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Contact Hours: **6**

Alzheimer's Disease

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COURSE OBJECTIVE: The purpose of this course is to prepare healthcare providers to deliver appropriate therapeutic interventions to persons with Alzheimer's disease, their family members, and caregivers.

LEARNING OBJECTIVES

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

- Summarize the epidemiology and the financial and societal impact of Alzheimer's disease (AD).
- Describe the pathophysiology of Alzheimer's disease.
- List risk factors and possible preventive measures for Alzheimer's disease.
- Describe the clinical manifestations and process of diagnosing AD.
- Discuss available pharmacologic and medical therapies.
- Define the role of rehabilitation in the care of persons with Alzheimer's disease.
- Identify strategies for addressing the effects of Alzheimer's disease.
- Describe effective ways to support families and caregivers.
- Discuss ethical and legal issues in caring for the AD patient, including end-of-life care.

INTRODUCTION

Alzheimer's disease (AD) is an irreversible, progressive, degenerative disease of the brain that damages and eventually destroys brain cells. This leads to loss of memory and impaired judgment, language, orientation, and executive functioning. Over time, the disease causes behavior and personality changes and eventually loss of physical function.

Alzheimer's disease is one of a group of disorders called dementias, which are brain failures characterized by progressive cognitive and behavioral changes. Other forms of **dementia** include:

- Vascular dementia
- Dementia with Lewy bodies
- Fronto-temporal dementia
- Korsakoff's syndrome
- Creutzfeldt-Jakob disease
- Mild cognitive impairment
- Other rare forms

Of these, Alzheimer's disease is the most common cause of dementia.

Alzheimer's disease results from a complex pattern of abnormal changes, develops slowly, and gradually worsens. The course of AD and the rate of decline vary from person to person. Alzheimer's disease can be present for many years before there are clinical signs and symptoms of the disease. On average, clients with AD live for 8 to 10 years after diagnosis, but some may live as long as 20 years.

It is the only one among the top 10 causes of death in America that cannot be prevented, cured, or slowed (Alzheimer's Association, 2015a).

Historical Perspective

Senile dementia—the loss of memory and other intellectual faculties that occur in the elderly—was recognized in the time of Hippocrates. In the centuries that followed, this condition was thought to be simply a result of old age, commonly called “hardening of the arteries.” Diseases of old age, however, were considered unimportant until the second half of the nineteenth century, when scientists began to learn more about preventing and treating these conditions.

SIGNIFICANT DEVELOPMENTS IN THE HISTORY OF ALZHEIMER'S DISEASE	
1906	German psychiatrist Alois Alzheimer first described the pathology of the disease after using staining techniques to identify amyloid plaques and neurofibrillary tangles in the brain associated with the symptoms of senile dementia.
1910	The disease was labeled Alzheimer's disease by Emil Kraepelin.
1931	After the invention of the electron microscope, it became possible to conduct further study of the brain by viewing actual brain cells, opening the door to research into many areas of brain disorders, including AD.
1968	Lawton Instrumental Activities of Daily Living Scale was developed to measure cognitive function. This tool is used to determine how a person is functioning at baseline and to identify improvement or deterioration over time.



1974	The National Institute on Aging (NIA) was founded.
1976	Alzheimer's was recognized as the most common form of dementia.
1980	The Alzheimer's Association was founded.
1983	National Alzheimer's disease month was declared.
1984	Beta-amyloid was identified as forming AD's characteristic plaques, which cause reduced neurological function. Nationwide infrastructure for Alzheimer's was research established by the NIA.
1986	Tau protein was identified as forming AD's characteristic neurofibrillary tangles.
1987	First Alzheimer's drug trial (tacrine) was begun; the first deterministic Alzheimer's gene was discovered.
1993	First Alzheimer's disease "risk factor" gene was identified, called APOE-e4. First Alzheimer's drug, tacrine (Cognex), was given approval by the FDA.
1994	President Reagan announced he had been diagnosed with AD. First World Alzheimer's Day was held.
1995	First transgenic mouse model was announced (human APP genes linked to a rare, inherited form of AD inserted into mice).
1996	FDA approved donepezil (Aricept), a cholinesterase inhibitor, for treating all stages of AD.
1999	An Alzheimer's vaccine was found to be successful in mice but caused symptoms of brain autoimmune response in humans.
2000	FDA approved rivastigmine (Exelon), a cholinesterase inhibitor, for treating all stages of AD.
2001	FDA approved galantamine (Razadyne), a cholinesterase inhibitor, for treating mild to moderate AD.
2003	FDA approved memantine, an N-methyl-D-aspartate (NMDA) antagonist that reduces certain types of brain activity by binding to NMDA receptors and blocking the activity of glutamate, which in AD can overstimulate nerve cells and kill them.
2004	The new imaging agent known as Pittsburg Compound B (PiB) was produced to be used with positron emission tomography (PET) for early detection of AD. Alzheimer's disease neuroimaging initiative (ADNI) was begun to share research data worldwide.
2009	An effort was begun to standardized biomarkers for AD.
2011	Alzheimer's disease advanced to become the sixth leading cause of the death in the United States and the fifth leading cause of death for persons over the age of 65. Canadian scientists used a technique known as deep brain stimulation (applying electricity to regions of the brain) to reverse AD-related memory loss. Annual assessment for cognitive impairment for all Medicare recipients was implemented as part of an annual wellness visit.



2012	Scientists discovered that specific antibodies that block the function of a related protein (Dkk1) are able to completely suppress the toxic effect of beta-amyloid on synapses (UCL, 2012). The first major clinical trial for prevention of Alzheimer's disease was begun.
2013	International Genomics of Alzheimer's Project (IGAP) researchers identified new genetic risk factors for AD.
2014	FDA approved donepezil combined with memantine (Namzaric) for treatment of moderate to severe AD. Rates of death caused by AD were found to be much higher than reported on death certificates.
2015	A UCLA study identified three distinct subtypes of AD: inflammatory, non-inflammatory, and cortical (associated with significant zinc deficiency). Research began to determine if they have different underlying causes and respond differentially to potential treatments.
Sources: Alzheimer's Association, 2015b; Irwin, 2015.	

Scientists continue the search for answers regarding causes, diagnoses, and treatments for AD. One promising target is beta-amyloid, a protein that builds up into plaques, and researchers are working on several ways to clear beta-amyloid from the brain or prevent it from clumping together to form plaques. Drugs are now being tested that are directed toward beta-amyloid.

There are many other new approaches to treatment that are being investigated worldwide. Whether or not these strategies work is not known, however, researchers believe the outlook is good for development of treatments that slow or stop Alzheimer's (Alzheimer's Association, 2015c).

EPIDEMIOLOGY

There continues to be no exact data on the incidence and prevalence of Alzheimer's disease available because: 1) there is no compulsory notification, 2) it is often quite difficult to distinguish between different types of dementia, and 3) as yet there is no exact diagnostic test. Therefore, statistics regarding AD are only estimates (Povova et al., 2015).

AD Worldwide

Worldwide it is estimated that close to 44 million people have Alzheimer's disease or a related dementia. It is most common in Western Europe (with North America close behind) and least common in Sub-Saharan Africa. Alzheimer's disease and other dementias are the leading cause of disability in later life (Alzheimer's Disease International, 2015).



AD Nationwide

As life expectancy in the United States has risen, so has the number of persons with a probable diagnosis of AD. An estimated 5.3 million Americans of all ages and 5.1 million Americans 65 and older had AD in 2015. This is projected to reach 13.8 million by the year 2050. In 2015, it was estimated that every 67 seconds someone in the United States develops the disease.

It is the sixth leading cause of death in the United States, with 1 in 3 seniors dying with Alzheimer's or another dementia (Alzheimer's Association, 2015a). In 2015, an estimated 700,000 people in the United States age 65 and older will die with Alzheimer's. Between 2000 and 2013 deaths attributed to AD increased 71%, while those attributed to the number one cause of death (heart disease) decreased 14% (Alzheimer's Association, 2015b).

AGE

Of those with AD, 4% are under age 65, 15% are 65 to 74, 44% are 75 to 84, and 38% are 85 or older. By 2025 the number of people 65 years and older with AD is estimated to reach 7.1 million, a 40% increase from 2015 (Alzheimer's Association, 2015c).

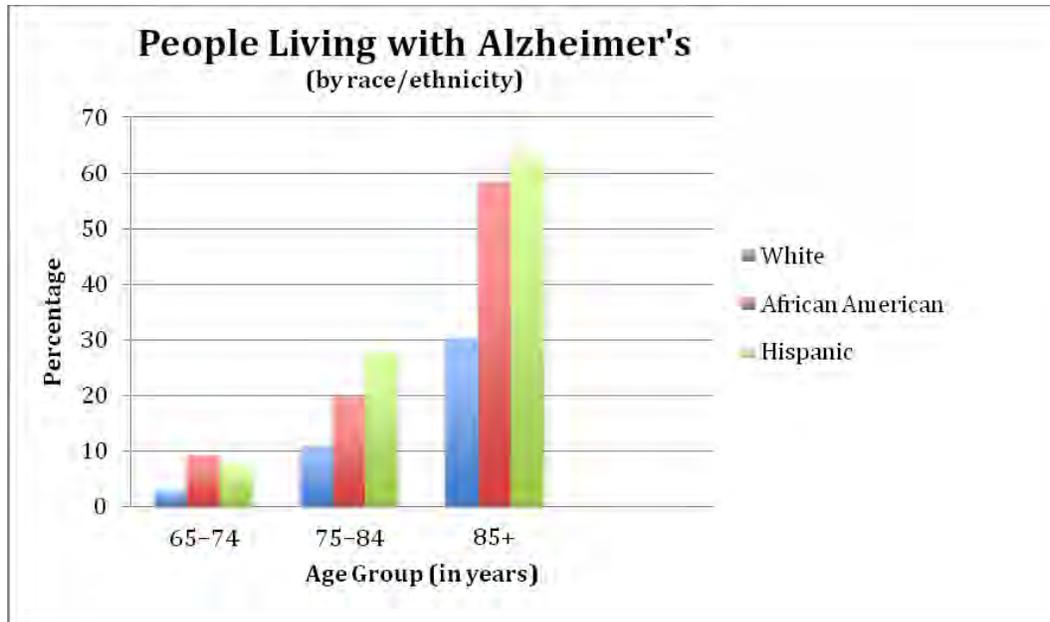
GENDER

Almost two thirds of all Americans with AD are women. It is estimated that of the 5.1 million people over the age of 65 with AD in the United States, 3.2 million are women and 1.9 million are men. This is explained by the fact that women live longer on average than men and not that women are more likely than men to develop dementia (Alzheimer's Association, 2015c).

RACE/ETHNICITY

Although there are more older whites living with Alzheimer's disease than other ethnic groups, older African Americans are almost twice as likely to have Alzheimer's and other dementias, and Hispanics are about 1-1/2 times more likely to have Alzheimer's and other dementias than older whites. This is related to the percentage of the population each represents. Health conditions such as high blood pressure and diabetes and other differences in socioeconomic characteristics that are risk factors for AD are more common in older African Americans and Hispanics than in older whites (Alzheimer's Association, 2015c).





Source: Created by Wild Iris Medical Education from data provided by Alzheimers.net (2015).

EDUCATION LEVEL

A study conducted by the University of Wisconsin showed that higher education is associated with lower age-related increases in the abnormal levels of tau protein in the cerebrospinal fluid of older adults. (Tau is a biomarker of neurodegeneration caused by Alzheimer's disease.) While the levels of tau increased in all the study participants as they aged, those with 16 years of education had smaller increases than the less-educated participants.

It is known that life experiences that engage the brain—such as higher education—result in a “cognitive reserve,” and that those with a higher reserve seem to develop dementia less frequently than those with a lower reserve. However, it is not known if this reserve only masks symptoms longer or whether it is protective against the disease (Almeida et al., 2015).

Financial Impact

Alzheimer's disease inflicts a heavy economic burden on families and on society as a whole. According to the Alzheimer's Association, the cost of caring for individuals with AD was estimated in 2015 to be \$226 billion annually and was projected to increase to \$1.1 trillion in 2050. Half the costs are covered by Medicare, with per-person expenditures three times higher for those with dementia than for those without dementia. The cost to Medicaid is 19 times higher for those with dementia (Alzheimer's Association, 2015d).

Although the number of persons diagnosed with AD is increasing, the mortality rate of these individuals is decreasing. Persons with AD have significantly more comorbid medical conditions and higher healthcare costs and utilization than demographically matched Medicare



beneficiaries. Medicaid is the only major source of financial assistance for long-term care for people with Alzheimer's disease.

The staggering costs of AD for families—home healthcare, adult daycare, caregiver respite, and long-term care—are seldom covered by medical insurance or Medicare, which is intended to cover the acute healthcare needs of people over 65 and disabled people under 65. Clients who have long-term care insurance, which may cover home healthcare, or those who are eligible for state-funded Medicaid programs, have some coverage for these services, but many families must pay all or most of the cost themselves.

ANNUAL MEDIAN COST PER PATIENT OF LONG-TERM CARE SERVICES IN THE UNITED STATES

- Homemaker services: \$44,616
- Home health aide: \$45,760
- Adult day healthcare: \$17,904
- Assisted living: \$43,200
- Nursing home facility, semi-private room: \$80,300
- Nursing home facility, private room: \$91,250

Source: Genworth, 2015.

Some individuals have long-term care insurance coverage, but once a diagnosis of Alzheimer's disease is made, the individual will not be able to apply for long-term care coverage. If it is already in place at the time of diagnosis, there are certain questions to be asked, such as:

- At what point after diagnosis can the person begin to collect benefits? Many policies require a defined level of physical or cognitive impairment.
 - What is the daily benefit, and is it adjusted for inflation annually?
 - How long will benefits be paid?
 - Is there a maximum lifetime payout?
 - What type of care does the policy cover?
 - How long after diagnosis will the policy begin to pay?
 - Are there tax implications for receiving these benefits?
- (Alzheimer's Association, 2015d)

The financial, emotional, and physical impact on friends and family of those with Alzheimer's disease or other dementias is extremely significant.



MEDICARE AND MEDICAID COVERAGE

Costs during the early stage of Alzheimer's disease:

- When a patient is undergoing diagnostic testing for AD, Medicare Part B covers 80% of the cost once the deductible has been reached.
- When a diagnosis has been made, Medicare Part B pays 80% of the cost for psychological counseling for associated mental health conditions, such as depression, if prescribed by a doctor.
- Medicare Part B pays 80% for physical and occupational therapies if medically necessary and prescribed by a physician.
- Medicare Part D helps pay for prescription drugs, and most Alzheimer's medications are on Medicare's approved drug list. Medicare Supplemental Insurance can cover the remaining 20% that Medicare Part B does not pay.
- There are Medicare Special Needs Plans available, a type of Medicare Advantage plan that is specifically designed for persons with Alzheimer's.

Costs during the middle stage of Alzheimer's disease:

- Medicare does **not** provide benefits for personal care or supervision either in the home or in an assisted-living setting.
- Medicare continues to pay for doctor visits and prescription drugs.

Costs in the later stage of Alzheimer's disease:

- Medicare covers up to 100 days for rehabilitation in a nursing home or skilled nursing facility, but it must be following an inpatient hospital stay of three days for management of a medical situation. If the stay is extended, Medicaid may pay for custodial care if the patient has an income and asset level low enough to qualify, while Medicare pays for "medically necessary" care.
- Medicaid covers extended stays in a nursing home or in-home long-term care for seniors who need assistance with activities of daily living (ADLs) due to Alzheimer's disease if the patient has an asset level low enough to qualify.
- Medicare will pay for home health care for up to 35 hours a week, but the person must be certified as "homebound," either physically or psychologically, and unable to function outside their home. The person also must require physical, occupational, and/or speech therapy or skilled nursing care.
- Rehabilitation care—including mental health services or physical, occupational, or speech therapy—may be covered only if it is shown that the patient can benefit from the therapy either by making continuous improvement or by maintaining current status.



Costs in hospice care:

- Medicare will provide all-inclusive hospice benefits for those who are believed to have six months or less to live. Very late-stage Alzheimer's disease patients qualify for this benefit, which includes all doctor, nursing, and personal care; prescription drugs; homemaker services; and counseling for the patient and family.
- Under the Medicare hospice benefit, the patient can receive respite care in a Medicare-approved hospital or skilled nursing facility for up to five days at a time to give caregivers a rest. Medicare pays 95% of the Medicare-approved amount.

(See also “Clinical Stages of AD” later in this course and “Resources” at the end of this course.)

Sources: Medicare.gov, 2015; Guerrero, 2015.

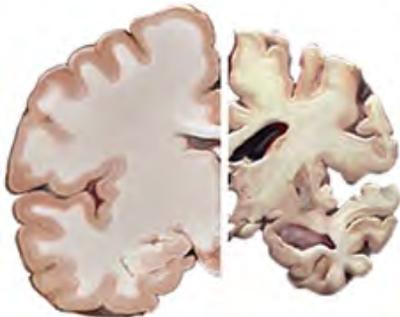
WHAT IS ALZHEIMER'S DISEASE?

Normal aging involves changes throughout the body, and the brain is not exempt. In normal aging some neurons die; others shrink and become less effective, especially in areas of the brain related to learning, memory, and executive function (the abilities required to plan, organize, and carry out tasks). Inflammation, the production of unstable molecules called free radicals, and breakdown of energy production within the cell also increase with age. These age-related changes in the brain vary from person to person, and a healthy individual may experience only a slight decline in memory as a result.

Pathophysiology

Aging itself is a major risk factor for developing Alzheimer's, but aging is not the direct cause of the disease. As we age, tangles develop in neurons, and plaques may accumulate in particular regions of the brain. The hallmark of AD is an exceptionally large number of neurofibrillary tangles and plaques in the brain. The brains of victims of Alzheimer's disease also reveal loss of neurons marked by shrinkage of parts of the cerebrum.

Healthy Brain Severe AD



Shrinkage of the brain due to Alzheimer's disease.
(Image courtesy of the National Institute on Aging/National Institutes of Health.)



PLAQUES

More than three decades of research have shown how AD steadily destroys brain function. Amyloid precursor protein (APP), produced by healthy neurons, is severed by two enzymes, called beta and gamma secretase. This process creates a short, sticky protein called **beta-amyloid**. Instead of dissolving in the fluid that surrounds the neurons, beta-amyloid protein folds into insoluble clumps called fibrils. The fibrils stick together, resulting in plaques on the surface of the neuron.

The most damaging form of beta-amyloid may be groups of a few pieces rather than the plaques themselves. The small clumps may block cell-to-cell signaling at the synapses, and they may also activate immune system cells that trigger inflammation and devour disabled cells. Beta-amyloid plaques are one of two characteristic lesions of AD.

TANGLES

The other lesion that characterizes AD is called a **neurofibrillary tangle** that forms inside the neuron itself. Normally, healthy neurons connect with each other through slender appendages or branches called neurites. The neurites contain microtubules that maintain the shape of the cell and serve as its life support system, carrying nutrients and neurotransmitters.

The walls of the microtubules are reinforced by tau proteins, which act like the rungs on a ladder. In AD, the tau proteins loosen and form neurofibrillary tangles. Without the normal reinforcing effect of the tau proteins, microtubules with loose tau proteins disintegrate, cutting off life support to the neuron, which then shrivels and dies.

DISRUPTION OF NEUROTRANSMITTERS

Alzheimer's disease reduces the production of certain neurotransmitters in the brain that normally act as chemical messengers, transmitting nerve impulses. These neurotransmitters include acetylcholine, norepinephrine, serotonin, and somatostatin. Reduction of acetylcholine is first apparent in the entorhinal cortex, which is adjacent to the hippocampus, an area of the brain associated with recent memory and storage of new information.

Causative and Risk Factors

Alzheimer's is a complex disease with no single, clear-cut cause and therefore no sure means of prevention or "silver bullet" cure or treatment. Scientists understand that for most people AD is an ecological disease related to the interaction of genetic, environmental, and lifestyle factors over many years, which lead to changes in brain structure and function.

Alzheimer's disease is classified by heritability and age of onset. Early-onset AD occurs in people under the age of 60 years and is often caused by inherited changes in one of three genes. Fortunately, early-onset AD is rare (less than 5%). It often progresses more rapidly than late-onset AD. Late-onset AD occurs after age 60 and is the most common form of the disease.



GENETIC FACTORS

Both early-onset and late-onset AD have a genetic component. Most early-onset AD is caused by an inherited change in one of three genes, resulting in a type known as early-onset familial Alzheimer's disease (FAD), a form that scientists know for certain is linked to genes. FAD makes up less than 1% of all cases of AD (NIA, 2015a).

The three genes are located on three different chromosomes, and each mutation causes abnormal proteins to be formed that play a role in the breakdown of amyloid precursor protein (APP) (Dawkins & Small, 2014). Breakdown of this protein is part of a process that generates harmful forms of amyloid plaque.

Everyone inherits two copies of each of these genes—one from each parent. A parent carrying a defective version of one of these genes has a 50-50 chance of transmitting the defective gene to each of his or her children. A single defective version of any one of these three genes will cause early AD nearly 100% of the time. This type of inheritance pattern is called autosomal dominant inheritance.

There is no scientific evidence that links these mutations with the more common late-onset AD. However, even though autosomal dominant inheritance of genetic mutations does not appear to cause late-onset AD, other genetic factors may increase the risk for developing the disease.

No specific gene that causes the late-onset form of the disease has been identified. However, one genetic risk factor that appears to increase the likelihood of developing the disease is the apolipoprotein E (APOE) gene. This gene comes in several different forms, and as yet its role is not understood.

The APOE protein is found in the neurons of healthy brains and in excess amounts in the brains of people with AD and Down syndrome. Inheritance of one or two copies of the gene version apolipoprotein E epsilon 4 (APOE e4) on chromosome 19 increases the risk of late-onset AD (NIA, 2015b).

EPIGENETICS

Findings suggest that lifestyle changes that raise the risk for Alzheimer's disease may be taking effect through epigenetic changes. Epigenetics is the study of biological mechanisms that switch genes on and off. Scientists have discovered that genetic and environmental factors can interact either positively or negatively to influence an individual's biological makeup, which can include the predisposition to different diseases such as Alzheimer's.

Chronic Stress

Chronic stress may be implicated in AD because of consistently high cortisol levels associated with neuronal atrophy and dysfunction, impaired cognition, and mood and affective disorders. Exposure to stress affects learning and memory, decision making, and



emotional responses and may predispose an individual to Alzheimer's disease and depression (Oliveira et al., 2015).

Depression

Although depression is common in individuals with AD or other forms of dementia and past research has identified it as an independent risk factor for cognitive decline, a new study has shown that depression and other behavioral changes can appear years before the development of memory loss. Currently, it is not known whether depression is a response to the psychological process of AD or a result of the same underlying changes in the brain (Masters et al., 2015).

Diabetes

Numerous studies have shown a clear association between type 2 diabetes mellitus and an increased risk of developing Alzheimer's disease. Other studies have shown that insulin resistance and deficiency can interact with beta-amyloid protein and tau protein phosphorylation, each leading to the onset and development of Alzheimer's (Li et al., 2015). Studies also show that elevated glucose levels and diabetes are associated with cognitive dysfunction, with common pathogenic factors operating in both conditions (Sridhar et al., 2015).

Hypertension

Researchers have known about the association of blood pressure with Alzheimer's disease, but in 2013 it was found that older people with hypertension were more likely to have biomarkers of Alzheimer's in their spinal fluid and that the more blood pressure varied over an eight-year period, the greater the risk of dementia.

High blood pressure can damage the small blood vessels in the brain, affecting the parts of the brain involved in thinking and memory. In one study, the use of potassium-sparing diuretics reduced the risk of Alzheimer's nearly 75%, while people who took any type of antihypertensive medication (especially a beta blocker) lowered their risk by one third (Johns Hopkins Medicine, 2014; Østergaard et al., 2015).

Vascular Disease

Cardiovascular disease increases the risk of developing AD. Autopsy results have shown that as many as 80% of persons with AD also have cardiovascular disease. Other studies suggest that plaques and tangles may be present in the brain without causing symptoms of cognitive decline unless the brain also shows evidence of vascular disease (Alzheimer's Association, 2015e).



Head Trauma

Research indicates a strong link between future risk of Alzheimer's and serious head injuries that cause loss of consciousness. The greatest risk occurs after a severe head injury that causes unconsciousness for more than 24 hours. A smaller risk is present with moderately serious head injury. Repeated mild injuries may increase the risk of cognitive difficulties in the future, but more research is needed to understand the association (Smith, 2015).

Oxidative Stress

Cumulative data from studies indicate that smoking during one's lifetime is associated with at least a 70% greater risk for AD, and the risk markedly increases with greater cigarette exposure. The relationship between cigarette smoke exposure and AD risk may be mediated or moderated by APOE genotype. Smoking is associated with an earlier onset of AD, and the primary pathophysiological mechanism shown to contribute to the neurobiological and neurocognitive abnormalities observed in smokers is cerebral oxidative stress.

The brain is very susceptible to oxidative stress caused by free radicals and other oxidizing agents, and cigarette smoke is a complex mixture of about 5,000 combustion products that contain a high number of oxidizing agents (Durazzo et al., 2014).

Evidence exists that pre- and post-natal exposures to environmental factors predispose to degenerative diseases in later life. Neurotoxic metals such as lead, mercury, aluminum, cadmium, and arsenic, as well as some pesticides and metal-based nanoparticles have been involved in AD. These pollutants have a similar mechanism of toxicity, which unite in a generalized mechanism based on the production of oxidative stress that leads to neurodegenerative disorders (Chin-Chan et al., 2015).

Vitamin D Deficiency

New research suggests that people with very low levels of vitamin D are at higher risk for developing AD and other forms of dementia. A study done in 2014 found that those persons with vitamin D deficiency were twice as likely to develop AD or other forms of dementia than those with normal vitamin D levels. More research is needed, however, as these results are only observational at this time, and it is not known if getting enough vitamin D can prevent AD or dementia (Knopman, 2015).

A study demonstrated that people with low blood levels of vitamin D perform worse on tests that measure how well their brain is working. Additional studies are examining how taking vitamin D and/or omega-3 supplements affects memory and how well the brain works (Alzheimer's Drug Discovery Foundation, 2014).



Obesity and Inflammation

Two important risk factors for Alzheimer's disease that may contribute to the development and/or progression of AD pathogenesis are obesity and age-related increases in inflammation. One consequence of obesity is chronic inflammation, which has been observed both in the brain and systemically (Christenson & Pike, 2015).

Neuroinflammation plays a key role in the pathophysiology of the disease, but it is not known whether inflammation is an underlying cause or a resulting condition of AD (Heppner et al., 2015).

These factors may be especially problematic for women following the onset of menopause, increasing the vulnerability of women for AD, and are most likely associated with the reduction of estrogens. Menopause is also associated with many additional changes, including increased central (abdominal) adiposity (Christenson & Pike, 2015).

Possible Preventative Strategies

At this time there is no definitive evidence about what can prevent Alzheimer's disease or age-related cognitive decline. However, a lifestyle that includes a good diet, physical activity, weight control, smoking cessation, social connections, and intellectual activity can maintain and improve overall health and well-being (Alzheimer's Association, 2015e).

REGULAR EXERCISE AND A HEART-HEALTHY DIET

Regular exercise and diet may be of benefit in lowering the risk of Alzheimer's disease and vascular dementia. Brain cells may directly benefit by the increased blood and oxygen flow that occur during exercise.

The National Institute on Aging (2015c) reports that research on rats and mice show exercise increases both the number of small blood vessels supplying blood to the brain and the number of connections between nerve cells. It has also been shown that exercise can stimulate the brain's ability to maintain old network connections and make new ones that are vital to healthy brain function.

Current evidence suggests that heart-healthy eating may also protect the brain. This involves limiting sugar and saturated fats and eating lots of fruits, vegetables, and whole grains. The two diets studied and found to be of benefit are the DASH (Dietary Approaches to Stop Hypertension) diet and the Mediterranean diet.



HEART-HEALTHY DIETS

DASH Diet

- Lots of vegetables and fruits
- Fat-free or low-fat dairy products
- Whole grains
- Fish and poultry
- Legumes, seeds, and nuts
- Vegetable oils
- Limited sodium, sweets, sugary beverages, and red meats

Mediterranean Diet

- Primarily plant-based foods such as fruits, vegetables, whole grains, legumes, and nuts
- Olive oil instead of butter
- Herbs and spices instead of salt
- Limited red meat (no more than a few times a month)
- Fish and poultry at least twice a week
- Red wine in moderation (optional)

Sources: Heller, 2015; Gunnars, 2015.

MENTAL ACTIVITIES AND SOCIAL CONNECTIONS

Research shows that maintaining strong social connections and mental activity may lower the risk of cognitive decline with aging. The reason for this link is unknown, but it is believed to be due to direct mechanisms in which connections between nerve cells in the brain are strengthened (Alzheimer's Association, 2015e).

- Read and write every day.
- Play games involving strategy (e.g., checkers, chess, cards).
- Do crossword puzzles, Sudoku, or other “brain” games.
- Seek out new activities and unfamiliar settings.
- Continue involvement in educational activities such as going to lectures.
- Take up new hobbies.
- Do routine activities (such as brushing teeth) with the nondominant hand.
- Keep in touch with family and friends and actively maintain those connections.
- Join a club or attend social activities.
- Volunteer for a cause of interest.
- Take advantage of all casual encounters with other people.



RECOGNIZING ALZHEIMER'S DISEASE

Clinical Manifestations

The hallmark of Alzheimer's disease is memory impairment. This is by no means the only characteristic feature, nor is it the most important. There are also many conditions apart from Alzheimer's disease that can lead to memory impairment. In AD, however, the memory impairment is associated with evidence of cognitive decline and impaired judgment, and it has an insidious onset.

MEMORY IMPAIRMENT

Memory has three modalities: immediate memory (remembering for a few seconds), short-term memory (remembering for a few minutes or hours), and long-term memory (remembering for a few years). Early in AD, short-term memory is impaired but long-term memory is preserved. Immediate memory is also affected and may be secondary to a short attention span.

It is important to differentiate the memory impairment of Alzheimer's disease from that sometimes noted in normal people, which is often called "benign" forgetfulness or age-associated memory impairment.

Age-related forgetfulness occurs because the brain is aging and changing, just as the body changes. Individuals with benign forgetfulness may have a problem remembering something but will most often remember it later on. They may forget where they parked the car but, given a bit of time, will remember where it is. Benign forgetfulness may also manifest itself by causing difficulties in learning new information, operating a new device, or remembering phone numbers. Benign forgetfulness is usually sporadic, but memory impairment in AD and other dementias is progressive and interferes with the person's activities of daily living and social and professional activities.

Early in the course of AD, individuals usually are aware of their memory deficit and may make notes to remember important things, but sooner or later the memory deficit is such that they may forget to check their notes. Later they may become frightened and apprehensive about their memory problems and may feel depressed and discouraged. As the disease progresses, individuals lose insight into their memory deficit and are no longer aware of it. It is at this point that they must be protected from themselves.

INABILITY TO ACQUIRE AND PROCESS NEW INFORMATION

One of the earliest manifestations of AD is the inability to acquire and retain new information and integrate it into one's acquired knowledge. Often the first indication that something is wrong becomes apparent when the individual is unable to develop new skills at work or has difficulty keeping abreast of current events. With severe memory loss, only highly learned material is retained and new material is rapidly lost.



Because of this difficulty in processing new information, a sudden change in a person's environment can trigger an episode of severe confusion. For example, the individual suddenly finds himself in a strange place and is unable to remember how he got there. As a result, the individual becomes agitated. In the early stages of AD, this type of problem does not last long. With explanations and reassurance, the individual soon becomes reoriented, alert, and rational.

LANGUAGE DIFFICULTIES

Language difficulties are present at the earliest stages of the disease. Initially they may be so subtle as not to be readily apparent to others and can be detected only by neuropsychological tests. As the disease progresses, these language deficits become more marked and are readily noticeable.

Anomia, the inability to find the right word, is a characteristic of AD. At first the person is aware of this and may make up for it by using sentences to describe an object he cannot name. This is confined in the early stages to objects the person is not in contact with on a regular basis. As the condition worsens, anomia comes to include common objects such as an eating utensil or a pen.

As the disease progresses, **agnosia** sets in. In addition to being unable to name an object, the person now cannot identify it. Loss of ability to recognize people they have not seen for a long time may occur, and as time moves on, the individual may not be able to recognize their spouse or other close relatives. The person becomes unable to follow any coherent train of thought.

Eventually **aphasia** develops, and the person is unable to understand what he hears. Spontaneous speech deteriorates. The person tends to repeat words and questions spoken by another (**echolalia**) without making any effort to answer questions. In the advanced stage of the disease, speech becomes unintelligible, and eventually the person becomes mute.

APRAXIA AND IMPAIRED VISUOSPATIAL SKILLS

Early in the course of AD, **apraxia** (the inability to carry out purposeful movements and actions despite lack of motor or sensory deficits) becomes evident. Newly acquired skills and complex or technical skills, especially those that require integration of different stimuli, become more difficult to perform. The actions that have become automatic, such as eating and dressing, are preserved until the late stages. This is due to the fact that complex skills are controlled mainly by the cerebral cortex, and the control of automatic action is consigned to the basal ganglia.

Visuospatial cognition is the ability to see and analyze objects in relation to their surroundings and to identify stimuli and their location. Impaired visuospatial cognition may explain why a person becomes lost in familiar surroundings or while driving a car. As the disease progresses, simple activities of daily living become impossible. An object may be recognized, but the person has no idea what to do with it.



POOR JUDGMENT

Eventually, the person with AD loses the ability to use correct judgment. This is often the point at which relatives recognize there is something seriously wrong. Poor management of one's finances is one of the most common presenting symptoms of AD. As the disease progresses, the person becomes severely impaired in handling problems, understanding similarities and differences, and exercising social judgment.

SELF-NEGLECT

One of the earliest manifestations of AD is when individuals begin to lose the capacity for self care. Initially, the person may require prompting, but as the disease progresses, the person will require complete assistance with all activities of daily living.

Signs of self-neglect include failure to take medications, refusal to seek treatment for serious illness, poor hygiene, inability to maintain housekeeping duties, dehydration, and malnutrition. In addition, the person may hoard things and live in hazardous or unsafe conditions.

PERSONALITY CHANGES

Many persons with AD experience major personality changes. These changes often precede the other early clinical manifestations of the disease, such as cognitive impairment. As dementia progresses, there is often an exaggeration of the premorbid personality (Cipriani et al., 2015).

In the early stages of AD, the person may experience increased irritability, anxiety, and depression. As the disease progresses, common personality changes can include:

- Apathy
- Loss of interest in previously enjoyed activities
- Insensitivity to others
- Paranoia
- Delusional thinking
- Social withdrawal
- Lack of initiative

BEHAVIORAL PROBLEMS

Behavioral problems are distressing and are often the most difficult manifestations of the disease for caregivers to cope with both physically and psychologically. These may include:

- Stubbornness
- Resistance to care
- Suspicion of others



- Use of abusive language and profanity
- Acting in response to delusions or hallucinations
- Rummaging through other people's rooms
- Stealing
- Hiding things
- Repeating questions or statements
- Performing compulsive activities
- Urinating in inappropriate places
- Angry outbursts
- Violence precipitated by trivial events
- Restlessness
- Wandering
- Reversals of the sleep/wake cycle
- Asocial sexual behaviors, such as masturbating in public

PHYSICAL DETERIORATION

Physical health remains well for most persons with AD until the late stage of the disease. Persons may experience falls, spend more time sitting in a chair or lying in bed, and eventually develop muscle rigidity. Later they may become incontinent, and finally they are bedridden. These persons eventually succumb to one of three most common causes of death—pneumonia, urinary tract infection, and infected decubitus ulcers.

Clinical Stages of AD

Several classifications have been used for determining the level of care needed for people with Alzheimer's and for comparing groups of such persons with one another. It is important to realize that classifications are arbitrary, and there is a great deal of overlap among the various stages.

The most commonly used classification divides the disease process into **three stages**. In the first stage memory is impaired, in the second stage there is evidence of gross deficit in cognition, and in the third stage severe intellectual deterioration and physical deficits become apparent.

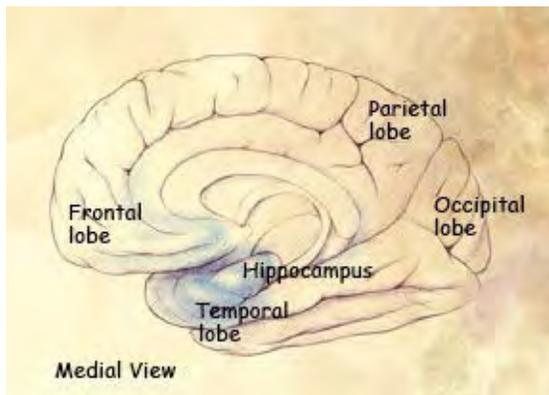
EARLY STAGE

Alzheimer's disease may be present 20 or more years before symptoms begin to appear and a diagnosis is made. In **early-stage (mild) AD**, a person may function independently (drive, work, and be part of social activities) but begin to experience problems with memory, language, and reasoning. Friends and family may begin to notice difficulties. This stage lasts from 2 to 4 years up to and including diagnosis.



This stage is typically marked by one or more of the following symptoms:

- Memory loss: poor recent memory
- Mild anomia
- Confusion about location of familiar places (beginning to get lost)
- Taking longer to accomplish normal daily tasks
- Having greater difficulty performing tasks in social or work settings
- Forgetting material that one has just read
- Trouble handling money and paying bills
- Making bad decisions due to impaired judgment
- Loss of spontaneity and sense of initiative
- Mood and personality changes, increased anxiety



Medial view of the brain, showing areas of **early damage** to the hippocampus and portions of the frontal lobe in blue. (Image courtesy of the National Institute on Aging/National Institutes of Health.)

MID-STAGE

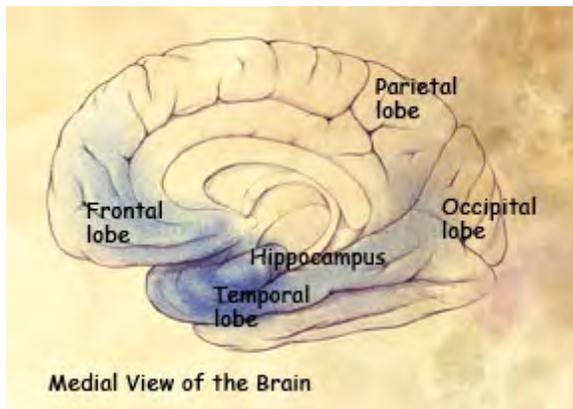
Mid-stage (moderate) AD involves areas of the cerebral cortex that control language, reasoning, sensory processing, and conscious thought. These regions continue to atrophy, resulting in more pronounced and widespread symptoms. Moderate Alzheimer's lasts from 2 to 10 years and is the longest stage.

Behavior problems, such as wandering and agitation, require more intensive supervision and care. Symptoms of this stage usually include:

- Increasing memory loss, both remote and recent
- Shortened attention span
- Problems recognizing friends and relatives



- Difficulty with language; problems with reading, writing, numbers
- Difficulty organizing thoughts and thinking logically
- Inability to learn new things or to cope with new or unexpected situations
- Restlessness, agitation, anxiety, tearfulness, and wandering, especially in the late afternoon or at night
- Loss of ability to tell time; late-day time disorientation and confusion, called “sundowning”
- Repetitive statements or movement, occasional muscle twitches
- Hallucinations, delusions, suspiciousness or paranoia, irritability
- Loss of impulse control (sloppy table manners, undressing at inappropriate times or places, vulgar language)
- Perceptual-motor problems (trouble getting out of a chair or setting the table)



Medial view of the brain, showing areas affected by **moderate AD** in blue. Note the spread of damage forward into the frontal lobe and backward into the temporal lobe. (Image courtesy of the National Institute on Aging/National Institutes of Health.)

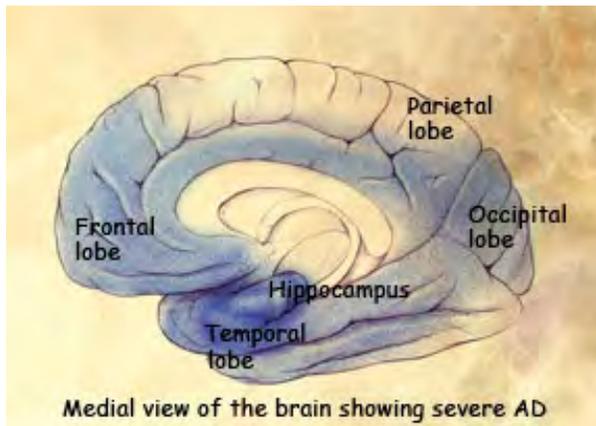
TERMINAL/LATE-STAGE

Late-stage (severe) AD lasts between 1 and 5 years. During this stage the person cannot communicate and is completely dependent upon others for care. Near the end, the person may remain in bed most or all of the time as the body begins to shut down. This stage is notable for the following:

- Severe impairment of all cognitive functions
- Physical impairment involving unsteadiness, repeated falls, reduced mobility
- Total loss of ability to care for oneself
- Inability to recognize immediate family members
- Weight loss



- Seizures
- Skin infections
- Groaning, moaning, or grunting
- Increased sleeping
- Lack of bladder and bowel control
- Impaired swallowing, which can lead to aspiration pneumonia (the most common cause of death in persons with AD)



Medial view of the brain, showing areas affected by **severe AD** in blue. Note the increased damage in the hippocampus (dark blue) and the spread of the disease throughout the frontal, temporal, occipital, and parietal lobes. (Image courtesy of the National Institute on Aging/National Institutes of Health.)

DIAGNOSING ALZHEIMER'S DISEASE

There is no single definitive test that can be done to identify Alzheimer's disease. Rather, diagnosis requires a complete medical evaluation that includes:

- A thorough medical history
- Mental status testing
- A physical and neurological exam
- Tests such as blood tests and brain imaging to rule out other causes of dementia-like symptoms

Clinical Diagnosis

Clinical diagnosis of AD is usually made during the early stage, when the person appears to be physically healthy but is having increasing difficulty making sense of the environment. The affected person and the family may mistake early signs of AD for normal age-related changes.



Deciding to seek diagnostic testing can be a major hurdle for the person and the family. Admitting that there may be the possibility of a diagnosis of Alzheimer's disease can be difficult to accept.

Although making a definitive diagnosis of Alzheimer's disease is difficult without doing an autopsy, tests and assessments by a skilled physician can diagnosis Alzheimer's with more than 90% accuracy (Alzheimer's Association, 2015f).

Screening

The United States Preventive Services Task Force concluded, as of 2014, that current evidence is insufficient to assess the balance of benefits and harms of screening for cognitive impairment. Screening refers to a one-time action, such as administration of a brief test using a formal screening tool that gives a score that may or may not accurately indicate the presence of a disease or the need for further evaluation.

In addition, these screening tests often result in false positives and false negatives. False positives may cause depression or anxiety, possible stigma, loss of long-term care insurance, loss of employment, or loss of a driver's license. The Task Force reported that diagnosis of dementia primarily occurs as a result of a clinician's suspicion of a person's symptoms or caregiver concerns and not as a result of formal screening (USPSTF, 2014).

The Alzheimer's Association recommends establishing a cognitive baseline for older adults in a medical setting, such as through the Medicare Annual Wellness Visit, and regular ongoing surveillance of an individual's cognitive abilities, the goal of which is early detection and thorough diagnostic evaluation for appropriate individuals (Alzheimer's Association, 2013).

MENTAL STATUS EXAMINATION

Screening for memory and cognitive deficits is done either to establish a cognitive baseline or as part of the workup for making a diagnosis of Alzheimer's disease. There are many types of **screening tools** to measure cognition. One of the earliest is the Mini-Mental State Examination (MMSE), which is often used for initial screening and for staging persons (*see also "Resources" at the end of this course*). The Blessed Information-Memory Concentration test is similar and is mainly used in primary care settings. Both evaluate memory, attention, and concentration. The Memory Impairment Screen (MIS), another screening tool, evaluates memory only.

Several single neuropsychological **tests** are also available, such as:

- Clock-drawing test
- Category fluency test (e.g., name all the animals one can in 60 seconds)
- Delayed word recall
- Trailmaking A and B (tests visual attention and task switching)



Screening instruments can combine these single tests. Two such tools are the Mini-Cog (see box below) and the 7-Minute Screen.

Caregiver-completed **questionnaires** can also be employed. These include asking an informant who knows the person well to answer a series of questions about the person's memory and other cognitive functions. Three such questionnaires are:

- Informant Questionnaire on Cognitive Decline in the Elderly (IQCODE)
- Alzheimer's Disease Caregiver Questionnaire
- AD8 Dementia Screening Interview

Medicare Algorithm for Assessment of Cognition

The Patient Protection and Affordable Care Act added a Medicare benefit known as the **Annual Wellness Visit (AWV)** in 2011. This benefit requires an assessment to detect cognitive impairment. The Alzheimer's Association put together a group of experts to develop recommendations on how this should best be accomplished. The resulting Medicare Annual Wellness Visit Algorithm for Assessment of Cognition includes:

- Health risk assessment information
- Patient observation
- Unstructured questions during the visit
- Structured cognitive assessment tool for patient
- Structured cognitive assessment tool for informants
(Cordell et al, 2013)

The mental status examination tools available were evaluated by the Alzheimer's Association, and the General Practitioner Assessment of Cognition (GPCOG), the Mini-Cog, and the Memory Impairment Screen (MIS) were selected as the best tools for mental status testing. These were assessed and found to:

- Require 5 minutes or less to administer
- Be validated in a primary care or community setting
- Be easily administered by medical staff members who are not physicians
- Have good to excellent psychometric properties
- Be relatively free from educational, language, and/or culture bias
- Be used by clinicians in a clinic setting without payment for copyrights

The GPCOG test has two components, a cognitive assessment conducted with the person and an informant questionnaire.



MINI-COG MENTAL STATUS EXAM

The Mini-Cog mental status exam includes three steps. The first and third steps test for memory problems, and the clock drawing test taps into a wide array of cognitive abilities that includes executive functions.

1. **Recall.** Ask the patient to listen carefully and remember three unrelated words (examples: apple, table, penny) and then to repeat the words. The same three words may be repeated to the patient up to three tries.
2. **Clock-drawing test (CDT)*.** Ask the patient first to draw the face of a clock either on a blank sheet of paper or on a sheet with the clock circle already drawn, and then put the numbers on the clock face. Then ask the patient to draw the hands of the clock to read a specific time. The times 11:10 or 8:20 are good examples because they require the patient to place the hands on the opposite sides of the clock face, which increases the sensitivity of the test.
3. **Delayed recall.** Ask the patient to repeat the three words previously stated.

Scoring:

3 recalled words = Negative for cognitive impairment

1–2 recalled words + normal CDT = Negative for cognitive impairment

1–2 recalled words + abnormal CDT = Positive for cognitive impairment

0 recalled words = Positive for cognitive impairment

*The clock-drawing test involves many cognitive areas that can be affected by dementia, including executive function, visuospatial abilities, motor programming, attention, and concentration.

(See also “Resources” at the end of this course.)

Source: Borson et al., 2000.

LABORATORY FINDINGS

Laboratory tests are performed to rule out other conditions that may cause or mimic the symptoms of AD. The American Association for Clinical Chemistry (2015) recommends measurement of:

- Vitamin B₁₂
- Vitamin D
- Thyroid function tests
- Complete blood count (CBC) to rule out anemia and infection
- Electrolytes
- C-reactive protein (CRP) and erythrocyte sedimentation rate (CSR) to rule out inflammation



- HIV antibody to rule out AIDS
- Rapid plasma reagin (RPR) to rule out syphilis
- Lyme's disease titer
- Drug screening for illicit drugs

Tests of cerebrospinal fluid measuring beta-amyloid 1-42, total tau protein, and phosphorylated tau should be considered in certain circumstances. These tests are done when the person appears to have a straightforward case of Alzheimer's disease or mild cognitive impairment due to Alzheimer's disease but is younger than 66 years old in order to confirm that the disorder is, in fact, present so that further workup can be stopped (Budson & Solomon, 2016).

Cerebrospinal fluid biomarkers have proven accurate for mild cognitive impairment and Alzheimer's disease, allowing for diagnosis of AD in its prodromal stage. Conversely, having all three biomarkers within normal range rules out AD (Molinie et al., 2014). At this time, efforts worldwide are being made to standardize methods and put quality control programs in place so that this test can be put into general use for routine diagnosis of AD.

IMAGING STUDIES

Structural Imaging

Today the standard testing workup for Alzheimer's disease includes structural imaging with **magnetic resonance imaging (MRI)** or **computed tomography (CT)**. The primary purpose for structural imaging studies is to identify or rule out other conditions that may cause symptoms similar to Alzheimer's but that require different treatment.

Although structural imaging studies cannot be used to diagnose AD, they are valuable for determining whether there is atrophy bilaterally in hippocampi, anterior temporal lobes, and parietal lobes. Combined with appropriate clinical information, this pattern may suggest Alzheimer's disease (Budson & Solomon, 2016).

Functional Imaging

Functional image studies (positron emission tomography, or PET) and single photon emission computed tomography (SPECT scanning) make amyloid plaques light up on a brain scan, enabling accurate detection of plaques in living people.

Such studies are helpful in differentiating different types of dementia but are not helpful in distinguishing between mild AD and normal aging or depression, which are some of the more common diagnostic possibilities.

Because amyloid plaques are present in many people with no symptoms of cognitive decline or Alzheimer's disease, the presence of amyloid plaques cannot be used to diagnose AD, and amyloid imaging is not recommended for routine use.

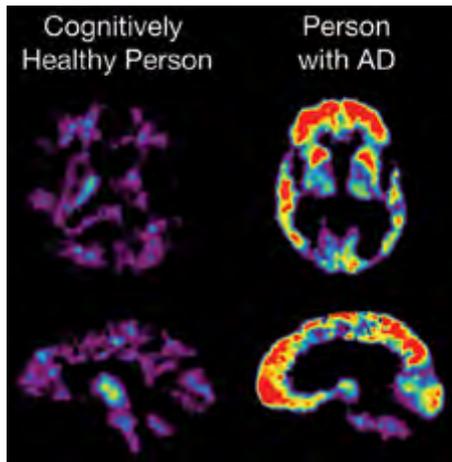


Functional imaging studies are helpful in two circumstances when considering a diagnosis of AD: 1) when the person is 65 years old or less, and 2) when in addition to AD, other forms of dementia are being strongly considered (Budson & Solomon, 2016).

The U.S. Food and Drug Administration approved three molecular imaging tracers for use in persons with possible AD or other causes of cognitive decline. These molecules are labeled with a radioactive tracer and bind to the beta-amyloid in the brain.

Molecular imaging technologies are currently being used as research tools, and in the near future they may help physicians to:

- Routinely diagnose AD at its earliest stages
- Identify individuals who are at high risk for developing AD
- Monitor progression of the disease
- Assess patient response to drug treatment
- Contribute to developing targeted drugs and therapies for dementia and AD (SNMMI, 2015)



PET scans of the brain. (Image courtesy of the National Institute on Aging/National Institutes of Health.)

FUNCTIONAL ASSESSMENT

As AD progresses, periodic assessment of the person's ability to function should be carried out. There are many rating tools, but one that is used commonly is the **Functional Activities Questionnaire (FAQ)**, which takes 10 minutes or less to complete. It evaluates activities of daily living and is completed by a family member or friend (known as the informant) who routinely observes the person in his or her day-to-day activities.

The informant is one who spends at least two days a week with the person and rates the person in the following 10 areas:

1. Writing checks and maintaining other financial records
2. Assembling tax or business records
3. Shopping alone for clothes, household necessities, or groceries
4. Playing a game of skill or working on a hobby
5. Heating water for coffee or tea, turning off the stove
6. Preparing a balanced meal
7. Keeping track of current events
8. Paying attention to and understanding a TV show, book, or magazine
9. Remembering appointments, family occasions, holidays, or medications
10. Traveling out of the neighborhood (e.g., driving or arranging to take the bus)

Rating:

- 3 points if dependent on others to complete the task
- 2 points if requires assistance
- 1 point if had difficulty, but performs independently
- 0 points if performs independently with no difficulty

Scoring:

- Scores range from 0 to 30, with higher scores indicating more functional difficulty.
- Scores higher than 10 suggest reduced functional ability.
(Pfeffer et al., 1982; Budson & Solomon, 2016)



The **Functional Dementia Scale (FDS)** is designed for use by caretakers of disabled older adults. It can be used to help plan strategies for immediate needs and track the progression of dementia. Identifying the level of functioning and assessing caregiver's needs help the healthcare provider identify appropriate community resources.

FUNCTIONAL DEMENTIA SCALE	
Rating 1 = None or little of the time 2 = Some of the time 3 = Good part of the time 4 = Most or all of the time	Task
1 2 3 4	Has difficulty completing simple tasks on own (e.g., dressing, bathing, doing arithmetic)
1 2 3 4	Spends time either sitting or in apparently purposeless activity
1 2 3 4	Wanders at night or needs to be restrained to prevent wandering
1 2 3 4	Hears things that are not there
1 2 3 4	Requires supervision or assistance in eating
1 2 3 4	Loses things
1 2 3 4	Appearance is disorderly if left to own devices
1 2 3 4	Moans
1 2 3 4	Cannot control bowel function
1 2 3 4	Threatens to harm others
1 2 3 4	Cannot control bladder function
1 2 3 4	Needs to be watched so doesn't injure self (e.g., careless smoking, leaving the stove on, falling)
1 2 3 4	Destructive of materials around self (e.g., breaks furniture, throws food trays, tears up magazines)
1 2 3 4	Shouts or yells
1 2 3 4	Accuses others of doing bodily harm to him or her or stealing possessions (when it is known the accusations are not true)
1 2 3 4	Is unaware of limitations imposed by illness
1 2 3 4	Becomes confused and is not oriented to place
1 2 3 4	Has trouble remembering
1 2 3 4	Has sudden changes of mood (e.g., gets upset, angry, or cries easily)
1 2 3 4	If left alone, wanders aimlessly during the day or needs to be restrained to prevent wandering
Scores range from 20 to 80; the higher the score, the greater the degree of dementia.	
Source: Moore, 1983.	



PHARMACOLOGIC AND MEDICAL MANAGEMENT

For successful treatment of Alzheimer's disease a partnership should be developed between the patient, caregiver(s), and the clinician. The current FDA-approved treatments can help improve or maintain the patient's cognitive and functional status. Caregivers and families can be helped by treatments that improve the behavioral and psychological symptoms of AD as well as non-pharmacological strategies that can help compensate for memory loss.

Drug Treatment

The goal for drug treatment is to help the remaining brain cells—even those that may be diseased—function more efficiently. The U.S. Food and Drug Administration has approved two types of medications for AD, cholinesterase inhibitors and a glutamate antagonist, to treat memory loss, confusion, and problems with thinking and reasoning.

CHOLINESTERASE INHIBITORS

Cholinesterase inhibitors prevent the breakdown of acetylcholine, a chemical messenger important for learning and memory. This allows for communication between nerve cells by keeping acetylcholine levels high. The three cholinesterase inhibitors approved for treatment of **early to moderate AD** are:

- Donepezil (generic & Aricept)
 - Rivastigmine (Exelon)
 - Galantamine (generic & Razadyne)
- (Budson & Solomon, 2016)

GLUTAMATE ANTAGONIST

The second type of medication is the glutamate antagonist memantine, approved for treatment of **moderate to severe AD**. Memantine regulates the activity of glutamate, a chemical messenger critically involved in the regulation of cognitive functions and memory. The drug also helps brain cells that use dopamine to function more efficiently. Memantine can delay worsening of symptoms for some people, but only temporarily. Memantine is prescribed to improve memory, attention, reason, language, and the ability to perform simple tasks.

- Memantine (generic & Namenda)
 - Memantine XR, Namenda XR
- (Alzheimer's Association, 2015g)

The cholinesterase inhibitor donepezil and glutamine antagonist memantine are often administered together and can significantly delay institutionalization in patients with AD.



Namzaric contains a combination of the two types of medications, memantine extended release and donepezil (Ross, 2014).

All of the medications may slow the progression of AD for a few months or even a few years, but they are not a cure. They may help some patients with activities of daily living (ADLs) and with behavioral symptoms such as delusions and agitation, and may even improve memory and speaking skills. However, physicians need to be realistic in explaining to the patient and the family the limitations of drug therapy.

Medical Management of Secondary Symptoms

Behavioral symptoms are common and can exacerbate cognitive and functional impairment. Thus, medical management of the patient with AD requires monitoring the secondary symptoms of AD, which can include:

- Depression
- Agitation
- Aggression
- Hallucinations
- Delusions
- Sleep disorders

The following classes of psychotropic medications have been used to treat these secondary symptoms:

Antidepressant medications for mood, irritability, and long-term management of anxiety:

- Citalopram (Celexa)
- Fluoxetine (Prozac)
- Paroxetine (Paxil)
- Sertraline (Zoloft)
- Trazodone (Desyrel)

Antipsychotic medications for hallucinations, delusions, aggression, agitation, and uncooperativeness:

- Aripiprazole (Abilify)
- Olanzapine (Zyprexa)
- Quetiapine (Seroquel)
- Risperidone (Risperdal)
- Ziprasidone (Geodon)
- Haloperidol (Haldol)



Antianxiety drugs for short-term management of anxiety, restlessness, verbally disruptive behavior, and resistance to treatment include:

- Lorazepam (Ativan)
- Oxazepam (Serax)

For sleep problems most physicians try to avoid prescribing any type of sleeping pills for older adults with dementia. Trazodone (Desyrel), an antidepressant that makes people sleepy, is commonly used as an alternative as well as anti-anxiety medications. Over-the-counter sleep medications should also be avoided (Alzheimer's Association, 2015h).

Managing Coexisting Health Problems

People with AD often have other health problems common to older adults, such as:

- Impaired hearing and vision
- Dental problems
- Hypertension
- Congestive heart failure
- Diabetes
- Hypothyroidism
- Genitourinary conditions
- Arthritis

Any of these conditions, alone or in combination, can further diminish the patient's ability to function. For example, people who do not see or hear well may be easily confused in unfamiliar situations. Couple those limitations with AD, and the confusion intensifies. Recognition and treatment of any and all coexisting conditions can help improve the patient's ability to function and quality of life.

IMPAIRED VISION AND HEARING

Impaired vision is not uncommon among older adults. It can diminish quality of life and sometimes lead to depression. Basic eye care services to detect and correct impaired vision can improve quality of life and increase a person's participation in activities, hobbies, and social interaction. Because people with AD may be unable to communicate about their visual impairment, it may go undetected.

Deterioration in a person's hearing may interfere with his conversational ability. Questions may be misinterpreted and answers may be inappropriate. Hearing impairment can also contribute to errors in judgment. If a person experiences buzzing in his ears because of excessive cerumen or other diseases, he may be under the impression that someone is talking to him. Some



improvement may occur with hearing aids, and an ear exam should be done to assess for excessive cerumen in the external canal.

DEPRESSION

Many older adults suffer from depression, and persons with AD are no exception. Unless treated, depression can further impair function. Antidepressants with limited anticholinergic side effects have been shown to be effective in treating depression in persons with dementia. Depressed persons with AD will also benefit from regular exercise. Effective treatment of the person's depression has a secondary benefit of reducing caregiver stress.

Management of Caregiver Burden

Caring for a person with dementia can be a heavy burden for family caregivers. Focusing on this burden is one aspect of management that must be considered along with management of the needs of the person with Alzheimer's. Families and caregivers want to provide the best they can for a relative with dementia, and the support they receive from healthcare providers can make a major difference in the quality of their lives and the quality of the care they provide.

Providers can offer assistance by putting caregivers in touch with local support groups and by referring them to resources that can enhance education and caregiving skills required as the disease progresses.

Management also includes assistance to patients and caregivers with nonmedical issues that will help to ensure that a patient's wishes for healthcare decisions are followed and that appropriate care is being provided. These may include:

- Planning for the future while the person still has legal capacity
 - Advance directives such as a living will
 - Durable power of attorney for healthcare decision making
 - Review of finances and power of attorney to manage income and assets
- Planning for changing care needs over the course of the disease
 - Maintaining a safe environment
 - Changes in behavior and communication
 - Maintaining nourishment and hydration
 - Bladder and bowel incontinence
 - Overall skin and body health
 - Preventing infections and pneumonia
 - Recognizing pain and illness



- Preferences for end-of-life care
 - Home
 - Residential care facility
 - Hospice care at home, in a hospital, or in a residential care facility
- Support for complying with mandated reporting requirements for driving impairment
- Determination of and reporting elder abuse

REHABILITATION FOR DEMENTIA PATIENTS

Because AD is a terminal disease, healthcare professionals have not traditionally considered persons with dementia to be appropriate candidates for restorative rehabilitation. In addition, Medicare did not provide coverage for Alzheimer's patients to receive physical, occupational, or speech-language pathology services if they did not show continuous improvement. In 2012 a proposed settlement to take effect in 2013 was reached as a result of a lawsuit that stated that these services are to be covered even when the goal is to maintain the patient's current condition rather than requiring that the patient show continuing improvement (Alzheimer's Association, 2012).

There are two main **goals of rehabilitation for persons** with dementia. First is to help maintain or improve function and engagement in daily activities to the extent possible as the disease progresses, and second is to provide caregivers the education and skills to create a supportive environment and to reduce disability.

Physical therapy, occupational therapy, and speech-language pathology services can be of great benefit to the person with dementia as well as family and caregivers. Both OT and PT can assist with making modifications to the environment that can help the person with dementia function at the highest possible level for as long as possible. (See also "Caring for the Person with AD" below.)

Occupational Therapy (OT)

Occupational therapists are concerned with five areas of human occupation when working with patients with dementia. These areas include:

- Activities of daily living (eating, hygiene, dressing, mobility, and sexual activity)
- Instrumental activities of daily living (care of others, household management, safety, maintenance)
- Rest and sleep
- Leisure
- Social participation



OT focuses on supporting the best functionality of the patient with dementia. OT looks at patient factors such as performance skills, performance patterns, work roles, previous interests and hobbies as well as current daily routines, taking into account the stage of dementia. The OT's most important role is finding the best fit between the environment, the demands of a task, and the cognitive ability of the patient (Fraker et al., 2014).

During the mid-stage of AD, the occupational therapist can provide guidance, education, and support for caregivers faced with challenging behaviors that often are present during bathing, dressing, toileting, and eating.

Physical Therapy (PT)

Physical therapists assess the person's risk for falls, the ability to walk safely, endurance, balance, and muscle strength. In the early and middle stages of AD, the focus of PT is on keeping people mobile and helping them continue to perform their roles in the home and community. In the later stages, PT can reduce the burden on family members and caregivers by helping the person maintain the ability to engage in activities of daily living for as long as possible.

A physical therapist's treatment plan would include physical activity that incorporates aerobic exercise, which has been shown to improve memory, delay AD onset, and in those who have AD, delay the decline in ability to perform ADLs (activities of daily living). The main goal of PT is to improve balance, muscle strength, and mobility in order to help the person maintain current physical abilities (Sponholz, 2015; Murphy et al., 2015).

Speech-Language Pathology (SLP)

The speech-language pathologist plays a major role in treating persons with dementia. SLPs manage cognitive, communication, and swallowing deficits that are associated with dementia. SLPs treat the cognitive aspects of communication, which includes attention, memory, sequencing, problem solving and executive functioning, and help with strategies that preserve these functions for as long as possible.

For persons with late-stage AD who are having problems swallowing, the SLP makes recommendations such as teaching compensatory strategies or altering the diet to prevent the risk of choking or aspiration pneumonia (ASHA, 2015).

CARING FOR THE PERSON WITH AD

The person with AD poses a number of challenges to the planning of care. Patient participation should be encouraged, but expectations should be aligned to the person's abilities. Goals should be planned without expectation of dramatic improvement.



Whether the person is at home or in an institution, **overall treatment goals** are the same: to maximize the person's functional abilities and quality of life and to provide competent, compassionate care that acknowledges and respects the person and family. Ideally, that care would be multidisciplinary, including medicine, nursing, social work, OT, PT, and SLP.

The **challenges of caring for someone with AD** include communicating effectively with the person; assisting with ADLs (activities of daily living) while helping maintain the person's independence; planning activities that will help maintain well-being and prevent boredom; and managing behavior problems such as agitation, wandering, and sleep disturbance. Meeting these challenges may become more difficult as the disease progresses.

Creating a Supportive Environment

A supportive environment includes both physical and social aspects that work together to support the unique needs and abilities of the person with dementia. A supportive and dementia-friendly environment helps people reach their full potential and does not cause needless dependency. This results in an improved quality of life for people with dementia, their family members, and caregivers (Department of Health, Victoria, Australia, 2014).

Some basic principles for creating and maintaining such an environment both in home and in a healthcare facility include:

Make change very slowly. Carefully prepare the person for any change in medications, nutrition, therapy, personnel, or location. Consistency in staff assignment has a calming effect on the person. The person should stay in the same room with the same roommate whenever possible.

Keep the person active as long as possible. Daily exercise, outdoors if possible, helps maintain physical and emotional function. Activities should be focused on making the person more comfortable and should be designed to allow him/her to use existing skills to perform familiar tasks. Avoid complexity in activities as this can create anxiety.

Maintain a routine. The person feels more secure when routines are established and followed closely.

Provide social stimulation without overload and encourage and maintain communication through every possible channel. Keep communications short and simple.

Give choice of activity and involvement. Provide different options for both indoor and outdoor activities in which the person takes either an active role or watches others.

Avoid crowds and large spaces without boundaries. Try to prevent sensory overload and provide boundaries and interior landmarks that are easily visible. This can be done using contrasting colors to demarcate boundaries.



Noise should be kept low and can be masked by the sound of music that was popular during the person's youth.

Older television shows can provide a familiar background and anchor the person in a period he or she can remember.

Monitor nutrition, attention to mouth and teeth, and footwear. Help with eating and oral hygiene to reduce the risk of infection. Comfortable, well-fitting shoes with nonslip soles help prevent falls.

Provide positive input. Praise and compliments for any achievement help maintain the person's self-esteem and encourage self-participation in activities of daily living.

Provide reality checkpoints, such as calendars with large days and dates, clocks with large numbers marking the hours, and reminders of special events such as birthdays, anniversaries, and holidays. Signage with figures illustrating the use of an area is helpful in orientation. The presence of personal items can help the person identify an unfamiliar room as his own.

Support bowel and bladder control. A consistent toileting routine helps preserve function and control. Use clothing with simple fasteners like Velcro or pants with elastic waistbands.

Assist with activities of daily living. The person frequently will have problems attending to basic hygiene and daily life activities. Drinking, eating, bathing, or dressing may require careful attention in order to avoid infections and eventual progression to a generally debilitated state.

Attend to the person's appearance. Keep the person clean and free from odors, dress him/her in his/her own clothes, and keep him/her well groomed. This is an aspect of care that is noticed by family members.

Closely attend to emerging symptoms and identify a person's problems before they become unmanageable. Keep in mind that the person is often unable to describe routine physical symptoms, even pain.

Support family caregivers. Commend their efforts, refer them to support groups, and assist them in creating a helping network. Families caring for a loved one at home need referrals to agencies offering respite care. Assist them in ways to understand and respond to a person's behavior and communication.

Offer information and referrals for legal matters, advance directives, end-of-life care, etc., which should be done at the time of diagnosis, while the person with Alzheimer's can still have a voice in the decisions made.



Communication Issues

As dementia progresses, the person's ability to communicate changes. These changes may include:

- Repetitious use of familiar words
- Inventing new words for familiar objects
- Losing train of thought
- Reverting back to native language
- Problems with organization of words
- Reduction in efforts to speak

Communicating with the person who has AD begins with patience, respect, and understanding. Remember that the person is not deliberately being difficult. Following are ways to communicate more effectively with someone with Alzheimer's:

- Make sure the person has his/her glasses and hearing aid.
- Reduce background noise and distractions.
- Identify oneself and call the person by name.
- Face the person, make eye contact, and speak directly in a calm, even tone.
- Speak clearly and slowly. Keep sentences simple; focus on one idea at a time.
- Use positive body language: relax, lean forward, and smile.
- Touch the person gently and reassure him/her.
- Do not offer too many choices.
- Pause often and get feedback; ask, "Is that okay?"
- Patiently wait for a response.
- Repeat your message as often as necessary.
- Write things down, if necessary.
- Make statements rather than asking questions (e.g., instead of asking if the person needs to go to the bathroom, say, "The bathroom is here.")
- Turn negatives into positives (e.g., instead of saying "Don't ...," say, "Let's do ...")
- Distract the person if he/she becomes anxious or agitated.
- Minimize questions, because they may make the person feel anxious or threatened.
- If the person does not understand, offer nonverbal cues, such as pointing, demonstrating the desired action (eating, drinking), or nodding.
- Do not talk to others about the person as if they were not present; even those unable to speak may still be able to hear and understand.



Nonverbal communication, especially touch, between caregivers and those with AD is also important. Permission should be sought before touching. Those who may be unable to respond verbally may respond to a smile, kind gesture, or caring touch. Or, for example, some persons may need reminders during a meal to begin or continue eating by placing the spoon in their hand.

Careful observation of the person's facial expressions, eye contact or lack of eye contact, and body language can help the caregiver assess comfort or pain, anger, hostility, and misunderstanding. For example, increased motor activity and shaking fists suggest frustration or anger. Experience and patience over time help caregivers gain skill interpreting these nonverbal signals.

Persons with AD may ask the same question repeatedly because they do not remember the answer given. Respond to the question, and then try to distract the person with an activity or a change of topic or a change of scene. Activities or events should not be discussed with the person until they are about to happen; otherwise, the person may retain the idea that something is going to happen but forget the details, triggering more questions.

Activities of Daily Living (ADLs)

During early Alzheimer's disease, a person will begin to demonstrate a lack of attention to personal hygiene and grooming. They soon forget to bathe, change clothes, or use the bathroom. To persons with AD, the tasks of daily living can be frustrating and overwhelming.

HABIT MEMORY

Habit memory outlives all other types of memory in AD because it is stored in an area of the brain unaffected until the late stage. One woman recalled her mother's deterioration from AD: "She finally quit smoking because she forgot to smoke, but she would pat her breast pocket (where she carried her cigarettes) and then go through the motions of smoking, holding up two fingers, putting them to her mouth, inhaling, and then blowing out, but without any cigarette." Habit memory enables persons in the early and mid-stages of AD to remain physically able to manage ADLs, but they may need reminders about hygiene and grooming.

Activities of daily living are actually quite complicated when broken down into steps. Brushing one's teeth, for example, requires recognition of the equipment used (toothbrush, toothpaste, sink) and remembering how to use each piece of equipment. In addition, the person must remember to find the equipment, put the toothpaste on the toothbrush, brush the teeth, and rinse the mouth.

Activity analysis (task breakdown) is useful to assist persons with AD to function on their own. This entails determining the manual and cognitive activities involved in the completion of a task (e.g., brushing the teeth) and organizing the task into manageable sections. **Verbal coaxing** allows the person to perform the activity, and when they complete tasks, the ability will be retained longer. **Providing cues** such as labeling, placing equipment and clothes out in view, and offering demonstrations are all useful.



Establishing and maintaining a routine in ADLs helps the person retain learned habits longer and therefore need less assistance. Once the routine becomes automatic, the person no longer needs to stop and think what to do next. A fixed routine for eating and toileting also reduces the incidence of incontinence.

BATHING AND DRESSING

Bathing can be a challenge because persons with AD may be frightened by showers. If it is not possible to offer a bath instead, using a shower bench with a hand-held shower may be less threatening. The bathroom should be prepared in advance, with water at the correct temperature, the room warm, and everything that will be needed at hand.

When approaching the person for bathing, one should explain what one is doing and will be doing next. Because being undressed can be embarrassing, only the part of the body being washed should be uncovered, leaving the rest covered with towels or bath blankets. During bathing, one can talk to and reassure the person. It may be helpful to make the experience more pleasant by playing relaxing music or using nice-smelling bathing products.

Many people with dementia do not like to have their hair washed at all; there are dry shampoo products available that can be used when this is an issue.

Inappropriate dressing may be one of the problems faced by caregivers. The person may no longer be able to coordinate colors, may put a shirt on backward, or may fasten buttons in the wrong order. Often persons will put on many layers of clothes or may want to remove clothing at inappropriate times.

Dressing can be simplified by offering one or two choices, or just laying out the garments to be worn. Labeling closet and dresser drawers may help the person locate certain clothing. If the person wants to wear the same clothes every day, duplicates can be made available while the other set is laundered. Many older persons, with or without AD, feel embarrassed when completely undressed, so removing and replacing one article of clothing at a time may work better. As AD progresses, the person may no longer be able to manipulate small buttons, hooks, or zippers. Adapting clothing with large zippers or Velcro closures make dressing easier. Pull-on skirts and pants are also easier for the person to use.

TOILETING

Caregivers need to understand that the person with AD may no longer respond to signals such as the urge to void or defecate. It is helpful to remind the person to use the bathroom frequently to empty the bladder. Setting up a regular schedule for toileting has proven effective in avoiding accidents. It is important to know that the person may forget where the bathroom is or may not recognize the toilet as the appropriate place to urinate. In this instance, the person will need to be taken by the hand and led to the bathroom, where cues can be provided to use the toilet.



Other ways to assist with toileting include:

- Make certain the path to the bathroom is clear with no obstacles.
- Learn to recognize signs that the person may need to use the toilet. These might include fidgeting, restlessness, or pulling at clothes.
- Make certain clothing is easy to unfasten and remove. Velcro fasteners are easier than zippers or buttons.
- Post a picture of a toilet on the bathroom door to help the person locate it.
- If incontinence occurs at night, avoid offering fluids for 2 to 3 hours before bedtime.
- If it is difficult to get to the toilet, a commode may be helpful.

(Alzheimer's Society, 2015)

Problems with bowel function usually do not arise until later in the disease. Constipation and fecal impaction can cause a great deal of discomfort and can lead to unwanted behavioral problems. It is extremely important for caregivers to continually assess and monitor the person's bowel function.

EATING

Eating habits and behaviors change during the course of AD and may be caused by physiologic or psychological factors. In early-stage AD, depression related to the diagnosis may result in anorexia and weight loss. Persons may forget to eat or refuse to eat. Confusion and agitation may lead to extreme eating behaviors such as gorging.

Physiologic factors affecting eating behaviors may include dental problems such as uncomfortable dentures, missing teeth, and/or periodontal (gum) disease. Neurofibrillary tangles and plaques can affect the function of the hypothalamus, which regulates appetite and hunger signals. Many persons with AD lose their sense of smell, which affects taste and appetite. Some medications can also affect appetite.

In addition to depression, other psychological factors that affect eating behaviors include new and unfamiliar environments, which create confusion and agitation; distractions such as loud noises; unappealing food; and unusual odors such as urine. Such factors are quite variable, since individuals progress through the stages of the illness at their own pace and in their own physiologic manner.

CASE

Mr. Florio often came to the nursing home on Sundays to take his wife out to lunch at a local restaurant. He observed that sometimes his wife would eat everything on her plate but at other times she would not eat anything at all.



A search was begun for an explanation, and Mr. Florio noted that when his wife faced the wall of the restaurant, she cleaned her plate, and when she faced the staff, other customers, or the cash register, she failed to eat at all. It became clear that the distractions offered by the busy restaurant produced her failure to eat.

DRIVING

Safe driving requires mental alertness, quick reflexes, and good judgment, all of which are eroded by AD, often before the person or the family is aware of the problem.

Once the diagnosis of AD is established, the physician needs to encourage the person to stop driving. Some persons do this willingly; others are reluctant to give up the independence that driving represents, thereby creating a significant threat to personal and public safety. This may pose a dilemma for caregivers, however it is generally accepted that those who refuse to quit driving even though they pose a hazard must be prevented from driving by other means, such as hiding the car keys or disabling the car.

Many states encourage physicians and other health professionals to report people with conditions that may affect their ability to drive safely. For instance, California has a public policy specifically requiring the reporting of individuals who have Alzheimer's disease. Other states with mandatory reporting of cognitively impaired persons include Oregon, Delaware, New Jersey, Nevada, and Pennsylvania. In Florida, any physician, person, or agency knowing of a licensed driver's (or applicant's) mental or physical disability to drive is authorized to report this to the Department of Highway Safety and Motor Vehicles.

Maintaining Nutritional Well-Being

Weight loss is common among persons with AD, regardless of quality of care. Wandering, restlessness, and agitation expend energy and interfere with food intake. In mid- and late-stage AD, persons are unable to feed themselves or to chew and swallow the food when it is placed in their mouths.

Those who are unable to swallow properly can become dehydrated and can aspirate food, leading to aspiration pneumonia. In the later stage of the illness, there is a profound memory loss that interferes with the recognition of food, the need to eat, and the mechanics of eating. In addition, the person may become resistant to being fed.

It is essential to maintain the nutritional well-being of the person with AD. Monitoring the person's nutritional status for weight loss and possible nutritional deficiencies should include:

- Oral assessment to check for denture problems, missing teeth, and gum problems, with referral for any treatment needed
- Review of medications to check for drugs, such as digoxin, that may affect appetite



- Assessment for vision problems that could cause confusion at mealtime
- Assessment for depression

The following steps can support the nutritional well-being of persons with dementia:

- **Reduce distractions.** Turn off the TV; avoid interruptions and social interactions during the meal to help the person remain focused.
- **Simplify eating.** Use bowls rather than plates and regular eating utensils rather than plastic utensils that may break in the person's mouth. Serve finger food such as fried chicken, French fries, cheese, small sandwiches, and fresh fruits if the person is having difficulty using utensils. An occupational therapist can offer guidance on what equipment may be appropriate and how to assist at mealtimes.
- **Allow sufficient time.** Problems with coordination can make eating slow. If the person feels hurried, the meal may be left unfinished.
- **Offer prompts and encourage drinking fluids throughout the day.** Dehydration can worsen confusion.
- **Assess the person's ability to successfully chew food.** Remind them to chew and show them how. Serve soft, chopped foods: scrambled eggs, cottage cheese, gelatin, mashed potatoes, and applesauce. Moisten meat or fish with sauces or gravy. Offer small bites, one at a time. A speech-language pathologist may be able to offer advice on strategies to help.
- **Provide snacks.** Ensure that nutritious snacks are available throughout the day and night.
- **Assess the person's ability to swallow food.** Remind them to swallow with each bite and show them how. Gently stroke the throat to promote swallowing. Avoid foods that are hard to chew or swallow, such as sticky foods, popcorn, nuts, and raw vegetables. Serve liquids at room temperature. Thicker liquids such as fruit nectars, milk shakes, and egg-nogs are easier to swallow and less likely to cause choking. It may be necessary to use thickening agents in liquids in order to avoid aspiration. It may also be helpful to request the services of a speech-language pathologist to assess the person's needs and make recommendations.

Providing Physical and Social Activities

Physical activity and social and cognitive stimulation can help maintain general well-being and prevent boredom and agitation in people with AD, especially in the early stage of the disease.

Persons with AD are capable of performing a variety of activities that fulfill their need to be active. These can include exercise and other gross motor activities, grooming, socialization, meal preparation, housework, crafts, light work, and special events.



Exercise can be utilized to avoid restlessness or agitation that a surplus of physical energy can cause. Walking in safe areas helps people sleep better at night. Someone who enjoyed dancing may still find pleasure in that activity.

Those living at home can help with household tasks appropriate to their abilities and interests. For example, a woman who is no longer able to cook a meal may be able to peel the potatoes, shell the peas, or set the table. Gardening or other hobbies, arts and crafts, or pets can all be enjoyable sources of stimulation.

Activities should be tailored to the individual's personality. Shy, introverted people should not be required to participate in group activities, whereas more outgoing individuals may be happiest in a group. Those who enjoy music, either as listeners or performers, can find pleasure in listening to the radio or to recorded music. Group sing-alongs may awaken pleasant memories of familiar songs.

People with AD who formerly liked to read may still like to leaf through magazines or books, especially those with interesting pictures. Television can be entertaining for some; for others, it can be frustrating and upsetting when they are no longer able to understand the story.

Simple games can provide enjoyment for people with AD, such as beanbag toss or other games with an obvious objective. Although the person with AD may regress to the level of a child, he or she should not be treated as a child. It is important to keep developmental level in mind when planning recreational activities.

Responding to Elder Abuse

Abuse of older adults is a well-kept secret in America. According to the National Council on Aging, hundreds of thousands of elders are abused, neglected, and exploited by family members and others. Many cases go unreported. Abuse may be physical, verbal/psychological, financial, sexual, neglect, or abandonment, and people with Alzheimer's disease or other cognitive impairment are at higher risk than other older adults.

Approximately 1 in 10 Americans aged 60 and older experience some form of elder abuse. It is estimated that only 1 in 14 cases of abuse are reported to authorities. In almost 90% of elder abuse and neglect incidents, the perpetrator is a family member. Two thirds are adult children or spouses (National Council on Aging, 2015). The overwhelming majority of victims of elder abuse are women. Neglect is the most common type of abuse, but the majority of victims of abandonment are men. Financial fraud, however, is the fastest-growing form of elder abuse.

Abused persons have considerable problems accepting the fact that someone they reared and nurtured is now abusing them. Many barriers exist that prevent elderly persons from asking for help. They may fear retaliation from the abuser. They may feel shame, guilt, and failure and may blame themselves for the abuse. Many stay in the situation for fear of the unknown. If they are institutionalized, they may fear that care will be withheld. In other situations, the abused elder may have grown up in an abusive environment and consider abuse to be normal behavior.



Abused elderly persons are likely to have special problems, such as incontinence, shouting, wandering, or symptoms of paranoid delusions. Some traits prevalent among elders might be stubbornness, hypercritical attitudes, and somatization (psychological distress expressed as physical symptoms). These may represent attempts by the person to deal with a new dependency role and can be irritating to caregivers, thus prompting abuse.

RECOGNIZING ELDER ABUSE

Signs of abuse include bruises in different stages of healing, fractures that have not been properly set, and lack of explanation for falls and injuries. Rope burns, which are commonly found around the wrist or ankles, can arise from the use of crude restraints. Other skin wounds may include cigarette burns, human bites, and lacerations. Welts may indicate use of belts or other objects for punishment. Food and fluid deprivation that result in malnutrition and dehydration are more subtle forms of elder abuse. Physical signs of neglect include severe weight loss, dehydration, poor personal hygiene, and pressure ulcers (bedsores).

Signs of emotional or psychological abuse can include sleep problems, anxiety, being kept isolated from others, or avoidance of the caregiver/abuser to touch or comfort the person. No single indicator can be taken as conclusive proof, but patterns or clusters of indicators can suggest a problem that should be investigated.

CAREGIVERS AND ELDER ABUSE

The responsibilities and demands of caregiving increase as the older person's condition deteriorates. Caring for a person with AD can lead to stress, depression, feelings of isolation, financial worries, substance abuse, and the perception that taking care of the elder is burdensome and without reward. Any or all of these can lead to the inability to keep from lashing out against the person in their care. Violent behavior by the person may also lead to physical abuse by the caregiver.

Respite care for the person and support group and counseling for the caregiver can help to prevent elder abuse. In severe cases of abuse, it is usually necessary to separate the person from the caregiver, initiate legal action, and find a safe facility for the person.

CASE

Mr. Moustaffa, a 72-year-old widower who lives alone, was being seen in the dementia assessment unit after referrals by a concerned neighbor. The patient was found to be suffering from early dementia, but much of his conversation made perfect sense. He repeatedly reported that his children "are ripping me off." Per agency protocol, the unit social worker visited Mr. Moustaffa in his home to further assess his living situation.

During her visit, the social worker found that the Mr. Moustaffa had written several checks for groceries in the past month, some amounting to \$200, but there was no food in the house. She learned that since Mr. Moustaffa was no longer able to drive, his son and daughter-in-law now



did all the shopping for him and that they gave him only a fraction of the groceries he was paying for and used the rest themselves. This information was used to assist in approaching the son and daughter-in-law with the concern of elder financial abuse.

BEHAVIOR MANAGEMENT

Behavioral symptoms of Alzheimer's disease include agitation and restlessness, vocal outbursts, wandering, sleep disturbances, “sundowning,” and inappropriate sexual activities. Although medications are available to treat these disorders—antidepressants, antipsychotic drugs, and sedatives—all have side effects and may interact with other medications, and most show limited efficacy.

Difficult behaviors usually are time-limited, and as the disease progresses, they often disappear. When they arise, however, they demand special attention.

Managing difficult behaviors effectively calls for special intervention training and education for staff and caregivers. Such training can help providers identify and anticipate problem behaviors and learn diversionary strategies to manage these behaviors. Gaining competence consequently builds confidence in caregivers and enhances the quality of life for people with AD. Inadequate training can result in overmedication of a person, inappropriate use of restraints, physically combative behavior, or isolation of the person. Healthcare providers and caregivers may also suffer stress and burnout.

Behavioral problems are major reasons why family caregivers decide to seek long-term care for their loved one. The staff can gain valuable insights from the family into the person's behavioral history, which will aid in planning effective interventions. Together with psychological and medical evaluations, this behavioral history can alert staff to important triggers for behavioral problems.

In many settings, the social needs of persons are unmet, which creates frustration and boredom. This can precipitate challenging behavioral symptoms. Studies have shown that meeting the social needs of people with dementia is very important for improving and reducing behavioral symptoms such as agitation, restlessness, and aggression. Social interaction involving babies and pets has been found to be the most stimulating and engaging (Ballard, 2015).

TRIGGERS AND DIFFICULT BEHAVIORS

The problem-solving approach to difficult behaviors requires a clear definition of the problem and the identification of precipitating and aggravating factors. This approach may lead to specific interventions for change.

Determining what triggers and reinforces a person's problem behavior involves discovering antecedents, describing the behavior, and determining what reinforcing consequences there are for it. What happens just before a behavior is an antecedent of the behavior. Every behavior—



positive or negative—is triggered by something. If the behavior continues or gets stronger, something that comes after the behavior—that is, some consequence of the behavior—is reinforcing it.

It is important to recognize that no behavior is triggered and reinforced only by internal factors or only by external factors. Caregivers can have a direct, immediate effect on many external influences, thereby influencing external triggering antecedents and reinforcing consequences of a person's problem behavior. By doing this, they can help reduce or even eliminate a problem behavior.

Agitation and Restlessness

Agitation is a state of extreme irritability often characterized by hitting, pacing, yelling, or restiveness. This can be caused by medications, physical discomfort, anxiety, fatigue, sleep loss, insecurity, sensory overload, sensory deprivation, or sensory distortions. Agitation may also result from impatience or irritability on the part of the caregiver.

An agitated person requires an assessment of any physical cause of discomfort or pain. This can include fecal impaction, localized or systemic infection, dehydration, urinary retention, osteoarthritis, or fractures. The person may be hungry or thirsty or may be suffering from inadequate sleep. The environment should be assessed for the presence of any irritants and level of sensory stimulation. Observe the person while performing activities of daily living to identify contributing factors. Assess caregivers' stress levels and provide teaching about how their own emotional state affects their patients or loved ones.

Speaking softly and calmly, the caregiver can gently and quietly take control of the situation. Ask the person with AD if he or she needs to use the bathroom. If not, try to determine what the person needs: an extra blanket, a drink of water, food, or a hug.

Another approach to the problem of agitation is the three Rs: **repeat**, **reassure**, and **redirect**. Using this approach, the caregiver repeats an instruction or answer to a question, reassures, and redirects the person to a different activity to divert attention from the problem.

Aggression and Combativeness

Aggression in the person with AD is relatively rare. It can be an isolated event, or it may occur regularly in some individuals. Aggression may reflect long-standing personality traits, or it may be totally out of character for the person. Aggression may be an extension of the sort of agitated behavior described above that has not been adequately addressed and has been allowed to escalate. For instance, physical aggression may result when a person is no longer able to express frustrations verbally.

Aggressive persons should be approached in a calm, gentle manner. All activities should be explained. Avoid situations known to provoke combative episodes. Distraction can be effective



in breaking the cycle of escalating aggression. The environment should be assessed for harmful objects, which should be removed. Medications may be used to interrupt escalation.

CASE

Mr. Hopkins is a 72-year-old who was admitted to the nursing home three months ago because of his family's inability to care for him at home any longer. He had been diagnosed with Alzheimer's six years earlier. Each Sunday he became quite happy during visits from his family, but each time the family got ready to leave, Mr. Hopkins would become more agitated, follow them to the door, and attempt to leave with them. When staff tried to lead him back inside, he would become belligerent and combative. This behavior often resulted in his receiving a medication, which made him drowsy. At one point, a staff member was injured when she fell while trying to avoid Mr. Hopkins' attempt to strike her.

Staff and family discussed his behavior and determined that Mr. Hopkins' agitation may be due to feelings of abandonment. They devised a care plan in which the family would inform the staff 15 minutes before their intended time of departure from visits. The family planned to leave a small memento with Mr. Hopkins at each visit, and a staff member would then begin discussing the memento with him, encouraging some reminiscing. The family would say a quiet good-bye, and Mr. Hopkins would not be allowed to walk them to the door. The staff member would remain with him in his room for approximately 10 minutes after their departure.

This intervention appeared to distract Mr. Hopkins from his feelings of abandonment without changing the nature of family visits. There were no further incidents of combative behavior.

Catastrophic Reactions

Catastrophic reactions are disproportionate responses to seemingly insignificant stimuli. These responses may be uncontrollable crying, extreme agitation, screaming, or combativeness. These reactions occur in response to the person's inability to handle a multitude of incoming stimuli. The person has decreased capacity to control emotional responses.

Prevention should be part of the care plan for any person prone to such behavior. Avoid situations and circumstances known to trigger these reactions. Simplify the environment and tasks demanded of the person. Distraction is most useful if the reaction is already in progress. Involvement in music- or food-related activities is often successful. It is important not to overreact to the person as this will only increase the possibility of escalation of the response.

Vocal Outbursts

Disruptive vocal outbursts—screaming, swearing, crying, shouting, negative comments to staff and/or other persons, self-talk—become increasingly common as AD progresses, confusion increases, and the ability to communicate is lost. Men generally display more aggressive vocalizations, such as swearing, while women typically exhibit more agitated vocalizations, such



as crying or complaining. Until these behaviors diminish in the final stages of the disease, they present an ongoing challenge to caregivers.

Caregivers need to remember that the person is not deliberately misbehaving; these are not temper tantrums. Remarks or attacks should not be taken personally, nor should attempts be made to try to reason with the person. Instead of focusing on the problem, caregivers need to acknowledge that the dementia is causing the problems.

Experienced caregivers often can anticipate outbursts and intervene to prevent them. Signs of an impending outburst vary from person to person, but such events are often preceded by restlessness, refusals, and blushing. Emotional triggers can include fear, anger, depression, grief, confusion, helplessness, loneliness, sadness, impatience, and frustration. Environmental factors such as poor lighting, seasonal changes, over-stimulation or lack of stimulation, loud noises, or excessive heat can also trigger outbursts.

Outbursts may also signal physical illness or discomfort, including pain, hunger, thirst, incontinence, constipation, infection, or fatigue. Once the outburst has subsided, a thorough physical assessment may reveal the underlying physical problem, which can then be remedied.

Managing outbursts triggered by environmental or physical factors is simpler than dealing with outbursts that stem from an unknown emotional or psychological cause. With training and experience, however, caregivers can better manage and even prevent vocal outbursts. Interventions begin with taking the person to a quiet room or taking a walk. Distractions can involve:

- Prompting the person to reminisce
- Engaging the person in group activities such as games, singing, or listening to music
- Carefully using touch, massage, hugging, or holding hands
- Giving the person something to hold, such as a soft doll or a stuffed animal
- Showing movies or interactive videos such as sing-alongs
- Using headphones to listen to soothing sounds such as mountain brooks or the ocean
- Playing audios of the spouse or other family members recalling happy times together

The techniques listed above are most effective as prevention measures. Once an outburst occurs, distraction is necessary to disconnect the person from the problem. Otherwise, there is a risk of reinforcing inappropriate behaviors, which may result in more frequent outbursts.

CASE

Mrs. Goh is a 78-year-old woman with AD who has been living in a nursing home for the past four years. She is known to have had a stroke resulting in expressive aphasia early in the disease process. Mr. Goh visits his wife daily at mealtimes and feeds her. He also reads to her while holding her hand until she falls asleep.



On his way to visit one day, Mr. Goh was involved in an accident and sustained a hip fracture. He was in the hospital for three weeks and then sent to a rehabilitation unit for short-term physical and occupational therapy. When Mrs. Goh was told about her husband's accident, her condition began to decline. She became bedridden and uninvolved with any activities of daily living. She also began yelling and screaming for extended periods of time. This behavior has become very disruptive to everyone. As her condition worsened, Mrs. Goh was moved to a semiprivate room in the front of the building. Her yelling is now audible to anyone entering the building.

The treatment team met to devise a plan of care. Their first step was a thorough assessment, with the following conclusions:

- Mrs. Goh's current method of communication is screaming.
- She is reacting to the loss of her husband's visits and other physical and social losses.
- She has discovered that screaming brings attention.
- By screaming she is able to exert some control over her life.
- The screaming occurs in the late afternoon, when she needs to use the toilet, or when she is overly fatigued.
- Previous tactics to control Mrs. Goh's screaming have been ineffective.

After completing the assessment, the following plan was developed and implemented:

- No more changes are to be made in Mrs. Goh's environment.
- Routines are to be established with Mrs. Goh's input, and the same caregivers will provide her care on a daily basis to establish consistency in her life.
- The activities director will work with Mrs. Goh to add new activities to her daily life.
- Arrangements are to be made for consistent volunteers to visit Mrs. Goh on a daily basis, attempting to establish a routine similar to her husband's.
- Mrs. Goh will be given a bell to ring if she needs something. Otherwise, she will be checked on every two hours.
- Caregivers will be instructed to respond quickly to the bell but not to her screaming.

After two months, Mrs. Goh began using the bell to call for assistance. She yells out occasionally, but this tends to occur when unavoidable changes are made in her routines.



Wandering

Wandering is a major behavior problem in persons with AD, more so than in persons with other types of dementias. For that reason, all persons diagnosed with AD should be registered in the **MedicAlert + Alzheimer's Association Safe Return** program, which is a nationwide emergency response service for individuals with Alzheimer's or a related dementia. Registration includes an identification bracelet that should be worn at all times. (See "Resources" at the end of this course.)

Agitation, restlessness, and sleep disturbances all lead to wandering, particularly at night, increasing the risk of injury to the person and others. Wandering is generally one of two types: goal-directed, in which the person attempts to reach an impossible goal such as going home or going to the store; and non-goal-directed, in which the person wanders aimlessly. Wandering patterns include:

- Moving to a specific location
- Lapping or circling along a path or track
- Pacing back and forth
- Wandering at random

Confusion and failing memory can lead to wandering because the person is unable to keep a clear destination in mind. Wandering may also represent a search for social interaction when the person can no longer communicate verbally. Unable to sleep, the person walks to keep busy or to find a loved one. Wandering in the late afternoon or early evening may be triggered by a fading memory of leaving work to go home.

Wandering may also be caused by a physical need, such as toileting. Caregivers can use large-print signs to mark destinations with a drawing of the activity. Placing a photo of the person as a younger adult on the room door may help a wanderer find "home."

Wanderers are more likely to have delusions and hallucinations. Medications used to treat these symptoms are aripiprazole (Abilify), haloperidol (Haldol), and risperidone (Risperdal). Severe depression is also a feature in the person who wanders, and this can be treated with antidepressants. Men are more likely to wander than women, and wandering often increases as AD progresses.

There are a number of technologies that can help keep wanderers safe. These devices mainly use **GPS tracking** and range from bracelets to normal looking tennis shoes with GPS chips embedded in them. These are effective only in areas with good cellphone coverage and in tandem with an attentive human monitoring the devices.

Doors leading to the outside in the home or residential facility should be kept locked. Often, simply changing to a new type of lock that the person is not familiar with can solve the problem. If this step does not work, deadbolt locks requiring keys should be installed. Regular door handles can be replaced with child-proof models that require a combination of actions to turn the



handle. It is important to recognize that one of the dangers of this approach is fire. Information and specific suggestions can be obtained from the local fire marshal.

To prevent wandering outside the home or a facility, caregivers can conceal or camouflage doors by:

- Placing a Velcro cloth strip or panel across doors
- Painting doorknobs the same color as doors
- Installing grid patterns on floors in front of doors
- Painting a door to look like a piece of furniture

All doors for staff-only should be the same color as the wall, while doors the person is expected to find and use should contrast with walls.

Safety locks, alarm systems, and personal monitoring devices can also help control persistent wanderers. Caregivers should use the least-restrictive methods possible to reduce, redirect, or prevent wandering. Interventions for goal-directed wandering involve distracting the person. A calm, gentle, and respectful approach helps to establish trust.

The family can help caregivers identify and anticipate wandering in the newly admitted resident. Staff needs to learn as much as possible about the resident's lifestyle prior to diagnosis with AD: what kind of work the person did, previous patterns of exercise, stress, and response to touch. Once a wanderer is identified, the facility can have photographs made and distributed to other units and assign special clothing or identification bands.

To prevent a person who seems at risk of wandering, approach the person from the front and use simple commands to change direction, if necessary, and guide the wanderer away from the exit. Diversions such as listening to music, looking at pictures, or exercising may be effective. Caregivers should avoid negative or harsh commands such as "Don't go out there!" and should not argue with the person.

Wandering in a safe area can be good exercise for the person with AD and helps manage non-goal-directed wandering. Many facilities are designed with these safe areas in the form of sheltered courts, gardens, lounges, or pathways.

SILVER ALERTS

Legislation has been introduced in Congress to establish a nationwide "Silver Alert" program for missing seniors, especially for those with dementia, and many states have already established such programs. These Silver Alert programs use a wide array of media outlets such as commercial radio and television stations and cable TV to broadcast the name and description of the missing person as well as the missing person's vehicle description and license plate number. Many states also use variable-message signs on roadways to alert motorists to watch for missing seniors. Silver alerts have also employed reverse 911 or other emergency



notification systems to contact residents of the neighborhood surrounding a missing senior's last known location.

Source: American Silver Alert Coalition, 2011.

Sleep Disturbances and “Sundowning”

Persons with AD often have disturbed sleep patterns due to medications, sleep apnea, and disruption in their biorhythms. Some persons are awake during the nighttime hours and sleep during the day. Others sleep fitfully for very brief periods, giving the appearance of being constantly awake.

Exercise and physical activity, such as walking during the day, help persons sleep better at night. The activities should be as vigorous as possible within the limitations of each person and should be done no later than four hours before bedtime. Those who are bedfast can still benefit from passive exercise.

Daytime napping can interfere with sleep at night. Napping may signal boredom or depression and the need for more stimulating daytime activity. Limiting fluid intake during the evening will reduce the need to urinate at night.

“**Sundowning**” refers to the phenomenon in which the person is more confused during the late afternoon and early hours. The person becomes more agitated, confused, and restless during these hours. This state may be caused by an alteration in the circadian rhythm, fatigue resulting in a reduced ability to tolerate stressful situations, or increasing confusion due to darkness and shadows. It can be of benefit to keep the home well lit in the evening, and to limit environmental distractions particularly during the evening hours.

CASE

Mrs. Perlman is a 72-year-old widow who moved in with her daughter Jeanne about six months after being hospitalized with pneumonia. She was diagnosed with Alzheimer's eight years ago and is now in the middle stage of the disease. Her level of confusion and disorientation increased when she entered the hospital, and her condition has remained the same since then.

Jeanne has gone to a local Alzheimer's support group since her mother has moved in with her, and she asked for help because her mother becomes “like another person after supper.” She says her mother does not recognize her, is disruptive, and that nothing seems to calm her down until she falls asleep. Mrs. Perlman is always much better in the morning.

The group asks questions to discover what can be done to help Jeanne with the problem of “sundowning.” They ask how a typical day goes, and Jeanne says her mother does not have an opportunity for a nap in the early afternoon, but she sleeps well at night. She says her mother is very hungry at suppertime, and since the fall daylight savings time change, her behavior has become worse.



Together they devised some methods to help Jeanne deal with her mother's behavior.

- To avoid extreme fatigue, Jeanne has her mother take a one-hour nap at 1 p.m. and doesn't allow her to sleep too long, as that could interfere with her sleep at night.
- To help relieve Mrs. Perlman's hunger and possible low glucose level, Jeanne gives her mother a high-carbohydrate snack at 4 p.m.
- To maintain the same level of light in the house, Jeanne turns on all the lights two hours before sundown. She closes the curtains one hour before sundown so her mother might not notice the changing light level outside
- Jeanne attempts to engage her mother in a quiet activity immediately after supper.

Two months later, Jeanne reports back to the support group that although her mother still has some increased confusion at nighttime, the frequency and degree of confusion and disruption has decreased significantly.

Repetitious Behaviors

Repetitious behaviors are those that occur on a continuous basis and generally serve no functional purpose. Mostly, these behaviors are tolerable, but they can become very annoying and may cause a great deal of frustration for caregivers. Examples of repetitious behaviors frequently encountered are questioning, following the caregiver, or performing one task over and over again.

Such behaviors are often the result of memory loss in the later stages of the disease. The person is unable to remember completing a task or receiving an answer to a question. Following a caregiver continually may be a sign of the person's insecurity.

People with dementia are often seeking something comfortable and familiar, something they feel they have some degree of control over. If the repetition is an action, turning it into an activity that makes the person feel useful, such as folding washcloths, sorting socks, or cleaning objects, may be helpful.

All behaviors have meaning. Repetitious activity often has a basis in the person's past, such as work. A man who picks up the chairs, places them upside down onto a table, and wiggles their legs may be demonstrating a behavior required in his work as a furniture maker or carpenter. A woman who worked in an office all her life may pace and exhibit restlessness. Simple measures such as dressing her in business attire and providing her with a small desk may prove to be a calming and reassuring activity.

Inappropriate Sexual Behaviors

Inappropriate sexual behaviors can be defined as being dysfunctional; serving no useful, healthy purpose; and not fitting within the setting or environment. These behaviors may include



masturbation, undressing, and sexual touching in public. Usually, however, behaviors of a sexual nature are seen as inappropriate because they bother or embarrass the caregiver.

Because of dementia, many persons lose the ability to determine whether the time, place, or way to express sexual needs is appropriate or not. These behaviors may be the only available mechanism for gratifying the person's basic sexual needs. Acts of sexual disinhibition result from damage mainly in the frontal and temporal lobes of the brain, disrupting the person's ability to control behaviors. Using distraction and redirection toward positive topics or activities is one way to interrupt such behaviors

It happens that persons with dementia may exhibit sexually aggressive behaviors, which may include fondling, exposing genitals, or attempting to have sex acts with people other than their partners. This behavior may be directed toward their own children, professional caregivers, or others because of the person's inability to recognize the individual is not their partner.

It is important that families be encouraged to hold hands, touch, and kiss the person as they always have. Recognizing the person's unmet needs is important in understanding abnormal behaviors. Providing a relaxing massage or going for a walk and holding the person's hand provides therapeutic touch that so many institutionalized older people need.

Persons who masturbate in public places should be gently led from the public area to their room. Do not scold or try to get them to understand the inappropriateness of their behavior, as that will only increase their negative feelings and agitation.

Every attempt should be made to determine whether the person is suffering from pruritus, an infection, or a chronic stress condition. Assess behaviors for any antecedent causes such as a visit from the family. If persons have truly problematic sexual behaviors such as touching visitors or staff persons intimately following a family visit, for instance, visitation should take place in the person's room, and once the family leaves, the person should immediately be involved in some activity.

Undressing in public may be due to physical factors such as being too warm or frustration about trying to remember how to dress and undress. Specially designed clothing that closes in the back makes disrobing difficult in inappropriate settings.

Because of the embarrassment and negative feelings about these behaviors, family members and caregivers must be given an opportunity to talk about their feelings.

CARING FOR THE CAREGIVERS

Family members provided an estimated 17.9 billion hours of unpaid work valued at \$217.7 billion in 2014. Over half of primary caregivers of people with dementia are taking care of parents, and 41% have a household income of \$50,000 or less. Approximately two thirds of caregivers are women, and 34% of them are 65 and older.



Nearly 60% of dementia caregivers rate their emotional stress at high or very high levels. About 40% of them have depression, and due to the physical and emotional toll, caregivers had \$9.7 billion additional healthcare costs of their own in 2014 (Alzheimer's Association, 2015a).

The Effects on Caregivers

Caregivers are often referred to as hidden victims because they commonly experience more psychological and health problems than those who are not caregivers. It is common for families to experience denial, depression, anxiety, anger, and guilt before and after the diagnosis is made. They may have unrealistic expectations, such as the diagnosis being incorrect or that the person can be cured. The caregivers may be confused because the person's condition may appear to improve at times before it worsens.

Family must come to terms with the realization that the person with AD has a terminal illness, that they will lose the relationship with the person as he or she was known, and that roles within the family will change.

Alzheimer's disease exacts a heavy toll on the family, especially the primary caregiver, usually a spouse or a daughter. Even though the family member willingly assumes the role of caregiver, the physical and emotional energy required can exhaust the most devoted individual. Over half of primary caregivers of people with dementia take care of parents. If an adult daughter or son is the caregiver, he or she often joins the "sandwich generation," caught between an elderly parent's needs and the demands of career and family at home.

As AD progresses, the physical energy required to care for the increasingly dependent family member may deplete the caregiver's capacity. By mid-stage AD, the person needs help with bathing, dressing, and a host of other activities. According to the Alzheimer's Association, 45% of caregivers report not getting enough sleep.

Hospitalization rates are high for caregivers who report physical and mental strains on their health. Physical demands include difficulties in feeding, inconsistency in the person's sleep patterns, coping with wandering behavior, and cleaning up the results of urinary and fecal incontinence. The mental strains reported most often are financial problems, lack of support, and no personal time.

Caregivers often lack social contact and support. They experience feelings of being isolated. Many give up their usual leisure activities and hobbies and often restrict time spent with friends and family. Many must give up or reduce employment. Those caregivers with more satisfying social interactions have been shown to have fewer negative psychological symptoms (Jones, 2014).

The lives of the caregiver and the person with AD are inextricably linked in a long, painful dance toward death. When the caregiver's quality of life suffers, it affects the quality of care for the person with AD. Without help and support from family, friends, health professionals, and community resources, caregivers are at great risk for:



- Emotional distress, such as depression and anxiety
- Fatigue and sleep deprivation
- Social isolation, when relatives and friends stop calling or visiting
- Family conflict
- Substance abuse

Helping Family Caregivers

Just as education and training for staff can improve care and quality of life for persons with AD, **educational interventions** for family members can make a positive difference in the caregivers' ability to cope with their difficult task.

The following are steps that can be taken by professionals to assist families involved in the care of an individual with dementia:

- Understand the family network, which includes identifying the major decision maker, the financial resources, and major concerns.
- Provide accurate information and educate the family about the disease process.
- Leave avenues open for follow up, as families often are overwhelmed.
- Offer Alzheimer's Association, National Institute on Aging, or other pamphlets and booklets to amplify and reinforce information.
- Explain the importance of support groups, friends, and religious organizations to avoid isolation.
- Assist the family in obtaining respite care at home, at a daycare center, or in a nursing home.
- Assist families who are dealing poorly with the increased demands to obtain counseling or psychological therapy and to identify specific stressors and potential solutions.

Educating caregivers and the general public about the **need for respite** best begins early in the caregiving experience in order to prevent burnout and other adverse effects. In the next decade, policies on long-term services and supports will require that a great deal of attention be paid to family caregivers and the direct-care workforce. It is likely there will not be a sufficient number of direct-care workers to replace unpaid caregivers in the future. It is imperative that policies be put in place to strengthen caregivers' abilities to give care and to support their own emotional, physical, and financial needs in the process (Rose et al., 2015).



ETHICAL AND END-OF-LIFE CONSIDERATIONS

Alzheimer's disease raises a host of ethical issues. There are three guiding ethical principles commonly applied in patient care:

1. **Beneficence:** The obligation to do good, preserve life, and prevent harm and suffering
2. **Respect:** The obligation to preserve and promote the autonomy and dignity of the person
3. **Equity:** The obligation to give treatment that is fairly and equitably distributed among individuals

The obligation to evaluate and treat physical illness is not diminished by the person's age or mental state. Ethical principles ensure a person's right to adequate treatment for preservation of life or prevention of suffering

Decision Making

It is not uncommon for caregivers to behave paternalistically toward the person with dementia. Persons with dementia should be given every opportunity to play a role in decision making, even if only about minor aspects of their environment. Some persons are capable of making many decisions, and others, none. This requires a constant individualized assessment done periodically to ascertain level of competence. Respecting the decision-making capacity of each person helps prevent steadily increasing dependence.

Individuals are presumed capable of acting in their own best interest, and a normal person has the legal and moral right to choose and refuse. It is this major right to make such choices that is at issue in Alzheimer's disease.

It is imperative that decision making and preferences about medical treatment should begin early in the disease process through execution of advance directives. In the absence of an advance directive, the surrogate should be guided by the values and expressed wishes of the person with AD.

LIFE-EXTENDING TREATMENT

Families and clinicians may have difficulty seeing dementia as a condition that causes death. Most view the cause of death, often pneumonia or urinary tract infection, as unrelated to the dementia. Advanced dementia, however, should be considered a terminal illness, and the goals of treatment should be to reduce physical discomfort and maintain well-being. The side effect of such treatment may be that life is prolonged. The focus then should shift from quality of life to quality of death (Arcand, 2015).

Ethical dilemmas often occur when decisions are being made regarding end-of-life issues such as withholding treatment and "letting nature take its course." The person's wishes, if known and expressed while still competent, should be considered. Persons have the right to refuse life-



extending treatment, and incompetence does not diminish that right. When a person with AD, family, and caregiver cannot agree on these matters, the decisions must be left to the courts.

The question of what type and degree of life support should be given is a difficult one since loss of intellect often is equated with loss of humanness. Ethically, the minimum requirement should be that the person be kept clean, adequately hydrated and nourished, and as free of pain and discomfort as possible.

The issue of physician-assisted suicide and active euthanasia was addressed in a 2014 Gallup Poll and revealed that nearly 69% of Americans believe that physicians should be allowed by law to end the life of a person who has a disease that cannot be cured “by some painless means if the patient and his or her family request. Strong majorities have supported this for more than 20 years” (Richard, 2015). The question remains under debate as to whether or not acts of withholding treatment (passive euthanasia) that allow a patient to die are morally different from active euthanasia. Increasingly, however, there is public pressure for a system that ensures a patient’s “right to die well.”

ARTIFICIAL NUTRITION AND HYDRATION (ANH)

In the late stages of AD, persons may become unable to consume sufficient oral feedings to prevent weight loss. If the person’s advance directive (see below) indicates that he or she does not want artificial nutrition and hydration (ANH), caregivers must respect that decision. However, if the decision was not made earlier, this is the time when the person’s surrogate (also called a proxy) decision maker, with the physician and other members of the healthcare team, must decide together whether to initiate tube feedings.

Deciding to initiate ANH means weighing the potential benefit and burden to the person. The physician and care providers need to help families understand that forgoing ANH is not “killing” or “starving” the person.

The Ethics Advisory Panel of the Alzheimer’s Association (2011) recommends assisted oral feeding coupled with hospice care, when needed, as the compassionate alternative to tube feeding. This recommendation is based on several studies that point out that tube feeding:

- Blocks the release of endorphins (cessation of food intake results in the release of endorphins, which reduces pain)
- Can result in backup to the esophagus, increasing the risk of aspiration pneumonia
- Is associated with increased diarrhea and related discomforts
- Results in increased use of physical restraints to prevent persons from pulling tubes out
- Does not usually improve nutritional status
- Does not lower the incidence of aspiration pneumonia or skin breakdown
- Does not improve longevity



- Denies the person the gratification of tasting preferred foods
- Increases pressure ulcer risk
(DeMarco, 2015)

The Alzheimer's Association (2011) emphasizes that "assisted oral feeding should be available to all persons with advanced Alzheimer's as needed. Neglect in this area should not be tolerated, and concerted efforts are called for to educate and support professional and family caregivers in techniques of assisted oral feeding."

Eventually, the ability to swallow is lost, at which time the person is considered terminal. The natural process of dying means the body no longer wants or needs food or fluid. This is often viewed as unnatural by caregivers and even some healthcare professionals. Families and healthcare professionals must understand that no longer eating or drinking is part of the dying process and is normal. Because some in our culture may treat dying as unnatural, they may turn to technology to prolong the process.

Legal Documents

Getting legal affairs in order—drawing up **advance directives, powers of attorney, wills, or trusts**—should be done as soon as possible after diagnosis, while the person is able to express personal wishes and participate in decisions. Referral to the local chapter of the Alzheimer's Association can help families find attorneys who specialize in elder law or estate planning.

This referral should not be made abruptly but as a suggestion, emphasizing that every adult, regardless of health status, should make such a plan. This helps ensure that one's wishes are respected in end-of-life care and disposition of property after death. Otherwise, families will need to make difficult decisions without knowing the person's wishes.

ADVANCE DIRECTIVES

Decisions surrounding the withholding or withdrawing of care are often complex. Further, a peaceful death is no longer easy to achieve. In 1991, the Patient Self-Determination Act went into effect requiring all healthcare institutions receiving Medicare or Medicaid funding to ask persons if they have advance directives.

An advance directive specifies a person's preferences for care in the event that he or she is unable to communicate those wishes—for example, in the advanced stages of AD. A **living will** is one type of advance directive. In an advance directive, the person can also name a representative to see that his/ her wishes concerning care are carried out. This is sometimes called a **durable power of attorney for healthcare** or **medical power of attorney**.

Physicians should have copies of advance directives available or be able to refer families to a source for the appropriate forms. Federal law requires hospitals to inform patients that they have a right to complete an advance directive, but advance directives are regulated by state law and



may differ from state to state. (The Family Caregiver Alliance provides more information; *see “Resources” at the end of this course.*)

CPR VERSUS DNR ORDERS

Another type of advance directive is a **do-not-resuscitate order (DNR or DNRO)**, which informs medical personnel that a person does not want to have cardiopulmonary resuscitation (CPR) performed in the event of cardiac or respiratory arrest. These DNROs are also regulated by state law. (DNAR, or “do not attempt resuscitation,” is another common acronym used in this context.)

A DNRO should be posted prominently, either on the head or foot of the bed, or if the person is at home, on the refrigerator, and also be included in the person's chart. The DNRO should be readily available in the event of an emergency to ensure that the person's wishes will be honored. Some persons prefer the additional safeguard of wearing a bracelet or necklace to alert care providers that a DNRO is in force.

Hospice Care

Hospice is a philosophy of care that emphasizes physical comfort, pain and symptom management, and death with dignity for patients with terminal illnesses. It encompasses the spiritual and psychosocial aspects of care, both for the patient and the family, and includes bereavement support for the surviving family members. Hospice care involves a team of health professionals, including doctors, nurses, social workers, clergy, therapists, and trained volunteers.

During the terminal stages of AD, hospice care can be particularly beneficial to patients and families. The main purpose of hospice care is to allow persons to die with dignity and without pain or distress. Hospice care can be provided in the patient's home, assisted living residences, nursing homes, or in specifically designated hospice care facilities. Medicare is the primary source of payment for hospice care, but private insurance, Medicaid, and other resources also will pay for it.

To qualify for insurance reimbursement (including Medicare) for hospice services, a physician and a hospice medical director must certify that the patient has less than six months to live. The National Hospice and Palliative Care Organization has published guidelines to identify which dementia patients are likely to have a prognosis of six months or less if the disease runs its normal course. Medicare covers the cost of hospice care in every state, as does most private long-term care insurance.

Physicians and other health professionals need to educate families about the benefits of hospice care for their loved one with AD and for themselves. Ideally, this education would begin at the time of diagnosis, when the person is still capable of expressing preferences about end-of-life care.



CONCLUSION

Alzheimer's disease is one of the most devastating conditions that affect human beings because it destroys the mind. Dementia impairs memory and interferes with the ability to make rational decisions, thus preventing persons from functioning effectively in their environment. As a result, dementia robs the person of dignity and independence. Because AD is completely irreversible, cannot yet be adequately treated, and is associated with a long survival period, it affects not only the patient's life, but also the person's family, caregivers, and society.

Researchers are working to understand the causes of this disease and to develop new treatments that can alter the course of the disease or cure or prevent it. Early diagnosis is important in order to intervene with treatments that can slow the progression of the disease. There are ten warning signs offered by the Alzheimer's Association:

1. Memory loss that disrupts daily life
2. Challenges in planning or solving problems
3. Difficulty completing familiar tasks at home, at work, or at leisure
4. Confusion with time or place
5. Trouble understanding visual images and spatial relationships
6. New problems with words in speaking or writing
7. Misplacing things and losing the ability to retrace steps
8. Decreased or poor judgment
9. Withdrawal from work or social activities
10. Changes in mood and personality

For caregivers, the challenges can be overwhelming. It is essential that professionals recognize the toll this disease takes on both the person with the disease and those who are charged with their care.



RESOURCES

Alzheimer's and Dementia Prevention (HelpGuide.org)

<http://www.helpguide.org/articles/alzheimers-dementia/alzheimers-and-dementia-prevention.htm>

Alzheimer's Association

<http://www.alz.org>



Alzheimer's disease (MedlinePlus)

<http://www.nlm.nih.gov/medlineplus/alzheimersdisease.html>

Alzheimer's Disease Education and Referral Center

<http://www.nia.nih.gov/alzheimers/>

Family Caregiver Alliance

<http://www.caregiver.org>

MedicAlert + Alzheimer's Association Safe Return

<http://www.alz.org/care/dementia-medic-alert-safe-return.asp>

Medicare.gov

<https://www.Medicare.gov>

Mini-Cog Mental Status Exam

http://www.alz.org/documents_custom/minicog.pdf

Mini-Mental State Exam

<https://www.mountsinai.on.ca/care/psych/on-call-resources/on-call-resources/mmse.pdf>

National Hospice and Palliative Care Organization

<http://www.nhpco.org>

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TEST

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1. In the United States, Alzheimer's disease is:
 - a. The sixth leading cause of death among adults.
 - b. More prevalent in older adult men than in women.
 - c. Most prevalent among older adults ages 75 to 84.
 - d. More common in those adults with higher cognitive reserve.

2. Which statement is **correct** regarding Medicare benefits for patients with Alzheimer's disease?
 - a. Medicare provides personal care benefits for patients in their homes.
 - b. Medicare covers the cost of custodial long-term care.
 - c. Medicare pays for rehabilitation only if shown patients can benefit from therapy.
 - d. Medicare does not provide benefits for hospice care.

3. The two characteristic lesions of Alzheimer's disease are beta-amyloid plaques and:
 - a. Tau nodules.
 - b. Neuronal fissures.
 - c. Glial cysts.
 - d. Neurofibrillary tangles.

4. Which form of Alzheimer's disease (AD) have scientists proved is caused by an inherited change in one of three genes?
 - a. Late-onset AD
 - b. Familial AD
 - c. Autosomal-dominant AD
 - d. Apolipoprotein E (APOE) AD

5. Chronic stress is a risk factor for Alzheimer's disease because it:
 - a. Causes early plaque formation.
 - b. Causes inflammation.
 - c. Triggers excessive cortisol production.
 - d. Increases neurofibrillary tangles.



- 6.** Smoking is believed to increase the risk of Alzheimer's disease because it:
- Causes physical symptoms of chronic stress.
 - Produces cerebral oxidative stress.
 - Increases the production of cortisol.
 - Interferes with glucose metabolism.
- 7.** Which is a **true** statement concerning strategies to prevent the development of Alzheimer's disease (AD)?
- Regular exercise and a heart-healthy diet may be associated with reducing the risk of AD.
 - It is recommended that all older adults begin taking vitamin D to reduce the risk of AD.
 - Older adults should avoid situations involving new activities or unfamiliar settings to reduce the risk of AD.
 - There is strong, definitive evidence about which lifestyle practices can prevent AD.
- 8.** Which statement correctly distinguishes benign forgetfulness from dementia?
- Benign forgetfulness does not cause problems in learning new things, whereas dementia does.
 - Persons with benign forgetfulness do not remember things later on, whereas persons with dementia may.
 - Benign forgetfulness interferes with professional activities, whereas dementia does not.
 - Benign forgetfulness is usually sporadic, whereas memory impairment in dementia is progressive.
- 9.** The inability of a person with Alzheimer's disease to identify an object or spouse is known as:
- Aphasia.
 - Echolalia.
 - Anomia.
 - Agnosia.
- 10.** The middle stage of Alzheimer's disease begins when:
- Mild anomia becomes apparent.
 - Memory impairment starts to develop.
 - Problems with reading, writing, and numbers are present.
 - Friends and family begin to notice difficulties.



- 11.** Which patient symptom is characteristic of mid-stage (moderate) Alzheimer's disease?
- Mild anomia
 - Sundowning
 - Trouble paying bills
 - Incontinence
- 12.** Which patient symptom is typically seen only in late-stage Alzheimer's disease?
- Loss of impulse control
 - Increased anxiety
 - Inability to sleep
 - Difficulty swallowing
- 13.** The most common cause of death in the patient with Alzheimer's disease involves:
- Skin infections from bedsores.
 - Urinary tract infections.
 - Injuries from falls.
 - Pneumonia from aspiration.
- 14.** Which is a **correct** statement concerning screening for cognitive impairment?
- Screening is recommended to establish a patient's baseline function.
 - Alzheimer's disease is diagnosed primarily by early screening.
 - Screening results often show false negatives, but not false positives.
 - The benefits of screening are known to outweigh the harms.
- 15.** The Mini-Cog screening tool tests patients for memory problems and:
- Executive function abilities.
 - Mathematical abilities.
 - Ability to recognize faces.
 - Ability to recognize objects.
- 16.** Which laboratory testing is recommended by the American Association for Clinical Chemistry in order to rule out possible causes of dementia other than Alzheimer's disease?
- A comprehensive metabolic panel.
 - Cerebrospinal fluid testing for tau and amyloid biomarkers.
 - Measurements of B₁₂, vitamin D, and thyroid function.
 - Liver function tests.



17. The primary purpose for structural imaging (MRI or CT) in the standard testing for Alzheimer's disease is to:

- a. Diagnose cognitive impairment.
- b. Detect amyloid plaques in the brain.
- c. Rule out other conditions that may cause similar symptoms.
- d. Distinguish between mild Alzheimer's disease and normal aging.

18. The Functional Dementia Scale (FDS) is used to:

- a. Determine pharmacologic strategies to compensate for memory loss.
- b. Assess caregivers' needs to identify appropriate community resources.
- c. Improve or maintain the patient's cognitive and functional status.
- d. Screen for early-onset dementia.

19. Which is a **correct** statement regarding drug therapy for patients with Alzheimer's disease (AD)?

- a. There are no FDA-approved drugs for treating severe AD.
- b. Memantine works by regulating the activity of glutamate.
- c. Cholinesterase inhibitors and glutamate antagonists are never given together.
- d. Donepezil (Aricept) has been shown to reverse the progression of AD.

20. Recognizing and treating coexisting conditions common to older adults helps support patients with Alzheimer's disease by:

- a. Identifying those persons at risk for psychosis.
- b. Slowing the progression of Alzheimer's disease.
- c. Improving their ability to function and quality of life.
- d. Shifting the burden more onto the caregiver rather than the patient.

21. Management of the patient with Alzheimer's disease involves:

- a. Primarily managing the medical needs of the patient.
- b. Overseeing only the nonmedical issues of the patient.
- c. Performing repeat functional imaging studies.
- d. Considering both the patient's needs and caregiver's burden.



- 22.** Which is a **true** statement concerning rehabilitation therapy for a patient with Alzheimer's disease?
- It can help the patient function at the highest level possible.
 - It improves the patient's cognitive level by providing a supportive environment.
 - It focuses on dealing with depression and other psychological factors.
 - It is not truly beneficial for persons with dementia.
- 23.** Which measure helps in creating a supportive environment for the patient with middle- to late-stage Alzheimer's disease?
- Providing social stimulation through challenging mental exercises such as crossword puzzles
 - Avoiding praise, as the patient will not remember it
 - Rotating caregivers each week to avoid burnout
 - Providing clearly visible boundaries and interior landmarks
- 24.** When the person with Alzheimer's disease has asked the same question several times even after it has been answered, the caregiver's best response is to:
- Ask the patient to try to remember what you said before.
 - Ignore the question and leave the room.
 - Respond to the question and then try to distract the patient.
 - Tell the patient you have already answered it and walk away.
- 25.** When assisting a patient with mid-stage Alzheimer's disease to perform activities of daily living (ADLs), it is helpful to:
- Avoid providing cues or verbal coaxing.
 - Establish and maintain a fixed routine for each ADL.
 - Reduce standards around hygiene and grooming.
 - Increase distraction during ADL performance to reduce frustration.
- 26.** To maintain the nutritional well-being of persons with middle- and late-stage Alzheimer's disease, it is recommended to:
- Provide finger foods such as cheese and fresh fruit.
 - Use plastic utensils to avoid injury.
 - Provide social stimulation during meals.
 - Offer snacks such as popcorn or raw vegetables.



- 27.** Which is a **correct** statement concerning elder abuse?
- Most victims of elder abuse are men.
 - People with cognitive impairment are at higher risk for elder abuse.
 - There are no clear signs to determine whether psychological abuse is occurring.
 - Most perpetrators of elder abuse are nursing home staff.
- 28.** The three Rs approach to calming an agitated patient with Alzheimer's disease involves:
- Responding, restoring order, and restarting the activity.
 - Reminding, reprimanding, and restraining.
 - Repeating, reassuring, and redirecting.
 - Rewinding, relaxing, and resuming.
- 29.** An effective method for managing or preventing vocal outbursts in the patient with Alzheimer's disease is:
- Isolating the patient from others.
 - Prompting the patient to reminisce.
 - Withholding attention until the patient is quiet.
 - Reminding the patient how disruptive his or her outbursts are.
- 30.** Which is a **true** statement about wandering in persons with Alzheimer's disease?
- Wandering in a safe area can be good exercise.
 - In cases of persons with Alzheimer's disease, wandering is never goal-directed.
 - Women are more likely to wander than men.
 - It is usually helpful to frequently remind the person not to go outside.
- 31.** Which intervention may help to restore a normal sleeping schedule in patients with Alzheimer's disease?
- Encouraging exercise and physical activity on a daily basis
 - Limiting fluid intake throughout the daytime
 - Awakening the patient early and encouraging staying up late
 - Allowing the patient to sleep as desired during the day
- 32.** To address inappropriate sexual behaviors in a patient with Alzheimer's disease, the caregiver's action is to:
- Explain to the patient that his or her behavior is inappropriate.
 - Assess the patient's behavior for antecedent causes.
 - Avoid touching the patient, thereby preventing misunderstanding.
 - Restrict the patient to a public area for observation.



- 33.** Which is a recommended step by which healthcare professionals can support caregivers of patients with Alzheimer's disease?
- Assist caregivers in obtaining respite care
 - Refrain from providing caregivers with many pamphlets and booklets on the disease
 - Recommend caregivers give up time-consuming leisure activities
 - Suggest caregivers arrange psychological therapy for the patient
- 34.** Which is a **true** statement about ethics in caring for patients with Alzheimer's disease (AD)?
- Incompetence negates the prior written request of a patient with AD to refuse life-extending treatment.
 - Family or caregivers should assume decision making as soon as possible for patients with AD.
 - When a patient with AD can no longer interact, it becomes morally acceptable to withhold further treatment.
 - Caregivers are obligated to preserve and promote the autonomy of a patient with AD.
- 35.** Which is a **correct** statement about the effect of artificial nutrition and hydration (ANH) in patients with Alzheimer's disease?
- ANH promotes the release of endorphins.
 - ANH improves longevity.
 - ANH lowers the incidence of skin breakdown.
 - ANH often leads to increased use of physical restraints.
- 36.** Which is a type of advance directive for patients with irreversible, serious disease?
- Last will and testament
 - Durable power of attorney for healthcare
 - Verbal agreement with the family
 - Charitable trust

