwells.
- Install alarms on all exit doors.
- Make safe wandering paths; remove clutter, throw rugs, furniture with sharp corners, and electrical cords.
- Provide a warm, homelike environment.
- Ask the family to bring in pictures and other small items from home.
- Provide activities that correlate with their abilities and interests.
- Place the individual's name and a familiar object on the door of his or her room.
- Remove items that may activate the desire to leave, such as coats, hats, and purses.
- Provide local police with information regarding AD and wandering. They ordinarily will not initiate a search for a missing person for 24 hours. Inform the officer that, for a patient with AD, this is critical. Have a written procedure to follow in the event someone is missing.
- Camouflage exit doors by painting them the same color as the walls.
- Take patients for a walk outdoors, weather permitting.
- Approach a fleeing patient cautiously. If the patient exits the building, approach him or her from the front, calmly walk alongside, and gradually angle back toward the door. The patient may be overwhelmed if several people attempt to overtake him or her.

Sundowning

Sundown syndrome occurs when the patient becomes restless in the evening or during the night. As with wandering, the cause is unknown. Experts feel it may be due to overfatigue, physical discomfort, reduced sensory stimulation, too much caffeine, shadows caused by the lighting, disturbing dreams or feelings of insecurity, or loneliness during the night.

Interventions for Sundowning

- Evaluate medications, time of administration, and their side effects.
- Question the family regarding the patient's sleep habits. Is the patient used to sleeping with a window open, with a night light, with soft music playing, with socks on, with two pillows? Incorporate these habits into the bedtime routine.
- Avoid caffeine and alcohol in the evening.
- Determine whether the patient is sleeping during the day. If this is the problem, keep him or her up and active. On the other hand, the patient may become fatigued and need a short nap early in the afternoon.
- Determine whether the patient is getting enough exercise. One or two vigorous walks (unless he or she is a frequent wanderer) earlier in the day may promote sleep at bedtime.
- Avoid putting clothes out for the next day. The patient may take this as a cue to get up and get dressed.
- Evaluate the bedtime routine:
 - Maintain a set time and routine.
 - Help the patient to the bathroom.
 - Avoid exercise or stimulation just prior to bedtime.
 - Give a light bedtime snack.
 - Give an analgesic for arthritis or other sources of pain and discomfort.
 - Give a gentle back or foot massage.

- Place a commode or urinal at the bedside if finding the bathroom is a problem.
- Provide adequate night lighting.
- Close the blinds or draperies to eliminate shadows.

If these interventions fail and sundowning persists, repeat the bedtime routine (take the patient to the bathroom, provide a glass of warm milk, etc.). If all else fails, allow the patient to stay up in a recliner or beanbag chair by the nurse's station. The patient may willingly return to bed later. If in the patient's home, the caregiver may need to adapt the sleep/wake schedule to match the patient, or a sitter may be hired to remain with the patient while the caregiver sleeps.

Psychotropic medications may be needed for agitation, delusions, or hallucinations. Sleeping medications are not recommended. The effects are short-term and may add to confusion on awakening.

Persistent sundowning is a common reason for admission to the long-term care facility. The caregiver becomes stressed from lack of sleep. The situation may also become dangerous if the patient wanders outside, turns on the stove, or turns up the thermostat.

Rummaging, Hoarding, and Pillaging

The degree to which rummaging, pillaging, and hoarding is a problem depends on whether the individual is at home or in a facility and whether or not it is infringing upon the rights of others. Consider Patient J, who goes from room to room aimlessly picking up items from others. She may take the items to her room or she may leave them in someone else's room. This is one of the most disturbing behaviors for other residents in the facility. The family of Patient F noted that she had over 200 rolls of toilet paper in her basement. Patient P had stacks of newspapers throughout the house, with only a narrow walkway going from room to room. Theorists believe these patients may be searching for something or attempting to maintain control of the environment.

Interventions for Rummaging, Pillaging, and Hoarding

In a dementia unit, patients may pillage from one another. This may present more of a problem to family than to the patient. In some facilities, the night-shift staff collects the items and returns them to the proper rooms.

- Monitor the patient with AD so the privacy and possessions of others are protected.
- Label every item that all residents bring into the facility on admission and throughout the stay.
- Try to note the pillaging habits. Many take the same type of items; for example, envelopes and other “mail” type items. Watch what patients do with the objects they take. They will frequently take them to the same place. This observation will help the staff find the objects.

Agitated Behavior/Aggression

Agitation is defined as improper behavior that may be verbal or physical and is not explained by an unmet need, confusion, or pain. Aggression is a hostile action directed toward other people, oneself, or objects. Agitation may be a result or a cause of many other behaviors associated with AD. Agitation may cause sundowning, shadowing, and/or wandering. It may result from delusions or hallucinations. Other causes of agitation include delirium, psychiatric disorders, medical problems, depression, drug side effects, sleep problems, and social and environmental factors. As the disease progresses, the AD sufferer’s insecurity increases. The coping mechanisms used earlier to block out awareness of functional losses are no longer effective. Agitation may change to verbal or physical aggression if not managed appropriately. It is estimated that more than 75% of those with dementia will exhibit agitation [52].

Interventions for Agitated Behavior

- Assess the situation to identify a possible cause for the behavior.
- Always use a calm, reassuring approach. If several people approach the patient or if attempts are made to “grab” or restrain them, the patient may be overwhelmed and will respond with increasing agitation, possibly striking out in an attempt of self-protection. Be aware of the significance of tone of voice. The patient may perceive anger and impatience even though the words are meant to be soothing.
- Remember that even severely demented persons are responsive to the people around them. They can sense tension and will respond with agitation. Use a firm, confident approach, but avoid sounding authoritative. It is patronizing when the caregiver sounds like a parent scolding a child.
- Avoid trying to use reason or logic or lengthy explanations. Comments such as, “If you are quiet, I will get you some ice cream” or “Don’t you realize you’re keeping everyone awake” are meaningless. This approach also denies the patient his feelings.
- Avoid trying to force patients to do something they clearly do not wish to do. Agitation will become aggression.
- Distraction may be an effective intervention if the appropriate approach is used.
- Try simulated response therapy (SRT). SRT is based on the belief that family members can influence and stabilize behaviors. The therapy uses audiotapes composed of a family member’s side of a telephone conversation and blank spaces that correspond to the patient’s side of the conversation. The family member reminisces about cherished and loved experiences of the person’s life. By utilizing selected memories, SRT creates comfort by altering their environment. Use headphones to exclude environmental sounds and a lightweight cassette player.

- Move the individual to a tranquil, quiet setting. A soothing voice or calming touch is often effective.

Patient H, for example, is seated at the table waiting for breakfast. The dining room is a flurry of commotion. Several call-ins mean the nursing assistants are trying to hurry in an effort to catch up on the day's tasks. Patient H is showing signs of agitation. His breakfast has been served, and he is able to feed himself; however, he is not eating. The nurse approaches him and urges him to eat. "You have to eat; this food is good for you. Here, just take a bite of cereal." At the same time she is attempting to get him to drink by holding a glass of juice up to his mouth. He pushes the glass away, and the nurse responds, "Why did you do that? That wasn't nice. Here, you need to drink this juice." The nurse continues her attempts to coerce him to eat. Finally, Patient H slaps the glass out of the nurse's hand, spilling juice down the front of her uniform. The nursing assistant approaches Patient H when the nurse leaves to clean her uniform. He gently touches him on the hand and tells him that he is going to move him to a quieter place. The nursing assistant sits down next to Patient H and gains eye contact. He places a bowl of cereal in front of him but makes no attempt to coax him into eating. Patient H picks up the spoon and begins to eat his cereal. The nurse reports and documents that Patient H is "combative."

This scenario is an example of agitation changing to aggression. The interventions for agitation and aggression are the same. If those interventions are implemented during agitation, aggression can usually be avoided. Physical aggression often contains an element of danger. The patient may strike out at the caregiver or other residents. Occasionally, two patients will "feed into" one another, causing each person to become aggressive, striking one another if within close range. The only solution is to keep the two parties separated at all times. When a person is physically aggressive, assess the level of danger for the caregiver, the individual, and other residents.

Avoid a "hands on" approach unless the situation is leading to immediate peril.

Catastrophic Reactions

A catastrophic reaction is defined as an overstated emotional response triggered by task failure. The patient feels he or she is expected to perform beyond capacity and feels frustrated and angry. A catastrophic reaction may have components of agitation or aggression but does not necessarily have violent tendencies. Assess the situation in an effort to determine what may have precipitated the reaction; in this way, further incidents may be avoided. Regularly assess the individual's abilities so the staff does not expect more than the patient is capable of doing.

In an example of distraction, Patient G was told that she would have a new roommate. The medical condition of her present roommate necessitated moving her to a different level of care. After the new roommate was admitted, Patient G began pacing the hallway. She muttered over and over, "I can't do it. I can't take care of her. I can't do it." This continued as various staff members attempted to calm her. Taking her to her room was not a solution. Seeing her roommate in bed only increased her agitation. Her daughter later came to visit and suggested she take her mother out for a ride and some ice cream. This was successful. Upon her return, Patient G was calm and went to bed that night without further incident.

Delusions and Hallucinations

Delusions and hallucinations are psychotic symptoms of dementia. AD is not considered a psychiatric illness, but the patient may have concomitant psychiatric illness with AD. These manifestations may be triggered by medications, physiologic malfunction, environmental stress, or insecurity. As previously noted, delusions are fixed false ideas or beliefs and may result from the person's misinterpretation of a situation. One evening at an activity, Patient R kept talking about "the people over there who were having a party." Patient R was looking at the

reflection in the window of the people in the room but misinterpreted what she saw. Hallucinations are sensory experiences that cannot be verified by anyone else. They may be auditory or visual and are usually disorganized and fragmented. An illusion is a misperception and is common among the general population; for example, one may bend over to pick up a piece of foil from the floor, thinking it is a dime.

Delusions and hallucinations may not need aggressive treatment unless they are bothersome to the patient who may then respond with aggression, fear, or violence. An assessment, as described earlier, may identify events that trigger these manifestations.

Interventions for Delusions and Hallucinations

Never argue or disagree with patients with AD about what they think they see or hear. They may become agitated and even violent. It is real to them and no amount of persuasion will change their minds. If a patient asks you, “Do you see that person over there?” saying, “I know you see something, but I don’t see it” does not deny the truth. If the patient is upset or frightened, be calm and reassuring with statements such as, “I know you are frightened, but we will keep you safe.” You are responding in a manner that will assist the patient and consider his or her feelings.

Check the environment for noises that may be misinterpreted and for lighting that may cast shadows. Assess for impaired hearing and vision because correcting deficits with hearing aids or glasses may improve the symptoms.

Consider whether the delusion has some basis in reality. In another example, it was reported by the nurse that Mrs. S was delusional; she insisted that she was going to California in a few days to visit her daughter. Three days later her son and daughter-in-law came to get her and flew with her to California. Similarly, the patient who claims her son is taking her money may be correct. These types of statements may be worthy of tactful investigation.

Consider whether the delusion is based on a past event from years ago. The person who talks about getting home to her children or getting up early to milk the cows may be reliving a happier time of life. These types of delusions are harmless. The staff should not feed into them, but it is important they understand that these beliefs are filling a need. In these situations, it is not the task of the staff to determine whose reality is appropriate.

Determine whether the delusion may be rooted in television. Patients with AD cannot always distinguish reality from fiction. Witnessing acts of violence on the screen can be frightening and upsetting.

Use distraction for delusions that appear distressful. Music, going for a walk, looking at pictures, or quiet conversation may be effective. Cover or remove mirrors if a patient becomes upset when the image is mistaken for that of someone else. Pharmacologic therapy must be considered when someone experiences frequent delusions or hallucinations that result in further behavior disturbances.

RESTORATIVE MEASURES TO MODIFY DISEASE PROGRESSION

In addition to medications and behavior management, a restorative approach and activities are beneficial and recuperative when planned and implemented effectively. It is useful for all healthcare providers to be aware of these techniques.

Reality orientation, reminiscence, and validation therapy are programs with specific purposes that may be utilized. Reminiscing is a natural process that people of all ages enjoy, but it is also stimulated in the elderly by the realization that life does not go on forever. For those with AD, reminiscing can be used as an intervention. In the early stage of AD, reminiscing can give a sense of pride and accomplishment to individuals who realize they are losing their grasp on reality.

Reality orientation and validation therapy have been in existence for decades. Whether or not these programs have an effect on cognitive or functional status is controversial. Few rigorous scientific studies have been completed to validate or refute their worth.

REMINISCENCE

To reminisce is to think about or relate one's past experiences, especially those personally deemed most significant. Reminiscing may extol the past and berate the present, it may enhance one's self-esteem and provide gratification, or it may be an obsessive process dwelling upon a particular past situation that resulted in depression and despair. Life review, a form of reminiscence, is a recall of life experiences for the purpose of reevaluating the past, to settle and integrate past conflicts. It involves the need to justify one's life. Most clinicians use the two terms interchangeably.

Reminiscing can be planned as a structured group activity for those in the early stages of AD. To be able to reminisce, one must have the capacity to remember the past; fortunately, long-term memory may remain for a long time. Attendance is voluntary and participants are not expected to talk about memories that they do not wish to share. The group process provides an opportunity for active participants to share memories of the past and to enjoy each other's company. When used correctly, reminiscing can be used as an intervention for anxiety, disturbances in self-concept, impaired adjustment, and hopelessness.

Avoid placing patients with AD and mentally unimpaired elders in the same group. Attendance may not be appropriate for those who have had unhappy lives or who have episodes of paranoia. The group should be no larger than four or five people, depending on the capabilities of the members. The leader (a staff member) introduces the topic. For people with AD, reminiscing about general topics is often

preferable to specific situations in the members' lives. The leader chooses a subject that reflects the current season, an upcoming holiday, or other special events. Weddings are a popular topic in June, and participants can be invited to bring their wedding pictures for others to see. Objects or pictures relevant to the topic can stimulate discussion and add to the enjoyment. Pictures of old cars, clothing, and household appliances usually trigger memories. Conducting reminiscing sessions with cognitively impaired elders requires sensitivity and vigilance on the part of the leader. The leader should "listen" to the feelings of the individuals rather than just hear the words. Giving positive feedback and asking questions encourages the process and may elicit even deeper memories. Participants who show signs of agitation or anxiety should be gently removed from the group. Lamenting reminiscences are past events that the individual interprets negatively. A person who laments frequently about one topic may benefit from counseling by a qualified therapist to resolve feelings about those experiences. Lamenting about many topics from the past may be a reflection of an individual's pessimistic but staple personality.

Individual reminiscence may be suitable for a person who has difficulty interacting with a group. Besides the benefits of improved mood and elevated self-esteem, the patient may develop a deeper trust in the listener, enabling the listener to achieve success with subsequent behavioral interventions.

REALITY ORIENTATION

Reality orientation (RO) was first described in the early 1960s by Taulbee and Folsom. RO is a planned, structured process designed to increase an individual's comprehension of person, place, time, and situation. This concept originated as a rehabilitation technique for traumatized war veterans [126]. However, it has been used for people who have moderate-to-severe degrees of confusion [56].

Professional articles written in the 1960s and 1970s promoted the use of RO as an intervention that was effective in minimizing or reversing behavioral or cognitive decline. However, there is little evidence that RO has long-term effectiveness [57]. RO is routinely used in some facilities based on the assumption that patients can benefit from reality. Although repeatedly attempted, RO seldom succeeds in correcting the perceptions of the cognitively impaired person. Short-term memory loss is one of the most significant manifestations of AD. The affected person is unable to retain information, and the use of RO techniques is generally an exercise in futility. Questions of time, date, and place should be answered honestly, but to persist in repeating this information is frustrating to both the patient with AD and caregiver. RO may be appropriate for people with depression or those who have confusion related to delirium. It may provide reassurance for those in the very early stages who are aware that they are losing their grip on reality. It does not work with patients with irreversible dementia because they no longer understand reality. More research is necessary to establish the population, disease stage, and parts of RO that prove most effective [125; 126].

Scenarios

Mrs. R had been a businesswoman prior to retirement 15 years ago. She commuted to Chicago every workday for 30 years. For the last five years she has resided in a long-term care facility. Every morning she walks to the nurse's station to "buy a ticket" so she can take the train to work. For several days, the staff would intervene with RO. "Mrs. R, you are in the nursing home now. You are retired and no longer work in Chicago." Mrs. R's agitation would sometimes escalate to a catastrophic reaction. One day, the nurse gave Mrs. R a "ticket" without comment. Mrs. R took the ticket and walked away contented. This approach was incorporated into the care plan, and there have been no further incidents.

Mrs. S waits by the door every night for her husband to come home. Mr. S died 15 years ago, but his wife does not remember this. For a staff person to say, "Mrs. S, your husband died 15 years ago" would be upsetting and needless. The staff members allow her to sit, knowing that in a few minutes she will have forgotten why she is sitting there. She will soon get up and move on to something else.

Caregivers and staff must take every patient's unique situation into consideration. The benefits of attempting to make patients with AD aware of present reality should always be weighed against possible adverse effects. It is the caring of the staff, the ability to "go with the moment" and to connect with their patients by accepting them as they are, that enhances the patient's behavior.

VALIDATION THERAPY

Naomi Feil developed validation therapy between 1963 and 1980 [119]. Feil de-emphasizes the significance of orientation and instead utilizes specific techniques to explore the meaning and motivation for confused statements [59]. Validation therapy is based on the premise that there is logic behind all behaviors and there are different stages and levels of disorientation among those diagnosed with an irreversible dementia. Validation assists disoriented individuals to restore the past, make closure, and justify their lives. The goal of validation therapy is to give the person a sense of identity, dignity, and self-worth through validation of the person's feelings. A structured learning program for the staff presented by a qualified consultant would be required in order to fully implement validation therapy as an intervention. Of the studies that have been performed to measure the efficacy of validation therapy, none have shown it to be significantly more effective than social contact or other therapies [119].

CARING FOR THE PATIENT WITH END-STAGE ALZHEIMER DISEASE

Every person with AD will eventually reach the terminal stage of the illness. No one can predict the onset or how long it will last. The final stage may last for a few weeks, or it may continue for several years. As the patient becomes more dependent, physical care requires more of the caregiver's time. Behavior poses fewer problems as the capacity for wandering, pillaging, and sundowning diminishes. The person with advanced AD is unable to initiate any interaction but may passively accept the attentions of familiar caregivers.

There are several manifestations of end-stage AD. Vocabulary is limited to five to six words or less, and the patient is nonambulatory, cannot sit up without assistance, and has little facial expression. The patient is inconsistent with bowel and bladder function, has difficulty swallowing, and may be losing weight. In addition, there may be recurrent infections, frequently of the urinary or respiratory tract.

Approximately 10% of patients in the late stage of AD experience seizures [142]. Conventional antiseizure medications such as phenytoin may be used; however, they may result in worsening of the cognitive and functional state. If the seizures are rare and the patient is in a safe environment, it may be decided not to use medications [6].

The primary goal of care during the terminal stage is to prevent complications associated with immobility and impaired physical functioning. Comfort should be paramount, with life extension generally no longer a consideration. Hospice services may be considered, with discontinuation of all life-sustaining measures or medicines. Special care should be exercised to prevent decubitus pressure ulcers, which may become a significant source of patient discomfort [6].

INTERVENTIONS TO CONSIDER

Impaired Mobility

At the beginning of the last stage, the patient may still be wandering but will exhibit significant changes in posture, gait, and balance. The hips appear to be internally rotated, causing a shuffling, scissor-type gait. Eventually, it will take two people to transfer and to assist the patient to walk. As mobility skills diminish, patients may be transferred out of bed with an automatic lifting device and placed in a recliner type chair. Supportive devices are needed to maintain body alignment and to relieve pressure. Contractures and rigidity will develop without appropriate intervention. In addition to frequent repositioning and adequate support, passive range of motion exercises should be completed two times per day, doing each motion at least three to four times.

High Risk for Impaired Skin Integrity

Immobility and incontinence place the patient at risk for pressure ulcers. A Pressure Ulcer Risk Potential assessment will identify areas requiring aggressive intervention. As mobility skills diminish, it becomes exceedingly difficult to maintain a scheduled toileting routine. The use of incontinence briefs avoids the soiling of outer clothing and enables the individual to participate in activities geared to his or her cognitive level. The briefs should be checked every two hours and perineal care given with each incontinent episode. A skin barrier provides additional protection. Soaps can be irritating and difficult to remove from the skin; therefore, caregivers should carefully and regularly inspect the skin for signs of breakdown.

Adhering to a positioning schedule and doing range of motion exercises, as described, are additional preventive measures. Use a turning sheet to avoid friction when moving the patient in bed. High protein supplements given between meals may be necessary to maintain adequate nutritional status. The fragility of the patient's skin presents a risk of skin tears and easy bruising. The staff should be aware how to handle the person to avoid these injuries.

Nutritional Considerations

As AD progresses, nutritional intake becomes a major concern. Ideally, the family and patient will have made decisions regarding the use of enteral feeding tubes in the early stage of the disease, should it become an issue. If this is not the case, the family should be encouraged to consider the possibility so a mutually agreed upon decision can be made if the need arises.

Eating alterations are made throughout the course of the disease. Adaptive eating devices may allow the affected individual to maintain independent eating skills for a longer period of time. Spoons will replace knives and forks. Patients may be able to manage a smaller, plastic glass better than a larger one. A “sippy” type cup often works better than a straw. Providing nourishing finger foods allows patients to self-feed. Adding thickeners to liquids increases ease of drinking and swallowing. By the terminal stage of AD, pureed or chopped foods are usually needed and the patient must be fed.

Risk of Aspiration

Diminishing cognitive awareness leads to dysphagia, which increases the risk of aspiration. The visual and olfactory stimulation that activates the swallowing mechanism in the brain stem is no longer effective. An evaluation by a speech-language pathologist may identify specific interventions that the staff can implement.

General caregiver guidelines for feeding those at risk for aspiration include:

- Allow the patient to rest before eating, as fatigue increases the risk for aspiration.
- Place the patient in an upright position at a 60- to 90-degree angle before, during, and for one hour after eating whether in bed or chair. Sit facing the patient.
- Maintain the patient’s head in midline with his or her neck slightly flexed during swallowing. Keep the head in alignment. Use supportive devices if needed.

- Minimize environmental distractions.
- Use a regular metal teaspoon for feeding, giving only ½ teaspoonful of food at a time.
- Allow the patient to see and smell the food, giving brief verbal descriptions.

The manifestations of the terminal stage place the patient with AD at risk for urinary tract and respiratory tract infections. Adequate fluid intake is an effective preventive measure for both types of infection. Indwelling catheters are not recommended; their use often agitates the person, predisposing to urethral tears. Frequent changes of position and prevention of aspiration may preclude respiratory infections.

Sensory/Perceptual Alterations

Severe cognitive impairment places the patient with AD at risk for sensory deprivation. Although the patient is minimally expressive, proper amounts of stimulation are needed to prevent continuous sleeping and agitation. The use of recliner type chairs enables dependent patients to be moved out of their room and to participate in appropriate activities. Listening to soothing music, hand massages, quiet talking, and olfactory stimulation with familiar odors are examples of sensory-centered activities.

HOSPICE CARE

The hospice philosophy is particularly suited to those with end-stage AD. The patient and entire family are considered the unit of care, and emphasis is placed on the quality of life rather than the length of life. Death is neither hastened nor postponed; the rendering of palliative care is the premise of hospice care. A person in the end stage is considered terminally ill and similar to any other individual with an incurable, fatal disease. Medicare payment is available for covered patients when the anticipated survival time is certified by a physician as being six months or less, if the disease runs its usual course.

Should the patient live past the six-month time period and still be considered terminal by his or her physician, the patient can be recertified to continue receiving hospice care [11].

The hospice philosophy can form the basis for care even though an agency is not involved. If the patient is in a long-term care facility, he or she has probably been there for some months or years. The staff is knowledgeable about the individual and knows the family. A therapeutic relationship nurtured over the years will continue. Occasionally, there is a patient who has no significant others left in his or her life. Family members have predeceased the patient or have drifted away, emotionally and physically separating themselves from the situation. In these cases, the staff members or caring volunteers become family by proxy, providing the love and attention that the dying person deserves.

Knowledge of the individual's status in regard to "heroic measures" is mandatory. By this time, most families realize the futility of prolonging life and seek a peaceful, dignified end for their loved one. In these cases, advance directives and DNR orders are taken care of well before they become an issue. Some states require that all attempts be made toward saving the life in situations where a legal guardian has been appointed. In some cases, this statute may be reversed through the efforts of the ethics committee and the state guardianship office. If the status of the individual is not known, implementing or not implementing lifesaving measures can lead to legal dilemmas for the facility and staff.

FAMILY ROLE AND COMMUNITY RESOURCES

Families are the other victims of AD. The disease is frequently not diagnosed until the person has manifested symptoms for a few years. The family is bewildered and distressed by the behavior of the patient. As the disease progresses, family members weather a number of crises and experience many emotional upheavals. One spouse described AD as a "funeral that never ends." There is no doubt that family members, especially spouses, will face many challenges throughout the course of the disease. However, many also experience feelings of great love, commitment, and devotion and find rewards in an unchangeable situation. A sense of humor is helpful to filling the role of caregiver. The patients also benefit from shared humor and laughter.

ROLE CHANGES AND REVERSALS

It may be difficult for the family to accept a diagnosis of AD. There is a sense of finality associated with the disease that implies hopelessness and despair. The family's ability to cope with future demands may well depend upon the information they receive at the time of diagnosis. This is the time for the family unit to communicate with each other in an open and straightforward manner. The spouse may be reluctant to share information with the children in an effort to prevent worry. The children may be hesitant to verbalize their concerns about the changes they note in the parent. There may be an unspoken group effort to deny the realities of the situation. Some spouses cover so well for the impaired person that other family members may not be aware of the problem until the caregiving spouse becomes ill or dies.

Gradual awareness of the implications of AD for the caregiver become evident as the spouse begins to realize that he or she must take on the responsibilities formerly assumed by the patient with AD. The realization may occur abruptly when the spouse realizes that he or she has never balanced the monthly bank statement, prepared an income tax form, or used the lawnmower or the washing machine. Assisting the affected individual with personal care becomes a challenge when, for example, the wife tries to help her husband shave or the husband tries to help his wife put on pantyhose and make-up.

FAMILY CAREGIVING ROUTINES

Families who deal successfully with AD tend to develop a workable routine early in the course of the illness. Flexibility is imperative. The affected individuals generally respond positively to consistent, predictable routines. It is helpful if the caregiver remembers what has always been important to the patient. If shaving twice per day, brushing teeth after every meal, or going to the hairdresser weekly was a custom, then that routine should be continued, if possible. Perhaps reading the paper with the morning coffee or going for a walk was an enjoyable beginning to the day that can be carried on.

IMPACT OF CHRONIC STRESS ON PRIMARY CAREGIVERS AND EXTENDED FAMILY MEMBERS

Families are systems with a power structure, lines of authority, assigned (albeit unspoken) roles and responsibilities, forms of communication or lack thereof, and problem-solving methods. The strengths and weaknesses of the family unit are revealed in a time of crisis. Children may find it difficult to make decisions for an impaired parent and the parent may resent the children's efforts. The healthy parent may be unable to successfully cope, expecting the children to take over additional responsibilities. When there are several children, one or two may be unofficially designated as being "in charge" while the others seek release from any obligations. Each family is different; making judgments is not the responsibility of healthcare providers.

Grief is an expected reaction to a critical situation that requires adjustment and response. Grieving is necessary; it allows loved ones to face reality, adapt, and adjust to present circumstances. The shock of hearing the diagnosis usually results in a sense of disbelief and denial. This response allows loved ones the time to assimilate the information and to integrate it into a frame of reference. The primary caregiver (and other family members) may experience feelings of anger as they realize the lifestyle changes that will have to be made with the situation (e.g., "It isn't fair that after 50 years of marriage, we have to deal with this."); with the patient (e.g., "If he asks me that question one more time, I'll scream."); and with other family members or friends who do not understand what is going on. Depression marked by feelings of despair and helplessness may be the beginning of grief resolution and adjustment. During the grieving process, it is not unusual for caregivers to socially withdraw from friends and previously enjoyable activities.

While grieving is normal and necessary, unresolved grief may result in dysfunctional responses. If denial, anger, or depression is unrelenting, referral to a physician or mental health clinic is justified. Even in the best situations, caregivers, whether they are the spouse or adult child, will inevitably experience periodic moments of stress. Persistent signs of anxiety, exhaustion, sleeplessness, irritability, or lack of concentration may indicate a need for professional support.

Guilt is a common feeling among caregivers and usually stems from unrealistic expectations they may have for themselves. Adult children who have spouses, children, and jobs feel distressed when they witness the frustration and exhaustion of the caregiving parent. The wife who promised never to place her husband in a nursing home finds that it is impossible to keep that vow. The husband who arranges for adult care two days per week finds that he is unable to enjoy any activities during that time. Joining an AD support group is often effective in helping families deal with feelings of guilt in a productive manner.

ASSISTING FAMILY MEMBERS TO COPE

When the diagnosis is AD, the family and affected individual need support, education, information, and encouragement. The family can benefit from a family meeting to acknowledge the disease, to identify the ways in which it may disrupt family life, and to clarify the tasks and roles of family members. Families will cope more effectively if they are educated about the disease so they will have some idea of what to expect as AD progresses.

Legal and Financial Issues

As the family adjusts to the situation, they may need encouragement to think about the future and any legal actions that should be taken in regard to legal and financial planning. Eventually, patients with AD will be unable to manage their own affairs, but they are usually able to participate and help with decision making when done early in the course of the disease. To delay this process can result in many financial and legal problems.

Admission to a Healthcare Facility

Physicians and other healthcare professionals may be required to consider the admission of a patient with AD to an advanced healthcare facility.

Most families experience mixed emotions of relief and guilt when they realize they can no longer care for their loved one. The healthcare team must fully understand the impact of AD and institutionalization on the family so they can effectively help them deal with their grief. Intervention begins when the family visits the facility prior to admission. Their future adjustment may be influenced by what they observe during this time. Introduction to the staff gives the family the opportunity to identify key people in various departments. They should be provided information that describes the facility routine and a typical day. Most importantly, the family should be encouraged to communicate openly and honestly with staff. It is helpful if there is a specific person they can go to for discussion and answers.

They should know that their feelings are normal and that staff is not judging them because of the patient's behavior.

Families may need suggestions for visiting. It is sometimes awkward to visit with a person who thinks the spouse is a sibling or the child is the spouse. The family is encouraged to bring old photos as a way of stimulating a response from the patient. The staff should direct them to other areas of the unit or building where they can take the patient when they come to visit and be invited to participate in care planning conferences and activities. Some families take great pleasure in feeding their loved ones, getting them ready for bed, or helping them bathe. On the other hand, there should be no pressure on those who choose not to help. Some families are exhausted from their caregiving demands prior to admission and welcome relief from further responsibilities.

COMMUNITY RESOURCES

Knowledge of resources enables one to give assistance to families who need information. There are services available in many communities that, when utilized, can ease caregiving burdens.

Hospice Care

Hospice agencies can be a tremendous help for those who qualify for the service. Care may be rendered at home or in a healthcare facility. Staff members are truly concerned with the total family unit. They are knowledgeable about community resources and can link the family to other services that they may require.

Respite Care

Respite care, or adult day care, may be a solution for spouses who are still employed. Care may be available 8 to 10 hours per day, 5 days per week. The recipient receives nourishing meals and snacks, and appropriate activities are offered. Other services may be available depending on the type of agency sponsoring the day care. Adult day care may be utilized for family caregivers who do not need full-time care but who would benefit from release of responsibilities once or twice per week, either for the entire day or a few hours.

Some nursing facilities offer temporary nursing care to allow caregivers to have freedom from care for a weekend or for a few weeks at a time. This allows the caregiver to take a vacation or to recuperate from illness.

Homemaker services are frequently available through family service organizations or nursing agencies. The homemaker provides no nursing care but will come to the home to prepare and serve a meal, do laundry and light housekeeping, run errands, or to stay with the patient while the caregiver performs those tasks. Home-delivered meals (Meals on Wheels) may be arranged in most communities where there is a documented need for such a service.

The Alzheimer's Association website also provides a wealth of information and education to patient's families and healthcare providers (<http://www.alz.org>). The Association also sponsors support groups located in every state. The Social Services department of hospitals and long-term care facilities can offer information about the availability of community services.

CONCLUSION

The incidence of AD continues to rise. It is a difficult disease to treat medically and handle emotionally. This review presents some of the elements of pathology, medical treatment, and care of victims of this progressive disease. It is hoped that the continued research into the causes of AD will provide some of the necessary information about the prevention and treatment of this relentless and socially damaging disease.

The following appendices contain information about specific nursing interventions and the management of a specialized nursing facility.

APPENDIX I: SPECIFIC NURSING AND CAREGIVER INTERVENTIONS

MAINTAINING NUTRITION AND ENHANCING MEAL TIME

Periodic functional assessments will identify problems related to nutrition and food intake. Interventions are altered to correlate with the problems as they arise. In the first stage, there may be only a need for a tray "setup," with liquids poured, food cut up, and bread buttered. As the disease progresses, the patient may continue to self-feed when appropriate assistance and cues are given. By the terminal stage, the affected person is dependent on caregivers for all fluid and food intake.

There are many ways to add additional calories to the diet of patients with advanced AD. Because they may not eat much, it is especially important that patients' food be nutrient-dense. Protein powders, such as those used by athletes, can be added to a number of foods. Calorie-rich shakes or bars are a way to add both extra calories and protein. Nutrient supplementation may be needed, and nutrient levels should be assessed periodically. Nutritious oils, such as flax oil, fish oils, and uncooked olive oil, can be added to food in small amounts; these provide both calories and nutritional value. Seasonings can help to stimulate a fading sense of taste. The staff can serve finger foods for snacks, such as crackers with peanut butter or cheese spread, small sandwiches, small pieces of peeled fruit and vegetables, raisins or other dried fruit, or small pieces of cheese. Cooking meat or chicken with vegetables, then straining or pureeing together can make broth or creamed soup.

Caregivers Should Establish a Regular Routine

Meals should be served at the same time each day and in the same place. In the long-term care facility, having a specific seating arrangement and making sure all residents are seated before serving begins is helpful.

Remove items such as extra silverware and condiments from the table. It may become necessary to place only one food at a time in front of a specific resident. Too many foods can be confusing and frustrating.

The patient should be taken to the toilet before each meal and assisted with hand washing. Make sure the patient's mouth is clean and that dentures are in place and in good condition. Note whether he or she wears glasses or a hearing aid. Make sure the patient is in a comfortable position, in good body alignment with feet flat on the floor. In the last stage, pillows or supportive devices are often needed to support a patient's head. Transfer patients from wheelchairs to dining chairs for eating.

All caregivers should use the same or similar methods of assistance, such as verbal cues, hand-over-hand techniques, or demonstration. Light pressure on the lips may remind the patient to open his or her mouth. Monitor individuals at each meal because their ability often fluctuates. A given patient may be able to eat independently for one meal and require assistance or feeding at the next meal.

Improving the Dining Environment

Avoid distractions by turning off radios and televisions in order to maintain a calm, quiet environment. Establish a cheerful dining room conducive to social interaction. Use tables that seat four to eight people. Place a clear plastic tablecloth over a colorful cloth or use plastic place mats. Having snapshots at the table may help ambulatory residents find their table. Set a small centerpiece in the middle of the table, but remove it if someone thinks it is edible. One study at a nursing home in Sweden noted significant improvements in behavioral symptoms (e.g., irritability, anxiety, depression) and nutritional intake when soothing music was played during meals [45].

The Use of Appropriate Dinnerware

Use plain dinnerware because plates with patterns can be confusing. Use dishes that are a different color from the tablecloth. Avoid the use of plastic eating utensils that can break in one's mouth. A spoon may work better than a fork. Use cups for soup to help facilitate patients' independence.

Use assistive devices to expedite mealtime. Plate guards prevent food from being scooped onto the table. Nonslip material or a wet washcloth under the plate prevents sliding. Convalescent feeding cups avoid dribbles and spills.

Serving Food to Patients with Advanced Disease

Serve familiar foods prepared in the usual way. Check the temperature of foods before serving them and debone all meats. Cut food into bite-sized pieces. Remove all wrappers, open all cartons, and pour beverages. Add condiments if the resident desires, then remove them from the table. Avoid tough, stringy, or dry foods. Crumbly foods such as hamburger are difficult to control in the mouth and may cause choking. Dry cereal in milk and soups containing pieces of food are confusing; patients may not know whether to chew or to swallow.

Meeting nutritional needs requires an interdisciplinary approach throughout the progression of the disease. The attending staff should consult with the dietician for suggestions about appealing, nutritious, and easy to handle foods. The speech-language pathologist can conduct a bedside swallow evaluation and instruct the staff on feeding techniques for the dysphagic individual. The benefits of assistive-eating devices can be evaluated by the occupational therapist. With accurate assessment and knowledgeable planning, the patient with AD can maintain adequate nutritional status throughout the course of the illness.

BATHING AND GROOMING SUGGESTIONS

Bathing procedures are often beset with disruptive behavior. Bathing can be a positive experience for both the patient with AD and caregiver if approaches are individualized for each patient. First, what were the patient's bathing habits? Did he or she take a tub bath, a shower, or a sponge bath? Patients who have never taken showers will be understandably upset when the water streams down over them. Is the patient used to bathing in the morning or evening? In long-term care facilities, bathing is usually done on both day and evening shifts. However, an individual who always took a shower upon arising may not adapt to having a shower after lunch. Did the patient bathe every day or only once or twice per week?

The staff should be aware of the individual's personal history. For example, nursing assistants dreaded taking Patient B for her shower. While she walked willingly to the shower room, once inside she became agitated, hitting and scratching the nursing assistant. Upon questioning the family, it was learned that she was a Holocaust survivor. The long, dark, green-tiled shower triggered horrible memories of gas chambers for Patient B. Giving a tub bath solved the problem.

The bathroom should be checked before the patient enters to be sure that all the necessary supplies are available. The patient is approached in a positive manner, saying, "It is time for your bath (shower) now and I will help you." Asking, "Do you want your bath now?" is likely to elicit a "no" answer.

With some individuals, it may be easier to start walking with them toward the bathroom and when ready to enter, tell them it is time for the bath. If they refuse, regardless of the approach used, avoid forcing the issue; wait and try later. A bath or shower may be omitted, substituting a sponge bath instead. Tell the patient in brief phrases what is happening with each step of the procedure. To start the shower without warning, for example, is quite likely to disturb them.

Special attention is paid to body areas where skin surfaces rub together, such as under the breasts, the underarms, genitalia, and thighs. The caregiver must wash and dry these areas if the patient cannot. Avoid the use of powders and cornstarch as they tend to "pill," causing even more skin irritation.

People with AD will frequently grab the caregiver's hands during the bath. Giving them a washcloth during the bath and a towel while drying is helpful. Never leave the person unattended in the bathroom. Use the time to inspect the skin for rashes, bruises, pressure ulcers, and growths. Patients may feel less vulnerable if towels are placed over their body, thereby avoiding total exposure.

The staff should think creatively and relinquish rigid ideas of how procedures should be performed. For example, Patient K always became agitated when the nursing assistant attempted to remove her clothing, whether for a bath or shower. After she was seated in the shower chair, the nursing assistant decided to forego undressing and to use the handheld shower to gently begin wetting Patient K's hands and arms. Upon feeling the water, Patient K immediately began taking her clothes off. This approach was written into the care plan.

Avoid the use of lotions, oils, or anything that may make a tub or shower slippery. Towel and lotion baths that can be completed in bed may be an acceptable substitute for some people. Saturate towels with warm lotion (so they are damp, not soggy) and place over the body, one area at a time, gently patting. Use washcloths for the face and for perineal care. Cover the patient with a bath blanket during the procedure. Rinsing and drying are not required.

Evaluate the bathing environment from the affected individual's perspective. Most facility bathrooms are large and cold, very different from a private home. Extra equipment is often stored in the bathroom, making it look ugly and frightening to the patient.

Check the temperature of the water and of the room (most elderly people are easily chilled), the lighting (bright, but without glare), and the color. Green or blue walls look gray and muddy to elderly eyes. While it may not be possible to renovate bathrooms, a few simple changes can improve the environment:

- Hang artificial plants and pictures that might cue the resident to bathing
- Have the walls painted or papered in shades of pink or yellow
- Add a colorful privacy curtain around the tub or across the end of the shower to enclose space
- Add towel racks and hang colorful towels. These are only for decoration; infection control policies forbid their use for patients

Evaluate the shower chair for comfort and safety. Consider adding grab bars and providing waterproof shoes for those who prefer to stand.

It may be more efficient to shampoo the patient's hair during the bath or shower. A simple wash-and-wear style is easier to maintain. In many cases, the patient with AD continues to go to the hair stylist well into the disease. An attractive hairstyle may increase self-esteem. If a woman has always worn make-up, encourage her to continue but supervise the task so that it is applied appropriately and looks attractive. Fingernails need frequent observation. File and trim nails regularly to prevent injuries from scratching. It is best to trim toenails straight across. The services of a podiatrist may be needed for some patients. Volunteers in long-term care facilities may be willing to give manicures for women who enjoy having their nails polished.

Shaving is a daily task for most men and contributes to a well-groomed appearance. Most men can handle an electric razor with supervision until the later stages of the disease. Applying aftershave can increase self-esteem. Provide assistance for those with beards and moustaches. Keep the beard free

of food particles that may become imbedded during meals. For women who are used to shaving, cream depilatories may be used for legs and underarms. Perform a skin patch test first to determine if a patient is sensitive to the product. Some older women develop hair growth on the upper lip and chin. These areas can be shaved or waxed regularly.

Dressing Hints for the Staff or Caregiver

Dressing is a complex activity of daily living. To dress, one must have fine and gross motor skills, balance, the ability to sequence, and the ability to tell right from left and top from bottom. The task can be overwhelming for patients with advanced AD. If a patient can make choices, take him or her to the closet to pick out the clothing. If this is too complicated, hold out two garments and ask the patient to choose one. When patients can no longer cope, the caregiver must make the choice. Dressing is easier if the clothing is large enough and made of a soft, slick, stretchy fabric. Try to maintain the individual's dressing style. As patients become more dependent, it will be necessary to adapt clothing to their needs. To facilitate dressing/undressing, follow the guidelines that are appropriate for the individual's abilities:

- Remove clothing from closets and drawers that is out of season or no longer fits. This simplifies decision making and avoids the problem of choosing inappropriate attire.
- Hang complete outfits together: pants, shirt, jacket, etc.
- Place pictures on dresser drawers to indicate the contents.
- Provide privacy for dressing.
- Provide duplicate outfits or arrange for daily laundering for patients who insist on wearing the same clothes every day.
- Lay out clothes in the order they are put on. Make sure the clothes are right side out.

Remember that putting on an article of clothing like underwear requires the patient to distinguish back from front, which foot to put in first and in which opening, and how to pull underwear up.

Adapt clothing to the individual's abilities as the disease progresses. Elastic waistbands and Velcro closures are easier to manage. Cardigan style tops may be easier than pullover styles for caregivers to handle.

ORAL CARE REQUIREMENTS

Preventive oral care will decrease the risk of needing extensive dental treatments later. Dentists should receive complete information regarding patients' medical history and current status. Almost all patients need oral care at least twice per day, for two minutes each time, if possible. Do the last brushing after the evening meal. Oral care is a complex task, and the patient may be unable to open the toothpaste container or to apply paste to the brush. The patient may forget to spit the toothpaste out or to rinse the mouth with water. Supervision is needed early in the disease to ensure that oral care is adequate. Flossing is recommended but may be difficult for the patient or caregiver to complete. A Proxabrush may be used to clean between the teeth. A fluoride toothpaste and fluoride rinses (available without prescription) will protect from decay. A soft toothbrush can be used to clean the mouths of those with dentures. Inspect the dentures regularly for fit and for condition. Evaluate the patient's medications to identify potential oral problems resulting from their use. Assess the patient for xerostomia, which may be a side effect of haloperidol or other medications. Artificial saliva may be administered.

SUGGESTIONS TO THE CAREGIVERS FOR BOWEL AND BLADDER ELIMINATION

Incontinence does not usually occur until the later stages of AD. As the disease progresses, the patient with AD experiences a number of physical and cognitive changes that inhibit the ability to use the toilet independently. A sudden change in urinary elimination habits should be investigated to rule out other causes, such as infection [48].

There are several types of incontinence. Functional incontinence is usually associated with AD. The involuntary passage of urine is related to cognitive, physical, or psychological functioning or to environmental barriers. The person with AD may be functionally incontinent due to the inability to:

- Recognize the signs of a full bladder due to changes in the brain that affect urinary control
- Articulate the need to void
- Manipulate clothing as a result of perceptual and fine motor control deficits
- Comprehend directions to the bathroom
- Find the bathroom due to disorientation
- Walk to the bathroom

Environmental reasons for functional incontinence:

- The bathroom is too far from the patient's room
- The bed is too high or has side rails, so the patient cannot get up and out
- The patient is restrained, making mobility impossible
- The patient is not able to identify the bathroom due to lack of cues
- Poor lighting makes it difficult to find the bathroom
- A lack of color contrast between the toilet seat and the floor causes confusion
- The patient mistakes the sink or waste-basket for the toilet

Incontinence can also have a psychological basis. The individual may receive behavioral messages from caregivers that incontinence is acceptable and is rewarded with attention and touch when caregivers remove soiled clothing. By this stage of the illness, the patient has relinquished control over many body functions and incontinence may be a means of exerting control over a bodily function [48].

There may be physiologic reasons for other types of incontinence. Prostatic hyperplasia causes overflow incontinence. Stress incontinence is associated with increased abdominal pressure and urethral sphincter failure. Urinary tract infections, inadequate fluid intake leading to bladder irritation, and certain medications are known to cause incontinence.

Staff Interventions for Incontinence

Complete a bowel and bladder assessment to rule out reversible causes of incontinence and provide appropriate treatment if required. Incontinence resulting from the disease process cannot be reversed; however, adaptations can be made to prevent soiling.

Steps to modify the environment for the patient:

- Place a picture of a toilet and the word “toilet” on the bathroom door.
- Increase lighting in the bathroom and hallway if needed.
- Check the room temperature. Arrange a warm, comfortable bathroom. Remove clutter from the bathroom that may distract the patient.
- Add an elevated toilet seat with arms to increase feelings of security. Install grab bars to facilitate independence.
- Avoid the use of restraints and side rails if possible. Keep the bed in the lowest position.
- Remove mirrors. The patient may see his or her reflection and think another person is already in the bathroom.
- Provide privacy. Group toileting in the long-term care facility is not conducive to successful voiding.

- Make sure the toilet seat is a contrasting color to the floor.
- Provide clothing that is easy to manipulate.

Behavioral interventions that the staff can implement [48]:

- Monitor the individual to identify signs of a full bladder, such as wandering, rubbing the genitals, or irritability.
- Ask the family what word the patient may use to indicate the need to toilet. Words such as “tinkle,” “pee,” or “take a leak” may be more familiar to the patient.
- Provide at least 6 cups of fluid daily. Do not assume the patient will drink just because fluids are available. Avoid fluids such as coffee and tea that may irritate the bladder.
- Implement a scheduled toileting, prompted voiding, or habit-training program. Each program requires caregiver assistance. Scheduled toileting and habit training are suitable for all patients with AD as long as they can sit safely on the toilet.
- Scheduled toileting requires a timed schedule for voiding. Take the individual to the bathroom every two hours and implement techniques to facilitate urination; if necessary, run water, dip the person’s hand in warm water, or pour warm water over the genitalia.
- Habit training is based on the person’s individual pattern of voiding. An assessment is required to identify the usual voiding times. The person is then taken to the bathroom at these times every day.
- Prompted voiding is a supplement to habit training and utilizes social reinforcement for appropriate toileting behavior. Patients are checked on a regular basis and asked to report verbally if wet or dry. They are prompted to use the toilet and are praised for maintaining continence and for attempting to use the toilet. Patients must be able to recognize some degree of bladder fullness or the need to void.

Eventually, the individual will become incontinent regardless of caregiver efforts. The use of adult diapers will prevent embarrassment from soiling clothing. Change the diapers frequently and provide adequate skin cleansing and drying to avoid skin breakdown. Giving the patients cranberry juice to drink may help eliminate odor and urinary tract infections.

FACILITATING MOBILITY

Mobility, like other skills, deteriorates as AD progresses. Most patients remain ambulatory for a surprisingly long time, but eventually they require assistance with getting out of bed and walking. In the last stage, the patient is immobile, with little weight-bearing ability. Diminishing mobility increases the risk for falls. Gait disturbances, such as leaning and shuffling, along with balance and coordination deficits are causes of impaired mobility.

To facilitate mobility:

- Investigate and treat any possible underlying cause of immobility. The person with impaired vision may need glasses; those with bunions or calluses may require the services of a podiatrist.
- Provide clothing that promotes mobility. Check laces on shoes, and make sure the shoes are comfortable, the right size, and slip proof. Check the length of slacks. Slacks or skirts that are too large or too long hinder walking.
- Consult with a physical therapist to determine the need for muscle strengthening exercises or for techniques to use for those with perceptual deficits.
- Implement range of motion exercises twice daily to maintain joint flexibility.
- Avoid the use of restraints. The associated inactivity promotes muscle atrophy and poor balance.
- Instruct all caregivers in correct techniques when the patient is unable to get out of bed independently. A one or two person pivot transfer with a transfer (gait) belt is appropriate if there is weight-bearing ability.
- Use a mechanical lifting device for those who have lost weight-bearing ability. Getting the patient out of bed provides a change of scene and encourages participation in activities.
- Avoid the use of assistive devices like walkers or canes. Most patients with AD are unable to safely use them because of cognitive impairment.

ACTIVITIES FOR THE PERSON WITH ALZHEIMER DISEASE: SUGGESTIONS FOR CAREGIVERS

Appropriate activities are an important component of the total plan of care for people with AD. The overall purpose of providing activities is to enhance their self-esteem and to benefit their emotional well-being. Activities focus on their remaining strengths rather than their limitations, in an attempt to provide structure and to normalize life as much as possible. Activities can promote physical exercise, stimulate mental activity, and help the patient maintain social and religious practices. Activities are used as a behavioral management technique by preventing boredom and reducing agitation and to prolong functional capabilities. Involvement should be voluntary. In the earlier stages, patients may resist participating in activities due to feelings of inadequacy and fear of failure. It may take two or three invitations for them to feel comfortable in accepting help. In the later stages, dependent patients must be taken to the activity. If caregivers know the individual, they will be aware of what types of activities they are likely to enjoy. Patients with AD in the later stages must be monitored throughout an activity so agitation and anxiety are quickly detected by the staff.

The activities area is a significant factor in the success of the program. Ideally, the room is quiet and free of distractions. Unfortunately, public areas of a facility where staff, visitors, and others must pass through are often used. A secure environment will allow those who wander to do so without intervention. People with AD are unable to focus on a task when they are continually responding to the sights and sounds around them. Easy access to bathrooms is a priority. It is less disruptive if patients can get up and go to the bathroom when the need arises. Patients with AD generally feel safer and more comfortable if activities are held in the same area every day. While they may not cognitively remember the room, their affective memories influence their feelings about the environment.

General Guidelines for Caregivers About Activities

Safety

Safety is the first concern when planning activities. Choose nontoxic supplies for activities such as painting or clay modeling. Avoid activities that require scissors or other potentially dangerous tools. Games that utilize many small pieces may be unsafe for patients with hyperorality. Food-related activities are popular, but staff members must be aware of dietary modifications (e.g., the use of thickeners or pureed foods) required by a person or any swallowing problems that may occur.

Monitor patients for agitation and signs of discomfort, incontinence, or choking, and initiate appropriate action if necessary. Utilize in-service opportunities to teach the activities staff how to respond to emergencies. They should also learn how to safely transfer patients from wheelchairs to dining chairs, how to assist with eating, and how to help their charges in the bathroom. Patients benefit tremendously when the staff has participated in AD classes and are knowledgeable in appropriate behavior management techniques.

Planning

Activities should be dignified, avoiding those that may be perceived as demeaning or childish. A well-planned and implemented program brings meaning, purpose, and joy to the patient's life. An assessment done upon admission will identify previous and current pastimes enjoyed by the person, and past roles and lifestyles can be validated. However, to ask someone to do a simplified version of a craft he or she once excelled in may not be successful. For example, an artist who is given a paint-by-number set or a child's coloring book may become frustrated and angry with the reminder that the mastery is disappearing. On the other hand, some skills remain even when patients are severely impaired. Given the opportunity, someone who enjoyed playing the piano may be able to sit down and render a familiar tune.

Activities that focus on routine daily tasks can improve the quality of life by maintaining these skills for a longer period of time. Combing hair, applying makeup, and polishing fingernails improve self-esteem and can delay functional loss. Household tasks are also effective activities.

Implementation of Activities

Activities should be:

- Purpose driven (e.g., making greeting cards to give to family)
- Voluntary on the part of the patient
- Noncompetitive
- Planned for small groups or on a one-to-one basis
- Planned for short periods of time
- Possible with only a few simple items
- Geared to the patient's present abilities with available staff/volunteers to assist
- Geared to the time of day (bathing and grooming or setting a table for a meal)

It is important to allow for quiet time. It is not necessary for the patient to be busy all of the time, as overstimulation causes anxiety and fatigue.

Activities have a greater chance for success when all staff members appreciate their value. Not all patients with AD can attend events, so it may be helpful for the activity staff to tell the nursing personnel which people would benefit most from a particular session. These patients can then be dressed and be taken to the toilet in time to attend. In some dementia special care units, the nursing assistants are trained to plan and present the activities. This simplifies the amount of coordination that is required between departments.

Other Activities That Caregivers Can Provide

Spiritual Activities

Participation in spiritual activities is very beneficial for those who were involved in religious activities in the past. The background and faith of the individual must be considered so the services are familiar and comforting. Clergy in the community may rotate their services to ensure that all faiths are represented during the year. Ask the members of the clergy to dress in their traditional garments. The environment can promote the feeling of a spiritual setting by holding services in a chapel or by utilizing items appropriate for specific religions, such as a cross or a rosary. Those who have received strength and reassurance in the past from their spiritual beliefs may continue to find support from such activities even into the later stages of AD. Religious services are most beneficial when the program is familiar; for example, well-known hymns and passages from religious text are comforting.

Music Activities

Singing, listening to music and dancing are entertaining for many patients. Musical programs may be either passive (listening) or active (singing or dancing). Consider the age and era of the audience when selecting the music. Adequate space and safe flooring are needed for dancing. Block out other environmental sounds to avoid excessive stimulation.

Arts and Crafts

Some patients enjoy arts and crafts that are within the realm of their abilities, and the end product gives a sense of accomplishment and productivity. Much planning and assistance may be required of the staff to avoid frustration. Arts and crafts are noncompetitive. There is no right or wrong, and one individual's product is not compared to anyone else's. A group activity provides the socialization and camaraderie of being in a group. For higher functioning individuals, consider quilting, woodworking, or ceramics. One facility adopted a project whereby the patients made rag dolls for children in a nearby pediatric chronic care hospital. Those in the advanced stages of AD may enjoy painting with their fingers, a large brush, or a sponge or working with clay. Art projects can also serve as communication tools, providing opportunities to control colors and designs.

An autobiography project may be satisfying to the patient and helpful to the staff. The project usually requires the help of the family. Photos from the person's past, up through the present time, are placed in a scrapbook with names printed underneath. Family members, friends, pets, and former homes may be included. The book should be readily accessible and can be used to help calm patients when they are anxious.

Pet Therapy

The therapeutic use of small animals provides sensory stimulation and encourages movement, reminiscence, social interaction, and opportunities for nonverbal communication. Pets provide unconditional affection and approval. Some facilities adopt one or more permanent pets. This requires preplanning and commitment on the part of the staff. Other facilities use an animal visitation program with pets provided at specific times by staff members, by volunteers, or from a local animal shelter. Everyone who wishes should have an opportunity to interact with the animal. Kittens or puppies are especially effective in drawing positive responses from those in the advanced stages of AD. Watching fish in an aquarium or listening to birds is often a pleasant pastime. Patients' allergies should be taken into consideration.

Horticulture

Horticulture activities are often familiar and have healing and therapeutic properties. With proper care, plants grow and produce new shoots, giving them the opportunity for nurturing and caring. Plants provide sensory stimulation when the patient feels the soil, sees and smells the blossoms, or tastes a tomato fresh from the vine. Plants can be correlated with seasons, with tulips and Easter lilies for spring and poinsettias for Christmas. Avoid poisonous or possibly harmful plants. Projects should be small and manageable. Hardy individual houseplants require little attention. Some facilities plant small outdoor raised gardens for those who enjoy more involvement. Plants can also be used as a foundation for other activities, such as reminiscing, as door prizes for patient-sponsored programs, or as gifts to family members. However, it is the process and not the end product that is the important feature of a horticulture program.

Physical/Recreational Activities

Regular physical exercise is beneficial for patients with AD. Consider wandering habits when planning programs to avoid physically exhausting the person. Physical activity facilitates bowel regularity, reduces tension, increases appetite, and may prevent complications associated with immobility. Exercise activities may include:

- Going for a walk
- Active range of motion exercises done to music; these can be done by patients in wheelchairs
- Balloon toss
- Horseshoes (with modified equipment)
- Bowling (with modified equipment)
- Exercise trails set up indoors or outside with items such as a finger ladder and exercise wheel
- Water therapy for facilities that have access to a pool (although this activity requires a high staff to participant ratio)

Intergenerational Programming

Interaction between children and patients can have many positive results for both generations. In one facility, a group of mothers and their preschool children and infants joined the residents once a month for morning exercises. In another facility, elementary school children each "adopted" a patient whom they visited weekly. It is better to avoid large groups of children at one time. Give the children prior instruction and encourage the participation of parents or teachers.

Community Activities

Activities outside of the facility require additional staff, a mode of transportation, and places to go that are accessible and accepted by the participants. Community activities are well worth the effort and planning. Staff members should identify restaurants, stores, museums, shopping malls, and other public places that will welcome patients with AD. Plan the outing for the time of day and day of the week that are the least busy, and choose places that have minimal stimulation. Make reservations when a restaurant outing is planned. Inform other staff members in advance which residents will be out of the building. For lengthy outings, it may be necessary to take patients' medications. Community outings can be very simple; examples include a ride through the country in the spring to see newly planted fields or in the fall to view changing colors, visiting the hometowns where patients once lived, going to a drive-in for an ice cream cone, or visiting a park. Going to country fairs, fishing at nearby lakes, having picnics, or attending theater productions requires more extensive planning but may be very enjoyable for those with early stage disease.

Individual Activities

Having items available for individual activities may soothe the patient's behavior. Boxes can be filled with objects that meet the individual's need to rummage. Picture books, greeting cards, playing cards, balls of yarn, and other small, safe items are suggested. Children's toys (e.g., abacus, clock, workbench, large strands of beads) may stimulate interest. Rocking is comforting to some patients; the availability of gliding rockers meets this need. Others may find comfort in stuffed animals or dolls. Some caregivers may feel this is demeaning. It is not the object that is demeaning, but rather the attitude of staff towards those who are attached to the objects. Whether or not it is appropriate depends on the response of the individual patient.

APPENDIX II: SPECIAL CARE UNITS

Admission to a long-term care facility at some point is inevitable for most people with AD. Few families have the emotional resources and energy to cope with care given 24 hours per day, 7 days per week. Like advanced directives, the topic of nursing home or long-term care facility placement should be discussed at the time of initial diagnosis. Making the decision for placement at a time of crisis places undue stress on everyone involved. The availability of special care units (SCUs) increases the options for families who must make decisions regarding a loved one.

PHILOSOPHY OF A SPECIAL CARE UNIT

Planning an SCU begins with developing a philosophy of care for those affected by AD. Each facility is different, and all must determine the best approaches to care for the needs of their residents. The written program philosophy describes the approaches to care that will be rendered. It is essential that the philosophy be understood and implemented by all staff members and that it is reflected in their interactions with patients and families.

The National Institute of Aging has completed research at SCUs around the country and has developed seven attributes that distinguish these units from other types of care [8]:

- A greater degree of separation between patients with and without dementia in physical space and social activities
- A greater effort to eliminate noxious auditory stimulation
- A greater number of simple activities planned for patients
- A greater tolerance of problematic behaviors
- A greater degree of participation in organized recreational programs by patients with dementia

- Less participation by patients in therapeutic programs aimed at promoting activities of daily living
- More methods used to train staff about dementia care

A study conducted in Canada identified several major characteristics of SCUs that contributed to positive outcomes in behaviors [62]:

- Patient's feelings of personal space
- Expression of personhood
- An unforced routine
- Patients choose their own schedule for self-care and daily activities
- Staff not restricted to traditional role boundaries
- A fully equipped unit kitchen
- Support from administration and family members

ADMISSION AND DISCHARGE CRITERIA

Persons with AD in different stages have very diverse needs. The purpose of an SCU is to provide individualized quality care. This goal is more readily achieved if the patients require similar management approaches. Admission should be restricted to those who are in corresponding stages of disease. The unit may be set up to care for residents in either the early or the middle stages of the disease.

Early stage units are designed to care for individuals who are wandering, pillaging, sundowning, and exhibiting other behaviors of this stage. Because it takes a great deal of staff time to effectively manage early stage individuals, those with heavy physical requirements are excluded from placement. The philosophy spells out the type of person for whom care will be provided. As the disease progresses, the needs of the residents change and transfer out of this specific stage unit will be necessary.

Middle stage units are prepared to care for individuals who manifest the behaviors of early stage but who also require more assistance in the activities of daily living. Mutual feelings of trust and friendship often develop between family members and staff. This relationship can be beneficial to the patient, but it may create resistance from the family when the transfer from the unit becomes inevitable. To avoid misunderstandings, written criteria for admission and discharge procedures are essential. Staff and family members must be informed of the criteria and the rationale for these standards.

Admission criteria may include:

- A score on a mental status examination within a certain range
- A medical diagnosis for AD or other irreversible dementia
- A specific level of mobility skill
- That the person does not need skilled nursing care
- The expectation (from history and assessment) that the patient will benefit from placement in the SCU

Before appropriate placement can be made, the following items must be completed:

- Assessment of the level of functioning
- Mental status examination
- Review of the personal medical history
- Review of the present medical status
- Interview with the family and patient
- Tour of the SCU by the family and patient

It may be advisable to write a policy that clearly states conditions for exclusion from the unit. Restrictions may be based upon an individual's:

- Lack of background medical data to support need for placement on unit
- History of serious medical problems or needs that require skilled care

- Inability to participate or benefit from the activity-focused program planned to meet the physical, cognitive, and/or psychosocial objectives
- Inability to respond to other residents, staff, family, or the environment
- Behaviors that present serious safety hazards to self or others
- Inability to respond to distraction techniques
- Problems related to substance abuse
- Ability to function at a level that would allow them to reside on a regular nursing unit

Discharge from the unit may be necessary when the patient:

- Needs skilled nursing intervention and care
- Requires assistance in mobility (in an early stage unit)
- Is unable to respond to other residents, staff, family, or the environment
- Presents serious and/or life-threatening safety hazards to self or others
- Is consistently unable to respond to distraction techniques

OBJECTIVES OF THE SPECIAL CARE UNIT

Delineating the objectives of the SCU and the approaches to meeting these objectives provides the staff with guidance in the planning of care.

Objective:

To maintain the patient's mobility and physical fitness for as long as possible.

Approach:

- Complete restorative assessments regularly
- Implement exercise and restorative programming
- Use physical restraints only when all other behavioral interventions have failed and when the life of the person or others is in danger

Objective:

To maintain optimal nutritional and hydration status.

Approach:

- Complete nutritional assessments regularly
- Plan food focused activity programs
- Plan activities with in-between meal nourishments
- Use behavioral interventions for food- or eating-based problems

Objective:

To avoid incontinent episodes.

Approach:

- Complete bowel and bladder assessments regularly
- Develop individualized toileting plans

Objective:

To involve residents in the activities of daily living.

Approach:

- Complete rehabilitation assessments regularly
- Plan and implement activities of daily living/restorative programs on the unit
- Assist patients to function at their highest physical level

Objective:

To enhance the cognitive well-being of the patients.

Approach:

- Encourage independence by utilizing their strengths
- Complete activity assessments regularly
- Use cueing and task simplification
- Use effective verbal and nonverbal stimulation

Objective:

To conserve psychosocial well-being.

Approach:

- Complete social service and activity assessments regularly
- Consult with mental health specialists, if necessary
- Focus on individual abilities rather than disabilities
- Focus on socialization skills
- Support and facilitate a peer community
- Educate the staff and family so they understand and have the skills to manage behaviors
- Provide a physical environment that is calm and soothing
- Provide furniture conducive to comfort
- Restrict the numbers of individuals (other than families) entering the unit
- Plan for dedicated staffing on the unit
- Avoid the use of physical and chemical restraints
- Encourage and assist residents to continue with previous spiritual activities
- Assist residents to attend church services when appropriate
- Provide one-to-one spiritual activities as required by care plan

Objective:

To foster the emotional well-being of the families.

Approach:

- Invite families to participate in care plan conferences
- Encourage families to assist in care plan approaches
- Facilitate the formation of family support groups
- Provide educational programs and resources to families

Objective:

To nurture the well-being of the staff.

Approach:

- Facilitate an interdisciplinary support system
- Invite all staff members on the unit to assist in care planning
- Emphasize the importance of the interdisciplinary process
- Provide continuing education for all aspects of care
- Participate in staff meetings

STAFF SELECTION

Choosing employees to staff the SCU is a crucial task that deserves much consideration. Assignment to the unit should be voluntary with dedicated staffing. The knowledge and commitment of the supervising nurse or manager will influence the total milieu of the unit. Ideally, all staff members will have a sincere desire to work with patients with AD and will have:

- Patience
- Tolerance of unusual behaviors
- Ability to handle stressful situations
- A calm, quiet demeanor
- The skills to interrelate with patients and families on all levels
- Flexibility and creativity
- Knowledge of dementia and behavioral management techniques

Departments of nursing, activities, social services, rehabilitation, and all nondirect staff (i.e., housekeepers, dietary and maintenance personnel, and administrators) who work with or have contact with patients and families should participate in an orientation program and ongoing training programs. The cost of training is exceeded by the benefits to patients, families, and staff.

ENVIRONMENT OF THE SPECIAL CARE UNIT

The impact of environment on the well-being of cognitively impaired people is well documented. Anxiety and aggressive behaviors frequently occur as a result of excessive environmental stimuli. On the other hand, physical and mental deterioration set in when there is a lack of stimuli. The SCU is planned to provide an environment that is safe, soothing, and serene, with appropriate sensory stimulation. Specific aspects of the SCU environment include:

- Minimum of 20 beds
- Locked unit in compliance with state regulations
- Use of lighting, colors, design, and texture to produce a calming effect
- Locked top drawer of dressers for safe storage of hearing aids, glasses, and dentures
- Minimal noise; intercom for emergency use only and non-ringing telephones; elimination of televisions and radios from public areas of the unit
- Tops of dressers and bedside stands free of personal belongings
- Restrictions on people entering unit to reduce excessive noise and stimuli
- Furniture in community areas that is accessible and conducive to physical comfort
- Carpeted halls to reduce noise level
- Use of labels and pictures for redundant cueing
- Locked storage areas
- Wandering trails
- Spaces for activities and dining
- Equipment and space for simple cooking projects
- Access to the outdoors

Continuous quality improvement programs may be used to measure the outcomes of AD care programming. Potential positive indicators include decreased episodes of agitation and catastrophic reactions and fewer symptoms of depression with improved mood, continence, and sleeping patterns of patients. A happy, relaxed appearance and interactions with staff and other residents are measurable benefits of the SCU. Other hypothesized outcomes include family indicators, cost indicators, and staff satisfaction.

Implicit Bias in Health Care

The role of implicit biases on healthcare outcomes has become a concern, as there is some evidence that implicit biases contribute to health disparities, professionals' attitudes toward and interactions with patients, quality of care, diagnoses, and treatment decisions. This may produce differences in help-seeking, diagnoses, and ultimately treatments and interventions. Implicit biases may also unwittingly produce professional behaviors, attitudes, and interactions that reduce patients' trust and comfort with their provider, leading to earlier termination of visits and/or reduced adherence and follow-up. Disadvantaged groups are marginalized in the healthcare system and vulnerable on multiple levels; health professionals' implicit biases can further exacerbate these existing disadvantages.

Interventions or strategies designed to reduce implicit bias may be categorized as change-based or control-based. Change-based interventions focus on reducing or changing cognitive associations underlying implicit biases. These interventions might include challenging stereotypes. Conversely, control-based interventions involve reducing the effects of the implicit bias on the individual's behaviors. These strategies include increasing awareness of biased thoughts and responses. The two types of interventions are not mutually exclusive and may be used synergistically.

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