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Contact Hours: 10

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 to address potential knowledge gaps include:

- Summarize the epidemiological 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.
- Identify the signs, symptoms, and diagnostic steps for the disease.
- Discuss available pharmacologic and medical therapies.
- Summarize strategies in the rehabilitation and care of persons with Alzheimer's disease.
- Identify interventions in managing problem behaviors.
- Describe effective support for families and caregivers.
- Discuss ethical, legal, and end-of-life considerations.

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, hip fracture, pulmonary embolism, cachexia, or dehydration (Rosenzweig, 2020).

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

- Alzheimer's disease
- Vascular dementia
- Dementia with Lewy bodies
- Frontotemporal dementia
- Mixed dementia (a combination of two or more types)

Other conditions that can result in dementia include:

- Argyrophilic grain disease (AGD), a common late-stage neurodegenerative disease of old
- Creutzfeldt-Jakob disease
- Huntington's disease
- Chronic encephalopathy caused by repeated traumatic brain injury
- HIV-associated dementia
- Normal pressure hydrocephalus
- Parkinson's disease dementia (NIH, 2021a)

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 reported as the sixth leading cause of death in the United States; however, studies have found that it is underreported as an underlying cause of death. It is the only cause of death among the top 10 that cannot be prevented, cured, or even slowed, although a controversial new drug, aducanumab, received accelerated FDA approval in 2021 (Alzheimer's Association, 2020a).

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.

SIGNIF	ICANT 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 at baseline and to identify improvement or deterioration over time.	
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	The first Alzheimer's drug trial (tacrine) was begun. The first deterministic	
	Alzheimer's gene, amyloid precursor protein (APP), was discovered.	
1993	The first Alzheimer's disease risk factor gene was identified, called APOE-e4. The	
	first Alzheimer's drug, tacrine (Cognex), was approved by the U.S. Food and Drug	
	Administration (FDA).	
1994	President Reagan announced he had been diagnosed with Alzheimer's disease. The	
	first World Alzheimer's Day was held.	
1995	The 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	A 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.
2018	Dementia Care Practice Recommendations were developed to help professional care
	providers deliver optimal quality, person-centered care.
2021	Aducanumab (Aduhelm), the first therapy to address the underlying biology of
	Alzheimer's disease, received accelerated approval by the FDA for limited use.
(Alzheii	mer's Association, 2021a; AACC, 2020)

Scientists continue the search for answers regarding causes, diagnoses, and treatments for Alzheimer's disease. Many factors contribute to the difficulty of developing effective treatments, including the inability of animal models to reliably predict whether an experimental treatment will be effective in humans, the slow pace of clinical study recruitment, and the relatively long time needed to observe whether an investigational treatment affects disease progression.

As of 2021, many drugs and medical devices are in development that aim to interrupt the disease process by impacting one or more of the brain changes associated with Alzheimer's. Researchers believe that future treatments will involve a combination of medications or devices aimed at several targets, along with risk reduction strategies similar to current treatments for AIDS and many cancers (Alzheimer's Association, 2021b).

SCOPE OF THE DISEASE

The scope of Alzheimer's disease is based solely on estimates, and the disease is often overlooked as a cause of death. Reasons for this include:

- There is a lack of routine testing in primary care.
- Individuals may have comorbidities that mask dementia as the primary cause.
- Cognitive impairment may make it difficult for someone to report the symptoms that would result in a diagnosis of dementia.
- Stigma attached to dementia is an important factor for avoidance of help-seeking behaviors and may delay diagnosis and the utilization of health and social services.
- The medical certifier who lists the cause of death may be unaware of a person's dementia. (Stokes et al., 2020)

Alzheimer's Disease Worldwide

Worldwide, it is estimated that over 50 million people were living with Alzheimer's disease or other form of dementia in 2020, and this number is expected to double every 20 years. Much of the increase will occur in developing countries and is related to increased life expectancy. About 60% of people with dementia live in low- and middle-income countries, but by 2050 this is expected to rise to 71%.

Demographic aging has increased over the last century, so the world population has a greater number of older people, the population mainly affected by dementia. The fastest growth in the elderly population is taking place in China, India and south Asia, and the western Pacific.

It has been suggested that approximately three quarters of people with dementia worldwide have not received a diagnosis, with one study estimating that 90% remain undiagnosed. In 2021 the country that ranked first in number of people with Alzheimer's disease was Turkey, with a rate of 57.64 per 100,000, and the country with the lowest ranking was Singapore, with a rate of 0.38. The United States ranked 44th, with a rate of 32.44 (WHO, 2021a, WHO, 2021b).

Alzheimer's Disease in the United States

As life expectancy in the United States has risen, so has the number of persons with a probable diagnosis of Alzheimer's disease. It is estimated that 6.2 million Americans ages 65 and older were living with Alzheimer's in 2021. Seventy-two percent of this number were ages 75 and older.

Among the states, South Dakota has the highest rate per 100,000 population (56.0), and the District of Columbia has the lowest rate (11.5). By 2025 every state across the country is expected to experience an increase of at least 6.7% in the number of people with Alzheimer's.

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The West and Southeast are expected to experience the largest percentage increases (Alzheimer's Association, 2021b).

AGE

More than 1 in 9 people ages 65 and older have Alzheimer's. In 2019 the rate of Alzheimer's per 100,000 people by age is described in the table below:

AGE DISTRIBUTION OF PEOPLE WITH ALZHEIMER'S			
Age (years)	Rate (per 100,000)		
45–54	0.3		
55–64	3.0		
65–74	24.9		
75–84	210.2		
85+	1,191.3		
(Alzheimer's Association, 2021b)			

GENDER

More women (12%) than men (9%) ages 65 and older have Alzheimer's disease or other dementias. Almost two thirds of all Americans with Alzheimer's are women.

The predominant explanation for this disparity is that women live longer than men on average, and older age is the greatest risk factor for Alzheimer's. Although there does not seem to be a large or consistent difference in the rate at which men and women develop Alzheimer's or other dementias, there may be differences in why they develop dementia. Differences may be based in biology (such as chromosomal or hormonal differences); differences in environmental, social, and cultural influences on men and women; or the combination of the two.

Lower educational attainment in women than in men born in the first half of the twentieth century could account for elevated risk in women, as limited formal education is a risk factor for dementia.

Other societal gender differences may also be a factor, including differences in occupational attainment between men and women, with a recent study showing that women who participated in the paid workforce earlier in life had better cognitive outcomes after age 60.

Evidence exists that women show more rapid cognitive decline and neurodegeneration than men despite having similar levels of beta-amyloid and tau, meaning the hallmark proteins of Alzheimer's disease may have more negative effects for women than men (Alzheimer's Association, 2021b).

RACE/ETHNICITY

Older Black and Hispanic Americans are disproportionately more likely than older White Americans to have Alzheimer's or other dementias. Alzheimer's affects 10% of White older adults, while 18.6% of Blacks and 14% of Hispanics ages 65 and older have Alzheimer's dementia. Japanese Americans have the lowest prevalence of dementia compared with all other ethnic groups.

The higher prevalence in other racial and ethnic groups compared with Whites appears to be a result of a higher risk of developing dementia in these groups compared with Whites of the same age. Genetic factors do not account for the differences. Instead, the difference is explained by disparities in health conditions, socioeconomics, and life experiences for older Black and Hispanic populations compared with older White populations.

Chronic health conditions associated with higher dementia risk, such as cardiovascular disease and diabetes, disproportionately affect Black and Hispanic populations. Social and environmental disparities include lower levels and quality of education, higher rates of poverty, and greater exposure to adversity and discrimination. These health and socioeconomic disparities are grounded in the history of systemic discrimination against Black populations and other people of color in the United States (Alzheimer's Association, 2021b).

EDUCATION LEVEL

Higher educational levels are widely associated with a higher cognitive reserve, lower risk of dementia, and delayed cognitive decline. However, scientific evidence supporting these claims is controversial.

Data suggest that more education seems to play a role as a form of cognitive reserve that helps people do better at baseline but does not affect actual level of decline. Higher levels of education are tied to having better cognitive function for longer lengths of time, but they are not linked with a person's risk of developing Alzheimer's dementia. Low education, however, is considered an important modifiable risk factor for dementia worldwide, despite the lack of a formal consensus definition of "low education" and, consequently, how much education is required to reduce dementia risk.

In the absence of a consensus definition of what is meant by education in general, and low education in particular, it is challenging to translate findings regarding education and dementia risk into policy recommendations. Results of meta-analyses, however, suggest reduced risks of 8% for Alzheimer's and 7% for any dementia for each year of education (Maccora et al., 2020).

MORBIDITY AND MORTALITY

Alzheimer's disease is officially listed as the sixth leading cause of death in the United States and the fifth leading cause of death for those ages 65 and older. Alzheimer's kills more people than breast cancer and prostate cancer combined. One in 3 seniors dies with Alzheimer's or another dementia.

Alzheimer's is also a leading cause of disability and poor health in older adults. Before a person with Alzheimer's dies, they live through years of morbidity as the disease progresses.

It is difficult to determine how many deaths are caused by Alzheimer's disease each year due to the manner in which causes of death are recorded. According to the latest available data, 121,499 people died from Alzheimer's disease in 2019. The CDC considers a person to have died from Alzheimer's if the death certificate lists Alzheimer's as the underlying cause of death, defined as "the disease or injury which initiated the train of events leading directly to death."

Between 2000 and 2019, deaths from heart disease decreased 7.3% while deaths from Alzheimer's increased 145.2%. During the COVID-19 pandemic to date, Alzheimer's and dementia deaths have increased 16%.

Severe dementia causes complications such as immobility, swallowing disorders, and malnutrition that significantly increase the risk of serious acute conditions that can cause death. One condition, pneumonia, is the most commonly identified immediate cause of death among older adults with Alzheimer's or other dementias. One autopsy study reported respiratory system diseases were the immediate cause of death in more than half of those with Alzheimer's, followed by circulatory system disease in about one fourth of them (Alzheimer's Association, 2021b).

Financial Impact of Alzheimer's

Alzheimer's disease inflicts a heavy economic burden on families and on society as a whole. The total lifetime cost of care for someone with dementia has been estimated at \$373,527 in 2020 dollars.

In 2021, the total national cost of caring for those living with Alzheimer's and other dementias was estimated to be \$355 billion, which does not include unpaid caregiving by family and friends. Dementia is one of the costliest conditions to society. Medicare and Medicaid are expected to cover \$239 billion (or 67%) of the total healthcare and long-term care payments for persons with Alzheimer's or other dementias. Out-of-pocket spending is expected to be \$76 billion (or 22% of total payments).

People with Alzheimer's or other dementias have twice as many hospitalizations per year as other older people, and have more skilled nursing facility stays and home health care visits per year. Overall, 1.3% of all emergency department visits were for people with Alzheimer's or other dementias. Thirty-two percent of individuals using home health and 31% of those using adult day services have Alzheimer's or other dementias. Approximately 10% of adult day service centers specialize in caring for individuals with some form of dementia. Forty-two percent of individuals in residential care facilities that assist with everyday activities have some form of dementia, as do 48% of nursing home residents.

In 2020, more than 11 million family and friends provided 83% of the help needed to care for people with dementia, totaling nearly \$257 billion in unpaid care. Approximately two thirds of dementia caregivers are women. About 30% are ages 65 or older. Over 60% are married, living with a partner, or in a long-term relationship. Over half of caregivers are providing assistance to a parent or in-law with dementia, and approximately 10% provide help to a spouse with dementia (Alzheimer's Association, 2021b).

ANNUAL MEDIAN COST IN THE UNITED STATES FOR LONG-TERM CARE SERVICES, 2021

Homemaker services: \$53,768

Home health aide: \$54,912

Adult day healthcare: \$19,240

Assisted living (single occupancy): \$51,600

Nursing home facility, semi-private room: \$93,075

Nursing home facility, private room: \$105,850

(Statista, 2021)

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:

- Is Alzheimer's disease covered? Most policies say they cover it, but not all.
- 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, 2021b)

MEDICARE AND MEDICAID COVERAGE

Although Medicare covers care in long-term care hospitals, skilled nursing care in a skilled nursing home and hospice and long-term care in a nursing home are not covered by Medicare.

Medicaid covers nursing home care and long-term care services in the community for those who meet program requirements for level of care, income, and assets. To receive coverage, beneficiaries must have low incomes. Most residents who qualify for Medicaid must spend all their Social Security income and any other monthly income, except for a very small personal needs allowance, to pay for nursing home care. Medicaid only makes up the difference if the resident cannot pay the full cost or has a financially dependent spouse.

Nationally, state Medicaid programs are shifting long-term care services from institutional care to home- and community-based services as a means to both reduce unnecessary costs and meet the growing demand for these services. Federal and state governments share the management and funding of the program, and states differ greatly in the services covered by their Medicaid programs (Alzheimer's Association, 2021b).

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 (\$203 in 2021).
- 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 and aggression) as well as physical and occupational therapies if prescribed by a doctor and medically necessary.
- Medicare Part D helps pay for prescription drugs, and most standard Alzheimer's medications are on Medicare's approved drug list, including the new FDA-approved drug Aduhelm. However, due to its uncertain clinical efficacy, Medicare will not cover the cost of the drug outside of an approved clinical trial.
- 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 during 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.
- Persons are eligible for home health care if they are certified to require part-time or "intermittent" skilled nursing care (less than 7 days a week or less than 8 hours each day over a period of 21 days or less).
- 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.
- 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. Some Alzheimer's patients may qualify as homebound, but they may not qualify for services because home health care is not intended to be for a "continuous" need.

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 a hospice doctor, sign a statement electing for palliative rather than curative care, and receive care from a Medicare-certified hospice agency. Very late-stage patients will qualify for all palliative care required as well as counseling for the individual and family.
- 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 hospital 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.

(Medicare.gov, 2021; Guerrero, 2021)

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

WHAT IS ALZHEIMER'S DISEASE?

Normal aging involves changes throughout the body, and the brain is not exempt. In normal aging, the volume of the brain decreases each year after age 65, with greatest loss in the frontal and temporal lobes and greater loss of white matter than grey matter in cognitively normal older adults. Cerebral blood flow decreases up to 5%–20%, with deterioration of mechanisms that maintain cerebral blood flow with fluctuation in blood pressure.

Age-related neuronal loss is most prominent in the largest neurons in the cerebellum and cerebral cortex. The hypothalamus, pons, and medulla have modest if any neuron or volume losses with normal aging. Age-related neuron loss is likely due to programmed cell death rather than inflammation, ischemia, or other mechanism.

Age also affects neurons with loss of dendritic tree, shrinkage of processes, and decrease of synapses. In some areas, dendritic connections may increase, which may be due to repatterning of the brain invoked to compensation for cellular death. Neurons continue to form new synapses, and new neurons are formed throughout the lifespan, but rates of loss are greater than gains.

Lipofuscin accumulates in certain areas of the brain, particularly the hippocampus and frontal cortex, both of which are associated with memory formation, but the impact of lipofuscin on function is unknown. **Neurofibrillary tangles** and **senile plaques**, which are two characteristic lesions of Alzheimer's disease, occur in certain areas of the brain in normal aging, but to a lesser extent than in Alzheimer's disease. More than 50% of cognitively normal individuals over age 85 have sufficient plaques/tangle burden to make a pathologic diagnosis of Alzheimer's disease.

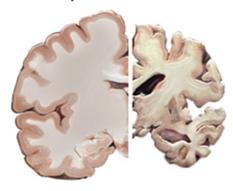
People with Alzheimer's disease experience impaired connections between neurons and neuron cell death, causing impairments in learning and thinking. Alzheimer's also causes the surface layer of the cerebrum to shrink, which directly affects a person's ability to plan, recall facts, and concentrate. This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



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

As neurons are injured and die throughout the brain, connections between networks of neurons may break down, and many brain regions begin to shrink. By the final stages of Alzheimer's, this is widespread, causing significant loss of brain volume (Taffet, 2021).

Healthy Brain Severe AD



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

Pathophysiology

The cause of Alzheimer's disease is poorly understood and includes many environmental and genetic risk factors that are associated with its development. There are several hypotheses for the cause of AD, but the exact cause is still unknown.

Alzheimer's is largely associated with amyloid plaques, neurofibrillary tangles, and loss of neuronal connections in the brain. Scientists do not know exactly what role plaques and tangles play in Alzheimer's disease, but it is believed that they disable or block communication among nerve cells and disrupt processes the cells need to survive. The destruction and death of nerve cells causes memory failure, personality changes, problems in carrying out daily activities, and other symptoms of Alzheimer's.

THE AMYLOID HYPOTHESIS

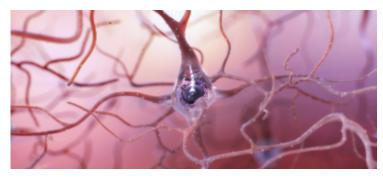
The amyloid hypothesis was first proposed in 1991 and states that extracellular amyloid beta deposits are the main cause of the disease. In Alzheimer's disease, plaques develop in the hippocampus, where memories are encoded, and in other areas of the cerebral cortex that are used in thinking and making decisions.

Whether beta amyloid plaques themselves cause AD or whether they are a by-product of the AD process is still unknown (Fan et al., 2020).

THE TAU HYPOTHESIS

The tau hypothesis was introduced in 2009 and proposes that tau protein abnormalities initiate the Alzheimer's disease process. Tau is mainly found in neuronal axons of the brain, combined with microtubules. The main function of tau is to stabilize microtubules, which is particularly important for neurons since microtubules serve as "highways" for transporting nutrients and neurotransmitters in dendrites and axons.

In this model, a process known as *hyperphosphorylation* causes tau to pair with other threads of tau into helical filaments, which eventually form neurofibrillary tangles inside nerve cell bodies. When this occurs, the microtubules disintegrate, and the structure of the cells' cytoskeleton is destroyed. This collapses the neuron's transport system. Intracellular neurofibrillary tangles (NFTs) are an important pathological feature of Alzheimer's disease (Fan et al., 2020).



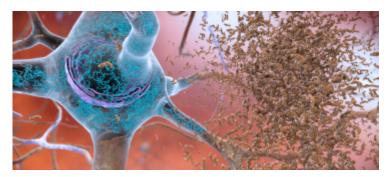
Healthy neuron.

(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.)

THE CHOLINERGIC HYPOTHESIS

The cholinergic hypothesis is the oldest of all the hypotheses and forms the basis for most of the Alzheimer's drugs available on the market today. According to this hypothesis, there is a reduced rate of production and transportation of the neurotransmitter acetylcholine in the brains of AD-affected individuals. This neurotransmitter is used by all the cholinergic nerve cells and has an important role in the both peripheral and central nervous systems. Studies have shown the cholinergic system is a crucial contributor to the learning and memory processes (Agarwal et al., 2021).

THE AUTOIMMUNE HYPOTHESIS

The autoimmune hypothesis suggests that Alzheimer's disease is initiated on a disruption of the blood-brain barrier (BBB) caused by either genetic or nongenetic risk factors. This disruption leads to an autoimmune response against pyramidal neurons located in the structures of the brain involved in memory formation and storage. The response caused by the adaptive immune system is not strong enough to directly kill neurons but may be sufficient to make them selectively vulnerable to neurofibrillary pathology (Arshavsky, 2020).

THE INFECTIOUS HYPOTHESIS

The infectious hypothesis proposes that a pathogen, such as a virus, bacteria, prion, etc., is the root cause of Alzheimer's disease. This hypothesis is supported by evidence that some pathogens, including herpes viruses and certain bacterial species such as chlamydia pneumoniae and spirochetes, are found more commonly in Alzheimer's patients. The bacteria are significantly more common in the brains of Alzheimer's patients who have chronic gum disease (Alzheimer's Society CA, 2021).

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 caused by genetics and the interaction of genes with other internal and external factors over many years, leading to changes in brain structure and function. This means that **genetics** plays an important role, together with how genes are affected by external factors such as environment and lifestyle **(epigenetics)**, some of which are modifiable and some of which are not.

GENETIC RISK FACTORS

The role of genetics in the development of dementia is not yet fully understood, but scientists have found over 20 genes that may increase the risk for the development of Alzheimer's.

Genes Linked to Early-Onset and Late-Onset Alzheimer's

There are two types of Alzheimer's disease, both of which have a genetic component.

Early-onset familial Alzheimer's disease (FAD). FAD is hereditary and appears well before the age of 65, usually between the early 40s and mid-50s. Studies of families have discovered three known genes that cause early-onset Alzheimer's, all of which affect processing or production of beta-amyloid:

- Amyloid precursor protein (APP)
- Presentiin-1 (PS1)
- Presenilin-2 (PS2)

There are also cases of early-onset AD that cannot be linked to one of these three genes, suggesting that perhaps there may be other genes not yet discovered (Strobel, 2021).

Late-onset Alzheimer's. Several genes have been implicated in the risk for late-onset Alzheimer's, with the APOE-e4 gene exerting the greatest impact on risk. This gene promotes the build-up of beta-amyloid, creating the distinctive plaques seen in the brains of AD patients, and is present in 40%–65% of those with Alzheimer's. Inheriting the APOE-e2 version of this

gene has been found to be a protective factor against AD; however, the mechanism underlying this remains unclear (Alzheimer's Association, 2021b; NIH, 2021b).

Down Syndrome and Alzheimer's

In Down syndrome, an individual is born with three copies of chromosome 21 (called *trisomy 21*) instead of two. People with Down syndrome have an increased risk of developing Alzheimer's, and this is believed to be related to trisomy 21, which includes the gene that encodes for the production of amyloid precursor protein (APP), which in people with Alzheimer's is cut into beta-amyloid fragments that accumulate into plaques.

Overall, people with Down syndrome develop Alzheimer's at an earlier age than people without Down syndrome and by age 40 have significant levels of beta-amyloid plaques and tau tangles in their brains. As with all adults, advancing age increases the likelihood that a person with Down syndrome will develop symptoms of Alzheimer's (Alzheimer's Association, 2021b).

TREM2 and Chronic Inflammation in the Brain

It is indisputable that neuroinflammation occurs in the AD-diseased cortex, and animal models and clinical studies strongly suggest that chronic inflammation significantly contributes to Alzheimer's disease pathogenesis.

In the central nervous system, the TREM2 gene is present on the microglia and is responsible for an exaggerated response of these cells to different irritants (toxic proteins, infectious agents, stroke, depression, hypertension, diabetes, and various neurodegenerative disorders), causing excessive inflammation. Chronic microglial activation leads to excessive neuroinflammation. Genome-wide associated studies have identified variants of the TREM2 gene and linked it with a two- to fourfold increased risk of developing Alzheimer's disease (Kulkarni et al., 2021).

EPIGENETIC RISK FACTORS

Studies have suggested that late-onset Alzheimer's disease is driven by epigenetic changes—how and when certain genes are turned on and off—in the brain and how behaviors and environment can cause changes that affect the way genes work. Epigenetic changes are reversible and do not change DNA sequence, but rather change how the body reads a DNA sequence.

Epigenetic regulators have been found to disable protective pathways and enable prodisease pathways in those with AD. Three different epigenetic regulator mechanisms have been identified:

- DNA methylation: DNA methylation regulates gene expression by recruiting proteins involved in gene repression or by inhibiting the binding of transcription factor(s) to DNA.
- Histones: Epigenetic changes alter gene expression without mutation of DNA by influencing production of histones that package and protect DNA. Histones are proteins

that bind to DNA, help give chromosomes their shape, and help control the activity of genes.

Noncoding RNA (ncRNA)—associated gene silencing: A noncoding RNA is a functional
molecule that is transcribed from DNA but not translated into proteins. They have been
implicated in the deposition of beta-amyloid plaques, the accumulation of neurofibrillary
tangles, and the neuroinflammation processes that lead to neuronal death.
(NIH, 2021c; Nativio et al., 2020)

Chronic Stress

There is evidence that chronic stress can accelerate aging, the main risk factor for Alzheimer's disease. During aging, the functioning of cell glucocorticoid receptors decreases, and free (toxic) cortisol can arise, leading to damaged cerebral areas. It is well documented that stress may affect the memory systems and ability to remember past events. While acute stress is somewhat adaptive and may have beneficial effects on memory functioning in specific situations, chronic stress is associated with a variety of alterations through the production of glucocorticoids, specifically cortisol, that could play a role in decreasing memory encoding and consolidation.

Chronic stress has been reported to accelerate AD pathogenesis, including extracellular beta-amyloid plaque deposition and intracellular tau hyperphosphorylation. The exacerbation of both may be due, at least in part, to excessive secretion of corticosteroids (Avila-Villanueva et al., 2020).

Fructose

New research suggests that Alzheimer's disease may be driven by the overaction of fructose made in the brain. This helps explain why diabetes and obesity are associated with an increased risk for Alzheimer's disease. It is proposed that Alzheimer's is a modern disease driven by changes in dietary lifestyle in which fructose can disrupt cerebral metabolism and neuronal function (Johnson et al., 2020).

Excess Deregulated Brain Iron

Recently, excess deregulated brain iron has been widely reported in the pathogenesis of neurodegenerative diseases, including Alzheimer's disease. Iron is an essential element involved in many biological processes in the central nervous system, including oxygen transportation, myelin production, and the synthesis and metabolism of neurotransmitters. High concentrations of iron are present in the brains of patients with Alzheimer's. Excess iron accumulates in the insoluble amyloid plaques and neurofibrillary tangles as characteristics of Alzheimer's. Elevated neuron iron exacerbates oxidative damage in neuronal cells, ultimately producing the pronounced cognitive deficits in Alzheimer's disease (Bao et al., 2021).

Diabetes Mellitus

People with diabetes, especially type 2, are at two times higher risk of developing cognitive dysfunction, Alzheimer's disease, and other dementias when compared to those without diabetes.

Much research has been done that indicates a possible connection between diabetes and Alzheimer's; however, these connections are not completely understood. Multiple factors involved in diabetes-related complications have been found to play a role in the development of neurodegeneration in Alzheimer's.

Diabetes raises the risk of heart disease and stroke and can cause damage to blood vessels. High blood sugar causes inflammation, which may damage brain cells. Many people with diabetes have been found to have brain changes that are the hallmarks of both Alzheimer's and vascular dementia, and research has suggested that each condition fuels the damage caused by the other. Many studies suggest dysregulation of insulin levels as a reason behind the development of Alzheimer's (Mayo Clinic, 2021a; Jash et al., 2021).

Cardiovascular Disease

Studies have indicated that cardiovascular disease and dementia share similar genetic and biochemical profiles and common triggers. Because the brain is highly vascularized, receiving 15% of cardiac output and consuming about 20% of the body's total oxygen supply, it is particularly vulnerable to impairment of cerebral perfusion. The risk of developing Alzheimer's appears to be increased by many conditions that damage the heart and blood vessels, including heart disease, diabetes, stroke, hypertension, and high cholesterol.

Hypertension is one of the leading factors. Prior to 2017, high blood pressure was defined as 140 systolic and 90 diastolic. Since 2017, it has been redefined as 130/80. Approximately 46% of the adult population in the United States are now classified as having high blood pressure.

A definite causative mechanism underlying the relationship between hypertension and dementia, and particularly Alzheimer's disease, has not yet been found. However, it has been suggested that long-standing hypertension, being closely related with endothelial dysfunction, arterial stiffness, and atherosclerosis, is linked with cerebral hypoperfusion (Alzheimer's Association, 2021b; Tini et al., 2020).

Hearing Loss

Mild, moderate, and severe hearing loss make the odds of dementia 1, 3, and 5 times higher over the following 10 or more years. The associations between hearing loss and the mechanisms underlying cognitive impairment remain unclear. There are several hypotheses in the age-related hearing loss and cognitive decline literature that are based on the premise that hearing loss can alter brain function and structure:

- Common cause: A common pathology could explain the connection, such as that of Alzheimer's disease or of vascular disease.
- **Social isolation model:** There is evidence that social isolation increases inflammation and glucocorticoids, which could affect brain structure and has been linked to dementia and cognitive loss.

- **Impoverished input:** Hearing-impaired individuals experience less cognitive stimulation, which may cause the loss of function in high-level brain areas.
- Increased cognitive load: Hearing loss leads to increased cognitive load on the brain, which in turn increases the risk of cognitive decline. The hearing-impaired individual must use more brain resources than the average person in order to listen, which may reduce the cognitive resources available to do other tasks, and that may lead to cognitive impairment.

Sensorineural hearing loss alone can lead to degeneration of hippocampal neurons. Following hearing loss, decreased neurogenesis is obvious in the subgranular zone (a brain region in the hippocampus where adult neurogenesis occurs), and tau protein phosphorylation is increased in the hippocampus, as is neuroinflammation (Shen et al., 2021; Cruz, 2021).

Depression

Depression is a risk factor for cognitive decline and dementia. Experiencing depression within the past 10 years increases the risk of dementia 4- to 6-fold for older adults. Multiple reports have suggested that a single episode of depression at any point in life is a risk factor for dementia. Chronic depression or recurrent episodes are common in late-life depression, and individuals with persistent depressive symptoms are at an even higher risk for dementia, especially when combined with cognitive deficits.

The explanation for this is hypothesized to be that late-life depression, particularly when it is persistent and treatment resistant, is associated with increased levels of proinflammatory markers, cerebrovascular lesions, and cognitive deficits that may lead to dementia or may speed conversion to dementia by decreasing brain reserve (Brewster et al., 2020).

Head Trauma

Several studies have found that incurring a moderate or severe head injury can increase the risk of developing Alzheimer's disease many years later. One study found that sustaining a moderate head injury increased the risk of Alzheimer's disease by 2.3 times, while severe head injury had a 4.5-times greater risk. The mechanism by which this occurs is thought to be linked to cerebral hypoperfusion that leads to the chain of causative events that ultimately result in the hallmark protein-linked brain changes seen in Alzheimer's (Alzheimer's Association, 2021b).

Smoking

Smoking is a significant risk factor for Alzheimer's disease. A large cohort study has shown that the risk of dementia and AD is dose-dependent, increasing with the increasing number of cigarettes smoked. Heavy smoking is associated with a >100% increase in risk of dementia and Alzheimer's disease after two decades of exposure.

Cigarette smoking is associated with higher beta-amyloid 42 levels (A β 42), excessive oxidative stress, neuroinflammation, and impaired neuroprotection found in the cerebral spinal fluid. Studies have demonstrated that high A β 42 CSF levels are strongly associated with Alzheimer's

disease. The primary hypothesis for Alzheimer's development suggests that A β 42 promotes plaque formation, accompanied by oxidative stress, cortical inflammation, and neuronal loss, while the abnormal deposition of protein aggregation causes neurotoxicity, cell death, and neurodegeneration. It is understood that the combined effects of oxidative stress and neuroinflammation lead to the accumulation of beta-amyloid (Liu et al., 2020).

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. Because the skin's ability to synthesize vitamin D from the sun decreases with age, vitamin D deficiency is more common among older adults.

A large study has shown that people with extremely low blood levels of vitamin D were more than twice as likely as those with normal vitamin D levels to develop Alzheimer's or other types of dementia. Other studies have shown no association. At this time, association between vitamin D deficiency and dementia risk is only observational, and more research is needed to show cause and effect (Graff-Radford, 2021a).

Obesity and Inflammation

Obesity, diabetes, and Alzheimer's disease share several common features, with inflammation emerging as the central link. High calorie intake, elevated free fatty acids, and impaired endocrine function lead to insulin resistance and systemic inflammation. This inflammation triggers neuroinflammation, which eventually interferes with the metabolic and regulatory function of the brain mitochondria, leading to neuronal damage and subsequent Alzheimer's related cognitive decline (Khan, 2020).

A recent study done among older adults has found that:

- After an average of 11 years, those who were obese at the start of the study had a 31% higher risk for developing dementia than those with a normal weight.
- Women who carried weight around the waistline had a 39% greater risk of dementia; however, there was no link between waistline and dementia in men.
- Those with both obesity and high waist circumference showed a 28% increased risk of dementia.
- The risk for dementia could not be explained by differences in age, marital status, smoking behavior, or other health conditions, including diabetes and hypertension.
 (Ma et al., 2020)

Ophthalmic Comorbidities

A recent study has found that age-related macular degeneration (AMD), cataract, and diabetes-related eye disease (DRED) are independently associated with an increased risk of dementia. The risk for dementia was found to be 26% higher among those with AMD, 11% higher among those with cataract, and 61% higher among those with DRED compared with people without these ophthalmic conditions. Risk for dementia was higher in those with both ophthalmic and system conditions (Shang et al., 2021).

Menopause

Menopause status has been found to be the main factor contributing to higher beta-amyloid levels, lower glucose metabolism, and lower gray and white matter volumes in women. There is growing evidence correlating menopause with risk and progression of neurodegenerative diseases. Loss of estrogen after menopause increases the risk of neurodegenerative diseases, which indicates that estrogen plays an important role in disease onset and progression.

Based on current literature, a decrease in estrogen, progesterone, and insulin-like growth factor-1 (IGF-1) hinders their neuroprotective effects, increases inflammation, and impairs beta-amyloid clearance. Estrogen can regulate beta-amyloid expression, accumulation, and degradation and has been shown to modulate the immune system. Lower estrogen concentration is related to hippocampal dysfunction and poorer performance on initial learning and memory retrieval.

In addition to estrogen, progesterone's neuroprotective effects are well documented. Circulating progesterone is decreased during menopausal transition and drops dramatically following menopause, reducing its neuroprotective effects. Although these neuroprotective effects are well known, the association between progesterone and neurodegenerative diseases, especially AD, is not very clear.

Estrogen hormones regulate gene expression and maintain their full activity only when IGF-1 levels are in the normal range. If the concentrations of one or both hormones are reduced, estrogens were no longer capable of regulating gene expression. Lower serum levels of IGF-1 are associated with an increased risk of developing AD dementia. Higher levels of IGF-1 may protect against subclinical and clinical neurodegeneration.

Lower serum levels of IGF-1 are associated with an increased risk of developing AD dementia and higher levels of IGF-1 with greater brain volumes even among middle-aged community-dwelling participants. Higher levels of IGF-1 may protect against subclinical and clinical neurodegeneration (Cheng et al., 2021; Anderson, 2020).

GENDER

One's gender plays a role in the development of late-onset Alzheimer's disease and involves both genetics and epigenetics. After advanced age, being female is the major risk factor for late-onset Alzheimer's. Women make up about two thirds of AD dementia patients, and postmenopausal women account for more than 60% of affected individuals.

Factors that may more severely affect women include:

- Family history and APOE genotype
- Depression
- Stroke
- Diabetes mellitus
- Hormone-related risks, including menopause and thyroid disease
- Lifestyle-related factors such as smoking, diet, exercise, and intellectual activity (Anderson, 2020)

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 the disease or slowing its progression.

EXERCISE

Regular physical exercise appears to be one of the best things an individual can do to reduce risk for dementia. Studies addressing the effect of aerobic exercise in middle-aged or older adults have reported improvements in thinking and memory and reduced rates of dementia. Regular exercise can significantly reduce the risk of developing Alzheimer's dementia by about 45% and other dementias by 30%. Aerobic exercise has been shown to result in a small increase in the size of the hippocampus, which is the equivalent of reversing one to two years of age-related shrinkage.

Exercise in research studies refer to aerobic exercise performed for a sustained period of time, usually 20–30 minutes. Physical exercise, however, can also mean a daily activity such as brisk walking, cleaning, or gardening. One study found that risk of Alzheimer's disease can be reduced by daily physical tasks such as cooking and cleaning. More research is needed to understand the level and intensity of exercise that is most effective (Alzheimer's Society, 2021a; Alzheimer's Association, 2021b).

DIET

Researchers hypothesize that making healthy food choices may improve cholesterol, blood sugar levels, and overall blood vessel health, which may in turn reduce the risk of cognitive impairment or Alzheimer's disease. Three diets have been studied and found to be beneficial.

- The DASH (Dietary Approaches to Stop Hypertension) 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.
- The Mediterranean DASH Intervention for Neurodegenerative Delay (MIND) diet is a hybrid that combines aspects of both of the above diets. There are five groups of foods to avoid in the MIND diet: sweets, red meat, cheese, fried or fast food, and butter or margarine.

Studies have shown that people who strictly follow any of these three diets had a lower risk of Alzheimer's disease. In addition, even modest adoption of the MIND diet approach, such as eating two vegetable servings a day, two berry servings a week, and one fish meal a week, appeared to lower the risk of Alzheimer's disease (Graf-Radford, 2016b).

SLEEP

Neurodegenerative disorders such as Alzheimer's disease are commonly associated with sleep disturbances. However, a major challenge has been determining the causal relationship between sleep and Alzheimer's and determining which came first, the sleep disturbance or Alzheimer's pathology.

During the day, beta-amyloid protein is made in the brain. Decreased sleep increases this production of beta-amyloid and the release of tau, promoting the formation of amyloid plaques and tau pathology. During sleep, the brain cells and their connections shrink, allowing more space between these cells so that beta-amyloid and other substances that accumulate during the day can be flushed away. Research indicates that individuals can reduce their risk of developing dementia by getting six to eight hours of sleep each night (Lucet, 2020; Budson, 2021).

PREVENTING HEAD TRAUMA

Because there is an association between traumatic head injury and an increased risk for Alzheimer's dementia, it is important to take the following protective steps:

- Wear a seat belt when driving or riding in a motor vehicle.
- Never drive while under the influence of alcohol or drugs.
- Wear a helmet or appropriate headgear when riding a bike or any other open vehicle and when taking part in any sport activities.

- Have a primary care provider or pharmacist review medications for safety concerns, including prescription medicines, over-the-counter medicines, herbal supplements, and vitamins.
- Have vision checked at least once a year.
- Perform appropriate-level strength and balance exercises.
- Make the home as safe as possible to prevent falls. (CDC, 2021a)

SOCIAL CONNECTIONS

Researchers have found that social isolation among adults ages 50 and older is strongly associated with about a 50% increased risk of dementia. Individuals with large social networks are 26% less likely to develop dementia than those with small networks. Experts are not certain about the reason for this association, but it may be due to direct mechanisms through which social and mental stimulation strengthen connections between nerve cells in the brain.

It has also been noted that living with family members does not decrease one's likelihood of developing dementia, as this does not provide the right type of social interaction to assure positive cognitive benefits. To be beneficial, individuals must be engaged and participate in social activities outside the family, such as sharing meals, engaging in conversations, playing games, attending lectures, and exercising with others (CDC, 2021b; Charvat, 2019).

FLU AND PNEUMONIA VACCINATION

Flu and pneumonia vaccinations are tied to a lower risk of Alzheimer's dementia. Having had at least one flu vaccination has been found to be associated with a 17% reduction in Alzheimer's incidence. Having more frequent flu vaccinations was found to be associated with another 13% reduction.

Vaccination against pneumonia between ages 65–75 reduced Alzheimer's risk by 25%–30% after adjusting for sex, race, birth cohort, education, smoking, and individual genetic factors. The largest reduction in the risk of Alzheimer's (up to 40%) was observed among those vaccinated against pneumonia who were noncarriers of the risk gene. More research is needed to explore the biological mechanism for this effect (Alzheimer's Association, 2020b).

MENTAL ACTIVITIES

Neurologists report that mental exercise can reduce the chances of developing Alzheimer's disease by up to 70%. Whenever the brain is challenged with new or different tasks, brain function improves. In order for an activity to be considered beneficial, the activity must:

- Engage the person's attention
- Involve more than one of the senses

• Break a routine activity in an unexpected way (e.g., brushing one's teeth with the nondominant hand)

Researchers have yet to uncover what elements make brain training interventions effective or which types or combinations of training are required in order to be effective. Mental activities that **may** have an impact on cognitive decline include:

- Reading and writing every day
- Drawing a map from memory
- Solving mathematical problems in the head
- Learning a new language
- Memorizing a list and testing recall of it
- 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 such as learning to play an instrument
- 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 (Cherry, 2021; ARPF, 2021)

ALZHEIMER'S DISEASE SIGNS AND SYMPTOMS

The cardinal symptoms of Alzheimer's disease include:

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

Memory Impairment

Early in the course of Alzheimer's, individuals are usually aware of their memory deficit and may make notes to remember important things. Sooner or later the memory deficit is such that they may forgetto 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

The following are early signs and symptoms of Alzheimer's disease memory impairment compared to typical age-related changes.

at this point that they require protection to remain safe.

COMPARING EARLY SYMPTOMS OF AD MEMORY IMPAIRMENT WITH TYPICAL MEMORY CHANGES				
Memory Impairment with Alzheimer's	Typical Age-Related Memory Changes			
Memory loss that disrupts daily life:	Sometimes forgetting names or			
Forgetting recently learned information	appointments but remembering them later			
Repeatedly asking the same question				
Needing to use memory aids				
Challenges in planning or solving problems:	Making occasional errors when managing			
Difficulty concentrating	finances or household bills			
 Taking much longer to do things than previously 				
 Having trouble following a familiar recipe or keeping track of monthly bills 				
Difficulty completing familiar tasks, such as:	Occasionally needing help to use a piece of			
Driving to a familiar location	household equipment (e.g., microwave setting) or other technical or mechanical			
 Organizing a grocery list 	device			
Remembering the rules of a favorite game				
Confusion about time and place:	Getting confused about the day of the week but figuring it out later			
 Losing track of dates, seasons, and the passage of time 				
 Forgetting where one is now and how one got there 				
Trouble understanding visual images and spatial relationships:	Vision changes related to cataracts or other age-related changes or diseases			
 Vision problems causing difficulty with reading and balance 				
Difficulty judging distance, determining color or contrast causing issues with driving				
New problems with words in speaking or writing:	Sometimes having trouble finding the right word			

• Stopping in the middle of a conversation and having no idea how to continue		
• Repeating oneself		
Struggling with vocabulary		
 Having trouble naming a familiar object or using the wrong name 		
Misplacing things and losing the ability to retrace steps:	Misplacing things from time to time and retracing steps to find them	
 Putting things in unusual places 		
 Losing things and being unable to go back over one's steps to find them 		
• As disease progresses, accusing others of stealing		
Decreased or poor judgment:	Making a bad decision or mistake once in a	
Using poor judgment dealing with money	while (e.g., neglecting to change the oil in the car)	
 Paying less attention to personal hygiene and grooming 	,	
Withdrawal from work or social activities:	Sometimes feeling uninterested in family	
 Losing the ability to hold or follow a conversation and withdrawing from 	or social obligations	
hobbies, social activities, or engagements		
Changes in mood and personality:	Developing very specific ways of doing	
 Becoming confused, suspicious, depressed, fearful, or anxious 	things and becoming irritable when a routine is disrupted	
Becoming easily upset at home, with friends, or when out of one's comfort zone (Alzhaimer's Association, 2021a)		
(Alzheimer's Association, 2021c)		

HOW MEMORIES ARE MADE

Memory formation is a cognitive process that involves:

- Receiving: A piece of information is received through the five senses.
- Encoding: The information received is converted into a form that can be stored and held in the short-term memory first. The incorporated memory stays there for just 30 seconds unless it is repeated over and over again in the mind (rehearsed).

- Consolidation/storing: Information from the short-term memory is transferred into long-term memory storage.
- Retrieving: The information stored in the long-term memory is recalled. (Alzheimer's Society, 2021b)

TYPES OF MEMORY AND ASSOCIATED AD SYMPTOMS

Alzheimer's disease (AD) is a progressive neurodegenerative disease marked by deficits in episodic memory, working memory (WM), and executive function.

Memory is a large part of a person's identity, and there are different types. Each type uses a different network in the brain, and therefore, one type can be affected by disease or injury while another type functions normally. Memory systems are divided into **two broad categories**:

- Declarative memory has a conscious component and includes memories of facts and events (i.e., "knowing what").
- Nondeclarative memory does not have a conscious component. It includes memories for skills and habits, simple forms of associative learning, and simple forms of nonassociative learning such as habituation and sensitization (i.e., "knowing how"). (The Human Memory, 2020)

Episodic Memory

Episodic memory is declarative and includes information about recent or past events and experiences, such as where a person parked their car this morning or the dinner a person had with a friend a month ago. These memories often include recalling emotions or feelings. Experiences that cause strong positive or negative feelings are easier to recall many years later. Memory of events that occurred in the distant past is referred to as *long-term* or *remote memory*. Because remote memories eventually become independent of the hippocampus and are stored in the neocortex, they are not as severely disrupted in AD (The Human Memory, 2020; UCSF, 2021a).

This explains why individuals with AD eventually "live in the past," such as wanting to milk the cows even though they haven't lived on a farm for over 20 years, wanting to go to work even though they retired 30 years ago, etc. It also explains why they're able to remember events many decades old but unable to remember what happened that morning.

Semantic Memory

Like episodic memory, semantic memory is declarative and refers to a portion of long-term memory that stores information about facts one knows about the world and language that is common knowledge, such as the meaning of words, names of colors, etc. It is also used to remember familiar faces or objects. 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. 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. 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.

 (Blanchard, 2021)

Procedural Memory

Procedural memory is a form of nondeclarative memory that includes 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 is one of the most common deficits in procedural memory observed in patients with Alzheimer's. It is a disorder of "how" and "when" to correctly perform meaningful and purposeful actions. A person with apraxia is unable to put together the correct muscle movements, which can also lead to problems with speech, such as:

- Distorted, repeated, or left-out speech sounds or words
- Inability to put words together in a correct order
- Struggling to pronounce the right word
- More difficulty using longer words
- Better writing ability than speaking ability

Other forms of apraxia include:

- Buccofacial or orofacial apraxia: inability to carry out movements of the face on demand
- Ideational apraxia: inability to carry out learned complex tasks in the proper order (e.g., putting on socks before putting on shoes
- Ideomotor apraxia: inability to voluntarily perform a learned task when given the necessary objects to do so
- Limb-kinetic apraxia: difficulty making precise movements with an arm or leg (e.g., buttoning a shirt or tying a shoe)

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• Gait apraxia: inability to take even a small step (Libon et al, 2020; NIH, 2021d)

Visuospatial Memory

Visuospatial memory gives one the ability to navigate in the environment and to identify, integrate, and analyze space and visual form, details, structure, and spatial relations in several dimensions. 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 (Kim & Lee, 2021).

Working Memory

Working memory, often referred to as *short-term memory*, is the capacity to temporarily store information in a flexible state so that it can be manipulated in order to complete goal-oriented behaviors (e.g., remembering the numbers when adding in one's head). Working memory dysfunction is possible in the later phases of neurodegenerative disorders such as Alzheimer's (Center for Cognitive Health, 2020).

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

Executive functioning refers to high-level cognitive skills required for control and coordination of other cognitive abilities and behaviors. Executive functions can be divided into organizational and regulatory abilities.

Organizational abilities are techniques used by individuals to facilitate the efficiency of future-oriented learning, problem-solving, and task completion. Organization requires the integration of several elements to reach a planned goal. These include:

- Attention: the capacity to be paying attention to a situation or task in spite of distractions, fatigue or boredom
- Planning: the ability to create a mental roadmap to reach a goal or to complete a task
- Sequencing: the ability to perceive and execute a set of actions that follow a particular order
- Problem-solving: the capacity to identify and describe a problem, and generate solutions to fix it
- Working memory: the ability to hold information in mind while performing complex tasks
- Cognitive flexibility: the ability to revise plans in the face of obstacles, setbacks, new information, or mistakes

- Abstract thinking: the ability to think about objects, principles, and ideas that are not physically present
- Rule acquisition: how individuals acquire skill in applying problem-solving rules
- Selecting relevant sensory information: how an individual analyzes incoming sensory information in order to form visually guided motor decisions

Regulatory abilities involve evaluating available information and modulating a response to the environment. These include:

- Initiation of action: the ability to begin a task in a timely fashion
- Self-control: the ability to manage emotions in order to achieve goals, complete tasks, or control and direct behavior
- Emotional regulation: the ability to keep one's emotions under control
- Monitoring of internal and external stimuli: the ability to monitor and change behavior as needed, plan future behavior when faced with new situations and anticipate outcomes to changing situations
- Initiating and inhibiting context-specific behavior: the ability to inhibit or control impulsive (or automatic) responses, and create responses by using attention and reasoning
- Moral reasoning: the logical process of determining whether an action is right or wrong
- Decision-making: the ability to be proficient in making choices between two or more alternatives (UCSF, 2021b)

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. As Alzheimer's progresses, the person becomes unable to complete tasks.

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, 2020).

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 illness. Psychological and behavioral symptoms affect up to 90% of patients diagnosed with dementia during the course of their illness. Patients with psychological and behavioral symptoms experience emotional distress, diminished quality of

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life, greater functional impairment, more frequent hospitalizations, increased risk of abuse and neglect, and decreased survival. Caregivers experience increased burden of stress and depression.

Some common psychological and behavioral changes are described in the table below:

PSYCHOLOGICAL AND BEHAVIOR CHANGES DUE TO AD		
Category	Examples	
Apathy and indifference	Apathy (the most common behavioral change associated with AD)	
	Lack of motivation	
	Reduced participation	
	Loss of interest in other people	
	Becoming less affectionate and emotionally expressive	
	Self-neglect	
Depression and dysphoria	Tearfulness and crying	
	Consistently low mood	
	Feelings of failure	
	Despair about the future	
	Suicidal thoughts and actions	
Euphoria and elation	Inappropriate giggling and laughter	
	Playing childish games	
	Feeling excessively good for no apparent reason	
	Making grandiose claims about abilities or wealth	
Anxiety	Being nervous or worried	
	Tenseness or shortness of breath without physiologic explanation	
Irritability and lability	• Stubbornness	
	Resistance to care	
	Suspicion of others	
	Agitation or restlessness	
	Aggression	
Inappropriate behaviors	Use of abusive language and profanity	
	Acting in response to delusions or hallucinations	
	Rummaging through other people's rooms	

	Stealing
	Hiding things
	Urinating in inappropriate places
	Angry outbursts
	Violence precipitated by trivial events
	Reversals of the sleep/wake cycle
Eating disorders	 Asocial sexual behaviors, such as masturbating in public Changes in weight (gain or loss)
	Changes in appetite
	Changes in appropriate eating behavior
	Preferences for only certain types of foods
Sleep disturbances	Difficulty falling or staying asleep
	Wandering or pacing in the middle of the night
	Reversal of sleep/wake cycles
Repetitive motor behaviors	• Pacing
	Performing compulsive activities
	Wandering, getting lost
Psychosis (during late-stage	Delusions (fixed false beliefs)
AD)	• Hallucinations (seeing or hearing things that are not actually there)
(UCSF, 2021c)	

Clinical Stages of Alzheimer's Disease and Related Signs and Symptoms

Patients with Alzheimer's disease go through different stages as the disease progresses and exhibit different signs and symptoms during each stage. The rate of progression of Alzheimer's disease varies widely. On average, people with Alzheimer's live between 3 and 11 years after diagnosis, but some survive 20 years or more.

Alzheimer's disease has been classified into either three, four, five, or seven stages used for determining the level of care the person requires 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 divides the disease process into five stages.

STAGE 1: PRECLINICAL ALZHEIMER'S DISEASE

Alzheimer's disease begins long before any symptoms become apparent. This stage is called *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 them. This stage can last for years, and even decades, before symptoms begin to appear and a diagnosis is made.

STAGE 2: MILD 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 that is usually 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.

Other problems during this stage may include:

- Problems remembering names
- Forgetting material that was just read
- Experiencing increased trouble with planning or organizing

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 some assistance with daily activities and self-care. The person may experience:

- Increasing trouble planning complicated activities (e.g., preparing a dinner)
- Trouble remembering events remote as well as recent memories
- Problems learning new things
- Trouble remembering their own name
- Being unable to recall information about themselves, such as their address or phone number
- Problems with reading, writing, and working with numbers

As the disease progresses, the person may:

- Know that some people are familiar but cannot remember their names
- Forget the names of a spouse or child
- Lose track of time and place
- Need help with daily self-care activities
- Become moody or withdrawn
- Have personality changes
- Be restless, agitated, anxious, or tearful, especially in late afternoon or at night
- Become aggressive
- Experience sleep problems
- Wander away from home
- Develop psychotic symptoms including hallucinations and delusions
- Lose impulse control
- Begin to lose bladder and bowel control

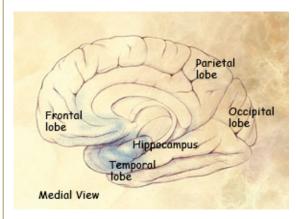
STAGE 5: SEVERE DEMENTIA DUE TO ALZHEIMER'S DISEASE

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 may occur:

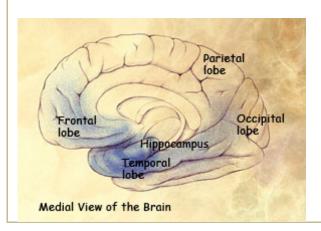
- Loses many physical abilities, including walking, sitting, and eating
- Able to say some words or phrases, but unable to have a conversation
- Becomes unaware of recent experiences and surroundings

- Needs help with all activities all of the time
- Becomes unable to recognize immediate family members
- Loses weight
- Experiences seizures
- Experiences skin infections
- Groans, moans, or grunts
- Sleeps an increased amount
- Loses bladder and bowel control
- Has impaired swallowing (which can lead to aspiration pneumonia, the most common cause of death in persons with Alzheimer's disease)
 (Mayo Clinic, 2021b; Johns Hopkins Medicine, 2021a)

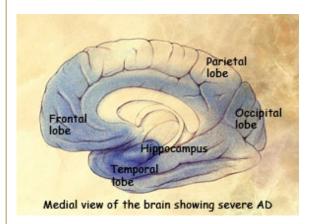
AREAS OF THE BRAIN AFFECTED DURING THE STAGES OF ALZHEIMER'S DISEASE



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 test that can diagnose Alzheimer's disease. Various approaches and tools are used to assist in making a diagnosis. Dementia can almost always be determined, but it may be difficult to identify the exact cause. Diagnosis is made using the following tools:

- Patient medical history
- Physical examination
- Neurological examination
- Mental cognitive status tests
- Diagnostic tests (to rule out other health issues that can cause similar symptoms to dementia)

Dementia: Alzheimer's Disease Patient Care

• Brain imaging (Alzheimer's Association, 2021b)

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, including Alzheimer's disease or other dementias
- 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 (Alzheimer's Association, 2021b)

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:

- Overall appearance
- Vital signs
- Heart and lungs
- Head and neck
- Abdominal exam
- Extremities

Specific exams for male and female

The neurological examination involves evaluating the person for problems that may suggest brain disorders other than Alzheimer's, which could include Parkinson's disease, brain tumors, or buildup of fluid in the brain. The exam includes:

- Cranial nerve testing
- Reflex testing
- Coordination
- Motor function and balance
- Gait
- Speech
- Muscle tone and strength
- Eye movement
- Sensory exam (Alzheimer's Association, 2021b)

Mental Cognitive Status Testing

A thorough mental status examination evaluates the following cognitive spheres:

- Attention and concentration
- Memory
- Language
- Visuospatial perception
- Praxis (cognitive ability to do complex motor movements)
- Calculations
- Executive functioning
- Mood and thought content

There is currently no cognitive assessment tool that is considered to be a gold standard. The most widely used tools are the Mini-Mental State Exam and the Montreal Cognitive Assessment.

MINI-MENTAL STATE EXAM (MMSE)

The Mini-Mental State Exam is the most popular and well known of mental status screening tests. It assesses multiple cognitive domains, particularly memory and language, which may be most relevant to dementia due to Alzheimer's disease. The MMSE can be performed in a relatively short time period (5–10 minutes) and is most sensitive to patients at the mild to moderate stage of Alzheimer's dementia. The tool consists of brief questions and simple tasks scored on a 30-point scale. It cover a wide range of functions, including memory, attention, orientation, and overall executive function.

Advantages of the MMSE include brevity and ease of administration. Disadvantages include the narrow scope, inability to detect subtle memory losses, and interpretation complexity. Such complexity is due to the fact that education and cultural background affect scores (Alzheimer's Association, 2021b; Slavych, 2019).

MMSE QUESTIONS AND SCORING

During the MMSE, a health professional asks the 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, state, and country 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 (Dementia Care Central, 2021a).

MONTREAL COGNITIVE ASSESSMENT (MoCA)

The Montreal Cognitive Assessment is a 30-point test that assesses short-term memory recall, visuospatial ability, and different aspects of executive function. It takes about 10 minutes to complete, with a score of 26 or above considered normal.

Advantages of the MoCA include its sensitivity as a screening tool for mild cognitive impairment, Alzheimer's disease, and dementia, as well as ease of use. The disadvantage of the MoCA for practitioners is the length of time required for administration (Mendez, 2021; Slavych, 2019).

ST. LOUIS UNIVERSITY MENTAL STATE EXAM (SLUMS)

The St. Louis University Mental State exam consists of 11 brief questions scored on a 30-point scale. It takes approximately 7–10 minutes to administer, and the questions cover a wide range of functions, including memory, attention, orientation, and overall executive functions.

Both the MMSE and SLUMS have a total of 30 points, however, the average score of the SLUMS is approximately 5 points lower than that of the MMSE, supporting the belief that the SLUMS is a more difficult test and thus likely to be more sensitive to mild cognitive impairment, picking up any issues sooner (Rosenzweig, 2021).

COMPUTERIZED TESTS

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

- Cantab
- Cognigram
- Cognivue
- Cognision

Automated Neuropsychological Assessment Metrics (ANAM)

The advantages of using computerized tests include the fact that tests are given exactly the same way each time, and using both clinical tests and computer-based tests can give clinicians a clearer understanding of cognitive differences experienced by their patients. Despite concerns regarding elderly patients' computer literacy, there are high completion rates, and patients have generally positive experiences completing them. The Cantab, for example, is intuitive to use, and its game-like nature is engaging and motivating (Alzheimer's Association, 2021b).

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

Medicare's Annual Wellness Visit (AWV) benefit requires, among other things, an assessment to detect cognitive impairments. Along with routine measurements and health risk assessment, during this visit functional ability and level of safety are assessed, as well as ability to perform activities of daily living. Screening is included for cognitive impairment and depression. Dementia rates have increased with AWV implementation, with varying effects by race and ethnicity (Lind et al., 2021).

Diagnostic 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	Inflammatory processes
(ESR)	
HIV antibody	HIV/AIDS
Rapid plasma reagin (RPR), venereal disease research	Syphilis
laboratory (VDRL)	
Toxicology screening	Illicit drug use, alcohol use
Paraneoplastic antibodies	Autoimmune encephalitis
Less Common Tests	Purpose
Cerebrospinal fluid (CSF) biomarkers: beta-amyloid, total	Confirm or rule out Alzheimer's
tau protein, and phosphorylated tau	disease
ApoE genotype	Confirm or rule out probable
	Alzheimer's disease
PSEN1, PSEN2, and APP	Genetic mutations
(Lakhan, 2021; OneCare Media, 2021)	

BLOOD TEST FOR ALZHEIMER'S DISEASE

An international research team has developed a 19-protein biomarker panel blood test for early detection and screening of Alzheimer's disease, with an accuracy level of over 96%. This test can also differentiate among the early, intermediate, and late stages of the disease and can be used to monitor the progression of the disease over time. The findings serve as a foundation for the development of a high-performance, blood-based test for AD screening and monitoring in clinical settings (Jiang et al., 2021).

ELECTROENCEPHALOGRAM (EEG)

EEG may be done to detect abnormal brain-wave activity. EEG is usually normal in people with mild Alzheimer's disease and many other types of dementia. But abnormalities do occur in delirium and Creutzfeldt-Jakob disease, another cause of dementia (Helpguide.org, 2021).

Imaging Studies

Imaging studies are particularly important for ruling out treatable causes of progressive cognitive decline.

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, tumors, or hydrocephalus, and to assess specific causes (i.e., neurodegenerative or otherwise) of dementia (Alzheimer's Association, 2021b; Lakhan, 2021).

FUNCTIONAL NEUROIMAGING

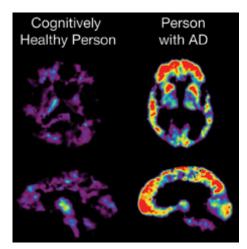
Functional neuroimaging enables in vivo (within a living organism) examination of how the brain functions. **Functional MRI (fMRI)** may detect abnormalities within the brain that cannot be found with other imaging techniques. FMRI can detect or measure changes in metabolism, blood flow, regional chemical composition, and absorption.

Blood flow to an area of the brain is very sensitive to changes in neural activity. This makes it possible to map changes in neural activity associated with a wide range of motor, sensory, and cognitive skills. The fMRI is done by exposing patients to a stimulus or having them engage in a cognitive activity while acquiring single-shot images of the brain. The region of the brain that is responding to the stimulus or is engaged in the activity will experience an increase in metabolism.

Research studies have found that fMRI scanning may inadequately represent an individual's typical brain activation pattern, particularly an individual with dementia. Therefore, multiple imaging baselines are recommended for comparison (UW, 2021; Paek et al., 2019).

MOLECULAR NEUROIMAGING

Molecular imaging provides detailed pictures of what is happening inside the body at the molecular and cellular level. Modalities include **positron emission tomography (PET)** and **single photon emission computed tomography (SPECT)**. Both are nuclear medicine techniques that use small amounts of intravenously injected ionizing radiation in the form of short-lived radioisotopes (radiotracers) so that activity in the brain or other organs can be studied to diagnose and determine the severity of a variety of diseases. PET and SPECT can help narrow down a diagnosis by revealing deficits common in Alzheimer's disease that are distinct from findings for other dementias, such as frontotemporal lobar degeneration and dementia with Lewy bodies.



PET scans of the brain.

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

A **combined PET/CT** exam fuses images from a PET scan and CT scan to provide details on both the anatomy from the CT scan and function of organs and tissues from the PET scan. A PT/CT scan can help differentiate Alzheimer's disease from other types of dementia.

An **amyloid PET** scan visualizes plaques present in the brain. Before amyloid PET, these plaques could only be detected by examining the brain at autopsy. Amyloid PET scanning makes amyloid plaques light up on a brain PET scan, enabling accurate detection of plaques in living people (SNMMI, 2021; USFC, 2021d).

Functional Assessment

Dementia is characterized by cognitive deficits that cause functional impairment to basic and instrumental activities of daily living. Functional status can be assessed by use of a validated tool, direct examination of the patient, or 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 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 valid and reliable instruments. Examples include:

- Lawton Instrumental Activities of Daily Living Scale
- Barthel ADL Index
- Katz Index of Independence in Activities of Daily Living
- Functional Activities Questionnaire (FAQ)

FUNCTIONAL ACTIVITIES QUESTIONNAIRE (FAQ)

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.

(AMA, 2019)

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, some FDA-approved medications can help improve or maintain the patient's cognitive and functional status and help lessen symptoms such as memory loss and confusion. Some medicines also improve the behavioral and psychological symptoms and can be used in addition to nonpharmacologic strategies (Alzheimer's Association, 2021d).

NEW DRUG FOR TREATING DISEASE PROGRESSION

Aducanumab (Aduhelm) was approved in the United States in 2021 for patients with mild cognitive impairment or the mild dementia stage of Alzheimer's. Aducanumab is an antiamyloid antibody intravenous infusion therapy that works by targeting beta-amyloid. This drug is the first to demonstrate that removing amyloid from the brain is reasonably likely to reduce cognitive and functional decline in people living with early Alzheimer's. Aducanumab must be used in patients with confirmed evidence of amyloid plaque buildup in the brain.

FDA approval, however, has been controversial. Aducanumab was approved under the accelerated approval pathway, which provides patients with a serious disease earlier access to medications when there is an expectation of clinical benefit despite some uncertainty about the benefit. The FDA advisory committee, however, stated that clinical trials did not demonstrate sufficient evidence of effectiveness (FDA, 2021; Alzheimer's Association, 2021b).

No European country has approved this drug, and most major U.S. hospital systems have refused to prescribe or administer it. Many private insurers have declined payment for the drug as well. Medicare's decision specifies that coverage can only occur "in CMS-approved, randomized controlled trials and in trials supported by NIH." None of the trials completed to date, however, have demonstrated that use of this medication results in meaningful improvement in outcomes for AD patients (Sachs, 2022).

The most common side effects include amyloid-related imaging abnormalities (ARIA), headache, and falls. ARIA is a temporary swelling in areas of the brain that usually resolves over time. Patients should not be offered aducanumab if they have a high risk of hemorrhagic side effects (Press & Buss, 2021).

Treating Cognitive and Memory-Related Symptoms

As Alzheimer's progresses, brain cells are damaged and cognitive symptoms worsen. While the following medications do not stop the damage caused by AD, they may help temporarily lessen or stabilize symptoms related to memory and thinking by affecting chemicals involved in carrying messages among and between the brain's nerve cells (Alzheimer's Association, 2021d).

CHOLINESTERASE INHIBITORS

Cholinesterase inhibitors are prescribed to treat symptoms related to memory, thinking, language, judgment, and other thought processes. These drugs support communication between nerve cells by preventing the breakdown of acetylcholine, a chemical messenger important for memory and learning. These medications include:

- Donepezil (generic & Aricept), approved for all stages of Alzheimer's
- Rivastigmine (Exelon), approved for mild to moderate Alzheimer's and Parkinson's diseases
- Galantamine (generic & Razadyne), approved for mild to moderate Alzheimer's

Newly diagnosed patients should be offered a trial of cholinesterase inhibitor. The average benefit of cholinesterase inhibitors in patients with mild to moderate dementia is modest. The medications should not be continued indefinitely in those who do not appear to be benefiting or who have significant side effects.

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 & Buss, 2021; Alzheimer's Association, 2021b).

GLUTAMATE ANTAGONIST

Glutamate is the principal excitatory amino acid neurotransmitter in cortical and hippocampal neurons. One of the receptors activated by glutamate is the NMDA receptor, which is involved in learning and memory. Glutamate regulators are prescribed to improve memory, attention, reason, language, and the ability to perform simple tasks by regulating the activity of glutamate, a chemical messenger that helps the brain process information. Glutamate has been shown to improve cognition and global assessment of dementia, but with small effects that are not of clear clinical significance. Improvement in the quality of life and other domains are suggested but not proven.

The glutamate antagonist approved for moderate to severe Alzheimer's disease is memantine.

- 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.

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 & Buss, 2021).

ANTIOXIDANT VITAMIN E

The antioxidant vitamin E (alpha-tocopherol) has been studied in the treatment of Alzheimer's due to its antioxidant properties. The data suggests that overall vitamin E at a dose of 2,000 IU per day provides modest benefit in delaying progression of functional decline 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. Vitamin E, however, is not recommended for the routine prevention of AD (Press & Buss, 2021).

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
- Vitamin B supplement
- Omega-3 fatty acids (Press & Buss, 2021)

Treating Behavioral and Psychological 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

Suvorexant (Belsomra) is the one drug approved by the FDA to address insomnia in those with dementia. This drug, an orexin receptor antagonist, is thought to inhibit the activity of orexin, a neurotransmitter involved in the sleep-wake cycle. Side effects of suvorexant may include impaired alertness and motor coordination, worsening of depression, suicidal thinking, sleep paralysis, compromised respiratory function, sleep-walking, and sleep-driving.

Other medications are used "off label," a practice whereby a drug is prescribed for a different purpose than the ones for which it is approved. These include the following:

Antidepressants. Selective serotonin reuptake inhibitors (SSRIs), in particular citalopram (Celexa), are useful in the management of agitation and paranoia, since symptoms are often driven by a mood disorder that is poorly verbalized. Trazodone is an alternative and is often used for sleep onset.

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

Anxiolytics. Benzodiazepine antianxiety medications are used for anxiety, restlessness, verbally disruptive behaviors, and resistance. They include:

- Lorazepam (Ativan)
- Oxazepam (Serax)

Antipsychotics. When nonpharmacologic interventions and approaches fail to manage symptoms that result in severe distress or safety issues, antipsychotic medication may be required. Such symptoms may include hallucinations, delusions, aggression, agitation, hostility, and uncooperativeness. 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. They include:

- Aripiprazole (Abilify)
- Clozapine (Clozaril)

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

Analgesics. Pain is an important source of behavioral issues. Using analgesics requires careful monitoring to balance risks and benefits of pain treatment versus persistent pain. Adequate pain control may be observed as improvements in behavior and function. Recommended medications include:

- Acetaminophen
- Low-dose morphine
- Buprenorphine patch
- Pregabalin

(Alzheimer's Disease, 2021b; Press & Alexander, 2021)

Managing Coexisting Health Problems

People with Alzheimer's disease often have other health problems common to older adults. Eighty percent of seniors have at least one chronic health condition, and 68% have two or more.

Self-management is a lifelong task for people with long-term conditions. The symptoms of dementia frequently reduce an individual's ability to organize and plan self-care. The most commonly described impact is the diminishing ability to administer medication safely. Most people with dementia require assistance in management of care for comorbid long-term conditions (NCoA, 2021).

Comorbid health issues, 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.

Medicare beneficiaries diagnosed with dementia are less likely to receive eye care than those without diagnosed dementia. Depending on visual acuity and functional status, this may have implications for injury prevention, physical and cognitive function, and quality of life. Barriers to receiving care need to be identified and measures to improve access to appropriate eye care need to be implemented.

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 (Perhing et al., 2020).

DEPRESSION

Depression is linked to cognitive impairment and overall functional capacity in AD patients. Although many antidepressant treatments are available, clinical trials indicate that antidepressants for treatment of depression in AD patients appear to be ineffective, and to this date no medication has been approved by the U.S. FDA for the treatment of depressive symptoms in AD. Numerous mechanisms underlying resistance to antidepressants in patients with AD have been hypothesized, with no clear results to date (Cassano et al., 2019).

Nondrug approaches for depression can include involvement of the person in support groups or counseling. It can be helpful to keep a predictable daily routine, taking advantage of the person's best time of day to undertake difficult tasks, such as bathing, assisting with daily exercise, and scheduling activities the person enjoys (Alzheimer's Association, 2021b).

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, toileting)

- 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 their deficits and looking for ways to maintain and prolong the person's independence.

EVALUATION PROCESS

Occupational therapists evaluate patients with dementia to determine their strengths, impairments, and performance areas that need intervention and to help patients 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	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	
	Barthel Index: assesses basic ADLs	
	Katz Index of Independence in ADLs: assesses basic ADLs	
Instrumental activities of daily living	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	
	Performance Assessment for Self-Care Skills: assesses functional mobility, basic ADLs, IADLs, and tasks with cognitive emphasis	
	Texas Functional Living Scale (TFLS): assesses IADLs, especially in older adults with Alzheimer's disease	

Leisure	• Interest Checklist: elicits information about the person's past and present leisure activities and interests and the degree of attraction toward them
Motor skills	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	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	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	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	Assessment and referral for vision or hearing loss

(AbilityLab, 2021, 2020a, 2020b, 2019; AOTA, 2021b; Coyne, 2021; Encyclopedia of Mental Disorders, 2021; Liebzeit et al., 2018; MD+CALC, 2021; Occupational Therapy Insights, 2019; O'Sullivan et al., 2019; Pashmadarfard & Azad, 2020; Physiopedia, 2021b; Pitt, 2021; Struckmeyer et al., 2020; U of I, 2020; Westergen, 2019)

INTERVENTIONS

As part of the interdisciplinary team, occupational therapists provide evidence-based interventions throughout the continuum of care and across the entire health spectrum for Alzheimer's patients and families, setting up a program to meet the goals of safety, independence, utilization of retained abilities, and improved quality of life for the patient as well as family and caregivers.

During Early Stages

Interventions in the early stages of Alzheimer's disease may focus on compensating for a loss of cognitive abilities and recognizing remaining abilities rather than remediating deficit areas. During this stage of the illness occupational therapists determine the most meaningful activities

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for the patient and suggest memory aids, such as calendars, journals, medication reminders, and daily routine schedules. Combining these with caregiver education improves independence and reduces caregiver distress.

During Middle Stages

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

- Use cues and prompting to assist with basic self-care tasks
- Offer ADL retraining along with balance and functional mobility retraining
- Encourage caregivers to allow the person to continue their routines to help prevent further loss of basic self-care skills
- Include increased verbal or visual cues, demonstration, physical guidance, partial physical assistance, and problem solving when providing ADL retraining
- Repeat ADL retraining using the same activity, same sequence, same time, and same place to help increase retention
- Give one-step, simple directions to avoid frustration

During Later Stages

During the later stages of dementia when the person becomes dependent in all or most self-care activities, occupational therapists focus on adapting the environment, instructing caregivers to promote conditioned occupational performance, and teaching ways to minimize any unwanted behaviors or complicating conditions:

- Educate caregivers on safe transfers, contracture management through home exercise programs, and proper positioning to avoid skin breakdown and increase comfort
- Teach ways to minimize any unwanted behaviors or complicating conditions
- Provide enjoyable sensory stimulation
- Refer caregivers to on-line or in-person support groups
- Provide education to family members and teach ways to reduce stress (AOTA, 2021; Stromsdorfer, 2020)

INTERVENTION TECHNIQUES

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

Teepa Snow's **Positive Approach to Care (PAC)** 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. PAC provides practical advice on ways to connect and interact with people who have dementia and focusses on doing things with, rather than to the person. PAC encourages and prepares caregivers to:

- Respond rather than react to a person with dementia changes and abilities in a way that is proactive
- Appreciate that with practice, common reactions to the person with dementia can become thoughtful responses that improve everyone's quality of life
- Recognize that the person with dementia is doing the best they can when faced with challenging situations
- Change their approach, behavior, and expectations for improved outcomes
- Modify the physical and sensory environment (lighting, sound, activity) to promote function and satisfaction (Alzheimer Society CA, 2021)

Occupational therapists can help meet caregivers' needs using **Skill2Care**, an intervention designed to reduce behavioral symptoms through an environmental modification approach. Strategies are tailored to the unique needs and environments of the person with dementia as well as the caregiver. Skill2Care involves occupational therapists training caregivers to reduce confusion and increase 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. Outcomes include:

- Improved caregiver skills and well-being
- Reduced challenging behaviors
- Slowed decline in daily functioning (Herge et al., 2020)

The **validation method** emphasizes listening to those with dementia in a way that shows empathy and respect so that the person feels valued, not judged. The role of the caregiver is to offer the person a means for verbal or nonverbal expression 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 (Wegerer, 2019).

Reality orientation is an approach used to help the person with dementia engage in and connect with their surroundings to decrease their confusion; increase awareness of time, place, and self; and improve their overall cognitive, behavioral, and social functioning by frequently referencing the time of day, date, season of year, location, and current surroundings and events in conversations with the person. Clocks, calendars, family photographs, and the like are often used to facilitate this process (Belser-Erlich & Bowers, 2019).

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 (APA, 2020).

Tailored Activity Program (TAP) is an occupational therapy intervention shown to reduce behavioral symptoms and to ease caregiver burden. It is a family-centric program providing people with dementia activities tailored to their abilities and interests. It trains formal and informal caregivers in use of activities as part of daily care routines. It has been shown to improve quality of life, reduce behavioral symptoms and caregiver burden, and improve caregiver sense of efficacy (Johns Hopkins, 2021b).

Environmental-based methods pertain to the arrangement of a space and the objects within it as well as sensory elements to address a dementia patient's behaviors and perceptions. These may include, but are not limited to:

- Type of lighting
- Labeling of rooms
- Nature of auditory stimuli
- Purposely or functionally designed rooms
- Multisensory interventions
- Noise regulation

Interventions employed in the home environment include maintenance of familiarity and minor home adaptations as needed (Fiser, 2019).

CASE

Louise, an 82-year-old woman with Alzheimer's disease dementia, has been placed in the nursing facility where Emelia works as a certified nursing assistant. The staff are just beginning to get to know Louise and learning what approaches work best when caring for her.

Emelia has found that Louise insists things are different than what they are. For example, she claims she has to go and get the mail or make dinner for her kids and becomes very agitated and resistant to any attempts at redirection. This often results in caregiver frustration.

Emelia had recently attended the training session provided by Parker, the facility's occupational therapist, in which various techniques for working with dementia patients were presented. Emelia remembered the validation method, and when Louise became agitated and insistent that she could not leave her room to go to breakfast because she had to feed her chickens, Emelia entered her world by asking her to talk about her chickens. As Louise talked to Emelia and answered her questions, Emelia guided her out of her room, down the hallway, and into the dining room for breakfast.

Physical Therapy

While not well known in the recent past, a growing body of evidence indicates that medical providers may be able to help delay or minimize patients' symptoms of dementia through prescribed physical therapy and exercise. A recent study has shown that one month of low-frequency, short-duration, practical physical therapy that addresses motor impairment and function was associated with decreases in gait, balance, and cognitive impairment among individuals with Alzheimer's.

The physical therapist develops a treatment program, including therapeutic exercises specifically targeted to individual patient needs, to help maximize and maintain the person's current functional mobility capabilities as well as to reduce the physical burden on caregivers, where feasible.

Primary goals of physical therapy for patients with Alzheimer's include:

- Optimizing functional mobility (including bed mobility, muscle strength, transfers, static and dynamic balance, coordination, endurance, and gait)
- Minimizing risk of falls and fall-related injuries
- Assessing and making recommendations related to environmental safety (in the home and/or care facility)
- Educating patients and family on the importance of physical activity as a neuroprotector of further cognitive decline
- Educating caregivers on how to safely assist patients with gross motor tasks, transfers, and other physical aspects of hands-on caregiving

A person does not need to remember having engaged in an exercise program to reap the benefits of it—just to participate in it. By slowing down cognitive decline and helping to maintain the person's current abilities, physical therapy can improve quality of life and performance of activities of daily living (Physiopedia, 2021a; Longhurst et al., 2020).

ASSESSMENT TOOLS

Timed Up and Go (TUG) Test 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 10–30 seconds.

Portable gait testing mat is a gait analysis system that analyzes a patient's ambulatory biomechanics. It measures gait 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.

Global Deterioration Scale (GDS)/Reisberg Scale is a commonly used scale that divides cognitive decline into seven stages to better understand how well a person thinks (cognitive decline) and functions (physical abilities). This test is most relevant for persons with Alzheimer's disease since some other forms of dementia, such as frontotemporal dementia, do not always include memory loss.

Pain Assessment in Advanced Dementia (PAINAD) is a reliable assessment tool used with patients who have advanced dementia and are judged potentially to 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.

Pain Assessment Checklist for Seniors with Limited Ability to Communication (PACSLAC) is a more intensive observational pain tool with five subscales: facial expression, activity and body movement, social personality and mood, and "other" (such as changes in eating and sleeping behaviors).

Functional Assessment Staging Tool (FAST) describes seven 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 (Natavio et al., 2020; Dementia Care Central, 2020a).

DEVELOPING A PLAN OF CARE

Physical therapy for patients with dementia focuses on optimizing and/or preserving balance, muscle strength, and mobility; preventing falls; and providing pain management and maximized safety in the home or facility setting. Physical therapists consider both patient and caregiver

needs when developing a treatment 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. Incorporating familiar objects or actions into the physical therapy regimen for patients with Alzheimer's disease and other dementias may prove helpful. Finding out what motivates the individual patient and incorporating favorite pastimes into the therapy plan allows for emotional development and increased feelings of comfort.

Therapeutic exercises may need to be tailored to accommodate cognitive limitations. Intense, multimodal programs (which may include passive, active, or resistive exercises; as well as gait, balance, and/or endurance training) may become overwhelming for some patients, such as:

- Those with limited attention spans
- Those who are easily over-stimulated by verbal instructions
- Those who become anxious/agitated when presented with excessive 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. Communication can be a major issue when working with patients with dementia, particularly in an instructional, task-oriented setting such as physical rehabilitation. Various communication strategies and teaching techniques for patients with dementia which may be helpful 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
- Mirroring: serving as a "mirror" by demonstrating a desired movement to the patient
- 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
- Active-assisted facilitation: taking the patient's hand or other body part and helping to move it through a desired motion
- Muscle memory training: training a person's procedural memory via motor repetition, in order to help the body more automatically respond to changes such as uneven or unstable surfaces

Physical therapists may involve the patient's family and caregivers in the treatment plan, instructing in strategies for maintaining routines and using cues to initiate motor tasks. Family education may include ergonomic training to help family members/caregivers more safely perform tasks such as how to safely assist patients with bed mobility, transferring, and ambulation, as well as how to correctly use and maintain adaptive equipment or assistive

devices. Ergonomic education and home safety assessments may help minimize risk of injury to both patients and caregivers.

In later stages of the disease, when cognitive decline is more pronounced, physical therapy interventions may shift to focus on more palliative measures, such as:

- Slowing the rate of functional/motor decline
- Instructing caregivers in proper joint positioning/mobilization to minimize risk of contractures
- Instructing caregivers in appropriate patient positioning/mobilization to minimize risk of pressure injuries or skin tears
- Instructing caregivers in the use and maintenance of higher-level assistive equipment, such as mechanical lifts, wheelchairs, etc.

Home assessments and safety recommendations can help make the home environment safer and may help delay the need for facility-based care (Staples, 2021; Sponholz, 2021).

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 falling 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 <-> 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, 2021).

SUPPORTIVE CARE FOR THE PERSON WITH ALZHEIMER'S DISEASE

Supportive care is an interdisciplinary effort focusing on preventing and relieving suffering and on supporting the best qualify of life for patients and their families facing serious illness. Effective supportive care for patients with advanced dementia can improve the patient's symptoms, lessen the burden on caregivers, and help to ensure that treatment decisions are well informed and reflect the patient's and family's values.

Addressing Challenges to Care

Caring for a person with Alzheimer's disease can be challenging, no matter the setting—hospital, institution, or the home.

CARE CHALLENGES IN ACUTE CARE SETTINGS

Admission to an acute hospital can be a frightening and confusing experience for the person with dementia. It is important to understand that hospitalization can have a negative impact on their physical, mental, and cognitive abilities, which can lead to increased behavioral and psychological symptoms, risk of poor outcomes, higher incidence of harm, and further cognitive decline. Consequences for persons with dementia admitted to the hospital include:

- Higher mortality rate
- Increased risk for falls
- Functional decline

- Spatial disorientation
- Possible malnutrition and dehydration
- Increased reliance on caregivers
- Depression and delirium
- Overstimulation
- Increased pain and fear partly due to impaired communication abilities

Goals in the acute care setting are typically speedy recovery and timely discharge, both of which are not applicable to the dementia patient.

Nurses are trained to manage acute illness, and dementia symptoms can impact the care they are able to provide. Nurses report that dementia patients require more time to carry out tasks, strain resources, and divert care from other patients. Likewise, nurses must prioritize the imminent needs of patients with acute illnesses, and this challenges them to meet the needs of the dementia patient. Nurses are not routinely given training in the care and understanding of dementia nor of strategies that are effective in managing behavioral issues.

Responsive Behaviors

People with dementia require structure and order in their environment, a definite challenge in a fast-paced, acute care setting. Nursing staff must approach the dementia patient with an easy-going, unrushed attitude or else experience negative responsive behaviors, defined as words, movements, or actions that dementia patients use in an effort to make their needs known. Examples include:

- Grabbing on to others
- Wandering
- Yelling and screaming
- Biting
- Pushing
- Throwing things
- Cursing
- Hitting
- Kicking
- Restlessness
- Repetitive sentences or questions
- Making noises
- Sexually inappropriate behaviors

Experiencing responsive behaviors in the workplace causes feelings of anger, fear, and sadness and are perceived by healthcare professionals as one of the most difficult aspects of providing care for dementia patients in acute care settings. Often, as a result, the patient is prescribed sedating medications, to which these patients are prone to experience adverse reactions, which can include:

- Sedation
- Dysphagia
- Stroke
- Parkinsonism
- Increased length of stay
- Increased mortality

Involving Family and Caregivers

Nurses welcome the familiarity that caregivers provide the patient in the hospital. Such familiarity helps reduce responsive behaviors. Family and other caregivers understand what is normal for the patient, and this helps the nursing staff identify changes that may be indicative of delirium, pain, or other treatable conditions and provide more patient-centered care.

It is important to keep open lines of communication with family caregivers. Besides utilizing the care recommendations they may provide, the clinician can also let caregivers know what is going well. Small successes are shared with the family, which can help promote the patient's successful transition in and out of the acute care setting.

By drawing on their knowledge and experience of the patient and care needs, family and informal caregivers' involvement in assessment, care planning, and delivery of care can improve outcomes for people, provide comfort, and help family and caregivers understand and cope (Røsvik & Rokstad, 2020; Yous et al., 2019).

PROVIDING PATIENT-CENTERED CARE IN ALL SETTINGS

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 another care setting, 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
- Providing seating near the bed to help with dressing
- Ensuring closet shelves are at an accessible height to prevent the person from climbing shelves and to avoid objects falling from overhead
- Securing book shelves, cabinets, and large TVs to prevent tipping
- 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
- Disconnecting the garbage disposal
- Discarding toxic plants and decorative fruits that may be mistaken for food
- 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 an automatic thermometer on plumbing to regulate water temperature
- 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, chemicals, and other potentially hazardous items
- 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, 2021b)

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. Independence is about what matters to a person: how they feel is just as important as physical independence. Dementia-friendly environments empower people.

A homelike supportive environment provides continuity and familiarity in everyday life, encourages family involvement, and strengthens social ties. The following elements are 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
- Experiential approach to communication
- Engagement in daily life experiences
- Flexible problem-solving for individual care issues
- 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
- Meaningful relationships
- Flexible management and supervisory approach (Victoria State Government, 2020)

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 them 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 can 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 their own.

Support bowel and bladder control. A consistent toileting routine helps preserve function and control. Use clothing with simple fasteners like Velcro (hook and loop) 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 their own clothes, and keep them 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 their caregiver or companion.
- Be patient and take time to listen to the person express their 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.
- Discuss which method of communication is most comfortable, which may include face-to-face conversation, email, or phone calls.
- Use humor to lighten a mood and make communication easier.
- Don't pull away; honesty, friendship and support are important to the person.

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 them 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, 2021b)

Ethical lying, also known as therapeutic lying, is an essential skill to develop. Because dementia patients must be kept safe and avoid becoming agitated and in distress, less-than-truthful communication may be required in order to accomplish these goals. It can, in some cases, be kinder to ethically lie than to be completely honest.

For example, reminding the person that a loved one has died can make the person upset and sad. Ethical lying can also help to ease difficult situations, such as when the patient needs to stop driving due to safety concerns. Having the car "disappear" or suggesting it has been stolen can be a more compassionate way to manage what is often a devastating loss for the patient. This also allows the caregiver to be perceived as being on the side of the patient and not the one who is taking away the right to drive (Piedmont Healthcare, 2021).

Nonverbal communication, especially touch, between caregivers and those with Alzheimer's is also important. As dementia progresses, nonverbal communication may become the main way a person communicates. 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. However, it is also important to avoid sitting too close to the person or standing over them to communicate. Meeting the person at eye level is preferable whenever possible.

Consider that the person with dementia will read and interpret others' body language, and sudden movements, tone of voice, or tense facial expression can upset or distress them. Make sure body language and facial expression match what is being spoken.

Visual prompts are also helpful for the person with dementia. These may include cue cards or a book with pictures a person can point at to communicate needs and wants.

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 (Alzheimer's Society, 2021a).

Supporting 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 in assisting 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 task, 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.

Offering choices can be helpful. With patients who refuse to attend to daily activities, such as bathing, it can be more effective to ask them "when" they would like to bathe instead of "if" they want to bathe.

BATHING AND ORAL CARE

It is common for persons with dementia to refuse to bathe. Bathing can be a challenge because persons with Alzheimer's disease may be frightened by showers or they may resist the invasion of privacy that comes with bathing in front of a caregiver. They also may believe they've already showered or bathed, and so it is not reasonable to do so again. The following are creative ways of managing resistance:

- Avoid a discussion as to whether a bath is needed or not.
- To avoid agitation, if the person adamantly refuses to bathe, wait and try again later.
- Partial baths may be sufficient, as bathing or showering is not needed every day.
- Follow the person's previous routines, including time of day and type of bathing preferred.
- Prepare the bathroom in advance.

- Always check the temperature of the water.
- Complete one step at a time, talking through each step.
- Be calm and gentle; don't rush and hurry.
- Use a seat and hand-held shower attachment, which can be less frightening for the person.
- Introduce warm shower water gradually, starting at the feet and moving up the body.

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 warfarin.

Oral hygiene is often avoided by persons with dementia. They resist doing it, and they don't want anyone else to do it for them. One solution is to use toothettes with diluted hydrogen peroxide solution. If the person consistently refuses to cooperate with oral care, fresh fruit such as apples can aid in cleaning the teeth (Piedmont Healthcare, 2021; Alzheimer's Association, 2021b).

DRESSING

Self-esteem for a person with dementia is still important, and past grooming habits should be considered, as well as the person's style and cultural clothing preferences.

- Try to maintain hairstyles, beards, and makeup the way the person liked to appear before developing dementia.
- To reduce the need to make choices, remove clothes that are seldom worn from the closet.
- Provide simple garments with large zipper pulls, Velcro fasteners, and few buttons. Pull-on pants and shirts are easier to put on.
- Use cardigan sweaters instead of pullovers.
- Lay out clothes in the order in which they will be put on.
- If needed, provide constant repetition of each step.
- Use nonskid shoes, such as washable rubber-sole shoes with Velcro fasteners, or slip-ons.

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 (Piedmont Healthcare, 2021; Alzheimer's Association, 2021b).

TOILETING

Caregivers must understand that the person with Alzheimer's may no longer respond to signals such as the urge to void or defecate, may forget where the bathroom is located even if they've been in the same house for years, and may forget what to do when they do find the bathroom. Family members and other caregivers may feel awkward when assisting with toileting, although this usually subsides over time. A matter-of-fact, calm, and reassuring manner with the person with dementia is the best approach.

Other ways to assist with toileting include:

- 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.
- Know that the person may not recognize the toilet as the appropriate place to urinate. Remove other 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.
- Post a colorful sign on the bathroom door to help the person identify the room.
- Set a regular schedule for using the bathroom.
- Monitor mealtimes and foods consumed so as to predict when it's time to use the bathroom.
- Respect the person's privacy as much as possible.
- Assist with removing or adjusting clothing as necessary.
- Help the person get in the right position, if needed.
- Give cues if the person doesn't know what to do.
- Talk through each step.
- Learn to recognize signs that the person may need to use the toilet. These might include fidgeting, restlessness, or pulling at clothes.
- Use a urinary alarm system for reminders.
- If incontinence occurs at night, avoid caffeine and fluids for 2–3 hours before bedtime.

When assisting the person to a public restroom, go together—don't let the person enter the restroom alone. If a female caregiver is assisting a male dementia patient, use the ladies' room and, if necessary, hand out cards to startled strangers stating the person has dementia. The same is true for a man caring for a woman. Many places now have all-gender bathrooms that may be utilized.

When the person suddenly loses bowel or bladder control, a medical evaluation should be done to rule out medical conditions such as urinary tract infection or medication side effects. When the person becomes incontinent, the following suggestions are helpful:

- Restrict fluid intake 2 hours before bedtime.
- Use incontinence aids such as disposable briefs and pads for beds and chairs or condom catheters for men at night.
- Dress the person in manageable clothing and consider eliminating underwear.

Constipation and fecal impaction can also 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. Avoid using laxatives, but encourage a high-fiber diet (Piedmont Healthcare, 2021; Alzheimer's Association, 2021b).

EATING

Eating habits and behaviors change during the course of Alzheimer's disease and may be caused by physiologic or psychological factors. Proper nutrition reduces the risk of constipation, dehydration, and vitamin deficiency. These conditions contribute to increased confusion and a decline in physical functioning.

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. It is also important to monitor what the person eats and drinks, as some inappropriate items may be eaten, such as soap or other household items. All items that look like food, such as dog biscuits, flower bulbs, artificial fruits, etc., should be secured so they are not eaten.

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. A nutritionist can make suggestions during this stage, and evaluation by a speech pathologist is indicated when the person begins to have trouble swallowing.

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, hunger, and thirst 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.

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, but limit the number. Put only one utensil and one food in front of the person at a time.
- 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, and remind the person to eat slowly and chew thoroughly. It may also be necessary to remind the person to swallow the food.
- 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. (Piedmont Healthcare, 2021; Alzheimer's Association, 2021b)

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.

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 bitesize 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 eggnogs 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, 2021b; Piedmont Healthcare, 2021).

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. Persons with Alzheimer's will typically have more difficulty seeing, processing information about the physical environment, and walking. Gait velocity decreases, variability of stride increases, and inability to multitask while walking occurs. All of these affect balance. A typical adjustment these people make is to change their gait so that they shuffle their feet instead of lifting them with each step.

Loss of balance is one reason why people with dementia are eight times more likely to fall than older adults without dementia. As a result, the incidence of hip fractures is higher, and recovering from one is extremely complicated for the person with dementia.

Balance is considered a skill, and as such, it can be improved. Almost any physical activity that safely gets a person moving is good for Alzheimer's symptoms, but low-impact workouts that include light resistance activities may be particularly helpful in improving balance, in part by strengthening leg muscles and maintaining bone density.

Recent studies have shown the benefits of music-cued exercises for people with dementia. A twice-weekly, home-based physical therapy program of music-cued gait training may help some people with mild to moderate AD increase their ambulation speed.

Some other ways to help the person move around more easily can include:

- Making the home safer by continually picking up and putting away any obstacles on the floor that the person could trip over or need to steer around
- Keeping useful items within reach so the person does not need to strain to reach or use a stepping stool
- Keeping the house well-lit, especially at night
- Providing nonskid slippers and shoes

Canes and walkers may help maintain balance, but there are important issues to consider. Canes and walkers may actually increase the likelihood of falls—especially if used incorrectly—due to the increased complexity of using a device while walking, which requires the ability to multitask. It is important for the patient to receive appropriate training in the use of any new assistive devices (preferably by a physical or occupational therapist) and for caregivers to consistently monitor usage for any difficulty or decline in the patient's ability to use such devices, with or without assistance.

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 diseases progresses, many individuals can gradually lose the ability to walk. In later stages they may 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 be safe.

In the later stages of severe dementia, the person loses the ability to sit up without assistance, requiring some form of external physical support such an arm rest, belt, or other device to keep from sliding down in the chair (Dementia Care Central, 2020b; Wittwer et al., 2020; Cohen & Verghese, 2019).

Supporting Instrumental Activities of Daily Living (IADLs)

Performing IADLs is the first ability to decline in persons with Alzheimer's disease, while the ability to perform basic activities remains unimpaired. 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 prepare food 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, 2021a)

DRIVING AND TRANSPORTION NEEDS

Driving is a complex task requiring an ability to make and execute split-second decisions. Dementia affects the ability to process many different pieces of information at the same time. Therefore, driving and dementia do not go together.

Once the diagnosis of Alzheimer's disease is established, healthcare professionals encourage the family to discuss the issue of driving with the person. 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 and others have optional reporting policies, while 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. Warning signs of loss of ability to drive safely include:

- Getting lost in familiar areas
- Not observing traffic signs
- Making slow or poor decisions in traffic
- Driving either too slowly or too fast
- Getting angry or confused while driving
- Swerving into wrong lanes
- Confusing the accelerator and brake pedals
- Hitting curbs
- Incorrect signaling
- Riding the brake
- Poor judgment about distance

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.

An occupational therapist with special expertise in driving rehabilitation may be recommended to perform a driving assessment. However, even if someone with early dementia passes a driving assessment, continued driving is very closely monitored as the dementia progresses.

It can be very upsetting for the person 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. It is usually best to completely remove the person's car once they are diagnosed with dementia. If it remains at the home, the vehicle should be permanently disabled and all car keys taken away.

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 (Piedmont Healthcare, 2021; FCA, 2021a)

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. Healthcare professionals 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, such as mealtimes.
- Use a pill box organizer and utilize a daily log of what medications are to be taken and when.
- Use simple language and clear instructions.
- Keep medications stored in a locked drawer or cabinet and not left out where the person 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 medications with meals, if allowed, and administer the most important medications first.
- Alternatively, with the prescriber's approval, give medications in the morning, when agitation is less likely to occur.

- Make certain the patient is wearing glasses and hearing aids, if needed, to minimize confusion.
- If a person refuses to take the medication, stop and try again later.
- 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 taking medication 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.
- Should the patient begin to have difficulty swallowing pills, request assistance from a healthcare provider to evaluate the form of medication being administered.
- 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.
- Have emergency numbers easily accessible. If a medication overdose is suspected, call poison control or 911 before taking any action. (Alzheimer's Association, 2021b)

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.

Walking provides good exercise and may relieve tension and stress. It may also help increase appetite. Simple exercises that encourage increased range of motion can help maintain optimal muscle functioning.

Keep things simple, as the confused person has a short attention span and may become easily frustrated when faced with multiple-step tasks or activities. Gardening, painting with water colors or finger paints, drawing, or coloring are good ways for confused people to express themselves.

Research shows that activities done in the past can still resonate with the older person who has advancing dementia. For example, a retired business executive may enjoy sitting at a desk with files filled with papers. Or someone who spent years as a homemaker may enjoy domestic activities like folding laundry or sweeping.

Keep activities on an adult level, though children's toys can be usefully adapted in the later stages of dementia, e.g., women often respond positively to baby dolls. The person may enjoy playing familiar games such as cards, bingo, or board games, or doing simple jigsaw puzzles.

Musical activities are usually successful whether the individual is making the music themself or just listening. Music, including group sing-alongs, can help recall pleasurable moments from the past. Dance music from their youth might encourage the person to dance.

Plan social visits for times when the person feels best and in environments that are calm and quiet. Busy settings full of noise and people are often stressful for the person with dementia.

Books, newspapers, magazine articles, and family photo albums can serve as cues for reminiscence and provide an opportunity for family conversation in which the person may still participate.

Certain television programs can be of great interest. Animal programs are often much enjoyed by those with dementia. It is important to know that some TV shows can be upsetting, particularly violent, suspenseful, or horror shows, since the person may no longer be able to understand what is real and what is fiction.

Many people with dementia regularly attend adult day programs specifically for those with dementia. It is common for the person to resist initially, but eventually they enjoy the new routine and social activities (Piedmont Healthcare, 2021).

Watching for Elder Abuse in Dementia Patients

People with Alzheimer's disease or other cognitive impairment are at higher risk of abuse than other older adults. Up to 5 million older Americans are abused every year, yet one study estimated that only 1 in 24 cases of abuse are reported to authorities. The majority of victims are female, whereas the majority of perpetrators are male. Adult children of the victim are the most common perpetrators, followed by spouses and other family members. Perpetrators also may include nursing home, assisted living, and other facility staff. The annual loss by victims of financial abuse is estimated to be at least \$36.5 billion. Older adults who have been abused have a 300% higher risk of death when compared to those who have not been mistreated (NCOA, 2021).

Types of abuse include:

- **Physical:** Causing physical pain or injury
- Emotional: Verbal assaults, threats of abuse, harassment and intimidation
- **Neglect:** Failure to provide necessities, including food, clothing, shelter, medical care, or safe environment
- **Abandonment:** An extreme version of neglect, in which a caregiver who has assumed responsibility for the person deserts or abandons them, most often in their own home or after a hospital stay, but also in public locations or with law enforcement
- Confinement: Restraining or isolated the person
- **Financial:** Misuse or withholding of the person's financial resources to their disadvantage, or the advantage of, someone else
- **Sexual:** Touching, fondling, or any sexual activity when the person is unable to understand, unwilling to consent, threatened, or physical coerced
- Willful deprivation: Exposing the person with Alzheimer's to the risk of physical, mental, or emotional harm by willfully denying the person of medication, medical care, food, shelter, or physical assistance (Alzheimer's Association, 2021b; Samuels, 2020)

RECOGNIZING ELDER ABUSE

Although currently there is no gold standard for screening people with dementia for signs of abuse, healthcare providers are in a position to identify abuse.

Signs of physical abuse can include:

- Bruises
- Pressure marks
- Broken bones, sprains, or serious injury, especially without a reported fall
- Abrasions
- Burns

Signs of emotional abuse can include:

- Unexplained withdrawal from normal activities
- Sudden change in alertness
- Depression
- Frequent arguments between caregiver and the person

- Increased fear or anxiety
- Unusual changes in behavior or sleep

Signs of financial abuse may include:

- Fraudulent signature on financial documents
- Unpaid bills

Signs of neglect can include:

- Pressure injuries
- Unattended medical needs
- Poor hygiene
- Unusual weight loss
- Unsanitary living conditions

Signs of sexual abuse can include:

• Bruises around the breasts or genital area

(NCOA, 2021)

CAREGIVER STRESS AND ELDER ABUSE

One of the leading causes of elder abuse is caregiver stress and other problems that prevent caregivers from properly caring for the elderly. Factors such as substance abuse or financial problems can lead to caregiver abuse of the elderly in both residential and institutional care settings. It must be recognized that not all caregivers are ready or equipped to properly care for the elderly.

The excessive stress and demands on caregivers can cause some to suffer from anxiety, depression, and psychological disorders. As anxiety and stress increases, caregivers may start to feel helpless and trapped in their situation. Individuals have different ways of relieving this stress, and some turn to substance abuse or abuse of their elderly family members.

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.

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.

Nursing home staff may also begin abusing the elderly under certain circumstances. Many facilities are understaffed, and that additional stress and exhaustion may contribute to abuse (Nursing Home Abuse Center, 2021; Piedmont Healthcare, 2021).

INTERVENING AND REPORTING ELDER ABUSE

Because older dementia patients usually cannot self-report instances of abuse, the responsibility for identification, intervention, and reporting rests largely with healthcare professionals, social service agencies, and police departments.

Factors involved in intervention include immediate care, long-term assessment and care, education, and prevention. Interventions vary from simple social service referral to the extreme of removing the person from the home.

Once suspected, elder abuse should be reported to Adult Protective Services. The National Center on Elder Abuse (NCEA) is a valuable tool in identifying state-specific resources to assist in reporting to the appropriate authorities.

Elder abuse is defined by state laws, but state definitions vary considerably from one jurisdiction to another. They contain many sections regarding who is protected, who must report, definitions of reportable behavior, requirements for investigation of reports, penalties, and guardianship.

Mandatory reporting laws for healthcare providers exist in all 50 states and the District of Columbia for confirmed cases, and 43 states mandate reporting of suspected cases. Thirty states have penalties for failing to report suspected elder abuse, and some require that licensed professionals who do not report elder abuse be reported to the appropriate licensing authority. All states have statutes providing immunity from civil or criminal liability to anyone who makes a report of abuse in good faith (Mills, 2019).

(For more information on reporting abuse, see "Resources" at the end of this course.)

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 large checks to his son for groceries in the past month, 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 but 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. These challenges can be met by using creativity, flexibility, patience, and compassion. It also helps for caregivers to avoid taking things personally and to maintain a sense of humor.

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

Behavioral problems are major reasons why family caregivers decide to seek long-term care for their loved one. Facility 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.

DICE Tool for Problem Behaviors

DICE is a tool that can be used to help understand and respond to behaviors. It involves asking a series of questions in regard to the patient, caregiver, and environment, as summarized in the table below.

DICE TOOL			
D	Describe what happens	• What does the person do?	
		• Is the patient's safety at risk?	
		 How distressing is the behavior to the caregiver? 	
		• Is the behavior threatening the safety of others?	
		 How did the caregiver respond to the behavior? 	
		 Who else was there when the behavior occurred? 	
		• How did the behavior relate to other events (e.g., bathing or mealtime)?	
I	Investigate possible	Recent changes in medications	
	causes	Patient's limits in the ability to do things	
		Medical conditions	

		 Underlying mental health issues Unmet needs Fear, loss of control, embarrassment Change in routine or lack of a daily routine Could a different response have been used? Are expectations realistic? Are there family or cultural issues? 			
		 Is the environment overstimulating or boring? 			
		• Is the environment disorientating or lack helpful visual cues?			
C	Create a plan	Respond to possible unmet needs			
		Discontinue any high-risk medications			
		Rule out potential medical causes			
		• Optimize treatment of mental health issues			
		Promote activity during the day and rest at night			
		Simplify tasks			
		• Create meaningful activities			
		Get more assistance			
		• Ensure the environment is safe			
		Simplify the environment			
		• Set up the environment for the task at hand			
		• Enhance the environment with labels, notes, pictures, etc.			
E	Evaluate the plan	• What was tried?			
		• What was helpful or not?			
		• What treatments or strategies worked?			
		Were there any unintended side effects?			
		• What environmental changes were made, and what was helpful or not?			
		 Are there any barriers to trying other strategies or changes? 			
(U	(UCSF, 2021c)				

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 away from them.

An agitated person requires an assessment for 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:

• Give the person space and time to calm down.

- Avoid confrontational body language, such as crossing your arms and standing over or directly in front of them.
- Avoid criticizing or correcting the person.
- Speak slowly, using a low and soothing pitch.
- Remember that anger or fear responses naturally subside within seconds in the absence of continued triggers.
- Reduce noise, clutter, or number of persons in the room.
- Keep routines and maintain a consistent environment, with familiar objects and photographs.
- Reduce intake of caffeine, sugar, and other foods that cause energy spikes.
- Use gentle touch, soothing music, reading, or taking a walk.
- Avoid restraining the person.
- Support the person's independence.
- Acknowledge the person's anger over loss of control and verbalize understanding.
- Validate the person's feelings and then attempt distraction or redirection.
- Keep dangerous objects out of reach. (FCA, 2021b)

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. Verbal outbursts are often triggered by fear, anger, depression, grief, confusion, helplessness, loneliness, sadness, impatience, and frustration. Environmental factors may include poor lighting, seasonal changes, overstimulation or lack of stimulation, loud noises, or excessive heat.

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 an underlying physical problem, which can then be remedied.

Caregivers are encouraged to remember that the person is not deliberately misbehaving; these are not temper tantrums. React by staying calm and reassuring. Validate the person's feelings and then try to distract or redirect the person's attention to something else. Remarks or attacks should not be taken personally, nor should attempts be made to try to reason with the person.

Managing outbursts triggered by environmental or physical factors is simpler than dealing with outbursts that stem from an unknown emotional or psychological cause. **Interventions** to prevent verbal outbursts may include:

- Assess for pain, hunger, thirst, constipation, full bladder, fatigue, infections, and skin irritation.
- Avoid being confrontational or arguing about facts.
- Redirect the person's attention.
- Remain flexible, patient, and supportive by responding to the emotion, not the behavior.
- Create a calm environment. Avoid noise, glare, insecure spaces, and background distractions.
- Allow adequate rest between stimulating events.
- Provide the person with a security object.
- Acknowledge requests and respond to them.
- Look for reasons behind each behavior.
- Explore various solutions.

• Don't take the behavior personally. (Alzheimer's Association, 2021b)

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 private room, but it was 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 daily life.
- The activities director will work with Mrs. Goh to add new activities.
- 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

Any person that has memory problems and is able to walk is at risk for wandering and getting lost. At least 6 out of 10 people with dementia will wander at least once, fueled primarily by Alzheimer's disease. If not found within 24 hours, up to half of wandering seniors with dementia suffer serious injury or death (ASAC, 2021).

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

Discovering the triggers for wandering are not always easy, but they provide insight into the behavior. Wandering may represent a search for social interaction when the person can no longer communicate verbally. Unable to sleep, the person may walk 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 issue 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; the lock(s) must be accessible to others and not take more than a few seconds to open.

- Do not try to restrain the person unless there are obvious hazards, such as traffic or harsh weather.
- Try to remain calm and reassuring instead of controlling.
- Avoid negative or hard commands such as "Don't go out there!"
- Avoid arguing with the person.
- Use a barrier, such as a curtain, to mask the door. A stop sign or "do not enter" sign may be effective.
- Paint a door to look like a piece of furniture.
- Try placing a large "Do Not Enter" sign on exit doors.
- 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.
- Do not lock a person with dementia in the home or car unattended.
- 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 person 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 (FCA, 2021b). (See also "Resources" at the end of this course.)

When the person has been admitted to a care facility, the family can help staff identify and anticipate wandering. Family can inform the staff about the person's lifestyle prior to being diagnosed with Alzheimer's, which can aid in understanding behavior (i.e., what kind of work the person did; previous patterns of exercise, stress, and response to touch; etc.). Once a person who wanders is identified, the facility can have photographs made and distributed to other units

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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.

Wandering in a safe area can be good exercise for the person with Alzheimer's disease and help manage non-goal-directed wandering. Many facilities are designed with these safe areas in the form of sheltered courts, gardens, lounges, or pathways (Alzheimer's Association, 2021b).

SILVER ALERTS

Silver Alert or Code Silver programs exist on a state-by-state basis. As a result, what incidents qualify for Silver Code may differ from state to state.

Silver Alert programs inform law enforcement agencies, media outlets, and the public about missing adults, usually older adults with cognitive disabilities or impairments. The information that is distributed includes photographs, a vehicle description 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 broadcast using dynamic message signs on roadways, radio stations, mobile phones, the internet, and television. Silver Alerts may also involve Reverse 911 or other emergency notification systems to alert nearby residents of the neighborhood surrounding the missing person's last know location.

(ASAC, 2021)

Sleep Issues and Sundowning

Restlessness, agitation, disorientation, and other troubling behavior in persons with dementia often worsen at the end of the day and sometimes continue through the night. This behavior is referred to as *sundowning*.

Possible contributing factors to sleep disturbance include:

- Mental and physical exhaustion from a full day trying to keep up with unfamiliar or confusing environment
- An upset in the biological clock, causing a mix-up between day and night
- Reduced lighting that increases shadows, which may cause misinterpretation of what is seen and thereby increase agitation
- Disorientation due to inability to separate dreams from reality when sleeping
- Sleeping less, which is common among older adults

The following are some **strategies** to help manage sleep issues and sundowning:

- Schedule major activities in the morning or early afternoon hours when the person is most alert.
- As much as possible, encourage a regular routine of waking up, meals, and going to bed.
- When possible and appropriate, include walks or time outside in the sunlight.
- Try to identify triggers that occur before sundowning events.
- Reduce stimulation during the evening hours, which may add to the person's confusion.
- Offer a larger meal at lunch and keep the evening meal lighter.
- Keep the home well-lit in the evening, which may reduce confusion.
- Do not physically restrain the person, as it can make agitation worse.
- Try to identify activities that are soothing, such as listening to music.
- Discuss with the provider about best times of day for taking medications.
- Limit daytime naps.
- Reduce or avoid alcohol, caffeine, and nicotine, which can all affect ability to sleep.

If the person is awake and upset, approach in a calm manner, determine what the person may need, gently remind about the time, and offer reassurance that everything is all right. Avoid arguing, and allow the person to pace back and forth, as needed, with supervision (Alzheimer's Association, 2021b).

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.

Perseveration and Compulsive Behaviors

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. These behaviors are due to the disease process and not because the person is purposely trying to be annoying. They may include:

- Checking locks, doors, or window coverings over and over
- Having rigid walking patterns, including pacing
- Collecting or hoarding items
- Counting or organizing objects repeatedly
- Going to the toilet frequently
- Selective eating habits
- Asking the same questions repeatedly

The caregiver can consider whether the person might have a need they are not able to express, such as boredom, hunger, insecurity, or need to use the toilet. Sometimes people engage in repetitive behavior because they are feeling anxious and the activity is soothing. It may be of benefit to see if there is a way to substitute the behavior with another activity, such as folding laundry, sweeping, or creative projects. Remove or hide objects in the environment that might trigger the behavior.

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. Other helpful measures to consider may include:

- Providing plenty of reassurance and comfort in word and touch
- Distracting with a snack or activity
- Avoiding reminding the person that they just asked the same question
- Ignoring the behavior or question, and instead refocusing the person into an activity such as singing or helping with a chore
- Not discussing plans with a confused person until immediately prior to an event
- Learning to recognize certain behaviors (e.g., an agitated state or pulling at clothing to indicate a need to use the bathroom)

When the person is very rigid and resistant to any interference with the activity, it is important to avoid provoking an aggressive reaction.

- Use a calm, matter-of-fact tone of voice.
- Do not become bossy or condescending.
- Distract the person with something appealing to them. (UCSF, 2021c; FCA, 2021b)

Shadowing is another repetitive behavior in which the person constantly follows their caregivers around. This behavior often occurs late in the day. They may imitate the caregiver or become anxious if the caregiver tries to spend any time away from them. For the caregiver, this can be a smothering experience. Even being able to use the bathroom alone can be a challenge. In Alzheimer's patients, shadowing represents a message of uncertainty, insecurity, or fear. Caregivers represent security and protection. Helpful suggestions include:

- Establishing and maintaining a daily routine to help the person feel more secure
- Saying reassuring words every day and often, such as, "You're safe."
- Avoiding moving household furnishings or other items around or rearranging them
- Using a simple white board to indicate the date or to tell the person when the caregiver will return
- Involving and engaging the person in familiar activities such as folding laundry or cleaning tasks
- Playing the person's favorite musical selections
- Making an audiotape of the caregiver's voice or any reassuring familiar voice

- Making a videotape of recent events to play for the person, or playing familiar movies
- Considering the use of a day center or hiring a professional caregiver (Alzheimer's Association, 2021b)

Inappropriate Sexual Behaviors

Because of dementia, many individuals 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.

Forewarn family and friends of the person's behaviors to better prepare them with what to expect and how best to respond. Because of the embarrassment and negative feelings about these behaviors, family members, friends, and caregivers must be given an opportunity to talk about their feelings.

If the person is disruptive or making someone else uncomfortable, make eye contact and say, "Stop," with a calm but firm tone of voice, and then distract with a different activity.

If it is thought that the person is seeking more physical affection or intimacy, consider pet therapy, a stuffed animal, and socially appropriate touching such as hand-holding, dancing, back rubs or massages, manicure/pedicure, or brushing/combing hair (UCSF, 2021c).

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 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 and difficulty solving problems
- Lack of choice in being a caregiver
- Having little help from family or friends for respite care (Mayo Clinic, 2020)

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. Family members who provide care to individuals with dementia or other chronic conditions are themselves at risk. Emotional, mental, and physical health problems arise from complex caregiving situations and the strains of providing care.

Higher levels of stress, anxiety, depression, and other mental health effects are common among caregivers. Depression and anxiety disorders in caregivers persist and can even worse after placement of the patient in a nursing home. Many caregivers report experiencing symptoms such as:

- High levels of stress and feeling frustrated, drained, guilty, and helplessness
- A loss of self-identity, lower levels of self-esteem
- Constant worry

• Feelings of uncertainty

Research has shown 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.

Caregivers who experience chronic stress may be at greater risk for their own cognitive decline, including loss in short-term memory, attention, and verbal IQ. Studies have found that caregivers have diminished immune response, leading to frequent infections and increased risk of cancers. Caregivers are less likely to engage in preventive health behaviors, and elderly spousal caregivers who experience stress have a 63% higher mortality rate than others the same age.

In response to increasing stress, caregivers have been found to have increased alcohol and other substance use, and to use prescription and psychotropic drugs more than noncaregivers. Spousal caregivers who are at risk of clinical depression are more likely to engage in harmful behavior toward the person.

Keeping family caregivers healthy and able to provide care is important to the nation's long-term care system, and with the aging of population, this will become more important in the future (FCA, 2021c).

Strategies to Manage Caregiver Stress

Although caregiving can have a negative impact on the caregivers' health and well-being, research demonstrates its effects can be alleviated at least in part by:

- A family physician assessment of caregiver needs that leads to a care plan with support services, and repeat assessments with changes in status of caregiver or care recipient
- Caregiver education and support programs, including national caregiving organizations, local elder care agencies, and websites (see also "Resources" at the end of this course)
- Respite care to reduce caregiver burden, such as in-home, adult care centers and programs or short-term nursing homes
- Financial support to alleviate the economic stress of caregiving
- Primary care interventions that address caregiver needs

Support and anticipatory guidance for the caregiver is especially helpful during care transitions and at the care-recipient's end of life (Swartz & Collins, 2019).

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 Home and Community-Based Services Waivers (HCBS) provide financial assistance to purchase home and community-based services and supports. These waivers allow the person with dementia to choose whom they wish to be a personal caregiver, which could be a family member.
- **Medicaid state plans** offer personal care services. Often states allow family members to be personal care providers and offer cash compensation.
- Adult foster care through Medicaid 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, 2021b).

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 an ongoing individualized assessment that is also 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

In the United States, the basic right to be free from unwanted treatment is long established, and people with decision-making capacity have the right to forgo life-sustaining treatment they do not want. People who lack decision-making capacity have the same right through the use of an advance directive or a surrogate decision maker. However, this legal framework and ethical consensus does not fully reflect the situation of a person facing dementia if there are no medical treatments to refuse (The Hastings Center, 2019).

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 lifeextending 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.

People with advanced dementia who have a valid advance directive most often document a preference for supportive care at the end of life. It has also been shown that people who have an advance directive are less likely to have burdensome treatments at the end of life, including feeding tubes, hospitalizations, and intensive care unit stays in their last months of life (Compassion & Choices, 2021).

AID IN DYING

In some states it is legal for mentally competent adults (ages 18 and over) with a terminal illness and a prognosis of 6 months or fewer to decide for themselves what a good death means in accord with their state's aid-in-dying laws. However, persons with Alzheimer's disease/dementia

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are **ineligible** to request life-ending medications under such "death with dignity" laws because their judgment and decision-making is impaired by their illness.

A person must be mentally competent and be capable of making their own healthcare decisions, and when making requests for medications under aid-in-dying laws, the person must be able to self-administer and ingest the medication at the time of their choosing. This, of course, also makes the Alzheimer's patient ineligible. Also, if a person is in the early stages of the illness without cognitive impairment and does not have another disease that is causing a terminal illness with 6 months or less to live, they do not qualify to make that request (DD, 2021).

Difficulty applying physician-assisted dying (PAD) for persons with dementia also raises different philosophical and ethical dilemmas regarding the nature of the illness itself: at what point is it ethical for the "previous" self to make decisions for the "present" (demented) self? In addition, the "previous" self may have underestimated the "present" self's ability to cope with the disease process (Jakhar et al., 2020).

ARTIFICIAL NUTRITION AND HYDRATION (ANH)

People living with dementia decline in their ability to eat and drink as symptoms progress. These include dysphagia, loss of appetite, inability to recognize food and utensils, difficulties with attention, and problems maintaining an eating routine. Decreased oral intake in the advanced stages of the disease is not believed to cause discomfort for the person living with dementia; however, family members and professionals may feel obligated to continue feeding to avoid feeling they are being neglectful.

ANH is sometimes offered via invasive procedures such as a nasogastric tube, percutaneous endoscopic gastrostomy (PEG) tube, intravenous hydration, and hypodermoclysis (subcutaneous fluid infusion). The evidence of the effectiveness of these interventions is limited, and they can have a negative effect on the well-being of the person with dementia.

Newer studies reinforce the outcome of earlier studies, which have found that there is insufficient evidence to conclude that tube feeding of individuals with advanced dementia is effective in improving survival, quality of life, or nutritional status. Alternately, for people with severe dementia, comfort feeding only (CFO) can be offered to provide food and fluids orally with the goal of comfort and pleasure (Anantapong et al., 2021; Ijaopo & Ijaopo, 2019).

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

An advance directive, also known as a *living will*, allows the person to document their wishes concerning medical treatments at the end of life in the event they are unable to communicate those wishes. The advance directive never expires, remaining in effect until the person changes it. Every new advance directive invalidates the previous one. In the advance directive, the person can name a representative to ensure wishes concerning care are carried out. This representative is called a *durable power of attorney for healthcare* or *medical power of attorney*.

It is important to note that emergency medical technicians cannot honor an advance directive. The only document they honor is the Do No Resuscitate (DNR) order (see below).

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

Three specific advance directives have been developed by some states in the U.S. to provide a measure of control to those with dementia, with the aim of helping them make their intentions known in case they are no longer able to communicate. Alzheimer's directives are documents that help the patient's family and caregivers know their preferences for healthcare. However, they may not be legally binding outside the states where they were developed. These include:

- Living with Dementia Mental Health Advance Directive
- Health Directive for Dementia
- Advance Directive for Receiving Oral Food and Fluids in the Event of Dementia

These directives provide a means for those diagnosed with dementia, while still retaining their decision-making capacity, to limit assisted feeding by hand when they reach the final/terminal stage of the disease. The instructions in the directive become effective when the person's appointed health care agent, in concert with the primary care physician, agrees that the patient is now in the final stage of dementia and is unable to make treatment decisions or to self-feed.

Unlike the standard advance healthcare directive, which specifies what medical actions should be undertaken if the person is too ill or incapacitated to make decisions, an Alzheimer's/dementia directive covers decisions involving day-to-day choices such as where you would like to be treated, who the preferred caregiver is, and who's authorized to be your healthcare agent (Death with Dignity, 2021).

DO NOT RESUSCITATE 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 orders are regulated by state law. (In 2005, the American Heart Associated moved from the traditional term DNR to "do not attempt resuscitation" (DNAR). However, most hospitals continue to use the term DNR.)

A DNR 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 search for a DNR order, 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 where paramedics or other EMS personnel can easily see it, such as taped to the foot of the individual's bed or on the wall nearby bed. Some people prefer the additional safeguard of wearing a bracelet or necklace to alert care providers that a DNRO is in force (Eisenhower Health, 2021).

Palliative Care and Hospice Care

Palliative care provides relief from distressing symptoms, including pain, shortness of breath, nausea, insomnia, and side effects of medications. People usually receive palliative care at clinics or hospitals, but home care may be possible. It can be provided at any point during the disease process as needed.

Hospice seeks to optimize the quality of life in the terminally ill (typically, those expected to live six months or less), while neither hindering nor hastening the dying process. The hospice philosophy emphasizes physical comfort, pain and symptom management, and death with dignity. 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. 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 6 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 (Death with Dignity, 2021).

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 often associated with a long survival period, it affects not only the patient's life, but also the person's family, caregivers, and society. 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.

The risk of developing Alzheimer's dementia increases with age, and as the population continues to age, the number of persons with Alzheimer's disease will also increase. Along with this, the need for caregivers and support for them will be greater than ever. Healthcare professionals must become educated about this disease and its impact in order to be aware of the ways in which they can effectively care for these individuals and their caregivers. They must understand the impact of this disease on the person and learn how to use effective strategies to manage difficult behaviors. It is important for healthcare professionals to use a person-centered approach, which involves developing a therapeutic relationship and getting to know the person's life story and preferences so as to provide the quality of care they deserve.



RESOURCES

Alzheimer's Association https://www.alz.org

Alzheimer's disease (MedlinePlus) https://medlineplus.gov/alzheimersdisease.html Alzheimer's disease and related dementias (National Institute on Aging) https://www.nia.nih.gov/alzheimers

Caregiver training videos (UCLA Health)

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

Family Caregiver Alliance

https://www.caregiver.org

Financial assistance for family caregivers

https://archrespite.org/consumer-information/caregiver-financial-assistance

Home safety checklist

https://www.alz.org/media/Documents/alzheimers-dementia-home-safety-checklist-ts.pdf

Mini-Cog screening instrument

https://mini-cog.com

Mini-Mental State Exam

https://www.dementiacarecentral.com/mini-mental-state-exam/

National Center on Elder Abuse (NCEA) state resources

https://ncea.acl.gov/Resources/State.aspx

Preventing Alzheimer's disease and dementia (HelpGuide)

https://www.helpguide.org/articles/alzheimers-dementia/alzheimers-and-dementia-prevention.htm

24/7 wandering support

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

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TEST

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- 1. In the United States, Alzheimer's disease is:
 - a. The cause of death in more people than breast cancer and prostate cancer combined.
 - b. The leading cause of death and disability for adults ages 65 and older.
 - c. More prevalent in men than in women.
 - d. More common in adults with a college education.
- 2. The most commonly identified immediate cause of death among older adults with Alzheimer's disease is:
 - a. Immobility.
 - b. Pneumonia.
 - c. Swallowing disorders.
 - d. Malnutrition.
- **3.** The two characteristic lesions of Alzheimer's disease are neurofibrillary tangles and:
 - a. White matter lesions.
 - b. Neuronal fissures.
 - c. Glial cysts.
 - d. Beta-amyloid plaques.
- **4.** Smoking is an epigenetic factor 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.
- **5.** 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. Researchers have found definitive evidence supporting cognitive training as a means of preventing Alzheimer's disease.

- **6.** Early signs and symptoms of memory impairment due to Alzheimer's disease may include:
 - a. Forgetting an appointment but recalling it later.
 - b. Making an occasional error when managing finances.
 - c. Misplacing items and retracing one's steps to find them.
 - d. Forgetting where one is located and how one got there.
- 7. Which patient symptom is typically seen only in the latest, severe stage of Alzheimer disease?
 - a. Loss of impulse control
 - b. Increased anxiety
 - c. Trouble remembering one's own name
 - d. Impaired swallowing
- **8.** The purpose for laboratory testing in diagnosing Alzheimer's disease is to:
 - a. Screen for and detect early stages of dementia.
 - b. Rule out other reversible forms of cognitive impairment.
 - c. Differentiate between stages of the disease.
 - d. Distinguish Alzheimer's disease from other forms of dementia.
- **9.** Pharmacologic treatment for patients with Alzheimer's disease:
 - a. a. Can improve a patient's cognitive and functional status.
 - b. b. Can cure Alzheimer's if prescribed early in the disease's progression.
 - c. c. Often increases a patient's behavioral and psychological symptoms.
 - d. d. Does not help lessen symptoms such as memory loss and confusion.
- **10.** Recognizing and treating coexisting conditions common to older adults helps support patients with Alzheimer's disease by:
 - a. Identifying those persons at risk for psychosis.
 - b. Slowing the progression of Alzheimer's disease.
 - c. Improving the functional ability and quality of life of patients.
 - d. Shifting the burden of caregiving away from the patient.
- 11. Which is an occupational therapy intervention that involves educating family caregivers and professionals to better understand how it feels to be living with dementia?
 - a. Reminiscence therapy
 - b. Tailored Activity Program (TAP)
 - c. Skill2Care
 - d. Positive Approach to Care (PAC)

- **12.** A physical therapy assessment tool that is used to determine fall risk in patients with Alzheimer's disease is the:
 - a. Global Deterioration Scale/Reisberg Scale
 - b. Timed Up and Go Test.
 - c. Pain Assessment in Advanced Dementia.
 - d. Functional Assessment Staging Tool.
- **13.** 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:
 - a. Ask the person to try to remember what was said before.
 - b. Ignore the question and leave the room.
 - c. Respond to the question and then try to distract the person.
 - d. Tell the person the question has already been answered and walk away.
- **14.** 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.
- **15.** 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.
- **16.** What is an effective strategy that healthcare professionals can employ to support family caregivers of patients with dementia?
 - a. Recommend and assist caregivers in obtaining respite care
 - b. Refrain from providing caregivers with a lot of pamphlets and booklets about the disease
 - c. Recommend caregivers give up their time-consuming leisure activities
 - d. Suggest that caregivers arrange psychological therapy for the patient
- 17. To qualify for most insurance coverages of hospice services, a person must:
 - a. Have a prognosis or less than one month to live.
 - b. Be certified as having less than six months to live.
 - c. Receive those services in a specifically designated hospice care facility.
 - d. Be mentally competent to make their own decisions at the time of care.