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Contact Hours: **9**

Dementia: Alzheimer's Disease Patient Care

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LEARNING OUTCOME AND OBJECTIVES: Upon completion of this continuing education course, you will have increased your knowledge of evidence-based guidelines for delivering appropriate therapeutic interventions to persons with Alzheimer's disease, their family members, and caregivers. Specific learning objectives include:

- Summarize the epidemiology and financial and societal impacts of Alzheimer's disease.
- Describe the pathophysiology of Alzheimer's disease.
- List risk factors and possible preventive measures for Alzheimer's disease.
- Describe clinical manifestations and the process of diagnosing the disease.
- 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 support for families and caregivers.
- Discuss ethical and legal issues, such as end-of-life care decision-making.

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. When the individual becomes incapacitated, death is usually caused by complications such as pneumonia, other types of infections, or blood clots (Rosenzweig, 2018).

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
- Frontotemporal dementia (Pick's disease)
- Wernicke-Korsakoff's syndrome
- Creutzfeldt-Jakob disease
- Mixed dementia, most commonly vascular and Alzheimer's
- Normal pressure hydrocephalus
- Huntington's disease
- Parkinson's disease
- Posterior cortical atrophy

Of these, Alzheimer's disease is the most common cause of dementia in older adults (NIA, 2017a).

Alzheimer's disease results from a complex pattern of abnormal changes, develops slowly, and gradually worsens. The course of Alzheimer's 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, a person with Alzheimer's lives for four to eight years after diagnosis. However, some may live for as many as 20 years.

Alzheimer's disease is the sixth leading cause of death in the United States, but it is the only one of the top 10 leading causes of death that cannot be cured or prevented and whose progression cannot be slowed (Alzheimer's Association, 2018a).

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. Prior to this period, people in the United States lived an average of 50 years and few reached the age of greatest risk for Alzheimer's disease. For this reason, the disease was considered rare and there was little scientific interest in it.

This changed as the average lifespan increased and Alzheimer's became more common in people aged 70 and older. During this period of time, advancements in medicine and the ability to look



inside the brain gave the medical community the realization that diseases could be the cause of this deterioration.

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 <i>Alzheimer's disease</i> 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 Alzheimer's disease.
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 was founded.
1976	Alzheimer's disease 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 Alzheimer's disease's characteristic plaques, which cause reduced neurological function. A nationwide infrastructure for Alzheimer's research was established by the National Institute on Aging.
1986	Tau protein was identified as forming Alzheimer's disease'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 Food and Drug Administration (FDA).
1994	President Reagan announced he had been diagnosed with Alzheimer's disease. First World Alzheimer's Day was held.
1995	First transgenic mouse model was announced (human APP genes linked to a rare, inherited form of Alzheimer's disease inserted into mice).
1996	FDA approved donepezil (Aricept), a cholinesterase inhibitor, for treating all stages of Alzheimer's disease.
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 Alzheimer's disease.



2001	FDA approved galantamine (Razadyne), a cholinesterase inhibitor, for treating mild to moderate Alzheimer's disease.
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 Alzheimer's disease can overstimulate nerve cells and kill them.
2004	The new imaging agent known as <i>Pittsburg Compound B (PiB)</i> was produced to be used with positron emission tomography for early detection of Alzheimer's. Alzheimer's Disease Neuroimaging Initiative was begun to share research data worldwide.
2009	An effort was begun to standardized biomarkers for Alzheimer's disease.
2011	Alzheimer's disease advanced to become the sixth leading cause of 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 Alzheimer's disease-related memory loss. Annual assessment for cognitive impairment for all Medicare recipients was implemented as part of an annual wellness visit. President Obama signed the National Alzheimer's Project Act into law, a framework for a national strategic plan.
2012	Scientists at the University College London 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. The first major clinical trial for prevention of Alzheimer's disease was begun.
2013	International Genomics of Alzheimer's Project researchers identified new genetic risk factors for Alzheimer's disease.
2014	FDA approved donepezil combined with memantine (Namzaric) for treatment of moderate to severe Alzheimer's disease. Rates of death caused by Alzheimer's disease were found to be much higher than reported on death certificates.
2015	A UCLA study identified three distinct subtypes of Alzheimer's disease: inflammatory, noninflammatory, and cortical (associated with significant zinc deficiency). Research began to determine if they have different underlying causes and respond differentially to potential treatments.
2017	An historic \$400 million increase for federal Alzheimer's disease research funding was signed into law, bringing annual funding to \$1.4 billion.
Sources: Alzheimer's Association, 2018b; Irwin, 2015.	

Scientists continue the search for answers regarding causes, diagnoses, and treatments for Alzheimer's disease. 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 yet known; however, researchers believe the outlook



is good for development of treatments that slow or stop Alzheimer's (Alzheimer's Association, 2018a).

SCOPE OF THE DISEASE

There continue 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) there is as yet no exact diagnostic test. Therefore, statistics regarding Alzheimer's are only estimates (Povova et al., 2015).

Alzheimer's Disease Worldwide

Worldwide, it is estimated that close to 50 million people have Alzheimer's disease or a related dementia. This estimate is expected to reach 131.5 million in 2050. Much of this increase will occur in developing countries and is related to an increase in life expectancy. More people are living longer and healthier lives, resulting in a greater proportion of older people who are at greatest risk for developing dementias. Currently, only 1 in 4 people with Alzheimer's disease is estimated to have been diagnosed.

Alzheimer's disease is most common in Western Europe (with North America close behind) and least common in Sub-Saharan Africa. Worldwide, Alzheimer's disease and other dementias are the leading cause of disability in later life (Alzheimer's Disease International, 2018a).

Alzheimer's Disease Nationwide

As life expectancy in the United States has risen, so has the number of persons with a probable diagnosis of Alzheimer's disease. An estimated 5.7 million Americans of all ages—5.5 million ages 65 and older and approximately 200,000 people under age 65—were living with Alzheimer's in 2018. This is projected to reach nearly 14 million by the year 2050.

In 2018, it was estimated that 484,000 Americans ages 65 or older will have developed Alzheimer's, and that every 65 seconds someone in the United States develops the disease. By 2050 this number is estimated to be one American every 33 seconds.

AD is the **sixth leading cause** of death in the United States, with 1 in 3 older adults dying with Alzheimer's or another dementia. Between 2000 and 2015, deaths attributed to Alzheimer's increased 123%, while those attributed to the number one cause of death (heart disease) decreased 11%. Alzheimer's kills more people than breast cancer and prostate cancer combined.

Between 2018 and 2025, every state across the nation is expected to have an increase of at least 13% in the percentage of people diagnosed and living with Alzheimer's disease. This is due to the increase in populations aged 65 and older. The West and Southeast are expected to experience the largest percentage increases (Alzheimer's Association, 2018a).



AGE

One in 10 people age 65 and older has Alzheimer's disease, and 81% are age 75 or older. The percentage of people with Alzheimer's increases with age (see table below).

AGE DISTRIBUTION OF PEOPLE WITH ALZHEIMER'S	
Age (years)	Percentage (rounded)
<65	4%
65–74	16%
75–84	44%
85+	37%
Source: Alzheimer's Association, 2018a.	

GENDER

More women than men have Alzheimer's disease or other dementias. Almost two thirds of all Americans with Alzheimer's are women. Of the 5.5 million people age 65 and older with Alzheimer's in the United States, 3.4 million are women and 2.0 million are men. This is explained by the fact that women live longer on average than men, and older age is the greatest risk factor for Alzheimer's disease (Alzheimer's Association, 2018a).

RACE/ETHNICITY

Although there are more non-Hispanic whites living with Alzheimer's and other dementias than any other racial or ethnic group in the United States, older African Americans and Hispanics are more likely, on a per capita basis, than older whites to have Alzheimer's or other dementias. Older African Americans are about two times more likely to have Alzheimer's or other dementias than older whites. Japanese Americans have been reported to have the lowest prevalence of dementia compared with other ethnic groups.

Health conditions such as cardiovascular disease and diabetes, which are associated with an increased risk for Alzheimer's and other dementias, are thought to account for the differences, since they are more prevalent in African American and Hispanic people. Socioeconomic characteristics, including levels of education, higher rates of poverty, discrimination, and greater exposure to adversity in early life may also contribute to the increased risk in these groups (Alzheimer's Association, 2018a).

EDUCATION LEVEL

A recent study led by the University of Southern California found that people with more education have lower prevalence of dementia, more years of cognitively healthy life, and fewer years with dementia. The study found that lifespan with good cognition of men and women 65 and older with a college education increased by an average of 1.51 years for men and 1.79 years for women. The increase in lifespan with good cognition was much smaller among those with the



least education—0.66 years for men and 0.27 years for women. Healthy cognition characterized most of the people with at least a college education into their late 80s, whereas people who did not complete high school had good cognition only up until their 70s. Higher education appears to provide lifelong cognitive benefits from both its effect on cognitive functioning and its effect on longer life (Crimmins et al., 2018).

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. Once Alzheimer's becomes apparent, however, patients with higher education or occupational levels appear to experience a somewhat more rapid cognitive decline. This is believed, at least in part, because they are assumed to have accumulated a greater degree of Alzheimer's disease pathology by the time dementia is apparent compared with those who have less education (Larson, 2017).

Financial Impact of Alzheimer's

Alzheimer's disease inflicts a heavy economic burden on families and on society as a whole. In 2018, the direct costs to American society of caring for those with Alzheimer's totalled an estimated \$277 billion, including \$186 billion in Medicare and Medicaid payments. In 2050 this is projected to be more than \$1.1 trillion. The lifetime cost of caring for an individual with dementia in 2018 was estimated to be \$341,840. Of the total lifetime cost of caring for someone with dementia, 70% is borne by families, either through out-of-pocket health and long-term care expenses or from the financial cost of providing unpaid care for a loved one.

Eighty-three percent of the help provided to older adults in the United States comes from family members, friends, or other unpaid caregivers. Nearly half of all caregivers who provide help to older adults do so for someone with Alzheimer's or another dementia, and about 34% of caregivers are age 65 or older. These caregivers provide 18.4 billion hours of care, valued at over \$232 billion. Approximately two thirds of caregivers are women, over one third of which are daughters. An estimated one fourth of dementia caregivers are members of the “sandwich generation,” caring not only for an aging parent but also for children less than 18 years of age.

Although the number of persons diagnosed with Alzheimer's disease is increasing, the mortality rate of these individuals is decreasing. Persons with Alzheimer's have significantly more comorbid medical conditions and higher healthcare costs and utilization than demographically matched Medicare beneficiaries. People with Alzheimer's or other dementias make up a large proportion of all elderly people who receive adult day services and home care. They have twice as many hospital stays each year as other older adults. Medicaid is the only major source of financial assistance for long-term care of people with Alzheimer's disease (Alzheimer's Association, 2018a).



ANNUAL MEDIAN COST IN THE UNITED STATES FOR LONG-TERM CARE SERVICES, 2018

- Homemaker services: \$47,934
- Home health aide: \$49,192
- Adult day healthcare: \$18,200
- Assisted living: \$45,000
- Nursing home facility, semi-private room: \$85,775
- Nursing home facility, private room: \$97,455 (maximum cost in Alaska: \$515,380)
(Genworth, 2018)

Some individuals have long-term care insurance coverage, and it is important to make certain it specifically identifies coverage for Alzheimer's. Once a diagnosis of Alzheimer's disease is made, the individual will not be able to apply for long-term care coverage. If the insurance 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 certain elimination period or 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 (e.g., skilled nursing home, assisted living, licensed home care)?
- Are there tax implications for receiving these benefits?
(Alzheimer's Association, 2018c)

The financial, as well as the 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 Alzheimer's, 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 therapy, occupational therapy, and speech-language pathology services. In 2018, changes to Medicare removed the caps on the amount of therapies individuals can receive. However, to receive Medicare benefits for these services, the law requires the therapist or therapy provider to confirm that the therapy services are medically reasonable and necessary when they reach certain amounts each calendar year.
- Medicare Part D helps pay for prescription drugs, and most standard Alzheimer's medications are on Medicare's approved drug list. Medicare Part B also pays for some portion of some drugs. Medicare Supplemental Insurance can cover the remaining 20% that Medicare Part B does not pay and can increase the quantity and range of Alzheimer's medications that are covered.
- Medicare Special Needs Plans, a type of Medicare Advantage plan, are specifically designed for persons with Alzheimer's.
- A 2017 change to Medicare was the addition of care planning as a service that assists patients in understanding both what medical options are available as well as alternative treatments, clinical trials, and even nonmedical support. Medicare will not necessarily pay for all these services but will pay to help develop a plan to access them.

Costs during the middle stage of Alzheimer's disease:

- During this stage, supervision is required, but not skilled care. Personal care assistance may be required in addition to supervision. Medicare does **not** provide benefits for personal care or supervision either in the home or in memory care residences, such as assisted living.
- Alternative therapies such as acupuncture or herbal medicine are not covered by Medicare.
- Medicare continues to pay for doctor visits and prescription drugs.

Costs in the later stage of Alzheimer's disease:

- When 24-hour care either at home or in a skilled nursing residence becomes necessary, Medicare begins to pay for additional services. However, qualification can be complex and coverage intermittent. Medicare covers up to 100 days for rehabilitation in a nursing home or skilled nursing facility, but it must be following a qualifying inpatient hospital stay of three days for management of a medical situation (observation services and the day of discharge are not considered part of an inpatient stay). If the nursing home or skilled nursing facility 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.



- Medicare does not pay for 24-hour-a-day care at home, meals delivered to the home, homemaker services, or custodial or personal care when this is the only care the person requires.
- Medicaid, a state and federally funded health insurance program for low-income families and the elderly, 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. Each state offers different benefits with regard to caring for persons with Alzheimer's or other dementias.
- Medicaid Waivers are state programs allowing persons to receive care in their homes, communities, and sometimes in assisted- or senior-living residences. Almost all Medicaid Waivers have both financial eligibility requirements and requirements that persons have functional limitations.
- 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.

Costs in hospice care:

- Medicare will provide all-inclusive hospice benefits for those who are certified to have six months or less to live by the hospice doctor and the patient's own doctor (if the person has one), if the patient accepts palliative care (i.e., to reduce suffering) instead of curative care, and if the patient signs a statement choosing hospice care instead of other Medicare-covered treatment for terminal illness and related conditions.
- The patient may have to pay copayments of up to \$5 for prescription drugs or products for pain relief and symptoms control.
- Under the Medicare hospice benefit, the patient can receive short-term inpatient or respite care in a Medicare-approved hospital or skilled nursing facility to give caregivers a rest. Medicare pays 95% of the Medicare-approved amount.
- Medicare does not cover room and board if the patient receives care in the home or if the patient lives in a nursing home or hospice inpatient facility.

(See also "Clinical Stages of Alzheimer's Disease" later in this course and "Resources" at the end of this course.)

Sources: Medicare.gov, 2018; Guerrero, 2018.



WHAT IS ALZHEIMER'S DISEASE?

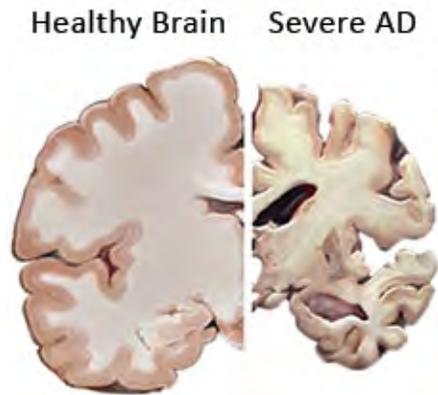
Normal aging involves changes throughout the body, and the brain is not exempt. In normal aging, some neurons die; others shrink and become less effective, especially in areas of the brain related to learning, memory, and executive function (the abilities required to plan, organize, and carry out tasks). 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.

People with Alzheimer's disease, however, experience impaired connections between neurons and neuron cell death, causing impairments in learning and thinking. Alzheimer's also causes the surface layer of the cerebrum to shrink, which directly affects a person's ability to plan, recall facts, and concentrate. This damage most often begins in a subcortical structure known as the *hippocampus*, the area of the brain associated with formation of memories.



Hippocampus of the brain associated with memory formation.
(Source: National Institute on Aging/National Institutes of Health.)

With increased cell death and disconnection in the hippocampus, brain tissue shrinks substantially and eventually affects the functioning of the brain. When Alzheimer's disease results in shrinkage of the brain, the ventricles become enlarged, resulting in a distinct and different appearance from that of a healthy brain (see illustration).



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

Pathophysiology

More than three decades of research have shown how Alzheimer's steadily destroys brain function. Overproduction and/or decreased clearance of amyloid beta peptides appear to be shared by all forms of Alzheimer's disease; however, the subsequent neurotoxin remains unknown and the initial events that trigger beta-amyloid plaque formation are poorly understood.

There is an abundance of information about Alzheimer pathology indicating that it is driven by two processes—extracellular deposition of beta-amyloid (plaques) and intracellular accumulation of tau protein (tangles). The brains of victims of Alzheimer's disease also reveal loss of neurons marked by shrinkage of parts of the cerebrum.

BETA-AMYLOID PLAQUES

The pathologic changes seen in Alzheimer's include amyloid plaques associated with neuronal injury. 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.

Beta-amyloid protein comes in several different molecular forms that collect between neurons. One form, beta-amyloid 42, is thought to be especially toxic. 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 Alzheimer's disease (Keene et al., 2018).

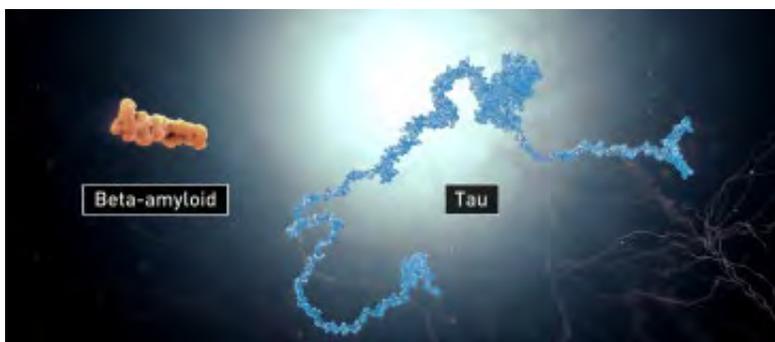
NEUROFIBRILLARY TANGLES

The other lesion that characterizes Alzheimer's 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 from the cell body to the axon and dendrites.

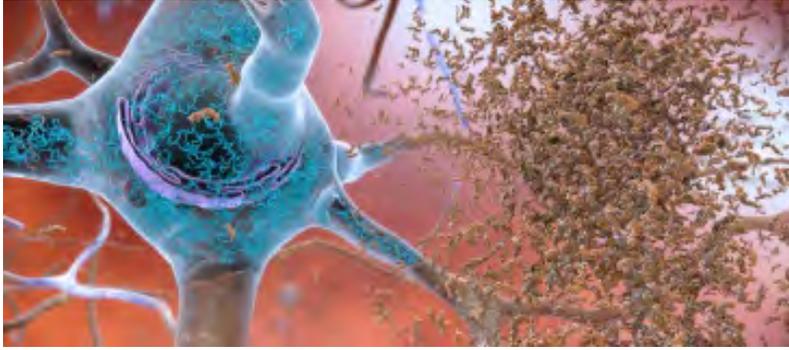
In healthy neurons, the walls of the microtubules are reinforced by tau proteins, which act like the rungs on a ladder. In Alzheimer's disease, the tau proteins loosen, become detached from the microtubules, stick to other tau molecules, and form neurofibrillary tangles inside the neurons. These tangles then interfere with cellular functions by displacing organelles and cutting off nutrition to axon terminals and dendrites. Without life support to the neuron, it shrivels and dies. When beta-amyloid in the brain reaches a certain level, tau rapidly spreads throughout the brain. The distinct progressive transmission of pathologic forms of tau between neurons across the regions of the brain has been suggested to account for the spread of Alzheimer's in the brain (Keene et al., 2018).



Healthy neuron.
(Source: National Institute on Aging/National Institutes of Health.)



Beta-amyloid and tau.
(Source: National Institute on Aging/National Institutes of Health.)



Neuron with beta-amyloid plaques and neurofibrillary tangles.
(Source: National Institute on Aging/National Institutes of Health.)

DISRUPTION OF NEUROTRANSMITTERS

Alzheimer's disease reduces the production of certain neurotransmitters in the brain that normally act as chemical messengers, transmitting nerve impulses. The brain of the person with Alzheimer's shows a loss of cholinergic neurons in the basal forebrain, decreased acetylcholine levels, and a decrease in the acetylcholine synthesizing enzyme choline acetyltransferase in the cerebral cortex. This enzyme plays an important role in information processing and memory.

Other neurotransmitters—including noradrenalin, serotonin, somatostatin, and other peptides—are also deficient in Alzheimer's, but cognitive impairment corresponds best with the loss of cholinergic input. Reduction of the neurotransmitter 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 (Agamanolis, 2016).

Etiology and Risk Factors of Alzheimer's Disease

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

GENETIC FACTORS

There are two types of Alzheimer's disease—early-onset and late-onset—both of which have a genetic component.

Early-Onset Alzheimer's

Alzheimer's that develops in people younger than age 65 (many in their 40s and 50s) generally progresses more rapidly than late-onset Alzheimer's disease. It is often caused by inherited changes in one of three genes on chromosomes 21, 14, and 1. Each of these genetic mutations causes abnormal proteins to be formed:



- Mutation on chromosome 21 causes formation of abnormal amyloid precursor protein (APP).
- Mutation on chromosome 14 causes abnormal presenilin 1 to be made.
- Mutation on chromosome 1 leads to abnormal presenilin 2.

These genetic mutations result in early-onset familial Alzheimer's disease (FAD). 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% 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 Alzheimer's nearly 100% of the time. This type of inheritance pattern is called *autosomal dominant inheritance*. Fortunately, early-onset Alzheimer's disease is rare (less than 5%) (Graff-Radford, 2017a; NIH, 2017).

Late-Onset Alzheimer's

No specific gene has been found that directly causes late-onset Alzheimer's disease, but having one form of the apolipoprotein E (ApoE) gene on chromosome 19 does increase the risk of developing this type of Alzheimer's disease. The ApoE gene is involved in several cellular processes, including cholesterol transport, development, synaptic plasticity, and immune regulation. There are three alleles (variant forms) of ApoE gene, which are called *epsilon 2 (e2)*, *epsilon 3 (e3)*, and *epsilon 4 (e4)*.

- ApoE2 is relatively rare and may protect against Alzheimer's disease.
- ApoE3, the most common allele, is believed to play a neutral role in the disease.
- ApoE4 increases the risk for Alzheimer's disease and is also associated with early-onset Alzheimer's.

Each person has either zero, one, or two ApoE4 alleles. Having more ApoE4 alleles increases the risk of developing Alzheimer's, but inheriting an ApoE4 allele does not mean the person will go on to develop Alzheimer's disease. Some with the allele never get the disease, and others who develop Alzheimer's have no ApoE4 alleles. One mechanism by which ApoE4 may increase Alzheimer's risk is by impairing beta-amyloid clearance from the cerebrum (Keene et al., 2018; NIA, 2017b).

CHRONIC INFLAMMATION

Research seems to indicate that chronic inflammation may be the result of the buildup of glial cells, which normally keep the brain free of debris. One type of glial cell, the microglia, engulfs and destroys waste and toxins in the healthy brain. In the Alzheimer's-affected brain, microglia fail to clear away debris, waste, and protein collections, including beta-amyloid plaques.

Research is being done in an attempt to find out why microglia cells fail to perform their important function in patients with Alzheimer's. One area of study includes a gene called *TREM2*, whose normal function is to signal the microglia cells to clear beta-amyloid plaques



and help fight inflammation. When this gene does not function normally, plaque builds up between the neurons.

Another type of glial cell, astrocytes, are also signaled along with the microglia to assist in clearing debris and plaques, but they too can fail to perform their function. In addition, they release chemicals that cause chronic inflammation and further damage to the neurons they are supposed to protect (NIA, 2017b).

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

The chronic stress hypothesis for the development of Alzheimer's suggests that increased stress may cause dampening of negative feedback control of the adrenocortical axis through down-regulation of hippocampal corticosteroid receptors, triggering excessive cortisol production. Higher levels of cortisol are associated with lower hippocampal volumes. Stress alters ensuing synaptic plasticity and firing properties of the hippocampal neurons and changes neuronal morphology, suppresses neuronal proliferation, and reduces hippocampal volume (Kim et al, 2015).

Depression

Depression is a component of Alzheimer's disease and may also be a trigger for developing the disease, although evidence is limited that some forms of major depressive disorder (MDD) can increase the likelihood of developing late-onset Alzheimer's. There may be subtypes of early-life MDD that bring about independent high risk for late-onset Alzheimer's, although identification of these subtypes is difficult. There may either be a common pathological event underlying both depression and Alzheimer's, or depression may sensitize the brain to a second event that precipitates Alzheimer's (Herbert & Lucassan, 2016).

Diabetes Mellitus

Numerous studies have shown a clear association between type 2 diabetes mellitus (T2D) and an increased risk of developing Alzheimer's disease. The precise mechanism, however, remains unclear. It is known that T2D can exacerbate neurodegenerative processes. Brain atrophy, reduced cerebral metabolism, and central nervous system insulin resistance are all features of both T2D and Alzheimer's. The T2D phenotype also promotes the accumulation of beta-amyloid and hyperphosphorylated tau (i.e.,



Alzheimer's pathology), causing inflammatory and oxidative processes that induce neuronal degeneration (Bharadwaj et al, 2017).

In addition, Alzheimer's disease is frequently referred to as *type 3 diabetes*, or a form of diabetes that specifically involves the brain. Findings suggest that type 3 diabetes begins early in the course of Alzheimer's and progresses with increasing neurodegeneration. Since insulin regulates glucose metabolism in the brain, a decline in insulin signaling through metabolic pathways corresponds with the progressive reduction in brain glucose utilization, which has been detected by positron emission tomography (PET) imaging.

Additional research that further explains the theory that Alzheimer's is type 3 diabetes includes:

- GSK-3 beta is an enzyme involved in the physiological and pathological progress of both diabetes mellitus and Alzheimer's. It is one of the key factors that leads to insulin deficiency and insulin resistance in patients with diabetes. In Alzheimer's, it plays an important role in hyperphosphorylation of microtubule-associated protein tau, a part of the molecular pathogenesis of Alzheimer's disease (Zhang et al., 2017).
- Toll-like receptor 4 (TLR4), a class of proteins that initiates the expression of a number of pro-inflammatory genes, is also involved in the physiologic and pathological progress of both diabetes and Alzheimer's. In diabetes, chronic TLR4 activation may contribute to insulin resistance, whereas in Alzheimer's, chronic TLR4 activation may lead to beta-amyloid deposition (Huang et al., 2017).

Hypertension

Hypertension is a strong risk factor for Alzheimer's disease. It is associated with cognitive decline, dementia, and the onset and progress of Alzheimer's. It has been found that the use of antihypertensive drugs reduces the risk of dementia and slows cognitive decline in Alzheimer's patients. Midlife hypertension has been associated with increased densities of amyloid plaque, cerebral amyloid angiopathy, and neurofibrillary tangles in postmortem brains. In animal studies, hypertension has been shown to accelerate Alzheimer's-related pathology in the hippocampus and impair hippocampus-dependent learning and memory. Collectively, these indicate there may be an association between hypertension and Alzheimer's (Moonga et al., 2017; Shih et al., 2018).

Vascular Disease

The more risk factors for vascular disease one has in middle age, the higher the risk may be of developing Alzheimer's later in life. Types of vascular disease include atherosclerosis and peripheral artery disease. Common risk factors for vascular disease include:



- Obesity
- High cholesterol
- Hypertension
- Diabetes
- Smoking

Autopsy results have shown that as many as 80% of persons with Alzheimer's also have cardiovascular disease. There is a question as to why some people develop plaques and tangles but do not develop symptoms of Alzheimer's. Vascular disease may assist researchers to find an answer. Autopsy 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. More research is necessary in order to understand the link between vascular health and Alzheimer's disease (Alzheimer's Association, 2018d; Gottesman et al., 2017).

Hearing Loss

Hearing loss is positioned as the largest potentially modifiable risk factor for dementia. It has been found that mid-life hearing loss, if eliminated, might reduce the risk of dementia by 9%. However, the underlying causal mechanisms leading to the connection between the two are not well understood. The hypothesis is that hearing impairment impacts cognitive load, changes in brain structure and function, and leads to social isolation and depression related to a common etiology. Depression and social isolation may mediate the relationship between hearing loss and cognitive impairment.

Studies have shown that hearing impairment is independently associated with a 30% to 40% rate of accelerated cognitive decline and a substantially increased risk of secondary all-cause dementia. Compared to people with normal hearing, people with mild, moderate, and severe hearing impairment, respectively, had a 2-, 3-, and 5-fold increased risk of incidental all-cause dementia over more than 10 years of follow-up. Neuroimaging studies have also demonstrated independent associations of hearing impairment with reduced cortical volumes in the auditory cortex and accelerated rates of lateral temporal lobe and whole brain atrophy (Lin & Albert, 2014; Uchida et al., 2018; Fortunato et al., 2016).

Studies are being done to determine if the use of hearing aids or cochlear implants have an impact on the effect of hearing loss and resulting cognitive impairment.

Head Trauma

Certain types of head injuries may increase the risk of developing Alzheimer's or other types of dementias later in life. The factors affecting risk seem to include age at the time of injury and the severity of the injury. The more severe a head injury is, the higher the risk, and sustaining a head injury around the age of 55 also increases the risk. Repeated mild injuries may also increase the risk for future difficulties in thinking and reasoning.



The risk is greatest if other risk factors are present, such as carrying one form of the ApoE gene. Many people who sustain a severe head injury never go on to develop Alzheimer's or other dementia, and more research is necessary to better understand the link (Graff-Radford, 2017b).

Oxidative Stress

Oxidation occurs when the body metabolizes oxygen to produce energy. This process produces free radicals, which can cause damage to cells, but they also stimulate repair. The body produces antioxidants, the most powerful of which is glutathione. As long as the body produces enough antioxidants, a careful balance is maintained and damage is prevented. However, when the amount of free radicals produced overwhelms the repair process, oxidative stress happens, causing damage to nearby cells, mitochondria, and DNA (Jat & Nahar, 2017).

Besides producing free radicals when the cells make energy, the body also detoxifies pollutants, pesticides, and tobacco smoke. There is a growing body of research that suggests a strong connection between smoking tobacco products and dementia, and it is now estimated that smoking may be responsible for up to 14% of all cases of Alzheimer's disease.

Smoking appears to cause oxidative stress, which results in harm to DNA, leading to cognitive decline. Oxidative stress also appears to promote the formation of amyloid plaques and neurofibrillary tangles in the brain. Smoking also damages arteries, interfering with the flow of blood to the brain, and boosts levels of homocysteine and inflammation, both of which have been linked to dementia.

Studies thus far indicate that smoking's effects on dementia risk depend on the dose—the more the person smokes, the higher the risk. Additionally, studies have found that people exposed to secondhand smoke were 29% more likely to have dementia than those unexposed, and individuals exposed for 5 to 9 years were 66 times more likely (UC Berkeley, 2017).

Vitamin D Deficiency

Research suggests that people with very low levels of vitamin D are at higher risk for developing Alzheimer's disease and other forms of dementia. Some studies have failed to show an association between the two, but one study did find that those persons with vitamin D deficiency were twice as likely to develop Alzheimer's or other forms of dementia as those with normal vitamin D levels. Because the skin's ability to synthesize vitamin D from the sun decreases with age, vitamin D deficiency is more common among older adults.

More research is needed, however, as these results are only observational at this time and the role of vitamin D in brain function, cognition, and the aging process is still unknown. In addition, more studies are needed to determine if the use of vitamin D supplements or



sun exposure can be of benefit in reducing the risk of Alzheimer's disease (Graff-Radford, 2018).

Obesity and Inflammation

Two important risk factors for Alzheimer's disease that may contribute to the development and/or progression of Alzheimer's pathogenesis are diet-induced obesity and age-related increases in inflammation. There is ample scientific and empirical evidence that obesity is related to Alzheimer's, which may be a metabolic disease. Diet-induced obesity has been implicated in the acceleration of beta-amyloid production.

People who have a high body mass index (BMI) are more likely to develop dementia than those with a normal weight. Individuals who develop dementia have been found to have a higher-than-average BMI some 20 years before the onset of dementia, but when they are close to overt dementia they have a lower BMI than those who remain healthy. Studies confirm both the adverse effects of obesity and weight loss caused by metabolic changes during the pre-dementia stage.

Aging, combined with a high-fat and high-sucrose diet, exacerbates the effects of inflammation/stress in the hippocampus, which is involved in memory formation, and energetic stress in the prefrontal cortex, which oversees complex cognitive, emotional, and behavioral function.

High-fat, high-sucrose foods produce significantly higher markers of inflammation, insulin resistance, and cellular stress in the areas of the hippocampus thought to be involved in the progression of Alzheimer's disease. These study results support the theory that aging alone plays a role in the progression of Alzheimer's and that obesity exacerbates the effects of aging on brain function (Kivimäki et al., 2017).

Menopause

Menopause causes metabolic changes in the brain that may increase the risk of Alzheimer's disease. A recent study may help to explain why women have Alzheimer's more often than men, even accounting for the fact that women live longer on average than men. This study indicates a critical period of opportunity to detect metabolic signs of higher Alzheimer's risk when women are in their 40s and 50s and proposes strategies that can reduce the risk, such as the use of antioxidants to protect brain activity and mitochondria and maintaining estrogen levels.

The test used in the study showed that women who had gone through menopause or who were perimenopausal had significantly lower levels of glucose metabolism in several key areas of the brain than those who were premenopausal. Additionally, these women showed lower levels of activity for an important metabolic enzyme as well as lower scores on standard memory tests. Researchers reported that the loss of the key neuroprotective element estrogen makes women more vulnerable to brain aging and Alzheimer's disease (Mosconi et al., 2017).



Possible Preventative Strategies

The question of whether Alzheimer's can be prevented continues to stimulate new research investigations. As of yet, however, there are no clear-cut answers, partially due to the need for more large-scale studies in diverse populations. Although **there is no definitive evidence** about what can prevent Alzheimer's disease or age-related cognitive decline, a lifestyle that includes the following elements may be helpful in lowering the risk for development of Alzheimer's or slowing its progression.

REGULAR PHYSICAL EXERCISE

The most convincing evidence for prevention is exercise, which may directly benefit brain cells by increasing collateral small blood vessel formation and increased blood flow to the brain. It has also been shown that exercise can stimulate the brain's ability to maintain old network connections and make new ones, which is vital to healthy brain function. The recommendation is 30 minutes of moderately vigorous aerobic exercise, including brisk walking, three to four days a week (Alzheimer's Association, 2018d).

DIET

A heart-healthy diet may also help protect the brain. The two most beneficial diets that have been studied are the DASH (Dietary Approaches to Stop Hypertension) diet and the Mediterranean diet.

- The DASH diet emphasizes vegetables, fruits, fat-free or low-fat dairy products, whole grains, fish, poultry, beans, seeds, nuts, and vegetable oils. It limits sodium, sweets, sugary beverages, and red meat.
- The Mediterranean diet includes relatively little red meat and emphasizes whole grains, legumes, poultry, fruits, vegetables, fish and shellfish, nuts, olive oil and other healthy fats, and red wine in moderation (Mayo Clinic, 2017; NIH, 2018a).

SLEEP

During normal sleep, the brain actively clears out "stray" beta-amyloid protein remnants discarded by neurons. But when sleep is disrupted, this cleaning process is stalled and beta-amyloid starts to collect in the small seams between cells of the brain. In a study at the National Institutes of Health, PET scans showed, even in healthy brains, a dramatic increase in this beta-amyloid protein of up to 5% in the thalamus and hippocampus after only one night of sleep deprivation. These regions of the brain are especially vulnerable to damage in the early stages of Alzheimer's disease. The fact that Alzheimer's itself disrupts sleep serves only to speed up and amplify this cycle. It is recommended that sleep be a priority and that everyone should sleep for at least six hours every night (NIH, 2018b).



PREVENTING HEAD TRAUMA

There is a strong link between the future risk of Alzheimer's and serious head trauma, especially when injury involves a loss of consciousness. It is recommended that individuals wear seat belts, use a helmet when participating in sports activities, and make the home as "fall-proof" as possible.

SOCIAL CONNECTIONS

Several studies in humans have appeared to demonstrate that strong social connections reduce the risk of cognitive impairment in older adults and that the opposite circumstance makes mental deterioration worse. The reason for this association is unclear, but it may be related to a direct mechanism through which social and mental stimulation strengthens connections between nerve cells in the brain (Alzheimer's Association, 2018d).

MENTAL ACTIVITIES

Currently, evidence for cognitive training's impact on the maintenance of cognitive function is encouraging but inconclusive and requires further study. Various studies do indicate that while it may not prevent Alzheimer's, keeping the brain active may help delay cognitive decline (Leshner et al., 2017).

Mental activities that may have an impact on cognitive decline include:

- Reading and writing every day
- Playing games involving strategy (e.g., checkers, chess, cards)
- Doing crossword puzzles, Sudoku, or other "brain" games
- Seeking out new activities and unfamiliar settings
- Continuing involvement in educational activities such as attending lectures
- Taking up new hobbies
- Playing online memory games or video games
- Doing routine activities (such as brushing teeth) with the nondominant hand
- Joining a club or attending social activities
- Volunteering for a cause of interest

BEHAVIORAL ACTIVATION

A recent study done in the United States focused on black patients, who have twice the rate of dementia as white patients, to learn whether behavioral activation could slow down cognitive decline and prevent dementia in older African Americans with mild cognitive impairment.



Behavioral activation uses goal setting and action plans in order to reinforce healthy cognitive, physical, and social activity in patients. Such action plans include visual cues, written schedules, and step-by-step sequencing to complete a task or goal, such as meeting a friend for lunch. The control group in the study received standard supportive treatment that included an organized, nondirective psychological treatment that promotes personal expression and expresses messages of optimism, respect, and empathy.

After 24 months, the outcome for cognition was measured by a decline in word recall using the Hopkins Verbal Learning Test. A secondary outcome was a decline in functional ability. Study results showed a 1.2% rate of cognitive decline in the behavioral-activation group compared with a 9.3% decline in the supportive-therapy group. Behavioral activation was linked to stable everyday function, whereas supportive therapy was linked to decline (Cassoobhoy, 2018; Rovner et al., 2018).

ALZHEIMER'S DISEASE SYMPTOMS

The cardinal symptoms of Alzheimer's disease include:

- Memory impairment
- Executive function and judgment/problem-solving impairment
- Behavioral and psychological symptoms

Memory Impairment in Alzheimer's Disease

Memory impairment is the most common initial symptom of Alzheimer's, and it is important to differentiate the memory impairment of Alzheimer's disease from that sometimes noted in people without Alzheimer's disease, which is often called *benign forgetfulness* or *age-related 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 eventually 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 Alzheimer's disease and other dementias is progressive and interferes with the person's activities of daily living and social and professional activities.



DIFFERENCES BETWEEN NORMAL AND ALZHEIMER'S-RELATED MEMORY LOSS	
Normal Age-Related Memory Loss (Benign Forgetfulness)	Memory Impairment with Dementia (Alzheimer's Disease)
Occasionally forgetting an assignment or a person's name but remembering it later	Forgetting things often and not remembering them later
Making an occasional bad decision	Making poor judgments and decisions a lot of the time
Failing to meet a financial obligation or balance a checkbook when more complicated than usual	Continually having problems managing monthly finances, and when balancing a checkbook, completely forgetting what the numbers represent and what needs to be done with them
Forgetting what day it is but remembering it later	Losing track of the date or time of the year
Forgetting one's destination for a moment	Becoming lost on one's own street, not knowing where one is, how one got there, or how to get back home
Occasionally forgetting the right word to use	Forgetting simple words, or substituting inappropriate words and making incomprehensible sentences
Occasionally misplacing things and finding them later on	Misplacing things often and being unable to find them
Being immersed in an activity and temporarily forgetting what one is supposed to be doing	Completely forgetting what one is supposed to do
Source: NIA, 2018.	

Early in the course of Alzheimer's, individuals are usually 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, causing them to 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 require protection to remain safe.

There are different kinds of memory that are supported by different systems in the brain. These various memory systems have a distinct purpose and distinct anatomy.

EPISODIC MEMORY

Episodic memory refers to memories of autobiographical events. Within episodic memory there are distinctions between immediate recall (e. g., remembering individual words studied in a list moments ago), memory for recent events, and memory of more distant events (i.e., remote memory). Memory for recent events—served by the hippocampus, entorhinal cortex, and other



structures in the medial temporal lobe—is prominently impaired early in developing dementia. But as the disease progresses, people gradually experience more long-term memory loss, referred to as *amnesia* (Squire & Dede, 2015).

People with Alzheimer's disease in the early stages do not appear to have any difficulty remembering distant events but may forget having done something five minutes ago. Memories of distant events often interfere with present activities, which can sometimes result in the person acting out routines from the past that are no longer relevant (Byrne, 2017; Wolk & Dickerson, 2017).

SEMANTIC MEMORY

Semantic memory refers to a portion of long-term memory that stores information about what one knows about the world and language that is common knowledge, such as the meaning of words, names of colors, etc. Unlike episodic memory, these things are not personal. They are common to all who speak the same language. Problems with semantic memory can include:

- **Anomia**, or the inability to find the right word. At first the person with Alzheimer's is aware of this and may make up for it by using sentences to describe an object they 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.
- **Aphasia**, or difficulty with and eventual loss of the ability to speak or understand spoken, written, or sign language. The person with Alzheimer's may substitute a word that is linked by meaning, use the wrong word but one that sounds similar, or use a completely different word with no apparent link. In the advanced stage of the disease, speech becomes unintelligible, and eventually the person becomes mute.
- **Agnosia**, or loss of the ability to recognize what objects are and what they are used for. This may involve failing to recognize who people are. Agnosia can be visual, auditory, or tactile, but visual is the most common form.

PROCEDURAL MEMORY

Procedural memory is the memory of how to carry out actions both physically and mentally, including actions that have become automatic. The loss of procedural memory can result in difficulties carrying out routine activities such as dressing, bathing, and cooking.

Apraxia describes the inability to carry out voluntary and purposeful movements despite the lack of motor or sensory deficits. This leads to progressive difficulty first with newly acquired skills and complex or technical skills, especially those that require integration of different stimuli. Actions that have become automatic, such as dressing, using utensils to eat, and other self-care tasks, are preserved until the late stages of Alzheimer's disease.



VISUOSPATIAL MEMORY

Visuospatial memory gives one the ability to navigate in the environment. It requires the formation, storing, and retrieval of mental maps. In persons with Alzheimer's, loss of this ability results in getting lost in familiar surroundings, wandering, and losing the ability to live independently.

WORKING MEMORY

Working memory refers to the capacity to temporarily store information that is needed to complete a specific task. It is the ability to not only remember information for a period of time but also to use, manipulate, and apply it, perhaps while also accessing other stored pieces of information (Byrne, 2017).

Executive Function, Judgment, and Problem-Solving Impairment in AD

Early in Alzheimer's, impairment of executive function can range from subtle to prominent. Family and coworkers may notice that the person is less organized or less motivated, and multitasking is often impaired. In addition, the person develops poor insight and reduced ability for abstract reasoning, and as Alzheimer's progresses, the person becomes unable to complete tasks.

Executive function refers to the high-level cognitive and mental abilities that help people engage in goal-directed actions. These include the ability to:

- Plan, problem solve, and initiate activities
- Understand and work through concepts and problems expressed in words
- Stay motivated
- Remain focused without getting distracted
- Regulate emotions
- Switch between tasks
- Self-monitor actions
- Use working memory
- Focus on important details, work toward a goal, and adjust to changes
- Stop an activity or task that has been completed

The patient with Alzheimer's often has **anosognosia**, which is a reduced insight into one's neurological deficits. Many patients underestimate their deficits or try to offer explanations or alibis for them when they are pointed out by others. It is often a family member and not the patient who brings cognitive impairment to the attention of healthcare professionals. Lack of



insight can present problems with safety, as patients may try to do tasks they are no longer able to perform, such as driving (Wolk & Dickerson, 2017).

Psychological and Behavioral Symptoms in AD

Psychological and behavioral symptoms are common in Alzheimer's disease, in particular during the middle and late stages of the disease.

Symptoms of dementia often cause psychological symptoms such as **anxiety** and a feeling of insecurity, and the patient with Alzheimer's may become dependent on a caregiver to help them manage their emotions. The caregiver may become the person's "anchor," and the patient may be distraught when the caregiver is not there to provide security (UCSF, 2018).

People with dementia often have **depression**, especially in the early to middle stages of the disease when they are aware that they are losing their functional abilities. They may grieve for future losses and worry about what will happen as their disease progresses. They may feel guilty about being a burden or becoming a burden on others, struggle with feelings of being useful, and feel hopeless (Day et al., 2018).

As the disease progresses the person may experience **apathy**, one of the most common psychological effects, which is defined as passivity or lack of interest or enthusiasm. It is essentially the feeling of **not** feeling, and the person usually is not aware of or bothered by it. It may, however, be difficult to distinguish between apathy and depression.

In late stages of Alzheimer's, the patient may develop **psychosis**, which may include delusions (fixed false beliefs) and hallucinations (seeing or hearing things that are not actually there) (Day et al., 2018).

Behavioral symptoms of Alzheimer's 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
- Agitation
- Aggression
- 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 and irritability
- Wandering, getting lost
- Reversals of the sleep/wake cycle
- Asocial sexual behaviors, such as masturbating in public

Many persons with Alzheimer's 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).

A significant behavioral symptom is **self-neglect**, which occurs when a person experiencing memory loss is unable to meet his or her own needs for eating a nutritious diet, carrying out appropriate hygiene, taking prescription medications, maintaining a clean home, obtaining medical care, or many of the others things that are usually performed on a daily basis without much thought. One of the earliest manifestations of Alzheimer's disease 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 (Day et al., 2018).

In the late stages of Alzheimer's, persons may spend more time sitting in a chair or lying in bed and eventually develop muscle rigidity, which leads to **physical deterioration** and a risk for falls. Eventually 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 Alzheimer's Disease

Alzheimer's disease has been classified into either three, four, five, or seven stages used for determining the level of care needed for patients with Alzheimer's, and for comparing groups of such patients with one another. These classifications are somewhat arbitrary, and there is a great deal of overlap among the various stages. One of the most commonly used classifications (to be discussed below) divides the disease process into **five stages**.



STAGE 1: PRECLINICAL ALZHEIMER'S DISEASE

During this stage of the disease there are no noticeable symptoms either to the person with the disease or those around him or her. This stage can last for years, and even decades, before symptoms begin to appear and a diagnosis is made.

STAGE 2: MINIMAL COGNITIVE IMPAIRMENT

During this stage, minor changes in memory and thinking ability develop that are not significant enough to affect work or relationships. The person may have memory lapses when dealing with information not easily remembered, such as conversations, recent events, or appointments. The person in this stage may also have trouble judging time required for completing a task and judging correctly the number of sequences of steps needed to complete a task. Making good decisions may become harder for people during this stage.

STAGE 3: MILD DEMENTIA DUE TO ALZHEIMER'S DISEASE

Alzheimer's disease is often diagnosed in this stage when it is clear to family and healthcare professionals that a person is having significant problems with memory and thinking that impact daily functioning. During this stage, the person may experience:

- Memory loss for recent events
- Difficulty with problem-solving, complex tasks, and sound judgment
- Changes in personality
- Difficulty organizing and expressing thoughts
- Misplacing belongings
- Getting lost

STAGE 4: MODERATE DEMENTIA DUE TO ALZHEIMER'S DISEASE

During this stage, which lasts from 2 to 10 years and is the longest stage, the person becomes more confused and forgetful and begins to require assistance with daily activities and self-care. The person may:

- Show increasingly poor judgment and deepening confusion
- Lose track of where they are, the day of the week, or the season
- Confuse family members or mistake strangers for family
- Become unable to learn new things or to cope with new or unexpected situations
- Wander
- Develop perceptual motor problems, such as getting out of a chair



- Experience even greater memory loss
- Become repetitive or make up stories to fill gaps in memory
- Need help with some daily activities, such as choosing appropriate clothing, grooming, toileting, and other self-care needs
- Become incontinent
- Undergo significant changes in personality and behavior
- Develop unfounded suspicions, delusions, or hallucinations
- Become restless or agitated, especially late in the day
- Lose impulse control, such as undressing at inappropriate times or places and uncharacteristically using vulgar language
- Have outbursts of aggressive physical behavior

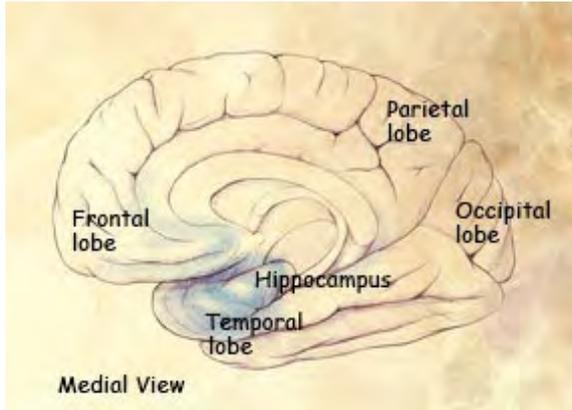
STAGE 5: SEVERE DEMENTIA DUE TO ALZHEIMER'S DISEASE

Severe dementia lasts between 1 and 5 years. During this stage of the disease mental functioning continues to decline and the person loses the ability to communicate coherently. Severe impairment of all cognitive functions occurs, and at this point the person requires total assistance with personal care. As the disease continues to progress the person may remain in bed most or all of the time as the body begins to shut down and the following occur:

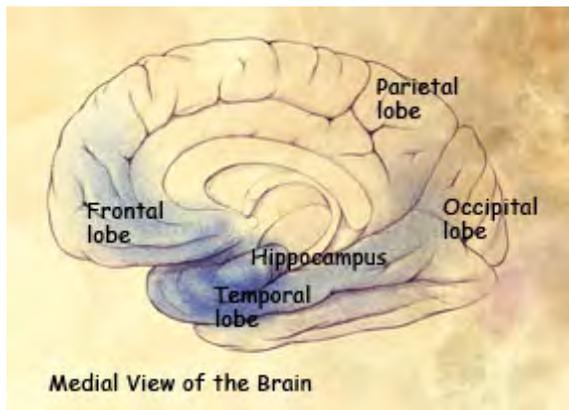
- Physical impairment involving unsteadiness, repeated falls, reduced mobility
- Inability to recognize immediate family members
- Weight loss
- Seizures
- Skin infections
- Groaning, moaning, or grunting
- Increased sleeping
- Lack of bladder and bowel control
- Impaired swallowing, which can lead to aspiration pneumonia (the most common cause of death in persons with Alzheimer's disease)
(Mayo Clinic, 2018; Johns Hopkins Medicine, 2018)



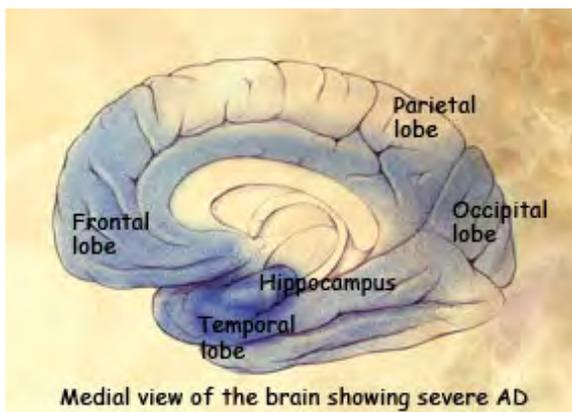
AREAS OF THE BRAIN AFFECTED DURING THE STAGES OF ALZHEIMER'S DISEASE



Preclinical stage: Areas of early damage to the hippocampus and portions of the frontal lobe (in blue).



Mild to moderate stages: Spread of damage forward into the frontal lobe and backward into the temporal lobe.



Severe stage: Extensive damage to areas during the final stage of Alzheimer's disease.

(Source: National Institute on Aging.)



DIAGNOSING ALZHEIMER'S DISEASE

Clinical diagnosis of Alzheimer's disease 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 Alzheimer's 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.

There is no single definitive test that can be done to identify Alzheimer's disease; however, Alzheimer's can be diagnosed today with over 90% probability using the following diagnostic tools:

- Patient medical history
- Physical and neurological examinations
- Neuropsychological testing
- Laboratory tests
- Brain imaging
(Cleveland Clinic, 2018)

Patient Medical History

The patient medical history helps to assess past and current health status and includes:

- Patient age and gender
- Chief complaint
- History of the current complaint
- Past medical history
- Current health status
- Psychosocial history such as marital status, living conditions, employment, sexual history, significant life events, diet, nutrition, and use of alcohol or other drugs
- Family medical history
- Review of systems to ask questions about current symptoms not included in the chief complaint
- Mood assessment to detect depression or other mood disorders that can cause memory problems, apathy and other symptoms that can overlap with dementia
- Review of all medications



Physical and Neurological Examinations

The physical and neurological examinations enable the clinician to assess the overall physical and neurological condition of the patient and provide more information about the current problem, helping to determine an appropriate plan of treatment. The physical exam may be a complete head-to-toe exam or a more focused examination, depending on the chief complaint. It generally includes:

- General appearance
- Vital signs
- Heart and lungs
- Head and neck
- Abdominal exam
- Extremities
- Specific exams for male and female

The neurological examination includes:

- Cranial nerve testing
- Reflex testing
- Coordination
- Gait
- Speech
- Muscle tone and strength
- Eye movement
- Sensory exam

(Alzheimer's Association, 2018f; Cleveland Clinic, 2018)

Neuropsychological Testing

Neuropsychological testing assesses the relationship between the brain and behavior. The tests help in the diagnosis and treatment of conditions that affect thinking, emotion, and behavior. These include Alzheimer's disease, various psychiatric problems (depression, anxiety disorders), medication-related conditions, substance abuse, strokes, and tumors. Neuropsychological testing includes mental status testing.



Mental status testing is done to evaluate memory, attention, and concentration, and to obtain an overall sense of whether a person is aware of symptoms. During a mental status examination, a clinician asks a patient a series of questions that are designed to test a range of everyday mental skills. Commonly used mental status examinations include the Mini-Mental State Exam, the Mini-Cog test, and the Montreal Cognitive Assessment.

MINI-MENTAL STATE EXAM (MMSE)

During the MMSE, a health professional asks a patient the following questions or instructs the patient to perform a task:

1. What is the date today? (3 points)
2. What is the season? (1 point)
3. What day of the week is it? (1 point)
4. What town, country and state are we in? (3 points)
5. What is the name of this place? (1 point)
6. What floor of the building are we on? (1 point)
7. I am going to name three objects. After I have said them, repeat them back to me. Remember what they are because I will ask you to name them again in a few minutes: apple, table, penny. (3 points)
8. I am going to spell a word forward and I want you to spell it backwards. The word is W-O-R-L-D. (5 points)
9. What are the three objects I asked you to remember a few moments ago? (3 points)
10. What is this called (showing the patient a watch)? (1 point)
11. What is this called (showing the patient a pencil)? (1 point)
12. Please repeat the following: No ifs, ands, or buts. (1 point)
13. Please read the following and do what it says, handing the patient a card that says, "Please Close Your Eyes." (1 point)
14. Please write a sentence. (1 point)
15. Please take this piece of paper in your right hand, fold it in half with both hands, and put it in your lap. (3 points)
16. Please copy this drawing (showing the patient a drawing of two overlapping pentagons) (1 point)

The maximum MMSE score is 30 points. A score of 20 to 24 suggests mild dementia, 13 to 20 suggests moderate dementia, and less than 12 indicates severe dementia. On average, the MMSE score of a person with Alzheimer's declines about two to four points each year (Alzheimer's Association, 2018f; Cleveland Clinic, 2018).



MINI-COG TEST

The Mini-Cog test 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 include executive function.

1. **Recall** (0–3 points). Ask the patient to listen carefully and to remember three unrelated words (examples: apple, table, penny) and then to repeat the words. The same three words may be stated to the patient for up to three attempts to repeat the words. Score 1 point for each word spontaneously recalled without cueing.
2. **Clock-drawing test (CDT)*** (0–2 points). 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. Score 2 points for a normal clock with all numbers placed in the correct sequence and approximately correct position (e.g., 12, 3, 6 and 9 are in anchor positions) with no missing or duplicate numbers. Hands are pointing to the 11 and 2 (11:10). Hand length is not scored. Inability or refusal to draw a clock (abnormal) = 0 points.
3. **Delayed recall.** Ask the patient to repeat the three words previously stated.

Scoring: The total score ranges from 0 to 5 points. A cut point of <3 has been validated for dementia screening, but many individuals with clinically meaningful cognitive impairment will score higher. When greater sensitivity is desired, a cut point of <4 is recommended, as it may indicate a need for further cognitive evaluation.

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

(Borson, 2015)

COMPUTERIZED TESTS

The U.S. Food and Drug Administration has cleared several computerized cognitive testing devices for use. These are the:

- Cantab mobile
- Cognigram
- Cognivue
- Cognision
- Automated Neuropsychological Assessment Metrics (ANAM)



Computerized tests have several advantages, including the fact that tests are given exactly the same way each time. Using both clinical tests and computer-based tests can give clinicians a clearer understanding of cognitive difficulties experienced by their patients (Alzheimer’s Association, 2018f).

INFORMANT QUESTIONNAIRES

Informant- or caregiver-completed questionnaires can also be employed to assess a patient for cognitive impairment. These include asking an informant who knows the patient well to answer a series of questions about the patient’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 ANNUAL WELLNESS VISIT

The Patient Protection and Affordable Care Act added a Medicare benefit known as the Annual Wellness Visit (AWV) in 2011, requiring an assessment to detect cognitive impairment. However, as of 2018, it has been found the AWV correlated with an increase in some measures of cognitive care, such as laboratory testing for reversible causes of cognitive impairment, but it does not appear to substantially increase recognition of undetected Alzheimer’s disease and related dementia diagnoses (Fowler, et al., 2018).

Laboratory Testing

Laboratory tests are performed to rule out other potentially reversible forms of cognitive impairment.

LABORATORY TESTS FOR COGNITIVE IMPAIRMENT	
Test	Associated With
Folate level	Folate deficiency
Vitamin B ₁₂	Vitamin B ₁₂ deficiency
Thyroid stimulating hormone (TSH) and T ₄	Thyroid disease
Complete blood count (CBC)	Anemia, infection
Electrolytes	Renal disease, dehydration
Glucose level	Diabetes
Urinalysis, microscopy and culture	Urinary tract infection
Liver enzymes	Hepatic disease

C-reactive protein (CRP), erythrocyte sedimentation rate (ESR)	Inflammatory processes
HIV antibody	AIDS
Rapid plasma reagin (RPR), venereal disease research laboratory (VDRL)	Syphilis
Drug screen	Illicit drug use
Paraneoplastic antibodies	Autoimmune encephalitis
Less Common Tests	Purpose
Cerebrospinal fluid (CSF) biomarkers: beta-amyloid, total tau protein, and phosphorylated tau	Confirm or rule out Alzheimer's disease
ApoE genotype	Confirm or rule out probable Alzheimer's disease
PSEN1, PSEN2, and APP	Genetic mutations
Sources: Cleveland Clinic, 2018; AACC, 2018; Lakhan, 2018.	

BLOOD TEST FOR ALZHEIMER'S DISEASE

Researchers at the Washington University of Medicine suggest that measures of beta-amyloid in the blood have the potential to help identify people with altered levels of amyloid in their brains or cerebrospinal fluid. They have developed a blood test for Alzheimer's disease that can detect early indicators of the disease long before first symptoms appear in patients (Bhandari, 2017). This blood test works by measuring the relative amounts of pathological and healthy forms of beta-amyloid in the blood.

Researchers have found that the test reliably detects beta-amyloid alterations in the blood of participants with mild cognitive impairment who also show abnormal amyloid deposit in brain scans. The test is able to detect Alzheimer's disease in people without clinical symptoms, on average, eight years before clinical symptoms appear, with an overall diagnostic accuracy of 86%. The test, however, is not yet ready to use outside of clinical trials. It is hoped that it will be readily available to the public within a few years (Nabers et al., 2018).

Imaging Studies

STRUCTURAL IMAGING

Magnetic resonance imaging (MRI) and **computed tomography (CT)** scans are the structural imaging techniques most commonly used in conducting diagnostic studies to determine a diagnosis of dementia. Structural imaging visualizes physical alterations in the brain that occur with aging and in various disease states. MRI is much preferred over CT for evaluation of dementia, as it allows for a broader range of brain tissue properties to be studied while avoiding exposure to potentially harmful ionizing radiation. However, CT scan is the best choice when a patient is too claustrophobic to undergo an MRI, has a pacemaker or ferromagnetic implant, or is unable to remain still long enough to tolerate the more time-consuming MRI.



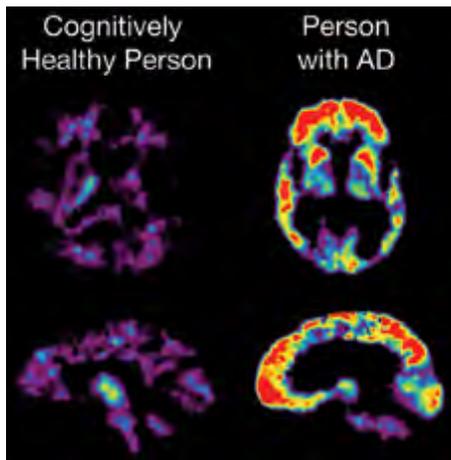
MRI is able to identify structural changes, including patterns of atrophy that characterize neurodegenerative disease and also shrinkage in specific brain regions such as the hippocampus, which may be an early sign of Alzheimer's disease. However, structural imaging is **not** used to diagnose Alzheimer's, as there is currently no agreed-upon standard values for brain volume that would establish the significance of a specific amount of shrinkage for any individual person at a single point in time.

The primary objectives of structural neuroimaging are to rule out potentially treatable causes of progressive cognitive decline, such as stroke, small vessel disease, or tumors, and to assess specific causes (i.e., neurodegenerative or otherwise) of dementia (Alzheimer' Association, 2018g; DeKosky, 2017).

FUNCTIONAL AND MOLECULAR NEUROIMAGING

Functional imaging enables in vivo (within a living organism) examination of how the brain functions. Research suggests that those with Alzheimer's typically have reduced brain cell activity in certain regions of the brain.

Functional imaging modalities include positron emission tomography (PET) and single photon emission computed tomography (SPECT). Both are nuclear medicine techniques that use ionizing radiation in the form of short-lived radioisotopes that are injected intravenously so that the activity in the brain or other organs can then be studied. Functional imaging can show a pattern of reduction of cerebral perfusion, which is often present in the brain of patients with dementia. The pattern of reduction of cerebral perfusion can be useful in distinguishing among the different types of dementia.



PET scans of the brain.
 (Source: National Institute on Aging/National Institutes of Health.)

Another functional imaging measurement is [F18] fluoro-deoxyglucose (FDG) PET/CT, which measures regional cerebral glucose metabolism. Glucose is the major source of energy for the brain, and FDG is an analogue of glucose—a substrate for the first step in the glycolytic pathway—that is transported into the brain. In many types of dementia, cerebral metabolism is regionally or globally reduced because of decreased blood flow and available oxygen or because

of decreased demand related to neuronal loss and dysfunction. The pattern of hypometabolism can aid in distinguishing among the various types of dementia (DeKosky, 2017; Lahkan (2018).

Amyloid PET imaging, a molecular imaging modality, is conducted in patients with Alzheimer's disease by injecting a trace amount of small molecules (F18-labelled amyloid tracer) to detect amyloid levels in the brain. Amyloid imaging provides a high degree of confidence in the diagnosis. A few tracers have been approved in the United States but are not yet reimbursed by the majority of commercial or government healthcare payers. Therefore, cost and availability limit widespread use of both functional and molecular neuroimaging at this time (DeKosky, 2017).

PET COVERAGE BY MEDICARE AND MEDICAID

The Centers for Medicare and Medicaid Services allows conditional coverage of one amyloid PET scan per patient in clinical studies so as to:

1. Exclude Alzheimer's disease in narrowly defined and clinically difficult differential diagnoses (e.g., Alzheimer's disease versus frontotemporal dementia), and
2. Enrich clinical trials that are seeking better treatments or prevention strategies for Alzheimer's disease, by allowing for selection of patients based on biological, clinical, and epidemiological factors.

(CMS, 2018)

Functional Assessment

Functional status can be assessed by direct examination of the patient or through obtaining information from a knowledgeable informant (i.e., family member or friend who routinely observes the person in his or her day-to-day activities). An assessment of the patient's functional status should include, at a minimum, an evaluation of the ability to perform instrumental activities of daily living (IADLs) (i.e., preparing meals, managing finances, etc.) and basic activities of daily living (ADLs) (i.e., eating, dressing, etc.). As Alzheimer's progresses, periodic assessment of the patient's ability to function should be carried out. Functional status can also be assessed using one of a number of available valid and reliable instruments.

There are many rating tools, and the one most commonly used is the **Functional Activities Questionnaire (FAQ)**. This tool is useful for monitoring functional changes over time. It may be used to differentiate those with mild cognitive impairment and mild Alzheimer's disease. (Mild cognitive impairment is not a form of dementia and does not interfere with everyday activities.) The FAQ is efficient to administer, taking 10 minutes or less to complete. It evaluates activities of daily living and is completed by an informant 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)

FAQ Rating:

- 3 points if dependent on others to complete the activity
- 2 points if requires assistance to complete the activity
- 1 point if has difficulty with the activity, but performs independently
- 1 point if never performed the activity and would have difficulty now
- 0 points if performs the activity independently with no difficulty
- 0 points if never performed the activity but could do so now

Scoring:

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

Two other functional assessment tools include the **AD8 informant-based questionnaire** and the **Quick Dementia Rating System**. The AD8 is a “yes/no” dementia screening tool designed to capture intra-individual change in cognitive and functional abilities of those patients with dementia. It takes only 2 to 3 minutes to complete and has been validated in many clinical settings around the world. The Quick Dementia Rating System is a 10-item multiple choice questionnaire that takes 3 to 5 minutes and provides a quantitative assessment of cognitive, functional, and behavioral domains to stage dementia severity. It combines a brief informant assessment with a brief performance measure to detect and stage dementia and other cognitive impairments (Galvin & Goodyear, 2017).

Another comprehensive Alzheimer's disease and related dementia staging tool is the **Functional Assessment Staging Test (FAST)**, which is a 16-item questionnaire designed to identify a number of factors that may influence the occurrence of problem behaviors. It should be used as an initial screening tool and as part of a comprehensive functional assessment or analysis of



problem behavior. FAST provides a clear assessment of the progression of Alzheimer's disease and categorizes stages of the disease from 1 to 7. Each stage identified by the FAST has a well-defined duration and set of cognitive and behavioral abilities affected, as well as the patient's mental age or developmental age (Fryling & Baires, 2016).

PHARMACOLOGIC AND MEDICAL MANAGEMENT

The current basis of management of patients with Alzheimer's dementia continues to be symptomatic, including treatment of behavioral disturbances, environmental manipulations to support function, and counseling regarding issues of safety. However, U.S. Food and Drug Administration–approved treatments can help improve or maintain the patient's cognitive and functional status. Caregivers and families are also helped by medicines that improve the behavioral and psychological symptoms of patients with Alzheimer's disease as well as nonpharmacologic 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 FDA has approved two types of medications for Alzheimer's disease—cholinesterase inhibitors and a glutamate antagonist—for treatment of symptomatic cognition and global functioning. Because the effects of these drugs are usually modest, it may be difficult to tell if the drugs are working.

CHOLINESTERASE INHIBITORS

Patients with Alzheimer's disease have reduced cerebral content of choline acetyltransferase, which leads to a decrease in acetylcholine production and impairs cortical cholinergic function. Cholinesterase inhibitors increase cholinergic transmission by inhibiting the breakdown of acetylcholine, a chemical messenger important for learning and memory. This allows for communication between nerve cells by keeping acetylcholine levels high. These drugs are symptomatic therapies and are not believed to be neuroprotective or to alter the underlying disease trajectory. The three cholinesterase inhibitors approved for treatment of **early to moderate Alzheimer's disease** are:

- Donepezil (generic & Aricept)
- Rivastigmine (Exelon)
- Galantamine (generic & Razadyne)

The average benefit of cholinesterase inhibitors in patients with mild to moderate dementia is a small improvement in cognition, neuropsychiatric symptoms, and activities of daily living. The relative effects appear to be similar for patients with more severe dementia at the time of diagnosis. Cholinesterase inhibitors cannot reverse Alzheimer's disease or stop the progressive destruction of nerve cells. The medication eventually loses its effectiveness because dwindling brain cells produce less acetylcholine as the disease progresses. Common side effects include



nausea and diarrhea, anorexia and weight loss, bradycardia and hypotension, and sleep disturbances (Press & Alexander, 2018).

GLUTAMATE ANTAGONIST

The second type of medication is the glutamate antagonist memantine, which appears to have modest benefits in patients with **moderate to severe Alzheimer's disease**. Memantine regulates the activity of glutamate, a chemical messenger critically involved in the regulation of cognitive functions and memory. Memantine has been shown to improve cognition and global assessment of dementia, but with small effects that are not of clear clinical significance. Improvement in quality of life and other domains are suggested but not proven.

- Memantine (generic & Namenda)
- Memantine XR, Namenda XR

Memantine appears to have fewer side effects than the cholinergic agents. Dizziness is the most common side effect, as well as headache and constipation. Confusion and hallucinations have been reported to occur at a low rate. Memantine use does, however, seem to increase agitation and delusional behaviors in some patients with Alzheimer's disease.

Memantine is commonly added to cholinesterase inhibitor therapy when patients reach a moderate stage of Alzheimer's disease. This combination leads to modest improvements in cognition and global outcomes in patients with advanced disease (Press & Alexander, 2018).

ANTIOXIDANTS

The antioxidant vitamin E (alpha-tocopherol) has been studied in the treatment of Alzheimer's. The data suggests that overall vitamin E at a dose of 2,000 IU per day provides modest benefit in delaying functional progression in patients with mild to moderate Alzheimer's disease, but with no measurable effect on cognitive performance. The benefits of vitamin E could also be cancelled out by combination therapy with memantine (Press & Alexander, 2018).

DRUGS WITH UNPROVEN BENEFIT

Several other therapies have been studied in patients with dementia with largely negative results, including:

- Estrogen replacement
 - Anti-inflammatory drugs
 - Ginkgo biloba
 - Statins
 - Vitamin B supplement
 - Omega-3 fatty acids
- (Press & Alexander, 2018)



Pharmacologic Management of Behavioral and Neuropsychiatric Symptoms

Behavioral and neuropsychiatric symptoms are common and, as mentioned earlier, are often more problematic than memory impairment. Such symptoms can include:

- Depression
- Anxiety
- Apathy
- Agitation
- Aggression
- Aberrant motor disturbance
- Aberrant vocalizations
- Hallucinations
- Delusions
- Disinhibition
- Sleep disturbances
- Wandering

One or more of these symptoms are present in 60% to 90% of patients with dementia, and the presence of these symptoms leads to more functional and cognitive impairment. Agitation, hallucinations, depression, and aggression are often the reasons why patients with dementia are placed in a skilled care facility (Lu, 2017). Although there are no FDA-approved medications for the behavior problems associated with dementia, the following medications are commonly used:

Antidepressants. Selective serotonin reuptake inhibitors (SSRIs), in particular citalopram (Celexa), are useful in the management of agitation and paranoia. These medications are well tolerated but have limited evidence of effectiveness in the treatment of neuropsychiatric symptoms of dementia other than for depression.

Anxiolytics. Antianxiety medications are used for anxiety, restlessness, verbally disruptive behaviors, and resistance. They include benzodiazepines, such as lorazepam (Ativan) and oxazepam (Serax). Benzodiazepines have limited value in patients with dementia and are not recommended for the management of neuropsychiatric symptoms. When benzodiazepines are used, they should be limited to brief stressful situations such as a change in residence or other anxiety-provoking events.

Antipsychotics. When nonpharmacologic interventions and pharmacologic approaches fail to manage symptoms that result in severe distress or safety issues, antipsychotic medication may be required. Atypical neuroleptics such as risperidone (Risperdal), olanzepine (Zyprexa), and



quetiapine (Seroquel) are most commonly used. Antipsychotic agents have limited effectiveness and are associated with increased mortality. When deemed necessary, low doses are suggested, and for short-term use when possible.

Analgesics. There is a weak association between pain and behavioral issues such as verbal or physical aggression and other agitated behaviors. Patients with dementia are often unable to express the fact that they are in pain. Studies have shown the effect of analgesics to be positive in patients with dementia. Acetaminophen (Tylenol) is generally the first line of treatment for suspected pain in patients with dementia (Press & Alexander, 2018; Lu, 2018; Franchi, 2016).

Managing Coexisting Health Problems

People with Alzheimer's disease often have other health problems common to older adults, such as:

- Impaired hearing and vision
- Dental problems
- Hypertension
- 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 Alzheimer's disease, and the confusion intensifies. Recognition and treatment of any and all coexisting conditions can help improve the patient's functional ability 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 Alzheimer's may be unable to communicate about their visual impairment, it may go undetected.

Deterioration in a person's hearing may interfere with his or her conversational ability. Questions may be misinterpreted and answers may be inappropriate. Hearing impairment can also contribute to errors in judgment. 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 Alzheimer's disease are no exception. Unless treated, depression can further impair function. SSRIs have been shown to be effective in treating depression in persons with dementia. Depressed persons with Alzheimer's disease will also benefit from regular exercise. Effective treatment of the person's depression has a secondary benefit of reducing caregiver stress.

REHABILITATION FOR PERSONS WITH DEMENTIA

The **goals** of rehabilitation for persons with dementia are to help maintain or improve higher cognitive function and engagement in daily activities to the extent possible as the disease progresses, devise strategies to compensate for declining function, and provide caregivers with the education and skills they need to create a supportive environment and reduce disability.

Occupational therapy, physical therapy, and speech-language pathology services can be of great benefit to patients with dementia as well as to their family members and other caregivers. (See also "Caring for the Person with Alzheimer's Disease" below.)

Occupational Therapy

Occupational therapists typically focus on five areas of human occupation when working with patients with dementia. These areas include:

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

The goals of the occupational therapist are to maximize the patient's involvement in both ADLs and IADLs, promote safety, and enhance a patient's quality of life. OT practitioners focus on identifying the patient's remaining abilities rather than on his or her deficits and looking for ways to maintain and prolong the person's independence.

EVALUTION PROCESS

Occupational therapists evaluate patients with dementia to determine their strengths, impairments, and performance areas that need intervention and to help patients to retain existing function for as long as possible. When working with dementia patients, occupational therapists use a family-centered model that includes family caregivers in all aspects of the process.



The process begins with an occupational profile, an analysis of occupation, and the use of standardized and nonstandardized assessment tools to evaluate specific domains, such as those described in the table below. During the evaluation process the occupational therapist also identifies caregiver concerns about occupational performance and the handling of difficult behaviors.

OCCUPATIONAL THERAPY ASSESSMENT TOOLS	
Domain	Tool
Activities of daily living	<ul style="list-style-type: none"> • Functional Independence Measure (FIM): Assesses the person's physical and cognitive disability and focuses on the burden of care • Kohlman Evaluation of Living Skills (KELS): Assesses a patient's ability to perform both ADLs and IADLs
Instrumental activities of daily living	<ul style="list-style-type: none"> • Routine Task Inventory: Assesses through observation the degree to which a person's cognitive restriction interferes with everyday task performance • Lawton Scale for IADLs: Assesses independent living skills and is useful in determining functional baseline and improvement or deterioration over time
Leisure	<ul style="list-style-type: none"> • Interest Checklist: Elicits information about the person's past and present leisure activities and interests and the degree of attraction toward them
Motor skills	<ul style="list-style-type: none"> • Berg Balance Scale (BBS) and Timed-Up-and-Go (TUG): Assess balance • Tinetti Falls Efficacy Scale (FES): Assesses both balance and gait
Cognitive function skills	<ul style="list-style-type: none"> • Allen Cognitive Level Screen: Performs a quick estimate of an individual's learning and problem-solving abilities during performance of three visual motor tasks of increasing complexity • Cognistat: Assesses neurocognitive functioning in the general domains of consciousness, orientation, and simple attention, and in the five major domains of language, constructional ability, memory, calculation skills, and executive skills
Physical environment	<ul style="list-style-type: none"> • Home Safety Checklist (HSC): Measures overall home safety • Home Environmental Assessment Protocol-Revised (HEAP-R): Evaluates the environment as the caregiver and person with dementia work together to adapt to progressive cognitive decline



Nutrition	<ul style="list-style-type: none"> • Minimal-Eating Observation Form-Version II: An interactive observational tool in which the therapist notes the presence or absence of aberrant eating, feeding, or swallowing behaviors • McGill Ingestion Skills Assessment (MISA): Assesses a person's ability to safely and independently consume a variety of food and liquid textures
Accompanying conditions	<ul style="list-style-type: none"> • Assessment and referral for vision or hearing loss
Source: Schaber & Lieberman, 2010.	

INTERVENTIONS

Occupational therapists provide evidence-based interventions throughout the continuum of care both as direct care providers and as consultants. They work as part of an interdisciplinary team to address all aspects of the patient's healthcare needs, providing interventions across the entire healthcare spectrum, which includes acute care, rehabilitation centers, skilled nursing facilities, outpatient facilities, the home, and community settings.

During Early Stages

Interventions in the early stages of Alzheimer's disease may focus on compensating for a loss of cognitive abilities rather than remediating deficit areas, recognizing that new learning during this stage becomes impaired. During this stage of the illness occupational therapists:

- Promote community involvement of the patient and caregiver
- Provide education to help the patient and caregiver prepare for the disease process
- Establish training strategies and assistive techniques based on the patient's functional cognition
- Assist to build on past skill sets and to maintain present abilities utilizing the patient's procedural memory
- Observe the person at home and recommend changes such as adjusting the demands of activity and increasing environmental supports
- Suggest memory aids such as calendars, medication reminders, and daily routine schedules
- Provide education regarding specific areas of deficit

During Middle Stages

During the middle stages of the illness when there is a greater decline in memory and high-level cognition, occupational therapists:



- Recommend memory loss programs
- Offer training to caregivers in coaching the person to perform ADLs with supervision in order to maintain the ability to perform an automatic skill
- Observe the patient at home and recommend changes (e.g., creating new routines, modifying existing routines, adding adaptive equipment, etc.) that will make routines easier to perform more independently
- Develop maintenance programs
- Simplify or adapt tasks, conduct activity analyses, and downgrade tasks to the patient's level of ability
- Identify what the person's hobbies and occupations are to ensure interventions are client-centered, which can assist with overall well-being
- Encourage engagement, education, and training

During Later Stages

During the later stages of dementia when the person becomes dependent in all or most self-care activities, occupational therapists:

- Assess the patient's functional cognition to determine the capacity for various intervention techniques
- Adapt activities to the patient's level of ability
- Provide training to caregivers in building habits and routines with ADLs
- Assist with maintaining physical, social, and occupational engagement
- Implement appropriate external assistance to support participation in a task
- Determine if the person has the ability to follow multistep commands or only a one-step verbal or tactile command
- Discover the cueing strategies the patient best responds to and teach caregivers how and when to use them
- Maximize performance with all activities by considering the time of day when the patient is most alert
- Stimulate activity in physical, social, and functional areas
- Modify activities the person once enjoyed to provide mental stimulation during times when wandering activity is of concern
- Perform a complete home safety evaluation to prevent falls or other injuries



- Focus on caregiver support and safety
- Provide training and education to the caregiver in the management of difficult physical, emotional, and behavioral changes
- Maintain emotional connection between the caregiver and patient by creating activities they can do together
- Recognize caregiver involvement and identify their concerns

(AOTA, 2018a; AOTA, 2018b)

INTERVENTION TECHNIQUES

Listed below are several evidence-based techniques occupational therapists use when working with patients with dementia.

Teepa Snow's **Positive Approach to Care** is an educational program that helps family caregivers and professionals better understand the changes in the brain and how it feels to be living with dementia. The program recognizes that human behavior is almost always an attempt to communicate or meet a personal need. The philosophy behind this approach is that the person with dementia is doing the best that they can, and if something is not working, it is the responsibility of the caregiver to change the approach toward the person and to discover what can be done differently to address a challenging situation. Often caregivers and providers do not recognize that they are the cause of challenging behaviors due to approaches that do not work or a lack of understanding about an individual's unique preferences or needs. This program encourages caregivers to be flexible and adaptable in their approach to the specific needs of the person with dementia (Murphy & Maidens, 2016).

Occupational therapists can help meet caregivers' needs using **Skill2Care**, an intervention designed to reduce behavioral symptoms through an environmental modification approach. Skill2Care involves occupational therapists training caregivers on reducing confusion and increasing safety for the patient with dementia by making changes in the living space, teaching communication skills, simplifying tasks for the patient, and engaging the patient in meaningful activities. Occupational therapists also refer caregivers to other community resources, such as respite care, nutritional services, or transportation services. Outcomes include reduced caregiver burden and distress with related behavioral symptoms (Hughes, et al., 2017).

The **validation method** emphasizes listening to those with dementia in a way that shows empathy and respect so the person feels valued, not judged. It is about the person's needs and advocates that, rather than trying to bring the person with dementia back into our reality, it is more positive to enter their reality, resulting in reduced anxiety and restored dignity.

Reality orientation is an approach used to help the person with dementia engage in and connect with their surroundings by frequently referencing the time of day, date, season of year, location, and current surroundings and events in conversations with the person. Studies have shown reality orientation to improve cognitive functioning.



Reminiscence is an approach that uses all the senses to help a person with dementia recall and talk about their life story. This approach has been shown to improve mood, well-being, and some mental abilities such as memory. It involves talking about things from the past using prompts such as photos, familiar objects, or music.

Tailored Activity Program (TAP) is an occupational therapy intervention shown to reduce behavioral symptoms and to ease caregiver burden. It focuses on the person's capabilities and the demands of the external environment in order to find the best activity interventions to manage behaviors while also enhancing engagement and pleasure.

Environmental-based methods include the use of music and natural sounds, aromatherapy, bright light therapy, and a multisensory approach such as Montessori, which focuses on rediscovering and supporting the person behind the dementia, providing activities with meaning and purpose based on the person's needs, interests, skills, and abilities. A multisensory approach helps reduce and prevent challenging behaviors, reduces boredom and loneliness through activities that support roles and routines, and improves self-esteem.

CASE

Marguerite, an occupational therapist, has begun working with John, a 78-year-old man with early-stage Alzheimer's disease. According to his history, John worked outdoors all of his life as a park ranger and was an avid gardener. He loves to be outdoors and continues to work in his garden on a daily basis. Recently, however, John has begun to wander off his property, and concerned individuals in the neighborhood have been bringing him back home.

John's family members ask Marguerite whether John should be allowed to continue working in his garden in the backyard and for ways to keep him safe and prevent him from wandering off and getting lost. Marguerite assesses John's ability to be oriented to his yard and his response to a stop sign set in his path. She finds that he ignores the stop sign and continues past it. Marguerite recommends that the best option for maintaining John's safety is to erect a fence around the garden in the backyard and install an alarm that will go off if John should open the gate. (Adapted from AOTA, 2018b.)

Physical Therapy

In the past, it was believed that physical therapy was not useful for individuals with dementia, as physical therapy involves patient education, compliance with instructions, and adherence to a plan of care. People with Alzheimer's disease or other forms of cognitive impairment make these aims difficult to achieve. However, it has been found to be true that individuals with cognitive decline can learn through repetition to create or preserve procedural memory—such as knowing how to walk, getting out of bed, or getting up from a chair—and can benefit from working with a physical therapist.

Upon initiation of rehab, a physical therapy assessment begins with a determination of the health literacy needs of patients, caregivers, and other healthcare professionals and ways in which all members of the rehabilitation team can communicate most effectively. An explanation of the goals of therapy are provided and needs identified.



Being aware that assessment and screening tools used to identify needs and set goals are different based on the patient population, physical therapists can assess a patient's risk for falls, ability to walk safely, performance of functional tasks, and presence of pain.

ASSESSMENT TOOLS

Timed Up and Go Test (TUG) is used to determine fall risk and to measure the progress of balance, sit-to-stand, and walking. It is designed for people with impairments including Alzheimer's disease. This test requires a chair with an armrest, a stopwatch, and a tape measure to mark off 3 meters (approximately 10 feet). The patient is seated in the chair. The stopwatch is started following the therapist's command to the patient to stand up and walk the measured distance, turn around, walk back to the chair, and sit down. The stopwatch is stopped when the patient is seated. Time to complete the task is averaged over two trials; if a patient takes 14 seconds or longer, they are classified as high risk for falling.

Tandem Stance Test assesses the individual's balance. The patient is asked to place one foot directly in front of the other, touching heel to toe. A chair can be used as needed to attain this position. Holding this position tests lateral postural stability by narrowing the base of support. The length of time the person is asked to hold this position is commonly 10 to 30 seconds.

The **GaitRite mat** is a portable gait analysis system that measures how a patient walks. It measures gait patterns for both time (temporal) and space (spatial) through pressure sensors in the mat. The patient is asked to walk on the mat walkway, and software converts the sensor data into foot placement patterns and overall gait patterns. The mat provides valid and reliable walking measurements such as footfall patterns, step length, cadence, and speed, and can measure changes in walking or gait patterns through replication of real-life scenarios.

The **Pain Assessment in Advanced Dementia (PAINAD)** is a reliable assessment tool used with patients who have advanced dementia and are judged to potentially be in pain. The scale requires close and attentive observation of the patient's breathing, vocalizations, facial expressions, and body language. Each is graded from 0 to 2, with 0 being normal, 1 being abnormal, and 2 being extremely abnormal. A score of 1–3 is interpreted as mild pain, 4–6 as moderate pain, and 7–10 severe pain.

The **Functional Assessment Staging Tool (FAST)** describes the progressive stages of Alzheimer's disease. It is a cognitive staging scale that can assist in identifying lost and preserved cognitive function. Findings are used to better identify interventions to enhance quality of life and reduce care burden and the costs associated with progressive cognitive impairment. The tool is recommended for use on initial examination and whenever assessing changes in cognitive function and dysfunction. FAST is determined through interview or report from an informant and/or by observation of patient performance.

DEVELOPING A PLAN OF CARE

The focus of physical therapy for patients with dementia is to improve balance, muscle strength, and mobility; to prevent falls; and to provide pain management. Physical therapists consider both



patient and caregiver needs when developing such a plan, which can include behavioral, cognitive, mental, physical, and functional domains.

The plan of care should enhance retention of the patient's remaining capabilities and appeal to the patient's individual abilities and interests. The physical therapist should consider using familiar objects or actions in the therapy regimen for patients with Alzheimer's disease and other dementias. Finding out what motivates the individual patient and incorporating favorite pastimes into the therapy plan allows for emotional development and increased feelings of comfort.

Therapists can offer multimodal exercises, such as using resistance bands for strength, power, balance, and gait training, for patients with limited attention spans, those who are easily overstimulated by verbal instructions, and those who become anxious and agitated with too many transitions between tasks. Physical therapists must often use nonlanguage interactions based on awareness of a patient's tolerance for interpersonal engagement, cognitive fatigue, or sensory overload.

Physical therapists must be aware that communication is a major issue when working with patients with dementia. Various communication strategies and teaching techniques for patients with dementia include:

- **Verbal cueing:** Using short, simple, or one-step verbal instructions
- **Visual cueing:** Pointing to an object or gesturing a movement
- **Tactile cueing:** Taking a patient's hand to indicate going for a walk
- **Task breakdown:** Breaking down tasks into short, simple steps to be completed separately
- **Chaining:** After mastering the steps in a task, linking them together into one fluid movement
- **Hand-over-hand facilitation:** Taking the patient's hand or other body part and moving it through a desired motion

Physical therapists involve the patient's family and caregivers in therapy, teaching them the importance of maintaining routines and cues that work to initiate tasks. They teach them how to safely move, lift, or transfer the patient; how to use adaptive equipment and assistive devices; and how to use good body mechanics to complete a task in order to prevent injury. They can also provide a home safety assessment (Ries, 2018; Cleveland Clinic, 2017; Jacobs, 2018; APTA, 2015). (*See also "Resources" at the end of this course.*)

CASE

Mr. Hartman, a 68-year-old retired professor, was diagnosed with Alzheimer's disease approximately one year ago and is referred to physical therapy for evaluation and treatment of increased falls in the home and community. During his initial evaluation, Mr. Hartman seems ill at ease and shows inconsistent ability to follow directions. Mr. Hartman's wife tells the



physical therapist that she is concerned about her husband's safety when walking in their yard, as he has fallen twice there, but that he loves to watch the birds come to their neighbor's backyard feeder.

Upon completing the evaluation, the therapist determines that Mr. Hartman demonstrates significantly decreased lower extremity strength, static and dynamic standing balance, and safety awareness. Having learned from his wife that Mr. Hartman enjoyed working as a carpenter's assistant during summer vacations when he was growing up, the therapist obtains a simple kit to assemble and paint a wooden bird feeder and centers his physical therapy sessions around this familiar activity.

While it is difficult for Mr. Hartman to follow complex instructions related to specific repetitive exercises, he is easily able to pedal a seated lower extremity ergometer while sanding the bird feeder pieces; practice repeated sit \leftrightarrow stand transfers while assembling the feeder; and work on balance by retrieving paints, sandpaper, and pictures of birds from different parts of the therapy gym, on high shelves, off the floor, etc., with close supervision. By the third physical therapy session, Mr. Hartman appears more at ease, and his wife states that he even seemed eager to come and work on his project today.

Speech-Language Pathology

The speech-language pathologist (SLP) plays a major role in treating persons with dementia. SLPs manage cognitive, communication, and swallowing deficits that are associated with dementia. SLPs assess, diagnose, and 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. They educate caregivers about communication difficulties and provide strategies to facilitate effective communication.

As the disease progresses, the Alzheimer's patient may develop difficulty with swallowing resulting from reduced muscle strength and coordination, which can lead to aspiration and, consequently, pneumonia. SLPs make diet modification recommendations consisting of altering the viscosity, texture, temperature, or taste of a food or liquid to facilitate safety and ease of swallowing and to provide additional sensory input for swallowing. Postural techniques involve adjusting the patient's posture or position during feeding, aimed at protecting the airway and providing safe transit of food and liquid (ASHA, 2018).

CARING FOR THE PERSON WITH ALZHEIMER'S DISEASE

The person with Alzheimer's disease 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 cared for 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 is



multidisciplinary, including medicine, nursing, social work, occupational therapy, physical therapy, and speech-language pathology.

The **challenges** of caring for someone with Alzheimer's disease include communicating effectively with the person; assisting with ADLs 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.

Providing a Safe Home Environment

As dementia progresses, physical and social environments prove ever more difficult for the person, and a safe environment is essential. Things to consider in creating such an environment include:

- Arranging furniture simply and keeping the arrangement consistent
- Keeping the environment uncluttered
- Removing loose rugs and taping down carpet edges that could contribute to falls
- Using extra lights in entryways, doorways, stairwells, hallways, and bathrooms
- Installing night lights in hallways and bathrooms
- Disposing of, or safely storing old medications, and locking up medications currently being taken
- Installing a hidden gas valve or circuit breaker on the stove so the person cannot turn it on
- Removing knobs from the stove
- Keeping appliances away from water sources such as sinks
- Installing locks out of sight
- Placing deadbolts either high or low on exterior doors to make it difficult for the person to wander away
- Removing locks in bathrooms or bedrooms so the person cannot get locked inside
- Disabling or removing guns or other weapons
- Installing a walk-in shower
- Adding grab bars to the shower or tub and at the end of the vanity
- Adding textured, nonslip stickers to slippery surfaces
- Securing and locking up all cleaning products



- Keeping the door to the laundry room locked
- Using appliances with automatic cut-off mechanisms
- Replacing long electrical cords on appliances with coiled or retractable ones
(Alzheimer's Association, 2018h)

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.

An environment can help support or hinder social connection and sense of self. It can give independence or force dependency. A homelike supportive environment provides continuity and familiarity in everyday life, encourages family involvement, and strengthens social ties. The following elements should be included in designing and creating a homelike supportive environment:

- Unobtrusive clinical support and the use of language common to the home, not to healthcare
- Smaller-scale living spaces
- Homelike kitchens
- Welcoming dining areas
- Homelike furniture and furnishings
- Personalization of bedrooms
- Warm colors
- Continuous indoor and outdoor spaces
- Sensitivity to culture, religion, and spirituality
- Family participation
- Engagement in daily life experiences
- Individualized care
- Flexible problem-solving for individual care issues
- Freedom of movement
- Individual control and decision-making wherever possible



Some basic principles for creating and maintaining such an environment both in the 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 designed to allow him or her to use existing skills to perform familiar tasks. Avoid complexity in activities, as this can create anxiety.

Maintain a routine. A person with dementia generally 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 they 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 the patient in his or her own clothes, and keep him or her well groomed. This aspect of care 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 may require 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. This 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 Alzheimer's dementia progresses, the person's ability to communicate begins to deteriorate, and the following changes occur:

- Difficulty finding the right words
- Repetitious use of familiar words
- Describing familiar objects rather than calling them by name
- Inventing new words for familiar objects
- Losing one's train of thought
- Reverting back to native language
- Problems with organization of words
- Reduction in efforts to speak
- Relying on gestures more than speaking

Communicating with the person who has Alzheimer's disease begins with patience, respect, understanding, and remembering that the person is not deliberately being difficult. If the individual has a vision or hearing deficit, it is always important to make certain hearing aids and glasses are being worn so as to avoid additional barriers to communication.



The following are ways to communicate more effectively with someone in the **early stage** of Alzheimer's:

- Avoid making assumptions about the person's ability to communicate.
- Do not exclude the person from conversations.
- Speak directly to the person rather than to his or her caregiver or companion.
- Be patient and take time to listen to the person express his or her thoughts, feelings, and needs.
- Give the person time to respond and do not interrupt unless the person requests help.
- Ask the person what help may be needed.

In the **middle stage** of Alzheimer's, as the disease progresses, the person will have more and more difficulty communicating. It is helpful to:

- Engage with the person in one-on-one conversation in a quiet place with minimal noise and other distractions.
- Speak slowly and clearly, keep sentences simple, and focus on one idea at a time.
- Face the person and maintain eye contact.
- Give the person adequate time to respond.
- Be patient and offer reassurance to encourage expression of thoughts.
- Ask one question at a time.
- Ask yes or no questions; avoid open-ended questions.
- Avoid correcting or criticizing. Listen and attempt to find the meaning in what is being said.
- Repeat what the person has said for clarification.
- 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").
- Avoid arguing.
- Offer clear, step-by-step instructions for tasks.
- Give visual cues or demonstrate tasks to encourage participation.
- Attempt written notes when spoken words seem confusing.

In the **late stage** of Alzheimer's, the person may rely on nonverbal communication such as facial expressions or vocal sounds. The following communication techniques are helpful during this stage of the illness:



- Approach the person from the front and identify who you are.
- Encourage nonverbal communication. To understand what the person is saying, ask him or her to point or gesture.
- Use touch, sights, sounds, smells and tastes as a form of communication.
- Consider the feelings behind words or sounds. Emotions are often more important than what is being verbally expressed.
- Avoid talking down to the person and 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.
- Use positive body language: relax, lean forward, and smile.
- Repeat your message as often as necessary.
- Distract the anxious or agitated person.

(Alzheimer's Association, 2018i)

Nonverbal communication, especially touch, between caregivers and those with Alzheimer's 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 Alzheimer's 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.

Basic Activities of Daily Living (ADLs)

To persons with Alzheimer's disease, the tasks of daily living can be frustrating and overwhelming. 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. It is important to remember that support for ADL function must recognize the person's functional ability and extent of cognitive impairment and provide person-centered care practices.



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 Alzheimer's disease to function on their own. This entails determining the manual and cognitive activities involved in the completion of a task and organizing the task into manageable sections. **Verbal coaxing** allows the person to perform the activity, and when they complete the 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 skills 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 GROOMING

Bathing can be a challenge because persons with Alzheimer's disease 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. Choose the most relaxed time of day for bathing and grooming. A partial sponge bath may be adequate, as a complete bath may not be needed every day.

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. With patients who refuse to attend to daily activities, such as bathing, do not ask them if they **want** to do it; ask them **when** they would like to do it. Offering choices can be very helpful.

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. Use an electric razor for shaving to reduce the risk of cuts, especially if the person is taking blood-thinning medications such as Coumadin.

DRESSING

It is important to provide a comfortable and safe area for dressing (e.g., bathrooms may increase risk for falls). Adjustable bed height may reduce bending and prevent caregiver injury. The following are principles and tips for accomplishing this everyday activity of living:



- Respect the individual's style and cultural clothing preferences. Obtain such information from the person with dementia and his or her family.
- Lay out two outfits to encourage freedom of choice.
- Ensure that dirty clothes are promptly removed.
- Use clothing as a conversation starter to engage the person.
- Explain all actions before progressing.
- Provide encouragement and positive reinforcements for as much independence as possible.
- Simplify the dressing process by laying out clothing items in the order they will be used.
- Give short verbal instructions and gentle physical prompting.
- Label drawers with the type of clothing they contain.
- Plan for sufficient time to dress.
- Choose comfortable, simple clothing options, such as those with zippers and Velcro instead of buttons and ties; pull-on pants and skirts are easier to put on.
- Provide comfortable, nonslip shoes.
(Prizer & Zimmerman, 2018)

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.

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 Alzheimer's, feel embarrassed when completely undressed, so removing and replacing one article of clothing at a time may work better.

TOILETING

Caregivers must understand that the person with Alzheimer's 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.

Because the person may not remember where the bathroom is, make the bathroom easy to find and use. A sign labeled with a word and/or colorful picture may be helpful. Check the location of mirrors in the bathroom; people with dementia may confuse their reflection for someone else already in the room and not go in because they think the toilet is occupied. Also, it is important



to know that the person may not recognize the toilet as the appropriate place to urinate. Remove objects in the environment that can be mistaken for a toilet, such as large planters. A bedside commode or urinal may be helpful if getting to the bathroom is a problem, especially at night.

Other ways to assist with toileting include:

- Talk to the family to assess urinary and bowel patterns.
- Make certain the path to the bathroom is clear with no obstacles.
- Encourage independence by providing assistance only as needed.
- Allow sufficient time and do not rush the person.
- 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, as are an elasticized waist and pull-up pants.
- Use a urinary alarm system for reminders.
- If incontinence occurs at night, avoid caffeine and fluids for 2 to 3 hours before bedtime.
- If it is difficult to get to the toilet, a portable commode or urinal may be helpful.
(Alzheimer's Society, 2018a; Prizer & Zimmerman, 2018)

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 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 Alzheimer's disease and may be caused by physiologic or psychological factors. In early-stage Alzheimer's, 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.

In the later stage of the illness, profound memory loss 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.

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 Alzheimer's 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.

Supporting the Eating Process

The following are helpful ways to assist the person with dementia to eat and to enjoy the process of eating:

- Provide a quiet, relaxing, and homelike atmosphere.
- Ensure the dining area is well lit.
- Maintain familiar dining routines.
- Reduce distracting stimuli.
- Play soothing music during meals to decrease agitation.
- Facilitate social eating with others in the earlier stages of the disease; limit social stimulation in the later stage.
- Allow the person to choose mealtimes or adjust times based on agitation or disorientation.
- Offer food choices.
- Offer culturally appropriate foods.
- Keep the table free of clutter.
- Use white dishes to help distinguish food from the plate, and use placemats of contrasting color to help distinguish the plate from the table. Patterned plates, bowls, and linens may be confusing.
- Provide bendable straws or lidded cups for liquids.



- To prevent overeating, limit access to food between meals, maintain a schedule, and monitor intake.
- Provide ample time to eat; do not rush the person.
- Ignore messy eating; it is more important for the person to eat than to be tidy.
- Sit level to the person, make eye contact, and speak with the person while assisting with eating.
- Model the sequence of eating.
- Provide verbal prompts or physical cues if required to encourage the person to eat.
- Encourage independence when possible.
- Adapt foods (e.g., finger foods) and provide assistance when utensils can no longer be used.
- Provide functionally appropriate foods and beverages to match swallowing capability.
- Use adaptive devices/utensils as needed.
(Alzheimer's Society, 2018; Prizer & Zimmerman, 2018)

Maintaining Nutritional Well-Being

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

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

- Provide a balanced diet with a variety of foods, including vegetables, fruits, whole grains, low-fat dairy products, and lean protein foods.
- Limit foods with high saturated fat and cholesterol; limit fats such as butter, shortening, lard, and fatty cuts of meats.
- Offer nutrient-dense foods.
- Cut down on refined sugars, which contain calories but lack vitamins, minerals, and fiber. But in the later stages of Alzheimer's, if loss of appetite is a problem, adding sugar to foods may encourage eating.
- Limit foods with high sodium and use less salt; use spices or herbs to season foods as an alternative.
- As the disease progresses, loss of appetite and weight loss may require supplements between meals.



- To maintain hydration, encourage fluids throughout the day or foods with high water content such as fruit, soups, milkshakes, and smoothies.
- Lack of physical exercise will decrease appetite. Encourage simple exercises such as going for a walk.

Monitoring the person's nutritional status for weight loss and possible nutritional deficiencies also includes:

- Reviewing medications to check for drugs that may affect appetite
- Assessing for vision problems that may cause confusion at mealtime
- Assessing for depression

Ensuring Proper Swallowing

Those who are unable to swallow properly can become dehydrated and aspirate food, leading to aspiration pneumonia.

- 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, and at the end of the meal, check the person's mouth to make sure food has been swallowed.
- Prepare foods so they are not hard to chew or swallow. Grind foods, cut food into bite-size pieces, or serve soft foods such as cottage cheese, scrambled eggs, mashed potatoes, or applesauce. Avoid foods such as popcorn or raw vegetables.
- Thicker liquids such as fruit nectars, milkshakes, and egnogs 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. A speech-language pathologist can assess the person's needs and make recommendations.
(Alzheimer's Association, 2018j; Prizer & Zimmerman, 2018)

AMBULATING

Because Alzheimer's and other types of dementia can affect areas of the brain that are responsible for movement and balance, problems with ambulation will slowly begin to occur. Balance and gait deficits may be present in those in the very early stages of Alzheimer's and may even appear in some people before cognitive impairment is evident. Some people take progressively smaller and slower steps; others begin to tilt forward, backward, or laterally when ambulating.

Novel surfaces may affect gait speed in those with very mild Alzheimer's, such as walking on shiny surfaces that appear icy or slick. Waiting in a line, taking a few steps forward, and stopping can become confusing. Getting in and out of cars can take longer.



As the disease progresses, many individuals can gradually lose the ability to walk. In the early stages, the person may require a mobility aid such as a cane to feel support. They may later require actual physical support by a caregiver to walk. As the disease progresses, the ability to ambulate even with assistance may be lost. Eventually the person may need a wheelchair in order to feel and to be safe.

In the later stages of severe dementia, the person loses the ability to sit up without assistance, requiring some form of physical brace such as an arm rest, belt, or other special device to keep from sliding down in the chair.

Important things to consider in aiding the patient with Alzheimer's during ambulation include:

- Do not discourage pacing or wandering as long as the person is safe, since attempts to prevent it can provide anxiety episodes.
- Daily activity is important; assistance may be needed for the person to participate.
- Reevaluate the need for assistance on an ongoing basis.
- Be patient and do not rush the person, since this will increase the risk of falling.
- Keep the environment safe by removing throw rugs, wiping up spills immediately, and keeping hallways and walkways clear.
- Make certain the person is wearing supportive, nonskid footwear; avoid slip-on shoes or slippers.
- Monitor the condition of the person's feet, since any blisters or other skin breakdown will cause pain, making walking more difficult and increasing the risk for falls.
- A gait belt can be useful to transfer a person from one position or place to another or while assisting the person who is unsteady.
- Numbness and decreased sensation to the lower legs will make it more difficult for the person to ambulate and increase the risk for falls.
- To assist with ambulation and provide physical support, stand close to the side and slightly behind the person.
- Combine toileting with ambulation; once the person is up, encourage walking after they use the bathroom.

(Gras et al., 2015; Rabins et al., 2016; NursePartners, 2018)

Instrumental Activities of Daily Living

Instrumental activities of daily living that healthcare professionals may be asked to assess and to assist with include shopping and meal preparation, driving and other transportation needs, managing medications, and physical and social activities.



SHOPPING AND MEAL PREPARATION

In the early stages of Alzheimer's, the person may begin to lose skills needed to shop for and prepare proper meals. Caregivers can assist the person to complete a menu and a shopping list. The list should be organized so that the items are divided up based on their location in the store to make it easier for the person to find things when shopping. Caregivers can accompany the person to the store if necessary.

It is important to keep the person involved in preparing food and drinks to help maintain skills and interest in eating and drinking. It is often helpful to break down meal preparation into individual tasks.

Other suggested activities for a person with dementia who is living alone or who needs extra support with meals include:

- Buying frozen or refrigerated ready-to-eat meals, which typically require little preparation and may help the person cook more easily
- Having meals delivered, such as through the Meals on Wheels program
- Shopping online if the person has difficulties going to the store
- Using simple notes about where certain foods are stored or placing pictures on cupboards or the refrigerator to assist the person in locating items
- Providing simple written instructions to help the person prepare, cook, or reheat food
- Planning meals that do not require any cooking, such as salads or sandwiches (Alzheimer's Society, 2018b)

DRIVING AND TRANSPORTION NEEDS

Once the diagnosis of Alzheimer's disease is established, healthcare professionals need to encourage the family to discuss the issue of driving with the patient. Each state has its own laws and policies regarding physician reporting of driving with dementia to the Department of Motor Vehicles. Some states have mandatory reporting policies, others have optional reporting policies, and some have no policy regarding the issue. Healthcare professionals should be aware of the regulations in their own state and local jurisdiction.

In the early stages of Alzheimer's disease and other dementias, some people may still possess the skills necessary for safe driving. Most dementia is progressive, however, and symptoms such as memory loss, visual-spatial disorientation, and decreased cognitive function worsen over time and eventually require that the person give up driving.

The decision to stop driving may be made by the person with Alzheimer's, but some may be unable to assess their own driving skills, insisting on driving when it is no longer safe to do so. It should be understood how upsetting it can be to lose the independence that driving provides,



and 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 doing so.

Research has suggested that people living with Alzheimer's disease overestimate their driving abilities, but caregivers can more accurately identify unsafe driving. It may be difficult to determine at what point an individual can no longer drive safely; the following are signs that the person should not continue to drive:

- Difficulty navigating to familiar places
- Poor lane control
- Confusing the brake and gas pedals
- Failing to observe traffic signs
- Making slow or poor decisions
- Hitting the curb while driving
- Driving at inappropriate speeds
- Becoming angry or confused while driving

Other signs that a person may no longer have the general skills necessary to drive include:

- Decreased coordination
- Difficulty judging distance and space
- Difficulty engaging in multiple tasks
- Being less alert to things happening around him or her
- Having mood swings, confusion, or irritability
- Requiring prompting to attend to personal care

If the person is reluctant to talk about driving, it may be helpful to reduce the need to drive by:

- Having groceries, meals, and prescriptions delivered to the home
- Arranging for a barber or hairdresser to make home visits
- Inviting friends and family over for regular visits
- Arranging for family and friends to take the individual on social outings



When driving is no longer an option, it is important to make alternative transportation arrangements so that the person's mobility and activity level are not unduly restricted. Rides can be provided by:

- Family
- Friends
- Neighbors
- Public transportation
- Taxis
- Senior and special needs transportation services

When driving privileges have been withdrawn but the individual persists in demanding to drive, last-resort **preventive strategies** include:

- Controlling access to keys. Keep keys out of sight. If the person demands to carry a set of keys, provide him or her with keys that will not start the vehicle.
- Disabling the vehicle. Remove a battery cable so the car cannot be started. Have a mechanic install a "kill switch" that must be engaged before the car will start.
- Parking the car out of sight. The trigger to drive is less likely to occur if the person cannot see the car.
- Selling the vehicle. If the car is not needed by family, this may be the best solution. (Hamdy et al., 2018; Family Caregiver Alliance, 2018a; Mayo Clinic, 2016)

MANAGING MEDICATIONS

Healthcare professionals working with patients with Alzheimer's disease have an important role in helping family caregivers take on the task of medication management. Surveys have shown that family caregivers of Alzheimer's patients may feel ill prepared and unsupported by healthcare professionals. Nurses can be effective in easing their concerns, making recommendations by carefully reviewing all medications, providing guidance on how to simplify the medication regimen, and making recommendations for problems such as patient resistance in taking medications. Consulting with a pharmacist can also be helpful.

The following information can be taught to family caregivers regarding how to manage patient medications:

- Make taking medications a normal part of the daily routine by pairing it with specific events throughout the day.
- Utilize a daily log of what medications are to be taken and when.



- Keep medications stored in a locked drawer or cabinet and not left out where the patient can find them.
- Know that herbal therapies and over-the-counter medications can interact with prescribed medications.
- Understand how to determine if medications are effective. For example, the patient may not be able to articulate pain but may be calmer and more easily engaged after receiving pain medication.
- Know which medications are priorities as well as which medications can safely be skipped now and then when the patient is resistant to taking them.
- Give medication with meals, if allowed, and administer the most important medications first.
- Alternatively, give medications in the morning, if allowed, when agitation is less likely to occur.
- Make certain the patient is wearing glasses and hearing aids, if needed, to minimize confusion.
- To cope with resistance, give medications covertly in food or drink. Covert administration can prevent exacerbation of a coexisting medical problem that could lead to the need for hospitalization (e.g., a patient with heart failure requiring diuretics).
- Create a list of distraction activities (e.g., listening to a favorite piece of music) to employ when the patient is resistant so that medication administration is more pleasant.
- Do not argue or try to convince the patient to take medications, since this can increase tension and agitation.
- Should resistance become routine, talk about medication options with the healthcare provider to see if some medications can be discontinued or given in an alternate form.
- Request assistance from a healthcare provider to evaluate the form of medication being administered should the patient begin to have difficulty swallowing pills.
- Acknowledge that mistakes will happen and develop a plan for dealing with errors that does not place emphasis on blaming.
- Know the types of medication mistakes that can happen, such as giving the wrong dose, and when and how to notify the healthcare provider if this occurs.

(Lindauer et al., 2017)

Healthcare providers should provide caregivers with a copy of the written care plan. It should reinforce the teaching points described above and include the phone numbers for prescribing healthcare professionals who can provide assistance. Reassess medication management goals of care every six months and document them clearly.



PROVIDING PHYSICAL AND SOCIAL ACTIVITIES

Persons with Alzheimer's disease and other dementias may withdraw from activities, family, and friends. It is very important, however, to maintain these connections, as they reduce the effects of memory impairment and lead to a better quality of life. Social and cognitive stimulation can help maintain general well-being and prevent boredom and agitation in people with Alzheimer's disease, especially in the early stage of the disease. Such stimulation can also encourage self-expression, lessen anxiety and irritability, make the person feel more engaged, and stir memories.

Persons with Alzheimer's are capable of performing a variety of activities that fulfill their need to be active. These can include exercise and other gross motor activities, such as 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 person who is no longer able to cook a meal may still 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 Alzheimer's 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 Alzheimer's, such as beanbag toss or other games with an obvious objective. Although the person with Alzheimer's may regress to the level of a child, they should not be treated as a child. It is important to keep developmental level in mind when planning recreational activities.

Other activities that have been found to engage people with dementia include:

- Baking or cooking simple recipes together
- Working around the house sweeping, folding laundry, clearing the table
- Doing arts and crafts using simple patterns and tools
- Reading a newspaper together



- Tending the garden or visiting a garden
 - Watching family videos
 - Working on simple puzzles
- (Alzheimers.net, 2018a)

Watching for Elder Abuse in Dementia Patients

Abuse of older adults is a well-kept secret in America, and people with Alzheimer's disease or other cognitive impairment are at higher risk than other older adults. 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. Forms of abuse include physical, verbal/psychological, financial exploitation, sexual, neglect, and abandonment. Perpetrators include adult children, other family members, and spouses, as well as nursing home, assisted living, and other facility staff.

Approximately 1 in 10 Americans aged 60 and older experience some form of elder abuse. One study estimated that only 1 in 14 cases of elder abuse are reported to authorities. Abusers are of both genders, and in almost 60% of elder abuse and neglect incidents, the perpetrator is a family member. Two thirds are adult children or spouses. Prevalence rates for abuse in people with dementia vary from study to study, but estimates range between 27.5% and 55%.

Elders who have been abused have a 300% higher risk of death when compared to those who have not been mistreated. Elderly financial exploitation and fraud is estimated to range from \$2.9 billion to \$36.5 billion annually, and is self-reported at higher rates than neglect, emotional, physical, or sexual abuse (NCOA, 2018; NCEA, 2018).

Many barriers exist that prevent elderly persons from asking for help. Abused persons may have considerable problems accepting the fact that someone they reared and nurtured is now abusing them. They may fear retaliation from the abuser. They may lack the cognitive or physical ability to report abuse. There may be cultural and language barriers. 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.

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, pressure ulcers/injuries (bedsores), and unattended medical needs.

Financial exploitation can have lasting effects on the person. Signs of this form of abuse could include missing checks, failing to make payments on time or not making them at all, missing credit or debit cards, missing property, having insufficient funds in banking accounts, or failing to pay for medical treatment needed.

Signs of emotional or psychological abuse can be more difficult to detect. This type of abuse can cause the person to be afraid of a caregiver or other person. Signs of this form of abuse can include:

- Withdrawal from normal activities
- Unusual signs of depression
- Changes in alertness
- Sleep problems
- Anxiety
- Being kept isolated from others
- Avoidance by 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 (Blanchard, 2018).

Elder abuse occurs in private homes as well as institutional settings such as nursing homes and other types of long-term care facilities. Abuse of older adult residents by other residents in long-term care facilities is now recognized as a problem that is more common than physical abuse by facility staff members (NCEA, 2018).

CAREGIVERS AND ELDER ABUSE

The responsibilities and demands of caregiving increase as the older adult person's condition deteriorates. 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 extremely difficult for caregivers to cope with, thus prompting abusive responses.

Caring for a person with Alzheimer's disease 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 caregivers' 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.

INTERVENING AND REPORTING ELDER ABUSE

The most important element in stopping elder abuse is identifying it before it begins. Contributing factors that underscore the likelihood of abuse and have been identified as contributors to the possibility of maltreatment include:

- Persons who have little contact with family, friends, or a social support system
- Drug and alcohol abuse by caregivers
- Declining physical and mental health of the person
- Sharing living quarters with the caregiver

All states have a mandatory reporting statute for elder abuse, but requirements as to who must report abuse or suspected abuse vary by state. Nurses are mandated reporters of elder abuse in all states and occupational and physical therapists in most of them. Mandated reporters can be held liable by both the civil and criminal legal systems if they know of possible elder abuse and intentionally fail to report it (StetsonLaw, 2016).

If the healthcare professional suspects abuse, it is important to document the signs. This documentation could include:

- Noting changes in the person's behavior
- Taking photographs of injuries
- Writing descriptions of the person's injuries
- Taking written statements from the person
- Taking written statements from any witnesses

Suspected abuse should be reported to the area's local Adult Protective Services agency. If the healthcare professional is reporting abuse or neglect in a nursing home or other long-term care facility, the state's long-term care ombudsman should be contacted. These professionals can investigate the claim and make the appropriate changes.

If the abuse is severe or it is suspected that the person is at risk for additional harm, healthcare professionals should first call 911. Police officers will investigate and make the appropriate decision on how to get the person the help they may need (Blanchard, 2018).



CASE

Mr. Moustaffa, a 72-year-old widower who lives alone, was seen in the dementia assessment unit after referrals by a concerned neighbor. The patient had previously been diagnosed with early dementia, but much of his conversation still 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 the visit, the social worker found that Mr. Moustaffa had written several checks for groceries in the past month, some amounting to \$200, but that 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 kept the rest of the money themselves. This information was used to assist in approaching the son and daughter-in-law with the concern of elder financial abuse.

LEARNING TO MANAGE PROBLEM BEHAVIORS

As Alzheimer's disease progresses, dementia can cause mood swings and changes in the person's personality and behaviors, including agitation and restlessness, vocal outbursts, wandering, sleep disturbances, “sundowning,” and inappropriate sexual activities. These behaviors can be very stressful for both the person with dementia as well as the caregivers. Basic principles for dealing with such behaviors include the following:

- Try to accommodate the behavior, not control it. If the person insists on eating with their fingers instead of a fork or spoon, provide finger foods instead. If the person insists on sleeping on the floor, provide a mattress to make it comfortable.
- Behavior problems may have an underlying medical reason. This may include pain or the side effects from medications.
- Caregivers can change the physical environment and their own behavior. Changing one's own behavior often will result in a change in the behavior of the patient with Alzheimer's disease.
- Behavior has a purpose. Consider what need the person might be attempting to meet and, whenever possible, attempt to accommodate the need.
- The core to changing behavior is disrupting patterns that have been created and trying different approaches.
- What works today may not work the next day because of the natural progression of the disease process.
(FCA, 2018b)

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 Alzheimer's. 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.

Agitation and Aggression

Agitation is a state of extreme irritability often characterized by hitting, pacing, yelling, cursing, arguing, threatening, and verbal or physical aggression. This behavior often progresses with the stage of dementia, from mild to more severe. Agitation can be triggered by a number of things, including environmental factors, fear, fatigue, and feelings of abandonment. Often it is triggered when the person perceives that control is being taken from him or her.

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 following strategies may be helpful:

- Reducing noise, clutter, or number of persons in the room
- Keeping routines and maintaining a consistent environment with familiar objects and photographs
- Reducing intake of caffeine, sugar, and other foods that cause energy spikes
- Using gentle touch, soothing music, reading, or taking a walk; speaking reassuringly
- Not restraining the person
- Supporting the person's independence
- Acknowledging the person's anger over loss of control and verbalizing understanding
- Validating the person's feelings and then attempting distraction or redirection
- Not being confrontational with the person about the behavior
- Keeping dangerous objects out of reach
(FCA, 2018b)



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 the person, and redirects the person to a different activity to divert attention from the problem.

CASE

Mr. Hopkins is a 72-year-old male patient 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.

Nursing home 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 goodbye, 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 the family visits. There were no further incidents of combative behavior from Mr. Hopkins.

Vocal Outbursts

Disruptive vocal outbursts—screaming, swearing, crying, shouting, negative comments to staff and/or other persons, self-talk—become increasingly common as Alzheimer's 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 are encouraged 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 are advised 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, overstimulation 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 Alzheimer's disease 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 became very disruptive to everyone. As her condition worsened, Mrs. Goh was moved to a semiprivate room in the front of the building, making her yelling 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 still yells out occasionally, but this tends to occur when unavoidable changes are made to her routines.

Wandering

Wandering is a major behavior problem in persons with Alzheimer's disease, more so than in persons with other types of dementias. Wandering occurs for a variety of reasons, such as boredom, medication side effects, or looking for something or someone. 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.

The following techniques may be helpful when dealing with the problem of wandering in the home care setting.

- Make time for regular exercise to minimize restlessness.
- Use large-print signs to mark destinations with a drawing of the activity.
- Place a photo of the person as a younger adult on the room door to help the person find “home.”
- Ensure that doors have locks that require a key. Position them high or low on the door, as many people with dementia will look only at eye level. It is important to recognize that a danger of this approach is fire safety; more information and specific suggestions can be obtained from the local fire marshal.
- Use a barrier, such as a curtain, to mask the door. A stop sign or “do not enter” sign may be effective.
- Paint doorknobs the same color as doors.
- Install grid patterns on floors in front of doors.
- Paint a door to look like a piece of furniture.
- Paint a black space on the front porch that may appear to the person with dementia to be an impassable hole.
- Add “child-safe” plastic covers to doorknobs.
- Consider installing a home security system or monitoring system such as a GPS tracking device. (These may be effective only in areas with good cellphone coverage and in tandem with an attentive human monitoring the devices.)



- Put away items such as the person's coat and purse. Some people will not go out without taking certain articles with them.
- Sew ID labels in the person's clothes or have the person wear an ID bracelet.
- Tell the neighbors about the person's wandering behavior and provide them with a telephone number.
- Always have a current photo available should the need arise to report the person as missing.

Caregivers can also leave a copy of the person's photo on file at the police department or register the person with 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*).

(FCA, 2018b)

It is estimated that about half of persons with dementia who go missing for more than 24 hours will either be severely hurt or die, and over 80% will die after being missing for 72 hours (ASAC, 2018; Kindly Care, 2018).

When the person has been admitted to a care facility, the family can help caregivers identify and anticipate wandering. The staff is instructed to learn as much as possible about the resident's lifestyle prior to diagnosis with Alzheimer's disease (i.e., what kind of work the person did; previous patterns of exercise, stress, and response to touch; etc.). Once a wanderer is identified, the facility can have photographs made and distributed to other units and assign special clothing or identification bands. Facilities should consider painting all doors for staff-only the same color as the wall, while doors the person is expected to find and use should contrast with walls.

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 Alzheimer's disease 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

Silver Alert programs inform law enforcement agencies, media outlets, and the public about missing adults, usually seniors with cognitive disabilities or impairments. The information that is distributed includes photographs, description of the vehicle if the person was driving, last known location, home location, and medical condition.



Law enforcement agencies are most often responsible for deciding to activate a Silver Alert. Information is broadcasted using dynamic message signs on roadways, radio stations, mobile phones, the internet, and television.

The majority of states have Silver Alert systems. Such systems are variously referred to as:

- “Missing Senior Alert”
- “Mattie’s Call”
- “Golden Alert”
- “Mozelle Vulnerable Senior Medical Alert Act”

Of the remaining states, some have alternative lost-persons alert systems, while some do not as yet have alert systems (Kindly Care, 2018; ASAC, 2018).

Sleep Disturbances

Persons with Alzheimer’s disease 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. This behavior is believed to be caused by a combination of factors, such as exhaustion from the events of the day and changes in the person’s biological clock, leading to day-night confusion.

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 each person’s limitations and should be done no later than four hours before bedtime. Those who are bedfast can 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, and eliminating or restricting foods that contain sugar and caffeine to early in the day will also improve sleep patterns (FCA, 2018b).

Sundowning

“Sundowning” refers to the phenomenon in which the person is more confused during the late afternoon and early evening 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. The following suggestions may be helpful:

- Make afternoon and evening hours quiet and calm, and include structured, quiet activity.
- Turn on lights well before sunset and close curtains at dusk to minimize shadows.



- Keep a nightlight in the person's room, hallways, and bathroom.
- Make sure the person is safe by blocking off stairs with gates, locking the kitchen door, and putting away dangerous items.
- Provide physical activity or exercise every day.
- Keep the person's daytime naps short and not too late in the day.
- Seek medical advice for assessment of pain, sleep disorders, other illnesses, or medication side effects if the problem continues.

(FCA, 2018b; NIA, 2017b)

CASE

Mrs. Perlman is a 72-year-old widow who was diagnosed with Alzheimer's eight years ago and is now in the middle stage of the disease. She moved in with her daughter Jeanne about six months after being discharged from the hospital following treatment for pneumonia. Her level of confusion and disorientation has increased since her discharge.

Jeanne began attending a local Alzheimer's support group once her mother moved in with her, and she has asked for help because her mother becomes "like another person after supper." She says her mother no longer recognizes her, is disruptive, and can't be calmed down until she falls asleep. Fortunately, her mother always seems much better in the morning.

The group asks questions to discover what can be done to help Jeanne with what many of them recognize as 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 devise these 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. but doesn't allow her to sleep too long, since that may 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 Speech or Actions (Perseveration)

Repetitious speech or actions are those that occur on a continuous basis and generally serve no functional purpose. Mostly, these behaviors are tolerable for caregivers, but they can also become very annoying and lead to a great deal of frustration. Often the behavior is triggered by anxiety, boredom, fear, or environmental factors. Examples of repetitious behaviors frequently encountered are questioning, repeating words or phrases constantly, or performing one task over and over again. To cope with perseveration, it can be helpful to:

- Provide reassurance with words and touch
- Distract with an activity or something to eat
- Not remind the person they asked the same question
- Attempt to refocus the person into an activity such as assisting with a chore
- Avoid talking to the person about plans until immediately prior to an event
- Learn to recognize the meaning behind certain actions (e.g., pulling at clothing could indicate the need to use the bathroom)

(FCA, 2018b)

Another repetitious behavior is referred to as “shadowing” and involves imitating and following the caregiver, or constantly talking, asking questions, and interrupting. This often occurs late in the day and can be very irritating for caregivers. When this occurs, the person can be comforted with verbal and physical reassurance. Distraction or redirection may also be helpful, as well as giving the person a task to complete, such as folding laundry (FCA, 2018b).

People with dementia are often seeking something comfortable and familiar, something that provides a feeling of control. 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 former 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

Because of dementia, many persons lose the ability to determine the appropriate time, place, or way to express sexual needs. Inappropriate behaviors may become the only available mechanism for gratifying such 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.



Such behaviors may include masturbation, undressing in public, making lewd remarks or unreasonable sexual demands, as well as sexual aggression, which may include fondling, exposing genitals, or attempting to engage in 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.

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.

If possible, identify what is triggering the behavior. 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 events 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

The role of caregiving often falls to a family member. As the disease progresses, care needs become greater, requiring more hours of the caregiver's time, and the more hours the caregiver devotes, the higher the risk of caregiver overload and stress-related health issues. The following are ten common risks for caregiver stress/overload:

- Being a live-in caregiver
- Being a woman
- Being an older caregiver
- Being socially isolated
- Caring for a person with Alzheimer's disease for many hours each day
- Experiencing one's own financial problems
- Having depression
- Having a lower educational level
- Having poor coping skills
- Having little help from family or friends for respite care (Alzheimers.net, 2018b)



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. Evidence shows that most caregivers are poorly prepared for their role and provide care with little or no support. More than one third of caregivers continue to provide intensive care while experiencing poor health themselves. Studies have shown that an important factor in the decision to place a relative in a long-term care facility is the family caregiver's own physical health.

Some aspects of caregiving can be positive, but caregiving can exact a toll on the caregiver's mental, emotional, physical, and financial well-being. Caregivers have higher levels of stress than non-caregivers and experience frustration, anger, exhaustion, and helplessness. Many report that being a caregiver is hard on them emotionally. Caregiving can result in feeling a loss of self-identify, lower levels of self-esteem, constant worry, or uncertainty. Caregivers also report feeling less in control of their lives. Caregivers who experience chronic stress may be at greater risk for cognitive decline, including loss in short-term memory, attention, and verbal IQ.

Research shows that female caregivers (about two thirds of all unpaid caregivers) fare worse than male caregivers, reporting higher levels of depression and anxiety, lower levels of subjective well-being, less satisfaction with life, and poorer physical health. In response to increased stress, many caregivers have been found to show an increase in alcohol and other substance use. Other studies have shown that caregivers use prescription and psychotropic drugs more than non-caregivers.

Caregivers have been found to have increased rates of physical ailments, increased tendency to develop serious illnesses, and high levels of obesity and bodily pain. They have also been shown to have diminished immune response, leading to frequent infections and increased risk of cancer. Caregivers also have an increased risk for developing cardiovascular problems such as high blood pressure or heart disease. Elderly caregivers of a spouse who experience caregiving-related stress have more than double the mortality rate than non-caregivers of the same age.

Caregivers have lower levels of self-care. They are less likely to employ preventive health measures. Women caregivers, when compared to non-caregivers, are twice as likely not to fill a prescription because of the cost. Nearly three quarters of caregivers report they do not see their healthcare provider as often as they should (FCA, 2018c).

Caregivers may also experience a negative financial impact. Many take a leave of absence from their work, some go from full-time to part-time work, and many need to quit their jobs. Some caregivers must reduce the amount of money they can save, use money from their retirement accounts, and decrease spending on their children's education to meet the financial needs in caring for a person with dementia (Hughes et al., 2017).



Supporting Family Caregivers

Effective approaches for supporting family caregivers that provide positive outcomes include:

- Assessment and referral to other resources
- Education and skills training
- Care coordination
- Counseling and support groups
- Respite care

Assessment and referral is used to identify the needs of caregivers and to find ways in which to meet those needs either through providing the services directly or by linking caregivers to other resources. Assessment should be family centered, culturally competent, and result in a care plan with clear outcomes. Assessment should be repeated regularly.

Education for caregivers should provide a basic understanding of Alzheimer's dementia and include appropriate skills for managing symptoms that require increasing levels of care over the course of the disease. An effective educational program actively involves caregivers through activities such as discussion, take-home assignments, and role playing. Training can be provided by social workers, nurses, psychologists, or other healthcare professionals. A small number of evidence-based programs deliver training online or through videos. (One example of such training is the UCLA Health Caregiver Training series [see "Resources" at the end of this course].)

Care coordination involves a multidisciplinary team that assesses needs and provides care to people with dementia and their caregivers. Dementia care coordination programs are aimed at improving quality of care and health outcomes for both persons with dementia and caregivers. Examples of such programs include:

- Partners in Dementia Care for Veterans
- Maximizing Independence at Home
- Aging Brain Care Medical Home Program

Counseling and supportive groups address the potential impact on mental health and relationship strain experienced by the caregiver. These include individual or family counseling as well as peer support groups, which may meet either in person or over the phone.

Respite care provides supervision for persons with dementia either in the person's home or at another site, giving the caregiver time away for self-care activities. Adult day centers provide planned activities and offer meals and transportation. In-home respite care may involve companion services or personal care workers to assist with bathing and feeding the patient (Hughes et al., 2017).



Compensation for Family Caregivers

When a family member becomes a caregiver, it may impact family finances by requiring the caregiver to make adjustments in employment status. In the United States, it is possible for a caregiver to be paid for caring for a family member with dementia. There are a variety of different programs that offer this option; however, there can be significant hurdles in the process of taking advantage of them.

Governmental programs that pay family members are offered in most, but not all, states. These programs include:

- **Medicaid waivers** that allow a person with dementia to choose whom they wish to be a personal caregiver, which could be a family member.
- **Medicaid state plans** that offer personal care services. Often states allow family members to be personal care providers and offer cash compensation.
- **Adult foster care** that allows an individual with dementia to move into the home of a caregiver to receive around-the-clock supervision. These programs provide compensation for providing care but do not provide cost of room and board.
- The **Caregiver Child Exemption** is a Medicaid exemption for an adult child who has a parent with dementia. It is similar to foster care; however, the adult child moves into the home of the parent to provide care. Medicaid rules usually require that the home be forfeited in exchange for care, allowing the home to be transferred to the adult child for compensation after residing in and providing care for their parent for a minimum of two years.

Other programs are available for veterans, and Paid Family Leave Programs are currently offered in a small number of states (Dementia Care Central, 2018).

ETHICAL AND END-OF-LIFE CONSIDERATIONS

Alzheimer's disease raises a host of ethical issues. Such issues can be addressed by considering these three guiding ethical principles that are 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 that is periodically conducted in a more formal fashion 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 healthy and competent adult 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 begin early in the disease process through execution of advance directives. In the absence of an advance directive, the surrogate decision maker should be guided by the values and expressed wishes of the person with Alzheimer's.

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 Alzheimer's disease, family members, and the 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.

Debate continues over the issue of medical aid in dying (MAID) or physician-assisted death (PAD). As of mid-2017, PAD was legal in Oregon, Vermont, Washington, California, Montana, and the District of Columbia. However, there are a number of limits, which include:

- The person must have a terminal illness.
- Healthcare providers must indicate the person has six months or less to live.



- The name of the provider who is permitted to write the prescription for the drugs must be indicated.
- Mandatory waiting periods and as many as three different consents by the patient may be required.
- The person must be mentally competent.

It is the issue of the person's mental competency where the beliefs are the strongest and the opinions the loudest. Under current state laws, it is impossible for someone with Alzheimer's disease, regardless of the stage of the disease, to have the option of PAD (Bloom, 2018).

The question also 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. The goal in withholding or withdrawing treatment is to avoid inflicting a burdensome intervention, not to end the patient's life. Increasingly, there is public pressure for a system that ensures a patient's "right to die well." Dying is a natural part of living, and it is important that people with dementia should be allowed to die in comfort. The support offered at this time must be in keeping with the person's wishes, spiritual views, culture, and life history (Arcand, 2015).

ARTIFICIAL NUTRITION AND HYDRATION (ANH)

In the end stage of Alzheimer's disease, 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. Physiologically, the digestive system begins to slow and the digestive tract loses moisture. The body begins to conserve energy for vital functions and does not expend it on digesting food (Lamers, 2017).

It is hard for many people to accept the dying person's lack of ability to eat. That is because we equate food with caring, and often families consider withholding nutrition to be cruel or neglectful and may worry that they are "killing" the person. It is important that families and healthcare professionals understand that no longer eating or drinking is part of the dying process and is normal.

Evidence-based research indicates the following:

The use of feeding tubes to deliver artificial nutrition and hydration at end of life is often part of the plan of care for people with dementia. Current evidence, however, suggests that tube feeding in advanced dementia is not beneficial and the burdens of the procedure and the feedings themselves outweigh any benefits. Evidence also reveals that healthcare providers may lack evidence-based knowledge about artificial nutrition and hydration to adequately inform families and surrogate decision makers (Smith & Ferguson, 2017).

When the person is close to death, family and caregivers should be aware that neither food nor hydration is necessary to maintain the patient's comfort. Intravenous fluids, TPN, and tube feedings do not prolong the life of the dying



patient, may increase discomfort, and even hasten death. Adverse effects of artificial nutrition can include pulmonary congestion, pneumonia, edema, and pain associated with inflammation. Conversely, dehydration and ketosis due to calorie restriction correlate with analgesic effects and absence of discomfort. The only reported discomfort due to dehydration near death is xerostomia (dry mouth), which can be prevented and relieved with oral swabs or ice chips. Supportive care and good oral hygiene are imperative for patient comfort at this time (Cobbs et al., 2017).

The Alzheimer's Association National Board of Directors weighs in on this issue, asserting that:

Research evidence supports no medical benefit from feeding tubes in advanced dementia and feeding tubes may actually cause harm in the advanced stages of AD. Additionally, it is ethically permissible to withhold nutrition and hydration artificially administered by vein or gastric tube when the individual with Alzheimer's dementia is in the end stages of the disease and is no longer able to receive food or water by mouth. Moreover, the Association recommends that evidence on the risks and benefits of tube feeding versus careful hand feeding be provided to individuals with Alzheimer's disease and their caregivers so they can make an informed decision (Alzheimer's Association, 2015).

Research on tube feeding shows the following:

- It not does improve nutritional status.
- It does not prevent or lower the incidence of aspiration pneumonia.
- There is no evidence suggesting that tube feeding reduces the incidence of pressure sores.
- There is no average difference in longevity between persons with advanced Alzheimer's who are tube fed and those provided with careful hand feeding.
- Tubing feeding has been associated with increased use of physical restraints to prevent persons from pulling tubes out of the nose or abdomen.
- Tube feeding denies the person the gratification of tasting preferred foods and the emotional and relationship benefits of interacting with a caregiver during hand feeding. (Alzheimer's Association, 2015)

Healthcare providers offer education to help families understand that forgoing ANH is not “killing” or “starving” the person. Family members are given information about potential problems associated with artificial nutrition and hydration, including “the discomfort related to the forceful introduction of physical devices into the esophagus, needed sedation, and infections often resulting from the procedure [of tube placement]” (DeMarco, 2015).



Other considerations include:

- Cessation of food intake results in the release of endorphins, which reduces pain.
- Feeding tubes and hydration block the release of endorphins and can result in weeks of unnecessary suffering.
- Percutaneous endoscopic gastronomy (PEG) feeding can result in back-up to the esophagus, increasing the risk of aspiration pneumonia.
- Lack of ambulation and artificial feeding often requires physical restraint to prevent patients from pulling out their feeding tubes and increases the risk for bed ulcers and skin infections.
- Artificial feeding deprives a patient of taste.
(DeMarco, 2015)

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 have 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 they are unable to communicate those wishes—for example, in the advanced stages of Alzheimer's disease. A **living will** is one type of advance directive. In an advance directive, the person can also name a representative to see that his or 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 VS. DNAR 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.)

For patients with severe dementia, CPR is unlikely to be successful. Outside a hospital, chances of survival are low and CPR itself may be harmful. Even if a cognitively impaired person is in the hospital, CPR is three times less likely to be successful (survival to discharge) than for those who are cognitively intact (Arcand, 2015).

A DNRO should be posted prominently to ensure that the patient's wishes will be honored in the event of an emergency. Emergency medical personnel do not have time to ask where a DNRO may be located, so it should be placed in an easily identifiable area. If the patient is in an institution, it should be prominently placed in the medical file. If the person is at home, it should be placed somewhere prominently where paramedics or other EMS personnel could easily see it, such as taped to the foot of the bed or the wall closest to the patient's bed. 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 Alzheimer's, 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 educate families about the benefits of hospice care for their loved one with Alzheimer's disease and for themselves. Ideally, this education begins 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 affects 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 Alzheimer's disease 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 to alter the course of the disease or cure or prevent it. Early diagnosis is important in order to intervene with treatments that may slow the progression of the disease. There are 10 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, work, or 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>

Family Caregiver Alliance

<http://www.caregiver.org>

Home Safety Assessment Checklist

<https://adrcnj.org/Portals/AgencySite/docs/checklist.pdf>

MedicAlert + Alzheimer's Association Safe Return

<https://www.alz.org/help-support/caregiving/safety/medicalert-safe-return>

Mini-Cog Mental Status Exam

<https://mini-cog.com>

Mini-Mental State Exam

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

National Institute on Aging

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

UCLA Health Caregiver Training Videos

<https://www.uclahealth.org/dementia/caregiver-education-videos>

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TEST

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1. Alzheimer's disease was first recognized as the most common form of dementia in which year?
 - a. 1910
 - b. 1976
 - c. 1990
 - d. 2010

2. In the United States, Alzheimer's disease is:
 - a. The sixth leading cause of death among adults.
 - b. The leading cause of disability in middle-aged adults.
 - c. More prevalent in men than in women.
 - d. More common in those adults with a college education.

3. Eighty-three percent of help provided to older adults in the United States comes from:
 - a. Home healthcare agencies.
 - b. Nursing homes.
 - c. Assisted living facilities.
 - d. Unpaid caregivers.

4. Which is a **correct** statement regarding Medicare benefits for patients with Alzheimer's disease?
 - a. Medicare pays up to 100% for personal care in a patient's home.
 - b. Medicare pays for custodial long-term care in a skilled nursing facility.
 - c. Medicare provides all-inclusive hospice benefits to those who have six months or less to live.
 - d. Medicare pays for 24-hour-a-day care at home when this is the only care the patient requires.

5. 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.



6. One mechanism by which the ApoE4 allele increases the risk of Alzheimer's disease is by:
 - a. Releasing chemicals that decrease inflammation to neurons.
 - b. Causing microglia cells to fail to perform their function.
 - c. Impairing beta-amyloid clearance from the cerebrum.
 - d. Clearing away waste and debris from the brain.

7. Chronic stress is a risk factor for Alzheimer's disease because it:
 - a. Increases neurofibrillary tangles.
 - b. Increases hippocampal volumes.
 - c. Triggers excessive cortisol production.
 - d. Promotes neuronal proliferations.

8. Which may be the most modifiable risk factor for dementia?
 - a. Hypertension
 - b. Depression
 - c. Hearing loss
 - d. Oxidative stress

9. Smoking is believed to increase the risk of Alzheimer's disease because it:
 - a. Causes physical symptoms of chronic stress.
 - b. Produces oxidative stress.
 - c. Increases the production of cortisol.
 - d. Interferes with glucose metabolism.

10. Which is a **true** statement concerning strategies to prevent the development of Alzheimer's disease?
 - a. Regular exercise and a heart-healthy diet may be associated with reducing the risk of Alzheimer's disease.
 - b. It is recommended that all older adults begin taking vitamin D to reduce the risk of Alzheimer's disease.
 - c. Older adults should avoid situations involving new activities or unfamiliar settings to reduce the risk of Alzheimer's disease.
 - d. There is strong, definitive evidence about cognitive training's impact on preventing Alzheimer's disease.



- 11.** Which is a **correct** statement about memory impairment in people with either benign forgetfulness or dementia?
- a. Memory impairment is sporadic in persons with dementia.
 - b. Persons with benign forgetfulness do not remember things later on.
 - c. Dementia is marked by occasional bad decision-making.
 - d. Benign forgetfulness may cause difficulties with learning new information.
- 12.** Which memory system refers to the “common knowledge” one knows about the world and language?
- a. Episodic memory
 - b. Semantic memory
 - c. Procedural memory
 - d. Working memory
- 13.** Which are considered to be **psychological** symptoms common in patients with Alzheimer's disease?
- a. Personality changes and self-neglect
 - b. Physical deterioration and psychosis
 - c. Angry outbursts and aggression
 - d. Depression and apathy
- 14.** Changes in memory and thinking that are not significant enough to affect work or personal relationships develop during which stage of Alzheimer's disease?
- a. Stage 1: Preclinical stage
 - b. Stage 2: Minimal cognitive impairment
 - c. Stage 3: Mild dementia
 - d. Stage 4: Moderate dementia
- 15.** Which patient symptom is typically seen only in the late stage of Alzheimer disease?
- a. Loss of impulse control
 - b. Increased anxiety
 - c. Inability to sleep
 - d. Impaired swallowing



- 16.** 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.
- 17.** Neuropsychological testing for a patient with Alzheimer's disease is done to:
- Assess the relationship between the brain and the patient's behavior.
 - Assess the patient's current mental health status.
 - Assess the patient's mood and other symptoms that overlap with dementia.
 - Assess the overall physical and neurological condition of the patient.
- 18.** The Mini-Cog test screens patients for memory problems and:
- Executive function abilities.
 - Mathematical abilities.
 - The ability to recognize faces.
 - The ability to recognize objects.
- 19.** A laboratory test that is currently available, but less commonly performed, to confirm or rule out Alzheimer's disease is the:
- Rapid plasma reagin test.
 - Complete blood count.
 - Folate level test.
 - Cerebral spinal fluid biomarkers test.
- 20.** A primary objective of structural neuroimaging (i.e., MRI and CT scans) in patients with suspected Alzheimer's disease is to:
- Study the pattern of cerebral perfusion.
 - Measure regional cerebral glucose metabolism.
 - Rule out potentially treatable causes of progressive cognitive decline.
 - Detect and localize levels of amyloid in the brain.

- 21.** Which is a **true** statement about assessing the functional status of the patient with Alzheimer's disease?
- The Functional Activities Questionnaire is useful for monitoring functional changes over time.
 - The Functional Activities Questionnaire is completed by the patient.
 - There is a need to assess the patient's performance with only those activities of living that are considered basic.
 - There is only one functional assessment rating tool for patients with Alzheimer's disease.
- 22.** The goal of current drug treatment for patients with Alzheimer's disease is to:
- Prevent further decline in cognitive function.
 - Stop the progression of the disease.
 - Help the remaining brain cells to function more efficiently.
 - Alter the underlying disease trajectory.
- 23.** Which is a **correct** statement regarding drug therapy for patients with Alzheimer's disease?
- Drug therapy can reverse the progression of Alzheimer's disease.
 - Cholinesterase inhibitors work by keeping acetylcholine levels high.
 - Memantine has more side effects than cholinesterase agents.
 - Cholinesterase inhibitors and memantine are never given in combination.
- 24.** Which is a **true** statement about using medications to manage behavioral and neuropsychiatric symptoms in patients with dementia?
- Antidepressants are very effective for treating sleep disturbances.
 - Benzodiazepines are recommended for long-term treatment of anxiety and restlessness.
 - Analgesics are not used because it is unknown if the patient with dementia has pain.
 - Antipsychotics have limited effectiveness and are associated with increased mortality.
- 25.** Recognizing and treating coexisting conditions common to older adults helps support patients with Alzheimer's disease by:
- Identifying those persons at risk for psychosis.
 - Slowing the progression of Alzheimer's disease.
 - Improving the functional ability and quality of life of patients.
 - Shifting the burden of caregiving away from the patient.

- 26.** Management of the patient with Alzheimer's disease involves considering the patient's needs and:
- Primarily managing his or her physical needs.
 - Ignoring his or her depressive symptoms.
 - Performing repeat functional imaging studies.
 - Addressing the caregiver's stress.
- 27.** A strategy that an occupational therapist may use for a patient with Alzheimer's disease is:
- Utilizing the patient's procedural memory.
 - Avoiding modification of existing routines.
 - Avoiding environmental adaptations.
 - Changing routines to require less patient participation.
- 28.** A physical therapy assessment tool that is used to determine fall risk in patients with Alzheimer's disease is the:
- GaitRite mat.
 - Timed Up and Go Test.
 - Pain Assessment in Advanced Dementia.
 - Functional Assessment Staging Tool.
- 29.** Which is a **correct** statement regarding physical therapy for patients with Alzheimer's disease?
- Assessment and screening tools to identify needs are always the same as for other patient populations.
 - Physical therapists do not provide pain management for patients with Alzheimer's disease.
 - Physical therapists are not involved in educating family members and caregivers.
 - Physical therapists must be aware that communication with patients is a major issue.
- 30.** Physical therapy benefits the patient with Alzheimer's disease by:
- Enhancing retention of the patient's remaining capabilities.
 - Providing a supportive environment to improve the patient's cognitive level.
 - Focusing on dealing with depression and other psychological factors.
 - Addressing swallowing deficits that are associated with dementia.



- 31.** A safe home environment for a person with Alzheimer's disease should include:
- Removing all carpeting from floors.
 - Turning off the water heater.
 - Locking up all appliances.
 - Removing locks on bathroom doors.
- 32.** One of the goals of creating a supportive environment for a person with Alzheimer's disease is to:
- Help the person accept dependency.
 - Decrease the need for family involvement in caregiving.
 - Help the person reach his or her full potential.
 - Minimize choices when engaging the person in activities.
- 33.** 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 person to try to remember what was said before.
 - Ignore the question and leave the room.
 - Respond to the question and then try to distract the person.
 - Tell the person the question has already been answered and walk away.
- 34.** Determining manual and cognitive activities involved in the completion of a task and organizing the task into manageable sections is referred to as:
- Person-centered care.
 - Activity analysis.
 - Activities of daily living.
 - Functional ability.
- 35.** When assisting a patient with Stage 3 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 activity of daily living.
 - Reduce standards around hygiene and grooming.
 - Increase distraction during ADL performance to reduce frustration.



36. When approaching the patient with dementia who refuses to attend to daily bathing, the healthcare professional explains what will be done and:

- a. Then asks the patient if they want to be bathed.
- b. Gives the patient a shower instead of a bath because it is quicker.
- c. Avoids offering choices regarding bathing to avoid creating confusion.
- d. Asks the patient when, not if, they would like to bathe.

37. To maintain the nutritional well-being of persons with Alzheimer's disease, it is recommended to:

- a. Offer finger foods to adapt to the person's needs.
- b. Encourage the use of eating utensils to maintain caloric intake.
- c. Provide social stimulation during meals.
- d. Offer snacks such as popcorn or raw vegetables.

38. Which is a **true** statement regarding the person with Alzheimer's disease and driving a vehicle?

- a. If a person who cannot drive safely still demands to drive, the vehicle should be disabled.
- b. The decision to stop driving should be made by the person with Alzheimer's.
- c. Persons with Alzheimer's underestimate their driving abilities.
- d. Driving should be discontinued in the early stages of dementia.

39. Which is a **correct** statement concerning elder abuse in patients with Alzheimer's disease?

- a. Most victims of elder abuse are men over the age of 85.
- b. People with cognitive impairment are at higher risk for elder abuse.
- c. There are no observable signs to indicate whether psychological abuse is occurring.
- d. Most perpetrators of elder abuse are nursing home staff.

40. The "three Rs" approach to calming an agitated patient with Alzheimer's disease involves:

- a. Responding, restoring order, and restarting the activity.
- b. Reminding, reprimanding, and restraining.
- c. Repeating, reassuring, and redirecting.
- d. Rewinding, relaxing, and resuming.



- 41.** 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.
- 42.** Which is a **true** statement about wandering in persons with Alzheimer's disease?
- Wandering in a safe area can be good exercise.
 - Tell the person, "Don't go out there!"
 - Patients who wander should never be allowed outdoors.
 - Listening to music is not effective in preventing wandering.
- 43.** 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 after the noon hour
 - Awakening the patient early and encouraging them to stay up late
 - Allowing the patient to nap as desired during the day
- 44.** To address inappropriate sexual behaviors in a patient with Alzheimer's disease, the caregiver's action is to:
- Scold the patient and state that they are behaving inappropriately.
 - If possible, identify what is triggering the patient's behavior.
 - Discourage the family from touching the person to avoid misunderstanding.
 - Keep the patient under observation in a public area.
- 45.** What is an effective approach for healthcare professionals in supporting family caregivers of patients with Alzheimer's disease?
- Assisting caregivers in obtaining respite care
 - Refraining from providing caregivers with many pamphlets and booklets on the disease
 - Recommending caregivers give up time-consuming leisure activities
 - Suggesting that caregivers arrange psychological therapy for the patient



- 46.** Which is a **true** statement about ethics in guiding the care of a patient with Alzheimer's disease?
- a. In patients with dementia, periodic reassessments of the patient's level of competence need not be conducted.
 - b. Caregivers and healthcare providers should behave paternalistically toward the person with dementia.
 - c. Patients with dementia should not be consulted in their own healthcare decision-making.
 - d. Surrogates follow the expressed wishes of the patient with dementia stated in his or her advance directive.
- 47.** Which is a **correct** statement about the effect of artificial nutrition and hydration (ANH) in patients with advanced-stage Alzheimer's disease?
- a. ANH improves nutritional status.
 - b. ANH lowers the incidence of aspiration pneumonia.
 - c. ANH reduces the incidence of pressure sores.
 - d. ANH may increase the use of physical restraints.
- 48.** Which is considered a type of advance directive for patients with irreversible, serious disease?
- a. Last will and testament
 - b. Durable power of attorney for healthcare
 - c. Verbal agreement with the family
 - d. Charitable trust