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Florida: Specialized Alzheimer's Adult Day Care, Level Two (345)

Author: Lauren Robertson, BA, MPT

Contact hours: 4

Cost: \$29

Course expires: April 2, 2027

Florida DOEA Approval: Approved by the FL Department of Elder Affairs, Curriculum Approval #SAADC 10350. Approved through April 2, 2027.

Certified Trainer: The author is certified as an ADRD trainer by the Florida Department of Elder Affairs and is available via e-mail at Lauren@ATrainCeU.com or by phone Monday-Friday from 9 a.m. to 5 p.m. (Pacific Time) at 707 459-3475.

Course Summary

This course is for those of you who provide direct care to clients in a specialized adult day care center. It will increase your awareness and understanding of Alzheimer's disease and related disorders. The course discusses Alzheimer's disease and other common types of dementia from the perspective of both workers and clients and includes information on how Alzheimer's and other types of dementia affect the brain. It describes tests that can be used for cognitive screening and the limitations of those tests.

You will learn about the areas of the brain associated with speech and language comprehension and how cognitive decline affects communication. Understanding how brain deterioration affects behavior is a critical skill for anyone working with a person experiencing the effects of dementia.

The concept of person-centered care, creating a dementia-friendly physical environment, and common medications and their side effects are discussed. Assessing pain and identifying malnutrition and dehydration are described, along with strategies for addressing these important issues.

The course includes a discussion of the importance of meaningful activities and provides information on validation therapy, new technologies, and safety issues. We conclude with information about family issues and caregiver stress.

Course Objectives

1. List the 3 overall services provided by an adult day care facility.
2. Describe 2 differences between Alzheimer's dementia, vascular dementia, and frontotemporal dementia.
3. List 3 ways in which normal cognitive changes that occur in older adults differs from cognitive changes seen in dementia.
4. Relate 3 differences between dementia, delirium, and depression.
5. Describe the purpose for a neurocognitive screening.
6. Relate 3 ways in which dementia affects communication.
7. Describe 5 challenging behaviors that might be associated with dementia.
8. Define person-centered care.
9. Describe 5 key points about pain in an older adult with dementia.
10. Relate the 2 most common classes of medications used in older adults with dementia.
11. List 5 risk factors for malnutrition and dehydration in older adults with dementia.
12. Describe 3 features of a meaningful activity.
13. Describe the 3 main components of validation therapy.
14. List the 2 key features of safety technologies.
15. Relate 5 ways to reduce caregiver stress.

1. Adult Day Care

Adult day care centers were created to reduce isolation, depression, and cognitive and physical decline among community-dwelling older adults. They are designed to help older adults continue to live at home or in the community for as long as possible. They typically provide a supportive, professional staff that addresses the nutritional, daily living, and social needs of adults with functional limitations within a group setting during the day (Ellen et al., 2017).

In the United States, there are more than 4,600 adult day service centers serving nearly 286,000 people (Caffrey and Lenden, 2019). In Florida, there are approximately 349 adult daycare centers providing therapeutic programs, social services, health services, and activities for adults in a non-institutional setting. Nearly half of adult daycare clients have Alzheimer's disease or a related disorder (FADSA, 2021).

A small number of centers in Florida are licensed to provide *specialized* Alzheimer's adult daycare services. These centers are specifically designated to treat clients with Alzheimer's disease and other types of dementia and generally enroll a higher percentage of clients with dementia than do regular adult day centers. Specialized dementia training and a specialty license is required to provide services as a Specialized Alzheimer's Services Adult Day Care Center. (O'Keefe, 2014, latest available).

In general, adult daycare clients are younger and more racially and ethnically diverse than users of other long-term care services. In 2018, about 57% of adult day services center participants were female, 45% were non-Hispanic white, and 39% were under age 65 (Lendon and Singh, 2021).

Most adult day participants attend at least 3 days each week and most use transport services provided by the centers. In 2022, the median cost of adult day care services in the U.S. was \$81 per day (Alzheimer's Association, 2023).

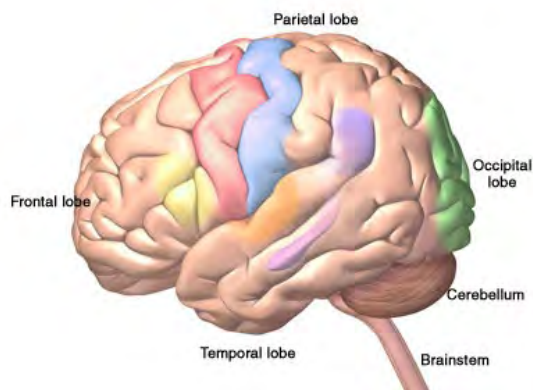
2. Understanding Brain Disease

The ugly reality is that dementia often manifests as a relentless and cruel assault on personhood, comfort, and dignity. It siphons away control over thoughts and actions, control that we take for granted every waking second of every day.

Michael J. Passmore
Geriatric Psychiatrist, University of British Columbia

Brain disease comes in many different forms and has many different causes. Because the brain is so important, any damage to the brain can have a profound impact on our ability to manage daily affairs, communicate effectively, and live independently.

The largest part of the human brain, the cerebrum, has four lobes: the frontal, temporal, parietal, and occipital lobes. The most recognizable and devastating effects of dementia occur because of damage to nerve cells on the outer surface of the lobes—the cerebral cortex.



An illustration of the cerebrum, cerebellum, and the brainstem. The outer surface of the cerebrum is made up of a thin layer of nerve cells called the cerebral cortex. Source: ©Zygot Media Group, Inc.. Used with permission.

2.1 Common Types of Dementia

Dementia is a syndrome, a collection or grouping of symptoms—the result of progressive deterioration and loss of brain cells and brain mass. Different types of dementia affect different parts of the brain. Some dementias start in a part of the brain that controls a specific function such as short-term memory or emotion. Other dementias affect the entire brain—or more than one part of the brain—causing other symptoms.

Although a small percentage of people experience early-onset dementia, in general, dementia develops in later adulthood. Aging is a risk factor for developing dementia but nevertheless dementia is **not considered** a normal part of aging. Determining if someone has dementia is important because some types of cognitive changes can be addressed or even reversed if the underlying cause is identified and treated.

Alzheimer’s disease is the most common cause of dementia, but it isn’t the only cause. Frontal-temporal dementia—which begins in the frontal lobes—is a relatively common type of dementia in those under the age of 60. Vascular dementia and Lewy body dementia are other common types of dementia (see table below). Dementia associated with Parkinson’s disease shares a common etiology with Lewy body dementia.

Some Common Types of Dementia			
Dementia subtype	Characteristic symptoms	Neuropathology	% of cases
*Alzheimer’s disease (AD)	<ul style="list-style-type: none"> • Gradual onset • Impaired memory, apathy, and depression • Language and visuospatial deficits • Changes in mood, anxiety, and sleep • Later stage: impaired judgment, confusion, major behavioral changes, neuropsychiatric symptoms • Executive functions more impaired affected than in other types of dementia 	<ul style="list-style-type: none"> • Cortical amyloid plaques • Neurofibrillary tangles • Neuroinflammation 	60–80%
Frontal-temporal dementia	<ul style="list-style-type: none"> • Early onset (45 to 60 yrs of age) • Behavioral and personality changes • Mood changes • Disinhibition, inappropriate touching, loss of social decorum • Loss of empathy • Language difficulties due to progressive aphasia • Problems with spatial orientation • Early onset (45 to 60 yrs of age) • No single pathology, considered a “family” of neurodegenerative disorders 	<ul style="list-style-type: none"> • No single pathology, considered a “family” of neurodegenerative disorders • Damage initially limited to frontal and temporal lobes • 3 subtypes <ol style="list-style-type: none"> 1. Behavior variant frontotemporal dementia 2. Primary progressive aphasia 3. Disturbances of motor function 	5–10%, prevalence thought to be underestimated

Some Common Types of Dementia			
Dementia subtype	Characteristic symptoms	Neuropathology	% of cases
<p>*Vascular dementia, including post stroke dementia</p>	<ul style="list-style-type: none"> • Stepwise onset • Similar to AD, but memory less affected, and mood fluctuations more prominent • Physical frailty, little or no physical exercise • Patchy cognitive impairment • May be preventable • Most common cause is related to cerebral small vessel disease • Single infarcts in critical regions, or more diffuse multi-infarct disease • Considered a “group” of syndromes • Following a stroke, ~2/3 experience cognitive decline • Increased mortality compared to stroke patients without dementia 	<ul style="list-style-type: none"> • Any dementia related to cerebrovascular disease • Most common cause is related to cerebral small vessel disease • Single infarcts in critical regions, or more diffuse multi-infarct disease • Considered a “group” of syndromes • History of stroke 	<p>20–30%</p>
<p>Dementia with Lewy bodies (shares a common etiology with Parkinson’s disease dementia)</p>	<ul style="list-style-type: none"> • Marked fluctuation in cognitive ability • Executive and attentional deficits • Rapid eye movement sleep behavioral disorder • Visual hallucinations • Significant visuospatial deficits • Parkinsonism (tremor and rigidity) • Adverse reactions to antipsychotic medications 	<ul style="list-style-type: none"> • Cortical Lewy bodies (alpha-synuclein) • Autonomic dysfunction • Symptomatic orthostasis • Decreased or increased sweating • Excessive salivation • Heat intolerance • Urinary dysfunction • Impotence • Constipation 	<p>~5-10%</p>

Some Common Types of Dementia			
Dementia subtype	Characteristic symptoms	Neuropathology	% of cases
Parkinson's Disease Dementia (shares a common etiology with Lewy body dementia)	<ul style="list-style-type: none"> Mild cognitive impairment in early stage Motor symptoms typically occur before cognitive and behavioral changes. Develops in about 80% of people with PD. 	<ul style="list-style-type: none"> Build-up of Lewy bodies (alpha-synuclein) in the brain 	

*Post-mortem studies suggest that many people with dementia have mixed Alzheimer's disease and vascular dementia pathology and that this "mixed dementia" is underdiagnosed. Source: Adapted with permission from Alzheimer's Disease International, 2019.

2.1.1 Alzheimer's Dementia

Alzheimer's disease (AD) is a progressive, irreversible, age-related brain disorder that affects as many as 5 million Americans over the age of 65. It is the most common type of dementia and is responsible for 60-80% of all cases (ADI, 2019).

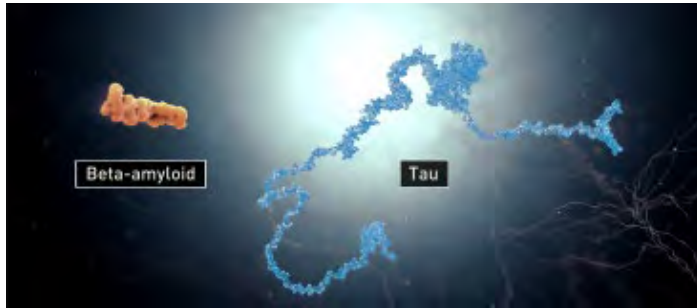
Worldwide, more than 50 million people live with dementia and because people are living longer this number is expected to triple by 2050 (ADI, 2019). In Florida, there are 580,000 residents currently living with Alzheimer's disease. By 2025, this number is expected to increase to more than 720,000 (Alzheimer's Association, 2023).

Did You Know. . .

For some time now, we have used the term "Alzheimer's disease and related dementias" to describe dementia and to make it clear that there is more than one kind of dementia. The term **neurocognitive disorder** is now recognized in the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5) as a new term for dementia.

Memory problems are a common early symptom of Alzheimer's dementia although language difficulties, apathy, depression, and vision and spatial difficulties can also be early symptoms. Although more than twenty types of dementia have been identified, Alzheimer's dementia is the most frequent (and most studied) cause of dementia in older adults. In general, executive functions are more impaired in Alzheimer's disease than in other types of dementia.

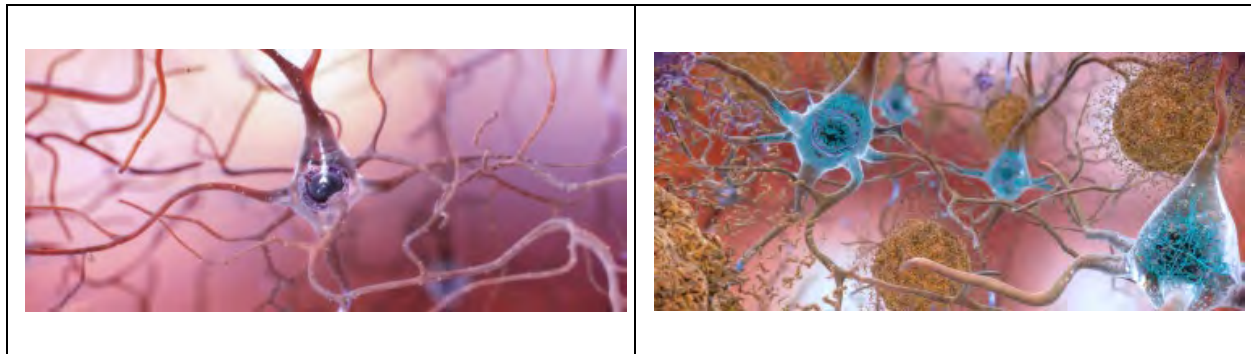
The exact cause of Alzheimer's dementia is still unknown. In Alzheimer's disease, and likely in other forms of dementia, damage within the brain is thought to be due to the formation of *beta-amyloid plaques*, *neurofibrillary tangles*, and the degeneration of neurons in the cerebrum.



Beta-amyloid plaques and neurofibrillary tangles (tau). Source: Image courtesy of the National Institute on Aging/National Institutes of Health. Public domain.

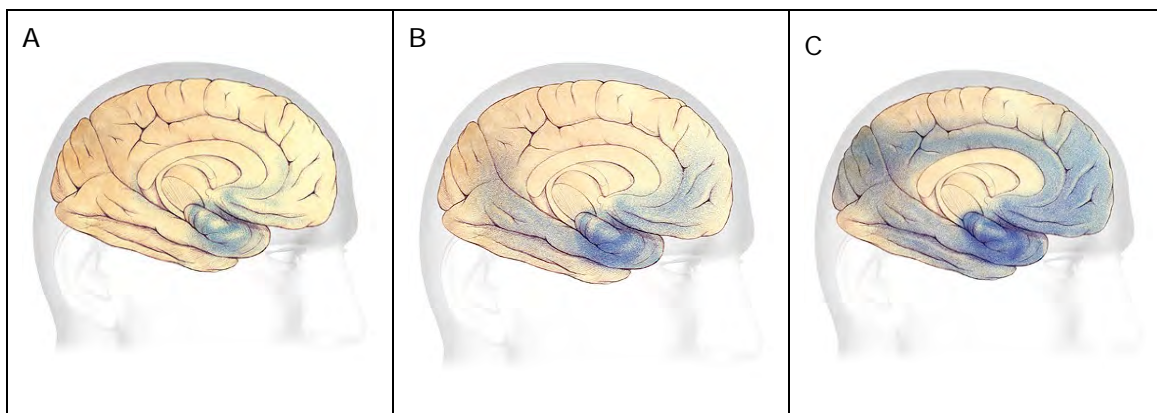
Brain imaging techniques such as magnetic resonance imaging (MRIs) as well as autopsies show that Alzheimer’s causes the brain to shrink, that connections between nerves weaken, and nerve cells are damaged and lost. Once a healthy nerve cell begins to deteriorate, it loses its ability to communicate with other neurons, with devastating results.

Degeneration of Cerebral Neurons



Left: A healthy neuron with many connections to other cells. Right: A dying nerve cell showing the nerve connections weakening and the main body of the cell deteriorating due to the presence of amyloid plaques and tau tangles. Source: Image courtesy of the National Institute on Aging/National Institutes of Health. Public domain.

The Progression of Alzheimer’s Disease



A: Plaques and tangles (shaded in blue) are beginning to form within a part of the temporal lobe called the hippocampus. B: As the disease progresses, damage spreads toward the front and rear of the brain. C: In severe Alzheimer’s, plaques and tangles have caused widespread damage throughout the brain. Source: The Alzheimer’s Association. Used with permission.

In Alzheimer's disease, plaques and tangles first appear in an area of the temporal lobe called the *hippocampus*, where new memories are formed (A). As the disease progresses, plaques and tangles spread to the front part of the brain, affecting judgment and other high-level mental functions; symptoms begin to be obvious at this stage (B). In the severe stage (C), plaques and tangles are found throughout the brain. Damage eventually affects memory, emotions, communication, spatial awareness, safety awareness, logical thinking, recognition of loved ones, and the ability to care for oneself.

2.1.2 Vascular Dementia and Vascular Cognitive Impairment

Vascular dementia is one of the most common forms of dementia after Alzheimer's disease, thought to be the cause of approximately 20-30% of the dementia cases worldwide (ADI, 2019). It usually has a stepwise onset, meaning symptoms can stay the same for a long period of time, then suddenly worsen. Memory may be less affected than in Alzheimer's disease while fluctuations in mood are more common. Cognitive impairment is often "patchy" because of small vessel damage throughout the brain. Vascular dementia can also affect judgment—but not as strongly as in someone with frontal-temporal dementia.

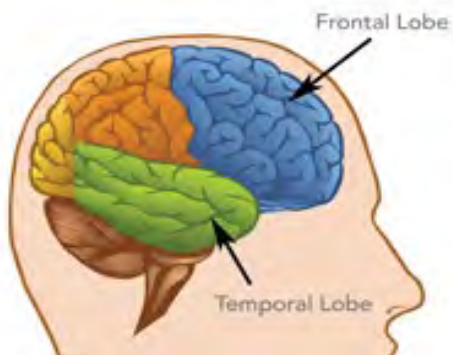
Diseases or disorders that damage the vessels supplying blood to the brain are risk factors for vascular dementia. This includes hypertension, heart rhythm irregularities, diabetes, high cholesterol, smoking, sleep-disordered breathing, and a sedentary lifestyle (UCSF, 2020). The risk of developing dementia from vascular damage can be significant even when individuals have suffered only small strokes or minor damage to the blood vessels (NINDS, 2023, December 19).

2.1.3 Frontal-temporal Dementia

Frontal-temporal dementia begins in the frontal and temporal lobes of the brain. It is a relatively common type of dementia in people under the age of 60 although new research is showing that it can start in older age. It is thought to be responsible for 5-10% of all cases of dementia. There is no single pathology attributed to frontal-temporal dementia—it is considered a "family" of neurodegenerative disorders.

Behavioral and personality changes associated with frontal-temporal dementia can be striking. This is because the frontal lobes are responsible for many of the traits and behaviors that mediate human behavior. Damage to this part of the brain can lead to mood swings, disinhibition, inappropriate touching, loss of social decorum, and loss of empathy in addition to language difficulties and problems with spatial orientation.

Certain subtypes of frontal-temporal dementia affect judgement, empathy, foresight, and planning. A second subtype affects language skills, reading, writing, and comprehension while a third subtype causes disturbances of motor function and muscle weakness or wasting, without behavioral or language problems (Alzheimer's Association, 2024).



Damage to the brain's frontal and temporal lobes causes forms of dementia called frontotemporal disorders. On the right, the areas of the brain affected by frontal-temporal dementia are shaded in purple. Left source: National Institute on Aging, public domain. Right source: Alzheimer's Association, 2020 Used by permission.

Because frontal-temporal dementia can also affect the hippocampus and because of the many variations found in the disease, it is often difficult to tell the difference between frontal-temporal dementia and Alzheimer's disease. It can also be confused with other psychiatric conditions such as late-onset schizophrenia.

2.1.4 Dementia with Lewy Bodies

Dementia with Lewy bodies (DLB) is another type of progressive dementia. Although DLB is less well-known than Alzheimer's dementia, it is not rare. DLB is caused by the build-up of abnormal proteins called *Lewy bodies* inside nerve cells in areas of the brain responsible for certain aspects of memory and motor control. It is not known exactly why Lewy bodies form or how Lewy bodies cause the symptoms of dementia (NINDS, 2024, January 19).

The similarity of symptoms between dementia with Lewy bodies, Parkinson's disease, and Alzheimer's disease can make diagnosis difficult. It is possible that either Lewy body dementia is related to these other causes of dementia or that an individual can have more than one type of dementia at the same time. Lewy body dementia usually occurs in people with no known family history of the disease. However, rare familial cases have occasionally been reported (NINDS, 2024, January 19).

Jim's Story

Jim, a 60-year-old executive assistant, began having trouble managing the accounting, paperwork, and other responsibilities of his job. He became increasingly irritable, and his daughter insisted he see a doctor. Jim was diagnosed with depression. He was prescribed an antidepressant, but his thinking and concentration problems worsened. When he could no longer function at work, his doctor diagnosed him with Alzheimer's disease.

A few months later, Jim developed a tremor in his right hand. He was referred to a neurologist, who finally diagnosed him with dementia with Lewy bodies. Having this diagnosis helped Jim and his daughter plan for the next steps in his treatment and care.

From: National Institutes of Neurological Disorders and Stroke, 2024, January 19.

2.1.5 Parkinson's Disease Dementia

Although Parkinson's disease is initially associated with progressive difficulties with movement (slowed movement, postural instability, resting tremors), about 80% of people with Parkinson's disease will eventually experience behavioral and cognitive changes. Symptoms are mild in the early course of the disease, then progressively worsen. This condition is closely related to Lewy Body dementia—both diseases are caused by the build-up of alpha-synuclein proteins, which clump together, causing damage to nerve cells in the brain.

2.1.6 Post-Stroke Dementia

The risk for cognitive impairment or decline is increased by a history of stroke. As many as two-thirds of stroke patients experience cognitive impairment or cognitive decline following a stroke and approximately one-third go on to develop dementia. The risk for developing dementia may be 10 times greater among individuals with stroke than those without. Mortality rates among stroke patients with dementia are 2 to 6 times greater than among stroke patients without dementia (Teasell et al., 2014).

2.2 Functional Impairments

Cognitive decline and functional changes are intimately related. Changes in vision, hearing, depth perception, reaction time, and gait affect all aspects of daily living. Visual and perceptual changes affect reading, comprehension of form and color, peripheral vision, and the ability to see contrast. Navigating around obstacles such as curbs, breaks in the sidewalk, stairs, and pets becomes more challenging. Because it becomes increasingly difficult to accurately detect motion and process visual information, driving is no longer safe.

Problem solving, self-management, and the ability to focus and pay attention are all affected or altered by dementia. Declines in the ability to think, remember, or reason interfere with a person's daily life and activities. (NINDS, 2023, December 19).

In a Norwegian study, participants living with a diagnosis of dementia reported they became more sensitive to stress, needed more rest in order to concentrate, and felt more fatigue. They reported frustration with increasing forgetfulness and difficulty expressing themselves. Additionally, they reported (Molvik et al., 2024):

- finding it more difficult to orientate themselves to their surroundings
- needing more predictability and more time to prepare for activities
- finding it painful to experience not remembering where they were going
- experiencing "a complete stop in thinking"

Gait variability (changes in stride length and speed) increases from early, mild cognitive impairment throughout all the stages of Alzheimer's disease. Increased gait variability may reflect the progression of cognitive impairment in neurodegenerative diseases, specifically for Alzheimer's disease dementia (Pieruccini-Faria et al., 2021).

Different types and stages of dementia cause different functional impairments. Vascular dementia can affect decision-making and judgment and leads to mood changes. Frontal-temporal dementia causes mood changes, apathy, and disinhibition*, difficulties with language, and weakness or slowing of movement. People with frontal-temporal dementia gradually lose control of their impulses—their behavior is often referred to as “odd,” “socially inappropriate,” and “schizoid.”

***Disinhibition:** a loss of inhibition, a lack of restraint, disregard for social convention, impulsiveness, poor safety awareness, an inability to stop strong responses, desires, or emotions.

Functional impairments associated with dementia with Lewy bodies include progressive cognitive decline, “fluctuations” in alertness and attention, depression, visual hallucinations, and parkinsonian motor symptoms, such as slowness of movement, difficulty walking, or rigidity (stiffness). Dementia with Lewy bodies is also associated with difficulty sleeping, loss of smell, and visual hallucinations (NINDS, 2024, January 19).

Functional impairments associated with Parkinson’s disease dementia include the onset of Parkinson-related movement symptoms followed by mild cognitive impairment and sleep disorders, which involves frequent vivid nightmares and visual hallucinations (NINDS, 2023, December 19). Cognitive issues such as impaired memory, lack of social judgment, language difficulties, and deficits in reasoning can develop over time.

Online Resource

Video: Changes in Vision - Teepa Snow | MedBridge (3:11)

<https://www.youtube.com/watch?v=iaUsRa5kNyw>

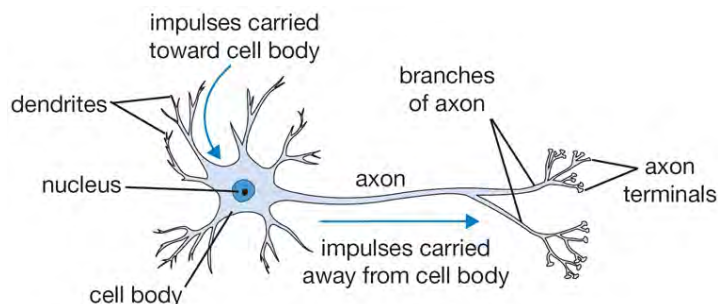
3. Normal Brain Function and Normal Aging

Aging carries with it a gradual decline of mental and physical functions. For most people, we can't run as fast, jump as high, lift as much, or remember things as easily as when we were younger. Even healthy older adults in good physical condition experience a decline in physical performance, strength, reaction time, and balance. These age-related changes are a normal part of aging and usually do not interfere with the ability to live independently.

3.1 Normal Brain Changes with Age

An aging brain experiences many changes. Certain parts of the brain shrink a little although there is not a significant loss of nerve cells, as occurs in Alzheimer's disease. Shrinkage typically is found in the prefrontal cortex and the hippocampus, areas of the brain important to learning, memory, planning, and other complex mental activities.

In certain brain regions, white matter (myelin-covered axons) is degraded or lost. This affects the brain's ability to send and receive nerve impulses and to interact with neurons in other parts of the brain. Because white matter connects the different regions of the brain, even a little loss or breakdown of myelin can affect cognition.



An illustration of a healthy neuron showing the nucleus, cell body, dendrites, and axons. The axon is covered with a myelin sheath, similar to the insulation on an extension cord. Source: WPclipArt.com. Used with permission. From <http://www.wpclipart.com/medical/anatomy/cells/neuron/neuron.png.html>.

Blood flow to the brain can be reduced as we age because arteries narrow and there is less growth of new capillaries. Due to these normal changes, some healthy older adults may notice a modest decline in their ability to learn new things and retrieve information.

Older adults may not perform as well on complex tasks of attention, learning, and memory compared to younger people. However, if given enough time to perform the task, the scores of healthy people in their 70s and 80s are often similar to those of young adults. In fact, as we age, adults often improve in other cognitive areas, such as vocabulary and other forms of verbal knowledge (NIA, 2023, April 5).

3.2 Differentiating Normal Aging and Dementia

Many people, including healthcare providers, do not understand the difference between normal, age-related changes and dementia—especially when cognitive changes are small. Someone with age-related changes can easily do all activities of daily living—they can prepare their own meals, drive safely, go shopping, and use a computer. They understand when they are in danger and have good judgment. Even though they might not think or move as fast as when they were young, their thinking is normal—they do not have dementia.

Dementia, by contrast cause a progressive impairment of memory, emotional control, judgement, and other cognitive functions. For a person with dementia, these changes eventually become severe enough to affect their ability to live independently.

3.3 Mild Cognitive Impairment

Mild Cognitive Impairment (MCI) is a stage of cognitive function between the expected decline seen in healthy aging and that seen in dementia. Individuals with MCI have a more pronounced cognitive impairment than what would be expected for their age and education, but do not meet functional criteria for dementia (Moreira et al., 2019).

Mild cognitive impairment can be accompanied by changes in behavior and personality. There are no tests for mild cognitive impairment; differentiating normal aging and mild cognitive impairment relies on screening, assessment, and client history.

Although mild cognitive impairment has been described as a transitional stage between normal cognitive aging and dementia, particularly Alzheimer's disease, individuals diagnosed with MCI do not always progress to Alzheimer's disease and may even revert to normal.

3.4 Cognitive Reserve and Cognitive Health

Cognitive reserve is a concept that suggests that individuals differ in their degree of resilience against age-related brain changes. It means the brain is able to operate effectively even when some of its function is disrupted. It also refers to the amount of damage that the brain can sustain before changes are evident.

People vary in cognitive reserve because of differences in genetics, education, nutrition, occupation, lifestyle, leisure activities, or other life experiences. For one individual, depending on these factors, the balance may tip in favor of a disease process that will ultimately lead to dementia. For another person, with a different reserve and a different mix of genetics, environment, and life experiences, the balance may result in no apparent decline in cognitive function with age.

There is evidence that reserve can be built up through a combination of life experiences, physical exercise, education, occupation, and participation in social and cognitively stimulating activities. These experiences may create a buffer against cognitive decline by enhancing neural connectivity and cognitive ability. This might protect an individual against the effects of disease pathology, compensate for damage, and recruit alternative neural pathways when required (Evans et al., 2018).

4. Treatable and Irreversible Dementias

Some causes of cognitive decline are treatable or even reversible while others, such as Alzheimer's disease, are progressive and irreversible. Once brain cells are damaged and lost, no matter what the cause, they cannot be repaired.

4.1 How Dementia Affects Cognition

Dementia affects cognition because of loss of cells and connections in the parts of the brain that control thinking, memory, judgment, learning, language comprehension, attitudes, beliefs, safety awareness, morals, and planning ability. Dementia also affects motor and sensory functions such as balance, spatial awareness, vision, pain processing, and the ability to modulate (control) sensory input.

4.2 Potentially Treatable Conditions

There are many conditions that can cause dementia-like symptoms. Some of these conditions, such as infections, constipation, reactions to or interactions between medications, and abuse of alcohol, prescription medications, or recreational drugs are reversible with appropriate treatment.

Other potentially treatable conditions are more complicated and usually require additional evaluation and testing. This includes head injuries and subdural hematomas from falls and nutritional or fluid deficiencies. Physiologic conditions that are potentially treatable include:

- metabolic and endocrine abnormalities
- poisoning from exposure to lead, heavy metals, or other poisonous substances
- brain tumors, space-occupying lesions, and hydrocephalus
- hypoxia or anoxia (not enough oxygen)
- autoimmune syndromes
- epilepsy
- sleep apnea (NINDS, 2023, December 19)

Delirium and depression—potentially treatable conditions that can also affect cognition—are particularly prevalent and often overlooked or misunderstood in older adults. Both conditions can be superimposed on dementia, particularly in older hospitalized patients.

4.2.1 Delirium

Delirium has an acute onset and a fluctuating course. For patients with behavioral and psychological symptoms of dementia, delirium can cause an abrupt worsening of their usual symptoms. History is the key to differentiating these symptoms from delirium (Cloak and Khalili, 2022).

The most common causes of delirium are related to medication side effects, hypo or hyperglycemia (too much or too little blood sugar), fecal impactions, urinary retention, electrolyte disorders and dehydration, infection, stress, or metabolic changes. An unfamiliar environment, injury, or severe pain can also cause an episode of delirium.

Inattention is the most frequent clinical symptom in a delirium episode. Other symptoms include difficulty with orientation and memory, hallucinations, changes in language and thought, and visuospatial difficulties.

The prevalence of delirium increases with age, and nearly 50% of patients over the age of 70 experience episodes of delirium during hospitalization. Delirium is under-diagnosed in almost two-thirds of cases or is misdiagnosed as depression or dementia. Early diagnosis of delirium can lead to rapid improvement. However, diagnosis is often delayed, and problems remain with recognition and documentation of delirium by healthcare providers (Hope et al., 2014).

4.2.2 Depression

Clinically, the most common diagnosis applied is *major depressive disorder*. This diagnosis includes at least one of two major symptoms—dysphoria* or anhedonia**. It can also include other symptoms such as sleep disturbances, feelings of guilt or worthlessness, changes in appetite, fatigue or reduced energy, agitation, suicidal ideation, and trouble concentrating or making decisions (Fisher et al., 2024).

***Dysphoria**: feelings of discomfort, psychological distress, profound unease, or generalized dissatisfaction with life.

****Anhedonia**: loss of interest in activities, an inability to experience pleasure.

Depression is a common mood disorders in Alzheimer's disease. Almost one-third of long-term care residents have depressive symptoms, while an estimated 10% meet criteria for a diagnosis of major depressive disorder. In the long-term care population, depression is both common and under-treated (Jordan et al., 2014).

Diagnosing depression in patients with dementia can be difficult. Denial and cognitive impairment can compromise self-report of depressive symptoms. And, as a person's dementia progresses, the presentation of depression may change, with non-verbal behaviors such as demanding behavior and clinging being more apparent than cognitive features (Dudas et al., 2018).

Depression in older adults has been linked to dementia, although it is unclear whether it is a risk factor for dementia, or a prodromal symptom*. In some cases, depression and dementia may be caused by common risk factors such as cerebrovascular disease. In others, they may not have a connection at all and simply occur together by chance. Among depressed older adults, it is difficult to assess who may be at increased risk for developing dementia and, by extension, who would benefit from specific interventions to decrease this risk (Wiels et al., 2020).

***Prodromal symptom**: a term used to describe a group of symptoms that may precede the onset of a mental illness. It is not a diagnosis.

Depression, although frequently present in those with Alzheimer's disease, is much more persistent in dementia with Lewy bodies. Depressive symptoms in Alzheimer's disease and dementia with Lewy bodies are associated with a greater cognitive decline and, in Alzheimer's disease, significantly relate to lower survival rates over a three-year period (Vermeiren et al., 2015).

4.3 Early Detection and Referral

In the context of dementia, early detection and a timely diagnosis is defined as "access to accurate diagnosis at a time in the disease process when it can be of most benefit to people with dementia and families." In recent years, *timely* diagnosis has been emphasized as being more person-centered and respectful of individual rights than *early* diagnosis (Molvik et al., 2024).

Early detection provides an opportunity to identify causes, coordinate medical care, plan for the future, and address potential safety issues. Ideally, it connects families with interventions and identifies appropriate candidates for clinical trials of potentially disease-modifying therapies that are anticipated to benefit patients in early disease stages (Tsoy et al., 2021).

Early detection also provides opportunities to identify treatable or potentially reversible conditions. Unfortunately, cognitive impairment, including mild cognitive impairment and dementia, are frequently not detected in primary care, and diagnosis is delayed until moderate or advanced stages in 50% or more patients with greater delays among racial and ethnic minorities (Bernstein Sideman et al., 2022).

Being diagnosed with dementia significantly impacts a person's life and can lead to worry and anxiety, post-traumatic stress, and even suicidal ideation. Nevertheless, some studies have suggested that being diagnosed with dementia can also provide psychological relief and promote healthy behaviors (Molvik et al., 2024).

There are racial/ethnic disparities in dementia incidence and prevalence, as well as social and medical risk factors for dementia. Undiagnosed dementia may be more common among racially/ethnically diverse individuals, particularly Black and Hispanic and Latino Americans compared with White Americans. In addition, beyond race/ethnicity, social determinants of health, comorbid medical conditions, and variability in health behavior patterns are likely associated with these inequalities (Tsoy et al., 2021).

5. Mental Status Tests

Mental status testing can be an important tool for detecting cognitive decline. Unfortunately, mental status testing is not done on a regular basis in primary care. The vast majority of people with cognitive impairment are detected only after they or their family members report cognitive or memory concerns to healthcare providers. When most cognitive impairment is detected, patients are further along the trajectory of cognitive decline and likely outside the optimal window for pharmacological or nonpharmacological (lifestyle and psychosocial) interventions (Jannati et al., 2024).

5.1 Neurocognitive Screening

Neurocognitive screening is used to detect cognitive changes before an individual would normally seek medical care. Screening ideally identifies very early signs of dementia and allows a clinician to make a referral for a more thorough cognitive evaluation.

The Affordable Care Act directs clinicians to assess their Medicare patients for possible cognitive impairment during their Annual Wellness Visit. This is intended to address the fact that as many, if not most of patients with dementia are unrecognized in the primary care setting (USPSTF, 2020, February 25).

5.2 Screening Tools

Screening tests are not intended to **diagnose** cognitive impairment or dementia; a positive screening test result should lead to additional testing. The most widely studied tool for neurocognitive screening is the *Mini Mental State Examination*. The Mini Mental State Exam (MMSE) is a 30-point instrument with 11 items that has been studied in various populations. Although sensitivity* and specificity** vary depending on the patient's age and education level, a general cut point of 23/24 or 24/25 is appropriate for most primary care populations (USPSTF, 2020, February 25).

***Sensitivity**: The sensitivity of a clinical test refers to the ability of the test to correctly identify those patients *with* the disease.

****Specificity**: The specificity of a clinical test refers to the ability of the test to correctly identify those patients *without* the disease.

Another widely used screening tool is the *Montreal Cognitive Assessment*. It is a 30-point test that assesses short term memory recall, visuospatial abilities, and several aspects of executive function. It takes about 10 minutes to complete with a score of 26 or above considered normal.

The *Saint Louis University Mental Status* exam is an assessment tool for mild cognitive impairment and dementia. It assesses 11 cognitive domains. A recent systematic review of this tool indicated that it appears to have adequate validity, sensitivity, and specificity in detecting cognitive impairment. Shortcomings included a lack of sufficient normative data, information on test-reliability, and limited application of other measures such as imaging studies and biomarkers (Spencer et al., 2022).

The *Mini-Cog* is a neuropsychological test that has been shown to be effective in detecting patients with dementia. Although its accuracy varies by region and method of interpretation, it has been shown to yield high sensitivity and specificity for detecting cognitive impairment. The test, consisting of a clock drawing test and three-item recall test, takes only 3 minutes to administer, making it suitable for use in a primary care setting (Limpawattana and Manjavong, 2021).

Administration of the clock drawing test alone allows for the differentiation of mild cognitive impairment and normal cognition with good sensitivity and excellent specificity. Additionally, patients with mild cognitive impairment often have episodic memory deficit, which means that a recall test on its own may also be useful in screening for mild cognitive impairment (Limpawattana and Manjavong, 2021).

The *General Practitioner Assessment of Cognition* (GPCOG) is a screening tool used to assess cognitive impairment and dementia in primary care. It is simple, brief, efficient, reliable, and valid and can meet the needs of general practitioners (Patil et al., 2020).

It has two sections a patient examination (GPCOG-patient, part 1) with a maximum score of 9, and a caregiver interview (part 2) with a maximum score of 6. Part 1 score of 9 indicates no cognitive impairment, someone scoring 4 points or less is very likely to have cognitive impairment (Patil et al., 2020).

The advantages of the GPCOG over current brief screening instruments are that it combines patient and informant data, is quick to administer, has been validated in a primary care setting, and has sound psychometric properties. Psychometrically, it performed better as a screening instrument than the AMT and slightly (although non significantly) better than the MMSE but was quicker and likely to be more acceptable to GPs and patients (Patil et al., 2020).

Although the GPCOG has been translated into several languages, there isn't enough research on how different cultures and languages might affect the test's results. This test requires the physical ability to write or draw. If the person cannot hold a pen or pencil, they will be unable to complete the clock drawing portion of the test (Heerema, 2022).

Other screening instruments include the Memory Impairment Screen, Abbreviated Mental Test, Short Portable Mental Status Questionnaire, Free and Cued Selective Reminding Test, 7-Minute Screen, Telephone Interview for Cognitive Status, and Informant Questionnaire on Cognitive Decline in the Elderly (USPSTF, 2020, February 25).

5.3 Limitations of Neurocognitive Screens

Most cognitive screening tools emphasize the detection of memory dysfunction but neglect other domains such as visuospatial or executive functions. However, an estimated 40-50% of dementias are caused by non-AD diseases, most commonly Lewy body disease, frontal-temporal dementia, and vascular disease, which frequently present with non-memory symptoms. Even AD can present with dysfunction in visuospatial, executive, or language rather than memory (Possin et al., 2018).

Despite a large body of evidence examining cognitive screening instruments, most instruments have been tested in only a few well-designed studies (USPSTF, 2020, February 25). Cognitive screens typically rely on a single, global cut-off score, which may fail to detect non-memory deficiencies. Few screening tools provide a valid profile of spared and impaired cognitive domains that could be used to assist with differential diagnosis. Brief screens rarely evaluate functional decline and neurobehavioral changes (Possin et al., 2018).

Mini Mental State Examination and the *Montreal Cognitive Assessment* tests have limitations, namely, they are not very sensitive to mild impairment, particularly in conditions other than Alzheimer's disease. The MMSE also shows education, language, and cultural biases (Yang et al., 2016) and both tools may be impractical as screening tools because they take at least 10 minutes to complete.

A Cochrane review of the effectiveness of the *Mini-Cog* found that it had a *sensitivity* of 76%, indicating that it failed to detect up to 24% of individuals who have dementia (e.g. false negatives). The *specificity* of the Mini-Cog was 73% indicating that up to 27% of individuals may be incorrectly identified as having dementia when these individuals do not actually have an underlying dementia (e.g. false positives). The review concluded that at the present time there is not enough evidence to support the routine use of the Mini-Cog as a screening test for dementia in primary care and additional studies are required before concluding that the Mini-Cog is useful in this setting (Seitz et al., 2021).

Language barriers and cultural differences are major barriers to successful screening. Limitations include:

- How the questions are asked.
- The validity of questions.
- How much time the client is given to answer.
- Comfort with the person giving the test.
- Your knowledge of a person's baseline.

Developing an effective dementia screening tool is challenging because the assessment of cognitive deficits is time-consuming and requires specialized knowledge and strong familiarity with neurologic diseases; inaccurate diagnoses are common. Because of these obstacles, the *U.S. Preventive Services Task Force* (USPSTF) has recommended that, for cognitive impairment in older adults, current evidence is insufficient to assess the balance of benefits and harms of screening for cognitive impairment (USPSTF, 2020, February 25).

5.4 Alerting Healthcare Personnel to Changes in a Client's Cognition

If you are working with a client and notice or suspect a change in mental status, try to determine whether your client is operating at his or her normal level or whether something has changed. If you notice something different in the person's behavior or demeanor—especially if the change is sudden—report your concerns to the nursing staff immediately. They will assess the client and decide on the next course of action.

6. How Brain Deterioration Affects Communication

Difficulties related to communication are among the earliest symptoms of dementia and tend to worsen as the disease progresses. Difficulty with word finding, replacing a word with an unrelated word, or not finding a word at all often occurs in the early stage. As the disease progresses, forgetting names of family members and friends, confusion about family relationships, and loss of the ability to recognize family members is not uncommon.

Losing the ability to communicate is embarrassing, frustrating, and stigmatizing. Needs go unmet and social interactions gradually become more stressful and tiring. Being unable to communicate needs and preferences can lead to conflicts and depression and make communication more difficult for caregivers.

In Alzheimer's, damage to the hippocampus affects the formation of new, short-term memories. This means a person does not remember the "what, where, and when" of recent events—what they ate yesterday, where they went 2 days ago, and the date of their next doctor's appointment.



Location of the hippocampus. Source: Image courtesy of the National Institute on Aging/National Institutes of Health. Public domain.

In **frontal-temporal dementia**, damage begins in the front part of the brain. Because of the location, memory is (initially) less affected than in Alzheimer's disease. This is because the front part of the brain is responsible for judgment, planning, moral reasoning, logical thinking, and social behavior. As a result, a person may become more impulsive, make sexual comments or socially inappropriate remarks, and gradually lose the ability to make decisions.

In **vascular dementia**, damage is caused by impaired blood flow to the brain. Cognitive changes can be widespread and not necessarily associated with a specific part of the brain. There may be a slowness of thought, problems with attention and concentration, and difficulties with language. Complex, fast-paced conversations or quick changes in topic may be difficult to follow.

In **Lewy body dementia**, abnormal clumps of alpha-synuclein (Lewy bodies) form throughout the cerebral cortex, brainstem, and midbrain. The location influences the symptoms, which vary from person to person. A person with Lewy Body dementia can experience paranoia, delusions, and hallucinations (usually visual), which are very real for the person experiencing them.

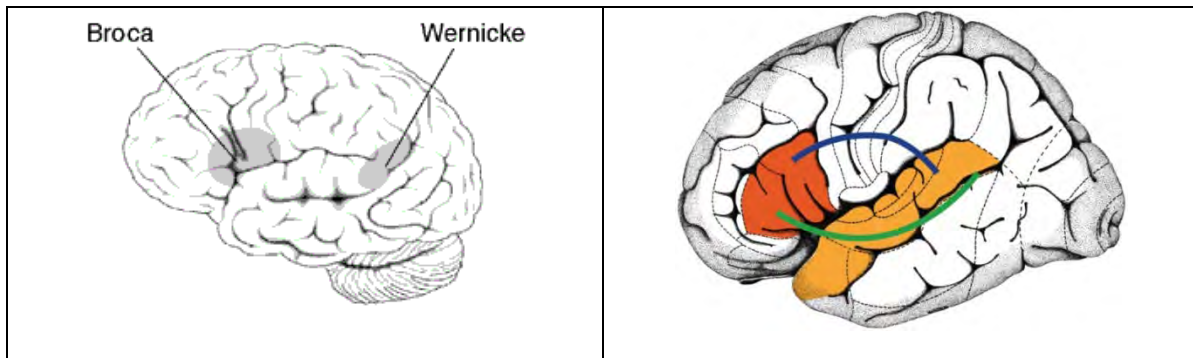
6.1 Areas of Brain Associated with Communication

Certain parts of the brain are responsible for speech and language, mainly located in the left side of the brain. These brain regions and their connections form a network that provides the hardware for language in the brain. Without this network, we would not be able to talk to or understand others (Brauer, 2014).

The loss or decline of language and communication skills is called *aphasia*. This is an acquired language disorder that affects a person's ability to comprehend and produce language. People with aphasia have trouble expressing themselves, finding the right words, understanding the words they are hearing—and also, have difficulty with reading and writing. Aphasia is a common symptom in a person with a stroke that affects the left side of the brain.

Wernicke's aphasia is caused by damage to the left **temporal** lobe. It is sometimes referred to as *fluent aphasia* because a person can speak but the words carry no meaning. Broca's aphasia is caused by damage to the left **frontal** lobe. It is sometimes referred to as *non-fluent aphasia* because a person's speech is short and choppy. Global aphasia is a combination of Wernicke's and Broca's aphasia in which a person is unable to understand the spoken word or communicate with speech.

Speech and Language Areas of the Brain



Left: Areas of the left side of the brain associated with processing speech and language. Source: Wikimedia Commons. Used with permission. Right: Broca's and Wernicke's brain regions are highlighted in red and orange. The blue and green lines illustrate connections that link the two regions with one another and form a network of language areas. *Frontiers for Young Minds*. Reprinted with permission.

Communication and emotions are related. An area of the brain located close to the hippocampus called the *amygdala* is involved with emotions, particularly emotional behavior, learning, and motivation. Damage to this part of the brain can affect a person's ability to read facial emotions as well as their ability to control their own emotions. Damage to the amygdala can affect a person's ability to understand when another person is frustrated, angry, or even happy. This likely affects a person's ability to follow non-verbal facial cues.

6.2 How Dementia Affects Communication

Dementia affects our ability to communicate, as well as our ability to comprehend what others are trying to communicate. A person with dementia may (Alzheimer's Society of Canada, 2024):

- Create new words for ones that are forgotten.
- Repeat a word or phrase (perseveration).
- Have difficulty organizing words into logical sentences.
- Curse or use other offensive language.
- Revert to their original language.
- Talk less than usual.

6.3 Managing Communication Challenges

Caregivers may not understand that, for a person with dementia, difficulties with communication increase a person's confusion and stress. For caregivers and healthcare providers, the ability to communicate effectively and successfully with people impaired by cognitive decline is a learned skill. Techniques that **improve communication** and reduce agitation, confusion, fear, or anxiety include (Zeman, 2015):

- Approaching from the front or side and sitting or kneeling at eye level.
- Assessing your client's body language.
- Monitoring your own body language, facial expression, and tone of voice.
- Introducing yourself each time and explaining what you are doing and why.
- Making sure the person with dementia can clearly see you.
- Reducing distractions.
- Speaking slowly and clearly using short sentences.
- Allowing extra time for a response.

Communication habits to be **avoided** include:

- Standing over or speaking "down" to a person
- Using words such as: "she's just like a baby" or "he's the same as my 2-year-old"
- Talking in complex or lengthy sentences
- Speaking quickly
- Using an impatient voice
- Failing to allow the person with dementia enough time to process what you are trying to communicate
- Rushing through any activity

Hallie Is Scared

Introduction: As many as two-thirds of stroke patients experience cognitive impairment or cognitive decline following a stroke; approximately one-third go on to develop dementia. This may be inadvertently overlooked because, following a stroke, the emphasis is often on recovery of functional abilities such as walking and activities of daily living.

Client Information: Hallie is a 90-year-old woman who moved from Phoenix to live with her daughter in Miami, Florida following a brainstem stroke. She is struggling with mobility and also has difficulty expressing her needs. She refuses to participate in any activities.

Prior to suffering the stroke, she lived independently in Mesa, Arizona with her alcoholic son. In the hospital following the stroke, she was given a feeding tube due to swallowing problems. When she arrived in Florida, she was able to walk a few steps with a walker but needed a great deal of assistance with transfers, toileting, and bathing. For more than a year after moving she was unable to name the town or even what state she was living in. She was, however, able to read and write and her vision was good enough to read the captions on the TV.

Now, almost 2 years after her stroke, Hallie is off her feeding tube, eating independently and enthusiastically, coloring intricate patterns in a coloring book. She is transferring and bathing with much less assistance. She is still unable to walk more than a few steps and has difficulty with memory and recall.

Timeline: Because of her improvement, Hallie's daughter feels her mother might enjoy the local specialized adult daycare program. The first time they attend, Hallie was withdrawn and refused to participate in any activities—even drawing. The activities director, Celena, tried to engage Hallie in a conversation but she just smiled and asked where her mother is. Celena asked Hallie to tell her about her mother, but she didn't (or couldn't) answer.

When Hallie's daughter came to pick up her mom, the daycare center administrator reported that Hallie didn't participate in any activities and wouldn't budge from her recliner—even to use the bathroom. The activities director feels that, with some gentle encouragement, Hallie will begin to participate in activities. She reported her observations and concerns to the facility administrator.

Intervention: The staff discussed Hallie's situation after the center closed that afternoon. The administrator asked Jeni, a registered nurse, to assess Hallie in the morning—to spend some time with her and try to draw her out. Hallie's daughter is also a nurse, and the administrator thinks that Hallie may be comfortable talking to a nurse. When Hallie arrives the next day, Jeni, using her dementia-specific training, approaches Hallie from the front, introduces herself, sits beside her, and offers her hand, which Hallie takes. She asks about Hallie's daughter and says that she too is a nurse. She tries to engage Hallie in a general conversation, but without success.

Hallie is very quiet and seems confused. She asks Jeni where she is and again asks for her mother. Jeni makes sure Hallie is comfortable, quietly assesses her hearing and vision, and makes sure Hallie is able to understand English. Finally, after some quiet back and forth, Hallie admits that she's scared. Jeni asks her why and she says she is scared because she can't remember things. This provides staff with the information they need to design activities that will help Hallie feel more comfortable at day care.

Discussion: It is normal for a person to feel uncomfortable in a new social situation. This is especially true for a person with memory problems. Hallie is new to adult daycare, in a new living situation, and new to Florida. The transition has been difficult for her. The staff acknowledge Hallie's fears and make sure to support and educate Hallie's family caregivers.

Hallie has many positive things going for her, considering the severity of her stroke. Her vision is good, she has a good sense of humor, she enjoys drawing, and she eats just about anything you put in front of her. Staff members learn that Hallie isn't fond of physical activity but is able to concentrate on her intricate drawings for long periods of time. She also likes TV. They design a program of activities that focuses on art, drawing, and painting. They encourage her to participate in the exercise class, which she does reluctantly. Eventually, the activities director realizes that Hallie does better with one-on-one exercise.

Client Perspective: Hallie tells her daughter that she doesn't want to go to "that place" although she isn't able to articulate what she means. Her daughter encourages Hallie to go again, telling her that they are having hamburgers for lunch. Hallie says she is OK with that and agrees to attend adult daycare again.

7. How Brain Deterioration Influences Behavior

Changes in behavior occur in the vast majority of people with dementia. These changes are referred to as *behavioral and psychological symptoms of dementia* (BPSD) or *neuropsychiatric symptoms of dementia* (NSP). More than 90% of people affected with dementia will eventually experience some type of challenging behavior associated with their dementia (Wang et al., 2020).

In some patients, behavioral and psychological symptoms appear before memory deficits develop. The severity of the symptoms can increase with disease progression, affecting the quality of life of both people with dementia and their caregivers. Though memory deficits are the best studied aspects of Alzheimer's, it is behavioral and psychological symptoms that are often the greatest source of burden for everyone involved (Mao et al., 2020).

Behavioral changes associated with dementia range from mild to severe; symptoms can be constant but usually come and go. They are associated with significant client and caregiver distress, increased rates of institutionalization, and increased mortality (Mao et al., 2020).

Among the many behavioral and psychological symptoms associated with Alzheimer's disease and other types of dementia, depression*, apathy, agitation, aggression, delusions, and hallucinations are some of the most common. These behavioral changes can lead to wandering, rummaging, hoarding, obsessive-compulsive behaviors, and sleep disturbances.

Common causes of behavioral changes include:

- Brain changes due to dementia.
- Unmet physical needs such as pain, discomfort, or fatigue.
- Boredom, lack of socialization, lack of meaningful activities.
- Frustration due to inability to understand, figure out, or complete a task.
- Cold, heat, noise, uncomfortable chairs, too much or too little light.

*See Module 4: Treatable and Irreversible Dementias for more on depression.

Video: Understanding Needs Driven Behaviors (4:49)

<https://www.youtube.com/watch?v=GSPrCUVroGg>

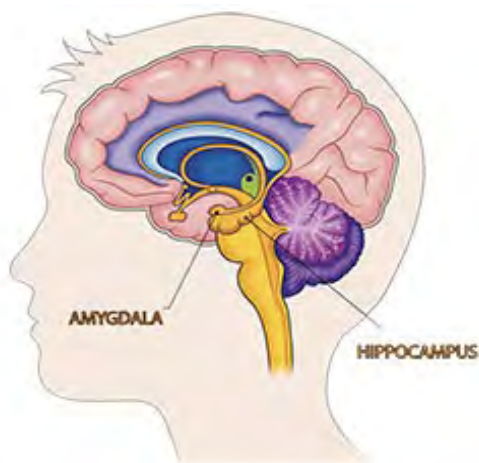
Source: Health Services Advisory Group, Inc., 2014.

7.1 Areas of the Brain Related to Behavioral Control

Structural and neurochemical changes in the brain affect a person's ability to process and act on information. These changes can affect a person's behavioral control, self-awareness, and their awareness of other people's emotions. A person's ability to interpret other people's emotional cues and social behaviors can also be affected by cognitive changes (UCSF, 2023)

In Alzheimer's disease, behavioral symptoms may be mainly due to frontal lobe abnormalities. Apathy has also been associated with frontal structures, while delusions have been correlated with frontal, parietal, and temporal structures. Depressive symptoms are thought to be due to damage to deeper brain structures, while agitation has been associated with temporal and frontal structures (Rouch et al., 2014).

Behavioral changes such as anxiety, agitation, depression, fear, and anger have been associated with damage to the amygdala, which is responsible for emotional control and is anatomically linked to the hippocampus.



National Institutes of Health, Source: iStock/jambojam. Public domain.

7.2 Challenging Behaviors Associated with Brain Deterioration

Changes to the brain often, although not always, can lead to a variety of challenging behaviors. Dementia lowers a person's ability to handle excessive noise, temperature changes, and high levels of commotion often found in public areas. Some of the most common challenging behaviors in people with dementia are apathy, agitation, and aggression, and depending on the type of dementia, delusions and hallucinations. Physical behaviors such as wandering, obsessions, and calling out are often related to a person's inability to communicate their needs.

7.2.1 Apathy

Apathy is a lack of interest or emotion, loss of motivation, indifference, and a blunting of emotions. It is one of the most common neuropsychiatric features of dementia, affecting 50–70% of people with the condition (Baber et al., 2021).

The presence of apathy in people with Alzheimer's disease is associated with increased functional impairment, a greater likelihood of rapid functional decline, and a lower self-reported quality of life. It is also associated with poorer performance in basic and instrumental activities of daily living, more rapid disease progression, and increased mortality in people with Alzheimer's disease (Dolphin et al., 2023).

Apathy is under-recognized, under-diagnosed, and poorly managed. It can be frustrating for caregivers, who often find it frustrating when it appears that the person with dementia is capable of doing a task but simply does not bother or will only do so with strong encouragement (Baber et al., 2021).

Apathy and depression often occur together. In Alzheimer's disease, apathy is associated with loss of nerve cells and disconnections within specific parts of the brain, including the amygdala. This disconnection within brain circuits suggests that impaired transmission of a key neurotransmitter called acetylcholine* is involved in apathy pathophysiology (Rea et al., 2014).

***Acetylcholine:** a neurotransmitter found throughout the body responsible for the contraction of muscles and plays a key role in memory, learning, cognition, attention, arousal, motivation. Depletion of this neurotransmitter is associated with Alzheimer's disease.

7.2.2 Agitation and Aggression

Agitation and aggression are inappropriate verbal or motor behaviors that occur in more than half of people who have dementia. These behaviors can be caused by pain, physical illness, depression, disorientation, separation from family or other unmet needs (NSW Health, 2022).

One example of an agitated behavior is a "catastrophic reaction". These are instances when a person suddenly becomes tearful, angry, and abusive. These are usually brief episodes caused by frustration over reduced ability to do simple tasks such as getting dressed, misunderstanding what someone has said or misinterpreting environmental cues. A non-aggressive behavioral response to the same situation might be to stop talking and withdrawal (NSW Health, 2022).

Aggression involves physically or verbally threatening behaviors directed at people, objects, or self. Aggression can include verbal insults, shouting, screaming, obscene language, hitting, punching, kicking, pushing and throwing objects, and sexual aggression (Burns et al., 2012, latest available).

Physiologically, aggression may be related to a decrease in the activity of certain neurotransmitters in the brain, especially serotonin* or acetylcholine. Frontal lobe dysfunction, which occurs in frontal-temporal dementia, may be a factor. Aggression may also be related to underlying depression or psychotic symptoms (Burns et al., 2012).

***Serotonin:** a neurotransmitter found throughout the body, that regulates mood, appetite, digestion, sleep, memory, and sexual desire. There is thought to be a link between serotonin and depression.

Agitated and aggressive behaviors can also be an attempt to communicate, and can be related to feelings of helplessness, loss of control, discomfort, pain, or fear. Agitation and aggression can be a response to a violation of personal space or a perceived threat and often occur during personal care tasks involving close caregiver-resident contact (Burns et al., 2012).

7.2.3 Delusions and Hallucinations (Psychosis)

Psychosis is a disturbance in the perception or appreciation of objective reality. This can include delusions and hallucinations.

Delusions are false ideas or beliefs or a misinterpretation of a situation. Delusions in people with dementia tend to reflect underlying memory loss or perceptual changes, such as the conviction that other people are stealing money or personal items, that their spouse or caregiver is an imposter, or that their spouse is being unfaithful (NSW Health, 2022).

Hallucinations are sensory events in which a person hears, tastes, smells, sees, or feels something that is not there. Visual hallucinations may be vivid in dementia with Lewy bodies, such as seeing brightly colored crocodiles in the house (NSW Health, 2022).

Auditory hallucinations (“voices”) are less common—their presence may indicate an underlying psychiatric disorder. More commonly, auditory illusions occur when the person misinterprets sounds. For example, discussion amongst the care team may be misinterpreted as plotting to kill people. Hallucinations may also be a side effect of prescribed medications (NSW Health, 2022).

Visual hallucinations have been attributed to decreased blood flow in three regions of the brain: (1) a region responsible for the processing of visual information, (2) an area involved with error detection, and (3) an area involved with inhibitory control of visual information (Heitz et al., 2015).

Delusions and hallucinations have also been associated with changes in the amount and availability of certain neurotransmitters within the brain. Excess dopamine as well as an increase in the number of dopamine receptors has been seen in patients with psychosis compared to people without psychosis. Because dopamine is involved with the regulation of many body functions, too much dopamine can cause hyperactivity, fear, and rage.

Urinary tract infections, poor lighting, sensory overload, and a reaction to a medication can also contribute delusions and hallucinations. In a person with **new** onset of visual hallucinations, the number one cause is medication side effects. For this reason, a person experiencing visual hallucinations should have all medications carefully reviewed.

7.2.4 Wandering or “Walking About”

Wandering for person with dementia is aimless, repetitive, hyperactive, and excessive movement. It can include wandering outside and becoming lost in the community. Wandering is associated with terms such as “elopement” and “getting lost”.

The desire to move about is often related to boredom, pain, discomfort, or disorientation. Wandering is more common in people with Alzheimer’s disease than other types of dementia. This tendency may be related to memories and habits from the past, buried deep in long-term memory.

Healthcare workers often see wandering as a problem and disruptive to their care routines. For safety and convenience, they may try to control or prevent the behavior. However, preventing residents from wandering could mean their losing the associated benefits of walking, including improved circulation, decreased pain and stiffness, improved sleep, and decreased risk of pressure sores and contractures (Adekoya and Guse, 2019).

Physical and pharmacological restraints are often used to prevent a person from wandering. Apart from the known harmful effects of restraints, such as pressure sores, anxiety, physical violence, falls, and high morbidity and mortality rates, the intervention is also ineffective. Nonpharmacological interventions are a safer and more effective option and include the use of electronic tagging and tracking devices, behavioral approaches, exercise, music therapy, aromatherapy, camouflaging doorknobs and exits, using strips of tape in front of exit doors, locked units, and environmental modifications (Adekoya and Guse, 2019).

A person's pre-dementia lifestyle may be a factor in whether a person is likely to wander. People who were physically active, had an interest in music, were extroverted and social, and people who dealt with stress by engaging in motor activities are more likely to wander. Learning about a person's earlier life allows caregivers to understand individual behaviors and consider effective interventions that address wandering.

For older adults with dementia who spend time in an organized setting such as adult daycare, the management of wandering should, at a minimum include (Silverstein & Flaherty, 2018, 2023):

- Identifying the risk for wandering.
- Providing appropriate staffing and supervision.
- Reducing environmental triggers for wandering.
- Using individualized nursing interventions to address the causes of wandering behavior.

7.2.5 Rummaging and Hoarding

It is unclear to what degree obsessive-compulsive behaviors such as rummaging and hoarding are related to brain deterioration. Memory loss, poor judgment, boredom, and confusion can contribute to the impulse to rummage and hoard. Likewise, feelings of paranoia may create a need to protect possessions and rummaging may create a sense of safety and security.

In people with dementia, hoarding might be due to lack of control, a fear of losing money or possessions, the need to "save for a rainy day," or simply to have something to do. Hoarding is associated with insecurity and anger and may be an attempt to hold onto possessions and memories from the past. Confusion can lead to rummaging through another person's belongings, which can be particularly frustrating for neighboring residents.

7.2.6 Sleep Disturbances

Sleep disturbances are common in older adults and are of particular concern in people with dementia. Sleep disturbances probably contribute to the onset and severity of some behavioral problems, particularly anxiety, increased confusion, wandering, and sundowning.*

***Sundowning:** an inexact and overused term used to describe increased confusion and restlessness in the late afternoon and early evening, possibly due to damage to the part of the brain that regulates sleep patterns.

A least one-third of people with dementia have difficulty sleeping and more than two-thirds of unpaid caregivers report sleep disturbances themselves. The precipitating factor for institutionalization of those with dementia is often a disturbed sleep–wake (circadian) cycle that leads them to remain awake at night, causing stress and fatigue for their families and caregivers. This behavior continues in nursing home environments, where residents experiencing daytime agitation also tend to sleep poorly at night and nap during the day (Figueiro et al., 2020).

The symptoms of sleep disruption vary according to the type of dementia and can include the following features:

- difficulty getting to sleep, decreased total sleep time, and waking often
- increased early-morning awakenings
- decreased slow-wave and rapid-eye-movement (REM) sleep
- episodes of delirium or disorientation during sleep
- increased daytime napping and daytime sleepiness
- agitation, verbally disruptive behaviors, hallucinations
- nighttime wandering (Burns et al., 2012)

Medications that affect daytime alertness can lead to sleep disturbances. In particular, antidepressants, anti-anxiety medications (such as benzodiazepines), and non-benzodiazepines (hypnotics) can negatively affect sleep patterns. These types of medications are commonly prescribed despite a lack of evidence that they are safe to use in cognitively impaired older adults.

7.3 Inappropriate Behaviors

The ability to control and suppress inappropriate behaviors is an important social skill. The loss of this ability—disinhibition—causes a lack of restraint, disregard for social convention, impulsiveness, poor safety awareness, and an inability to stop strong responses, desires, or emotions.

Inappropriate behaviors are particularly common in a person with frontal-temporal dementia. Disinhibition, impulsivity, and socially inappropriate behaviors are common, together with perseveration*, loss of empathy, apathy, and cognitive inflexibility.

***Perseveration:** repetition of a word, phrase, or thought. The inability to shift from one idea to another.

Healthcare providers and caregivers may consider a behavior to be inappropriate when, in fact, the behavior is completely appropriate to the situation. For example, wandering is logical for a person who is bored. Loudly expressing frustration is appropriate when a client is cold or in pain. Whether a behavior is labelled “inappropriate” is often related to the amount of distress the behavior causes caregivers.

7.3.1 Anxiety and COVID-19

Extended lockdowns during the COVID-19 pandemic caused a great deal of stress and anxiety in both patients and caregivers due to isolation, restrictions on movement, loss of social contacts and relationships, and loneliness. Increased anxiety due to fear of contagion and grief or even mourning for the loss of family members or friends undermined mental health (Cagnin et al., 2020).

Early studies have indicated that the COVID-19 pandemic and related restrictions negatively impacted both people with dementia and their caregivers. Since the outbreak of COVID-19, worsening cognitive function, neuropsychiatric symptoms, and functional decline in people with dementia have been reported. In an Italian study, researchers found that more than half of people with dementia experienced worsened neuropsychiatric symptoms. The most commonly observed symptoms were increased agitation, apathy, and depression. Caregivers also reported increased levels of burden, anxiety, depression, and distress during the pandemic (Wei et al., 2022).

7.3.2 Employee Response to Inappropriate Behaviors

Direct care workers, as well as licensed staff, often lack dementia-specific training in how to address inappropriate behaviors in their clients with dementia. The most common behaviors you will encounter are anxiety, aggressive behaviors, and difficulties with communication.

To address these behaviors, begin by acknowledging that each person is worthy of respect—this is the basis for person-centered care. Also remember that there is often a reason for unwanted or inappropriate behavior—even if you don’t understand that reason. Use person-centered care as the basis for your interactions with all clients. This means treating clients and caregivers with dignity and respect.

When discussing difficult or unwanted behaviors with caregivers and fellow workers, ask them to describe what they are seeing instead of using generic terms such as “agitation” or “depression”. Consider the cause, frequency, timing, and trajectory of the disturbances, and any relationship to environmental changes or medication changes. There may be a relationship with changes in a person’s environment, or symptoms might worsen in the evenings, following family visits, or when providing personal care (Cloak and Khalili, 2022).

Callie Disrobes at a Birthday Party

Introduction: Older adults with dementia often exhibit unexpected, challenging behaviors that may be difficult for healthcare workers and family members to understand and manage. These behaviors can be caused by fear, hunger, environmental issues, boredom, side effects of medications, loud noises, lack of exercise, or pain, among other things. In this example, Callie is a 96-year-old woman with moderate to severe dementia who participates in activities at a specialized daycare facility 3 times a week. During a birthday party in the dining room, she suddenly (and quietly) began to remove her clothes.

Client Information: Callie is a client at a specialized daycare facility in south Florida. Although she can walk with assistance, she usually prefers to sit quietly by herself in the living room. She rarely interacts with other clients and prefers simply to watch visitors come and go. Callie often smiles but rarely speaks. However, on occasion she has a negative reaction to large crowds or noisy environments. Staff members understand this and try to remove her from these stressors.

Timeline: On a very warm day in August, a family member has arranged for a birthday party in the living room for her mother. All the residents were invited, including Callie, but the staff forgot to take Callie to a quiet part of the room. With everyone's attention on the celebration, no one noticed that Callie had begun removing her clothing. A staff member turned just in time to see her take off her slacks and underpants.

Intervention: All staff members had received dementia-specific training and knew that when something unexpected happens, the safety and dignity of the client must come first. Rather than immediately trying to get Callie dressed, which might have caused a negative reaction, the activities director simply asked everyone to leave the room for a few minutes. Jennifer, a nursing assistant, sat next to Callie and quietly asked if she could help Callie get dressed. Callie responded with a definite "no" and pulled off the rest of her clothing.

Another staff member brought a sheet to cover Callie but stood by the door to maintain privacy and see if her help was needed. Jennifer stayed by Callie's side and after a few minutes asked Callie if she could help. Callie's response this time was that she was cold. Promising her some birthday cake if she would get dressed, Jennifer was able to help Callie get dressed; after Callie had moved to a quiet area (with a piece of cake), the party goers were brought back into the room.

Discussion: Disinhibition, the loss of awareness of what is appropriate behavior, affects many individuals with dementia. If the staff had gotten upset and embarrassed her, Callie may well have reacted negatively. Temporarily removing the others from the room respected Callie's dignity and gave her a few moments to experience physical discomfort without her clothes. Once the room quieted down, she accepted assistance and a "reward" for getting dressed again.

Staff members discussed the incident in a meeting the next day and agreed that they had forgotten to keep an eye on Callie as the birthday party got underway. They were reminded that Callie is uncomfortable with noise and lots of activity but that overall, they did a good job diffusing the situation while taking Callie's dignity and safety into account.

Client Perspective: Callie was unable explain why she took off her clothes, but it was clear that she felt no embarrassment when she did it. In fact, when asked about the incident, she claimed she didn't remember a birthday party or even being in the dining room that day.

Source: *Kisses for Elizabeth: A Common Sense Approach to Alzheimer's and Dementia* (2012), by Stephanie Zeman, RN, MSN.

8. Interventions

Treatment interventions are usually based upon goals set by the family and the healthcare team. Interventions are designed to maximize function by addressing cognitive, mood, and behavioral impairments, as well as to treat any modifiable or reversible causes of impairment (USPSTF, 2020, February 25).

Non-pharmacologic approaches based on family caregiver interactions have the strongest evidence base for the successful management of challenging behaviors. This includes caregiver training and support, increasing the activity of the person with dementia, enhancing communication, reducing the complexity of the physical environment, and simplifying tasks for the person with dementia (Kales et al., 2015).

Caregiver training typically focuses on understanding behavioral responses to discomfort, unmet needs, or attempts to communicate. Creating soothing environments with optimal levels of stimulation and responding to patients in ways that de-escalate problematic behaviors are good management tactics. Distraction, giving patients clear instructions and simple choices, and trying not rewarding challenging behaviors is recommended (Cloak and Khalili, 2022).

The Alzheimer's Association offers both online educational modules and in-person training classes, which also provide caregivers with professional and peer support. For patients whose behavioral and psychological symptoms occur primarily during personal care, a randomized, multi-site study showed that training caregivers to use a protocol called *Bathing without a Battle* reduced agitation, bathing time, and antipsychotic use (Cloak and Khalili, 2022).

8.1 Person-Centered Care

The most widely used and recognized person-centered care approach has four key elements:

1. valuing people with dementia and those who care for them,
2. treating people as individuals,
3. looking at the world from the perspective of the person with dementia, and
4. a positive social environment (Røsvik and Rokstad, 2020).

Person-centered care has been shown to reduce agitation and improve quality of life in nursing home residents (Ballard et al, 2019). It is designed to be an alternative to or to complement pharmaceuticals in reducing challenging behaviors in individuals with dementia. It has been identified by the *Committee on Quality of Health Care* as one of the main areas that the healthcare system should address to improve the quality of healthcare, especially long-term care.

8.2 History, Needs, and Well-Being

Well-being is a much larger idea than either quality of life or customer satisfaction. It is based on a holistic understanding of human needs and capacities. Well-being is elusive, highly subjective, and the most valuable of all human possessions.”

Dr. Bill Thomas, *What Are Old People For? How Elders Will Save the World*

Considering a client’s personal history, preferences, and needs guides caregivers in the development of appropriate, meaningful activities and contributes to the well-being of people accepting care as well as their caregivers. A person’s past medical and social history helps us understand their current needs and behaviors. Person-centered care should be the basis of care for people with dementia.

Understanding a person’s history, especially people with behavioral symptoms of dementia, helps establish priorities related the nature and urgency of interventions. Knowing a person’s history helps caregivers understand symptoms and identify reversible exacerbating factors, including environmental issues, medications, discomfort, substance use, and pre-morbid psychiatric disorders. It also creates a baseline for measuring the effectiveness of treatment (Cloak and Al Khalili, 2022).

This understanding of a client’s needs and wants should be part of a systemic framework for an individual’s plan of care. A flexible plan of care and good case management reduces caregiver fatigue and anxiety, delays institutionalization, and encourages the use of community services (Jerez-Barranco et al., 2022).

The effectiveness of a plan of care is related to information, support and advice, coordination of the care provided and, to a lesser extent, practical help. Case management for patients with dementia should assist both the patient and the underlying system of support (Jerez-Barranco et al., 2022).

A good plan of care offers supportive care in all its stages for both formal and informal caregivers. Formal caregivers are meant to have in-depth knowledge and competencies to deal with dementia patients, while informal caregivers need to be recognized as indispensable players in dementia care. Both need to form and maintain collaborative relationships to guarantee high-quality care to patients.

Supporting caregivers could be considered a win-win solution—beneficial for caregivers, patients, and the healthcare systems. On the opposite side of the spectrum, the unregulated use—and sometimes abuse—of antipsychotic drugs is a no-win situation, detrimental for the health of the patient and a strain on the budget of healthcare systems. Non-pharmacological interventions (including psychosocial/psychological counselling as well as interpersonal and environmental management) should be attempted first, followed by the least harmful medication for the shortest time possible (Guzzon et al., 2023).

8.3 Aligning the Environment to Individual Needs

The built environment is the constructed, physical surroundings (interior and exterior) where a person eats, bathes, sleeps, and interacts socially. There is a profound and direct connection between the environment and how people feel and behave. Buildings thoughtfully designed for the care of people with dementia encourage community, maximize safety, support caregivers, cue specific behaviors and abilities, and redirect unwanted behaviors (Campernel & Brummett, nd).

Among the central principals in the design of dementia-friendly environments are safety and security, simplicity, good structure, and familiarity. Simple, structured, and familiar environments orient people and support wayfinding. Familiarity is related to predictability and continuity; it is also important for creating feelings of being “at home” in addition to supporting social relationships, identity, autonomy, and privacy (Førsund et al., 2018).

A *therapeutic environment* recognizes that people with dementia are influenced by their surroundings and do better with environments that are individualized, flexible, and designed to support differing functional levels and approaches to care. Homes or buildings thoughtfully designed for the care of people with dementia encourage community, maximize safety, support caregivers, cue specific behaviors and abilities, and redirect unwanted behaviors (Campernel & Brummett, nd).

Unfamiliar, chaotic, or disorganized environments have the opposite effect—they cause anxiety, disorientation, and contribute to behavioral problems. Specific design principles have been shown to reduce unwanted behaviors and enhance a sense of well-being in people with dementia:

- Providing public spaces and places for semi-private interactions.
- Keeping spaces clean and free of odors.
- Providing sunlight and ventilation and providing views to the outside.
- Getting rid of dark nooks and crannies.
- Creating spaces to cue specific behaviors (activity kitchen, art and music therapy area, bistro/bar, rummaging room, library, coffee shop/internet café, quiet room, living room).

The following video from the Social Care Institute for Excellence outlines the elements of a dementia-friendly environment in a care home. The principles apply to adult day care as well.

Video: The Dementia Environment in a Care Home (7:25)

<https://www.youtube.com/watch?v=hdbwvmhj5ZQ>

8.4 Evidence-Based Intervention Programs

Evidence-based programs that include input from team members and caregivers can reduce or even eliminate agitated or aggressive behaviors. Staff education is particularly important and can reduce behavioral outbursts and decrease restraint use.

“Multimodal” interventions use different tactics and activities based upon the needs of the person with dementia. This approach utilizes the skills and services of multiple professions, which ideally form a team to assess and implement approaches for each individual under their care.

8.4.1 Psychosocial and Environmental Interventions

Cognitive stimulation, music therapy, exercise, massage, therapeutic touch, acupressure, and tactile massage can be successful for treating challenging behaviors. Individual behavioral therapy, bright light therapy, aromatherapy, animal therapy, multisensory stimulation,* Montessori activities, and individualized, person-centered care are also recommended (Burns et al., 2012).

***Multisensory stimulation:** a controlled multisensory environment uses light, sound, scents, and music to initiate sensations. These have both relaxing and activating effects on the various parts of the brain related to sensory perception. The specific design directs and arranges the stimuli; it creates interest, brings back memories and guides relationships.

8.4.2 Cognitive Therapy

Cognitive stimulation, uses a variety of psychosocial and cognition-focused interventions, is widely used in dementia care. Cognitive stimulation program are typically provided in a group setting, where participants engage in various activities and discussions to improve their overall cognitive and social performance (Ryan et al., 2023).

Cognitive stimulation therapy (CST) was developed for people with mild to moderate dementia. It aims to enhance cognitive and social functioning using group therapy incorporating reality orientation, reminiscing, socializing, and actively stimulating participants. There is evidence that it can improve cognition in people with mild to moderate dementia over and above any medication effects (Binns et al., 2020).

8.4.3 Social Participation and Social Identity

People with dementia describe losses that affect their independence and ability to contribute to society. Loss of autonomy, control, and connection, memory problems, and the unpredictable progression of the disease lead to worry and anxiety. People report feeling stigmatized, no longer normal, embarrassed, or stupid. Dementia threatens their identity and sense of worth and changes their roles and the relationship to others (Bjørkløf et al, 2019).

Loss of social contact and feeling unable to participate in meaningful activities leads to loneliness, isolation, emptiness, and boredom. The decline in function and abilities has a significant impact on daily life and some express that life loses purpose, and that happiness is gone (Bjørkløf et al, 2019).



A man enjoying a familiar activity. Southeastern Veterans Center by padmva is licensed under CC BY-NC-ND 2.0.

Reduced social participation can lead to the loss of a person's social identity derived from a profession, job, or membership in a group. For example, an older person who identifies as a "care provider" may not want to attend a support group for fear that he or she would become a "care recipient" (Goll et al., 2015).

Some people try to uphold independent and youthful identities. They avoid groups for older people in case they become identified as "old" and thus stigmatized. They emphasize their self-sufficiency, distinguish themselves from "old" people whom they describe as dependent and decrepit, and avoid opportunities for support (Goll et al., 2015).

Talking therapies like CBT can enhance late-life social participation. However, since lonely and socially fearful older people are unlikely to engage in therapy without significant support, a more effective strategy might add CBT principles in pre-existing community groups. For example, organizations might challenge fears about attendance by emphasizing the friendliness of groups, implementing a "buddy" system for new members, normalizing social fears, and facilitating gradual steps towards participation (Goll et al., 2015).



Individual activities in adult day care setting. Source: ADEAR, 2014. Public domain.

8.4.4 The Benefits of Respite Care

Respite care is an often-overlooked intervention that benefits people with dementia as well as their caregivers. It provides caregivers with a break, reduces caregiver stress, and provides stimulation and social interaction for the person with dementia. When people with dementia attend a day care program, caregivers report decreased behavioral problems.

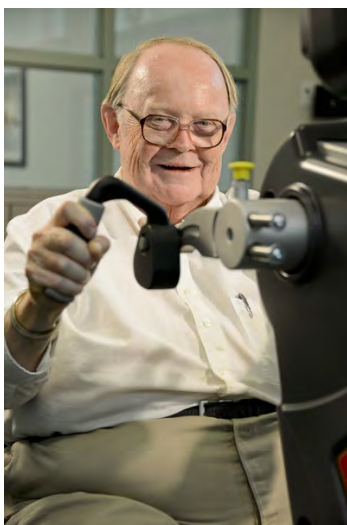
While some supportive services for family caregivers are available, many caregivers are not aware of them—especially individuals who are new to the family caregiving role. By the time they learn about these services they often find they cannot access them for a host of reasons such as cost, scheduling, distance from home or work, lack of availability of childcare or respite services, or services are not culturally competent (RAISE, 2022).

There has been a call for increased support for home and community-based services provided through Medicaid. Additionally, adding long-term services and benefits to Medicare for respite, adult day services, and home modifications is being discussed. Increasing funding for programs that provide community-based support for people with dementia and their family caregivers, programs for professional caregivers who support people with dementia, and the VA's Caregiver Support Program is crucial (RAISE, 2022).

Despite the benefits to the caregiver, daycare services are underutilized. Caregivers may feel guilty or may find it difficult to hand over responsibility for their loved one to another caregiver—even for a short time. Respite care may not be provided in a culturally competent way, which considers the needs and preferences of diverse cultural and ethnic groups. Add to this the cost of adult day services and the lack of available services, especially in rural and minority communities.

8.4.5 Exercise and Physical Activity

Physical activity may be a protective factor against cognitive decline. Several small studies have demonstrated significant benefits for Alzheimer's clients on cognition and also on quality of life and depression. Physical activity may also be beneficial in clients already suffering Alzheimer's dementia, improving clinical symptoms (Holthoff et al., 2015).



Man exercising on an upper extremity bike. Southeastern Veterans Center by padmva is licensed under CC BY-NC-ND 2.0.

Walking, resistance training, and seated exercises that focus on improving aerobic endurance, strength, balance, and flexibility have beneficial effects on physical function in individuals with cognitive impairment and dementia. Exercise improves a person's ability to perform basic activities of daily living such as eating, dressing, bathing, using the toilet, and transferring from bed to chair.

At the University of California at San Francisco, a group exercise program for individuals with mild-to-moderate dementia called *Preventing Loss of Independence through Exercise* (PLIÉ) has had some promising results. The seven guiding principles of the program are (Chao et al, 2021):

1. repetition with variation
2. progressive, functional movement
3. slow pace and step-by-step instruction
4. participant-centered goal orientation
5. body awareness, mindfulness, and breathing
6. social interaction
7. positive emotions

Consistent with the relationship-centered approach of integrative medicine, PLIÉ instructors are taught to incorporate these guiding principles in a flexible manner based on participants' in-the-moment needs and experiences, rather than having a scripted "package of care" (Chao et al, 2021).

The results suggest that PLIÉ may be associated with improvements in physical performance, cognitive function, and quality of life in individuals with mild to moderate dementia as well as reduced caregiver burden when compared with an existing program that involved daily chair-based exercises. The improvement observed with PLIÉ was substantially larger than what has been observed with currently approved dementia medications and affects a broader range of outcomes (Barnes et al., 2015).

8.4.6 Animal-Assisted Therapy

Animal-assisted therapy is an intervention in which animals meeting specific criteria become an integral part of the treatment process. Animal-assisted therapy improves a person's mental and physical health. It is relaxing, reduces the feeling of anxiety, contributes to the lowering of loneliness, and helps in the recall of memories. In the area of physical health, animal-assisted therapy helps to reduce blood pressure and improves cardiovascular health, decreases the number of medications, and reduces physical pain (Klimova et al., 2019a).

For individuals with dementia, animal-assisted therapy (Klimova et al., 2019a):

- Contributes to slightly higher physical activity; people can pet the animal, or if able, go for a walk.
- Relieves so-called *sundown syndrome*, which manifests itself in increased agitation, restlessness, disorientation, and aggressive behavior.
- Improves short-term memory and communication skills.
- Enhances eating habits.
- Reduces loneliness.



Pet therapy visit by K9 Playgroups is licensed under CC BY-NC-ND 2.0.

8.5 Intervening Using the Problem-Solving Approach

Behavioral therapy using antecedent-behavior-consequence (ABC)—also called the problem-solving approach—may provide sustained improvements in behavior. One meta-analysis found that behavioral management techniques that focus on individual client's behavior and individually oriented techniques provided longer lasting (several months) positive effects on behavior when compared with placebo (Nowrangi et al., 2015).

In this approach, caregivers are encouraged to *problem solve*—to look for and understand the root cause of a behavior. Intervention includes solving problems within the environment, managing medication issues, and brainstorming with other caregivers. The problem-solving approach encourages caregivers and healthcare workers to identify critical points for intervention based on observing the *antecedent*, *behavior*, and *consequence* (A, B, C) of a challenging behavior.

- **Antecedent**—what *caused* the behavior?
- **Behavior**—what *is* the behavior?
- **Consequence**—what are the *consequences* of the behavior?

The problem-solving approach is particularly effective when successful strategies are shared by staff, caregivers, and family members and used to uncover the cause of a particular behavior. This method helps staff and caregivers understand when and how often a behavior occurs and offers the opportunity for discussion and planning.

In a Norwegian study, researchers worked with healthcare workers in a small, rural nursing home to identify the effectiveness of the problem-solving approach in addressing challenging behaviors in residents with dementia. At the start of the study the care workers described what they understood about—and how they responded to—challenging behaviors. Most regarded challenging behaviors as a symptom of the resident’s dementia, including physical attacks, such as hitting, spitting, and pinching (Lykkeslet et al., 2014).

Prior to the study, the care workers shared their understanding of why certain disruptive behaviors occurred. During the first year of the study the staff reported that, as a result of being encouraged to look for the cause of a behavior, they began to get into the habit of searching for meaning in patients’ behaviors and gradually began to change their attitude toward the people they were caring for. Health workers said they were learning to see peculiar behavior more as a result of a challenging situation than as a symptom of a difficult patient (Lykkeslet et al., 2014).

One of the care workers gave an example of a patient who did not want to eat her food:

She refuses to open her mouth, so it is impossible to feed her. Any new caregiver who helps her will often fail. When I assist her, I always start by touching her hand, holding her hand, and then she gradually starts to eat.

The care worker added that this patient might have misunderstood the situation and therefore did not trust the new caregiver, who had to spend some time building trust (Lykkeslet et al., 2014).

You cannot go straight to the task—she needs some preparation to understand what is going on and what she has to do.

By observing the patient’s reactions, the care worker understood that the patient needed time to prepare. She needed to understand that the situation was a meal and that the care worker wished her well (Lykkeslet et al., 2014).

Another care worker said she began to understand patients with poor verbal language.

We try to read their body language. Perhaps she is in pain ... sometimes she can tell us ... other times we get no answer.

Sometimes the care workers saw the behavior as a response to a critical situation: “because he is vulnerable, he becomes angry.” As the study progressed, researchers began to observe changes in the care provider’s attitudes and approach to activities. They noted that when the caregivers experienced a situation as challenging, they more frequently started to reflect on the patients’ needs (Lykkeslet et al., 2014).

9. Physical Causes of Behavioral Symptoms or Pain Indications

Although challenging behavioral symptoms in people with dementia can be associated with the dementia itself, the picture is usually more complicated. Understanding factors that predict different types of challenging behaviors is of primary importance because it guides which strategies should be chosen to address the underlying causes with the goal of preventing and managing the symptoms (Cho et al., 2021).

Physical causes of challenging behaviors can be attributed to personal factors (medical conditions, pain, premorbid personality, and unmet needs), social factors (communication with caregivers, caregivers' stress and depression, and lack of social activities), and environmental factors (overstimulation, lack of established routines) (Cho et al., 2021).

9.1 Acute Medical Causes of Behavioral Symptoms

People with dementia may be disproportionately affected by undiagnosed illnesses compared with those without cognitive impairment. In a study of community dwelling older adults with dementia, more than a third had an undetected illness that was associated with behavioral and psychological symptoms, including agitation, repeated questioning, crying out, delusions, and hallucinations (Kales et al., 2015).

9.2 Pain in Older Adults with Dementia

Pain is a common, underrecognized, underreported, undertreated, and often disabling condition in people with dementia. Pain affects a person's quality of life and is associated with physical disability and neuropsychiatric symptoms such as agitation and aggression. Pain also increases stress for family caregivers who are themselves at risk for adverse mental and physical health outcomes (Porter et al., 2022).

Nearly two-thirds of people with dementia report bothersome pain. This is not surprising, considering the prevalence of musculoskeletal disorders, neuropathy, medical conditions, uncomfortable beds and chairs, lack of appropriate exercise, and inactivity. Pain is one of the most cited reasons for a decrease in quality of life in people with dementia.

There are many reasons for under-recognition of pain. For a person with dementia, it may be difficult to accurately report symptoms, pain may be more intense some days than others, and a person may fear being judged or disbelieved. Many people accept pain as a normal part of aging and fear that if their pain is treated with narcotics, they may become addicted. Additionally, a person may not be in pain during the doctor visit or may not feel pain when they are sitting quietly (Resnick et al., 2019).

For providers and caregivers, under-recognition and under-treatment of pain in a person with dementia can be associated a lack of knowledge about how to evaluate pain in older adults, communication difficulties, or the assumption that pain is a normal part of aging (Resnick et al., 2019).

An effective approach to assessing pain in older adults with dementia is to assume that they do have pain, especially if they have conditions or medical procedures that are typically associated with pain (Horgas, 2018). Key points about pain in people with dementia:

- Pain is **not** a normal part of aging.
- People with dementia feel pain.
- Pain may be difficult to assess.
- Pain is often caused by other medical conditions.

Jenna Wakes up Screaming in Pain

Introduction: Pain can be difficult to assess in older adults with dementia. Depending on the level of dementia, a client may be unable to communicate effectively and may not remember an episode of pain a short time later. Caregivers and healthcare providers must learn to identify, assess, and address the causes of pain in this vulnerable population.

Client Information: Jenna, a retired nurse now in her mid-90s, has moderate to severe dementia. She lives at home with 24-hour care from her two daughters and a daytime caregiver. Although Jenna has chronic back pain, she rarely complains about pain and her daughters successfully manage her back pain with Tylenol, ice, heat, exercise, and positioning. Jenna keeps as active as she can, walks with assistance, and exercises every day on the floor or in her recliner. Her bedroom is fitted with transfer poles and grab bars and Jenna is still able to get to the bathroom independently during the night.

Timeline: Recently, in the middle of the night, Jenna's daughter found her mother sitting on the toilet, moaning in pain, and grabbing between her legs. "It hurts, it hurts" she screamed, doubled over in pain. Her daughter thought Jenna might be impacted but her mother shouted "No, it hurts here" pointing between her legs, "not back there! Get me a cup of hot water." She punched her daughter several times in the stomach for emphasis. Jenna proceeded to pour 15 cups of warm water between her legs, at which time the pain subsided, and she went back to bed. The next day, although Jenna had no recollection of the night before, her daughter took her for an abdominal ultrasound, a blood test, and a urine test. All came back negative.

A week later, the same thing happened again. Jenna was up every 20 minutes to the bathroom to urinate, culminating in an episode of screaming, writhing pain at 3:30 in the morning. Her daughter found a significant amount of very hard stool at the end of her mother's rectum and was able to evacuate the stool. The pain subsided. After a discussion with Jenna's primary doctor, the daughters established a bowel program. The doctor ordered a strong laxative to be used as needed in addition to a stool softener. This helped Jenna's constipation but did nothing for her episodes of severe nighttime pain. The daughters were desperate. Jenna wasn't a complainer, so her daughters knew the pain was real.

At one point the pain was so severe that her daughter took Jenna to the ER at 2 a.m. Jenna fought and kicked so hard that it took three nurses to hold her down for a urine sample. The doctor did a cursory examination, said Jenna was agitated due to her dementia, and prescribed an antipsychotic. Jenna's daughter recalled that antipsychotics are not recommended in older adults with dementia but nevertheless decided to see if the antipsychotic helped. The antipsychotic put Jenna to sleep for almost 48 hours. The nighttime pain was unaffected.

Intervention: The daughters asked the primary care physician for a referral to a urologist, who recommended Jenna stop drinking coffee and orange juice, and prescribed a topical hormone cream. This helped a little, but Jenna continued to experience severe nighttime pain.

After some research, one of the daughters (an RN) came across an article on interstitial cystitis (related to bladder spasms), which fit the symptoms almost perfectly. The daughters decided to try the recommendations in the article, i.e., avoiding acidic food, excessive vibration, and additives in soaps and detergents that can trigger bladder pain. They continued to restrict caffeine, tomatoes, and orange juice, bought hypoallergenic soap and laundry detergent, got a wheelchair with pneumatic tires and a good-quality seat cushion, and continued to use the hormone cream. The pain stopped almost immediately and did not return. Nevertheless, when they returned to the ER a couple of months later because of a UTI, the same doctor again prescribed antipsychotics.

Discussion: Jenna's case is complex due to her age, the intermittent and severe nature of her pain, and her inability to describe her symptoms except by screaming and moaning. Her primary care physician was unable to offer the slightest bit of direction except, when asked, to refer Jenna to a urology specialist. The urologist put the daughters on the right track and fortunately they were able to use their own medical knowledge, common sense, and experience to eventually figure out what was causing Jenna's pain. Jenna has not experienced another episode of nighttime pain.

Client Perspective: When asked, Jenna always reports that she slept well—even when she had a severe bout of nighttime pain. She occasionally remembers the nighttime pain but doesn't remember hitting her daughter or demanding hot water. Even after a difficult night, she usually awakes with a smile on her face and a kiss for her daughters.

9.3 Common Measurement Tools for Assessing Pain

The most critical aspect of pain assessment is that it be done on a regular basis using a standard format. Pain should be re-assessed after each intervention to determine whether the intervention was effective.

The self-report of pain is typically viewed as the gold standard in pain assessment. In dementia, however, self-reports are affected by a person's ability to communicate about their pain. A person with dementia may also be unable to comprehend and use pain scales to indicate their pain level of pain.

Family caregivers can be used as proxies although it is important to note that family members typically, as a group, report higher levels of pain than a patient self-reports. Pain reports from a family caregiver is sometimes referred to as the "silver standard."

Both physiologic and behavioral responses can indicate the presence of pain. Physiologic responses include tachycardia, increased respiratory rate, and hypertension. Behavioral responses include splinting, grimacing, moaning, grunting, distorted posture, and a reluctance to move. A lack of physiologic responses or an absence of behaviors indicating pain does not mean there is an absence of pain.

My Mom Is Blind, Not Deaf—and She Is in Pain

I brought my mom to the ER because of severe pain, increased confusion, and weakness. A young male doctor came into her room, identified himself, and shouted “Hello, I’m your doctor. Do you have any new or worsening pain?” My mom turned towards him and smiled but didn’t answer. The doctor shouted again in an even louder voice “Do you have any pain? Are you in pain?” My mother smiled but didn’t answer. I leaned over and asked her in a normal voice if she was in pain and she said no, meaning she was not in pain at that moment. I told the doctor that my mom is blind but hears very well. He didn’t look at me or ask me any questions. He shrugged and left the room.

The doctor returned a few minutes later with a diagnosis of agitation related to dementia and prescribed an antipsychotic. Although a very low dose was prescribed, my mom had a very bad reaction. After we returned home, she was so disoriented and sleepy for the next 48 hours that we thought she was dying. Her pain was unaffected.

9.3.1 Behavioral Pain Scale

The Behavioral Pain Scale (BPS) was developed for use with critically ill patients in the ICU. It evaluates and scores three categories of behavior on a 1 to 4 scale:

1. Facial expression: 1 for relaxed to 4 for grimacing
2. Upper-limb movement: 1 for no movement to 4 for permanently retracted
3. Ventilator compliance: 1 for tolerating ventilator to 4 for unable to control ventilation

A cumulative score above 3 may indicate pain is present; the score can be used to evaluate intervention but cannot be interpreted to mean pain intensity. The patient must be able to respond in all categories of behavior—for example, the BPS should not be used in a patient who is receiving a neuromuscular blocking agent.

9.3.2 Pain Assessment Checklist

Pain behavior *checklists* differ from pain behavior *scales* in that they do not evaluate the degree of an observed behavior and do not require a patient to demonstrate all of the behaviors specified, although the patient must be responsive enough to demonstrate some of the behaviors. The checklists are useful in identifying a patient’s “pain signature”—the pain behaviors unique to that individual. The Pain Assessment Checklist for Seniors with Limited Ability to Communicate (PACSLAC) is a caregiver-administered tool that evaluates 60 behaviors divided into 4 subscales:

1. Facial expressions (13 items)
2. Activity/body movements (20 items)
3. Social/personality/mood (12 items)
4. Physiological indicators/eating and sleeping changes/vocal behaviors (15 items)

A checkmark is made next to any behavior the patient exhibits. The total number of behaviors may be scored but cannot be equated with a pain intensity score. A high score may not represent more pain than a low score. In other words, a patient who scores 10 out of 60 does not necessarily have less pain than a patient who scores 20. However, in an individual patient, a change in the total pain score may suggest more or less pain.

9.3.3 Advanced Dementia Scale (PAINAD)

The Pain Assessment in Advanced Dementia (PAINAD) scale assesses breathing, negative vocalizations, facial expression, body language, and ability to be consoled. However, interpreting the behaviors in PAINAD is complex; there is considerable overlap between behavioral symptoms of dementia and behavioral symptoms of pain, which often causes generalized distress. A positive score on PAINAD might be blamed on pain when there is some other cause of distress, including boredom, hunger, or fear. This highlights the challenge of identifying pain in people with dementia and raises concerns about the validity of PAINAD (Dunford et al., 2022).

Pain Assessment in Advanced Dementia (PAINAD)				
	0	1	2	Score*
Breathing	Normal	<ul style="list-style-type: none"> Occasional labored breathing Short period of hyperventilation 	<ul style="list-style-type: none"> Noisy labored breathing Long period of hyperventilation Cheyne-Stokes respirations 	
Negative vocalization	None	<ul style="list-style-type: none"> Occasional moan/groan Low level speech with a negative or disapproving quality 	<ul style="list-style-type: none"> Repeated, troubled calling out Loud moaning or groaning Crying 	
Facial expression	Smiling or inexpressive	<ul style="list-style-type: none"> Sad Frightened Frown 	Facial grimacing	
Body language	Relaxed	<ul style="list-style-type: none"> Tense Distressed Pacing Fidgeting 	<ul style="list-style-type: none"> Rigid Fists clenched Knees pulled up Pulling/pushing away Striking out 	
Consolability	No need to console	Distracted or reassured by voice or touch	Unable to console, distract, or reassure	
PAINAD Scoring: 1-3 = Mild; 4-6 = Moderate; 7-10 = Severe *Some institutions have developed policies in which a PAINAD score of four or greater must be addressed in the nursing care plan. Public domain.				Total:

10. Common Medications and Their Side Effects

People with dementia are more likely to be prescribed medications for treatment of cognitive problems, behavioral symptoms, and multiple comorbidities, compared with people without dementia. Most geriatric patients with dementia take five or more medications, commonly defined as polypharmacy (Ruangritchankul et al., 2020).

The use of multiple medications can lead to greater risk of drug-related problems, including potentially inappropriate medications, drug-drug interactions, and adverse drug reactions. This can result in an increased risk of hospital admission, morbidity, mortality, and healthcare burden. These problems tend to occur more frequently—and are more serious—in older adults with dementia than in younger population (Ruangritchankul et al., 2020).

Antipsychotics, anti-epileptics, and antidepressants are the most commonly used medications in older adults with dementia. Older adults, particularly those with dementia, are vulnerable to the adverse effects of these medications. This can include worsening cognitive impairment, aggression, restlessness, sedation, falls, bleeding, and changes in cardiovascular and gastrointestinal function (Jordan et al., 2015).

10.1 FDA Approved Medications for Dementia

There are several FDA approved pharmaceuticals that may temporarily slow cognitive, functional, and behavioral decline, especially in the early stages of cognitive decline:

Cholinesterase Inhibitors

1. Donepezil (Aricept)
2. Rivastigmine (Exelon)
3. Galantamine (Razadyne)

Increase Glutamate Levels

4. Memantine (Namenda)

Combination

5. Namzaric

Anti-Amyloid Antibodies

6. Aducanumab (will be pulled of the market in 2024)
7. Lecanemab

The first three medications are cholinesterase inhibitors, which work by increasing the levels of acetylcholine, a neurotransmitter in the brain involved in learning, alertness, judgment, and memory. Cholinesterase inhibitors do not reverse the progression of Alzheimer's disease or repair damaged brain cells, and the medications lose their effectiveness over time.

Because cholinesterase inhibitors increase the availability of acetylcholine, they can overstimulate the parasympathetic nervous system. Although side effects can differ somewhat, all three medications can cause nausea, vomiting, gastrointestinal (GI) issues, loss of appetite, and weight loss.

The fourth medication, memantine (Namenda), regulates glutamate, a chemical messenger involved with learning and memory. For people with moderate to severe Alzheimer's disease, memantine has been shown to improve symptoms related to cognition, function, behavior, and clinical global changes. Side effects include dizziness and headaches.

The fifth medication, Namzaric, was approved by the FDA in 2014. It is a combination of Namenda and Aricept. It is indicated for the treatment of moderate to severe Alzheimer's dementia in patients stabilized on memantine and donepezil. Namzaric is taken as a capsule for once-daily oral administration. To facilitate dosing for patients who may have difficulty swallowing, the capsules can be opened to allow contents to be sprinkled on food (CenterWatch, 2020). Side effects include diarrhea, nausea, vomiting, weight loss, headache, and dizziness.

The approval of the anti-amyloid antibody medications (aducanumab and lecanemab) has caused a great deal of controversy because they were approved by the FDA using an expedited pathway based upon limited data, evidence of significant side effects, and limited benefits (Henry and Pellegrino, 2023). Aducanumab has serious side-effects including brain bleeds and edema in the brain. This medication is being pulled off the market by its manufacturer (Biogen) in 2024. Side effects of lecanemab include infusion-related reactions, amyloid-related imaging abnormalities, and headache.

In 2023, the U.S. Food and Drug Administration announced the supplemental approval of Rexulti (brexpiprazole) oral tablets for the treatment of agitation associated with dementia due to Alzheimer's disease. This is the first FDA-approved treatment option for this indication (FDA, 2023). Side effects include drowsiness, dizziness, weight gain, restlessness, increased appetite, and shaking.

10.2 Antipsychotics

Antipsychotics are often used off-label to manage behavioral symptoms associated with dementia. These drugs are widely used in people with Alzheimer's disease and other types of dementia despite only modest evidence suggesting clinical improvement. Because they often have a sedative effect, they can lead to falls, fractures, and excessive sedation.

A study in the United Kingdom indicated that patients who received an antipsychotic for 12 months were significantly more likely to have died by the 24-month and 36-month follow-up periods compared to patients who had received a placebo. Other studies have found a link between the use of antipsychotic drugs in dementia patients and an increase in the risk of acute pulmonary diseases, hip fracture, thromboembolism, and stroke (Guzzon et al., 2023).

The American Geriatric Society (AGS) Beers consensus criteria* for safe medication use in elders recommends **avoiding** antipsychotics for treatment of neuropsychiatric symptoms of dementia due to the increased mortality and cerebrovascular events risk “unless nonpharmacologic options have failed and patient is threat to self or others”. All atypical antipsychotics now carry a black box warning from the FDA about this risk, and a similar warning applies to conventional antipsychotics.

***Beers Criteria:** The Beers criteria are commonly used to identify “potentially inappropriate medications” for older adults, meaning the risk may outweigh the benefit.

Article: Risks Run High When Antipsychotics Are Prescribed for Dementia

Source: Scott Hensley, March 18, 2015, National Public Radio

<http://www.npr.org/blogs/health/2015/03/18/393813044/risks-run-high-when-antipsychotics-are-prescribed-for-dementia?sc=ipad?f=1001>

10.3 Best Practices in Adult Day Care

Adult day care staff should be aware of the adverse effects of any medications a client is using. For example, some medications increase the risk of falls while others affect cognition. Weight loss, extremely low body fat, and dehydration can also decrease the effectiveness of some drugs. If you notice a change in cognition or behavior, report your observations to your supervisor so a comprehensive evaluation can be completed.

In Florida, adult daycare staff are allowed to “supervise self-administered medication” which means (O’Keeffe et al, 2014, latest available):

1. Reminding participants to take medication at the time indicated on the prescription.
2. Opening or closing medication containers or assisting in the opening of pre-packaged medication.
3. Reading the medication label to participants.
4. Observing participants while they take medication.
5. Checking the self-administered dosage against the label of the container.
6. Reassuring participants that they have obtained and are taking the dosage as prescribed.
7. Keeping daily records of when participants received supervision.
8. Immediately reporting apparent adverse effects on a participant's condition to the participant's physician and responsible person.

If a daycare client is unable to self-administer a medication, a person licensed under Florida law must be available to assist that person. A physician, advanced registered nurse practitioner, dentist, licensed practical nurse, RN, or physician's assistant can administer medications (O’Keeffe et al., 2014).

11. Malnutrition and Dehydration

In older adults, physiologic changes can lead to malnutrition and dehydration. This includes changes to the gastrointestinal system, reduced function of salivary glands, and reduction of taste and smell. Difficulty swallowing, decreased appetite, and changes in eating habits also occur as dementia progresses.

Malnutrition is an inadequate diet in which either the quantity or quality of nutrients does not meet nutritional needs. It includes both over-nutrition and undernutrition.

Undernutrition affects up to 10% of older people living at home, 30% of those living in care homes, and 70% of hospitalized older adults. Malnutrition in older adults with dementia (ADI, 2014):

- Increases frailty, skin fragility, falls, hospitalization, and mortality.
- Tends to be progressive, with weight loss often preceding the onset of dementia and increasing as the disease progresses.

Dehydration occurs when fluid loss is greater than fluid intake or when there is an excessive loss of body fluid. It is one of the ten most frequent diagnoses related to the hospitalization of older adults in the United States. Nutrition studies demonstrate that a loss of only 1% to 2% of total body water may result in impaired cognitive performance; in older adults this percentage was shown to be even lower (Sfera et al., 2016).

Despite these serious issues, nutrition is an almost totally neglected area of study in people with dementia. Studies indicate that 20% to 45% of people with dementia living in the community experience clinically significant weight loss over one year, and that up to half of people with dementia in care homes do not get enough food (ADI, 2014).

11.1 Risk Factors for Malnutrition and Dehydration

Swallowing disorders and lack of oral care are 2 of the most common risk factors for malnutrition and dehydration in older adults. For a person with sensory changes related to dementia, eating takes time. The lack of individualized help from properly trained staff, unappetizing food (or food served cold), staff or caregiver neglect, and food and drug interactions are very common. Something that takes a few minutes for a younger person, may take a half hour or more for a person with dementia.

Illness, depression, and loneliness also affect a person's desire to eat—especially if housebound with little or no help. Someone with dementia and limited mobility may not feel hungry at appointed mealtimes, may be unable to open a package containing utensils, or may not remember to eat, leading to skipped meals. Cultural and language differences also affect a person's desire to eat and drink. This is especially true if food preferences are not considered.

11.2 Signs and Symptoms of Malnutrition and Dehydration

Signs and symptoms of **malnutrition** include weight loss and decreased muscle mass, lightheadedness and dizziness, and an inability to keep warm. A sore mouth or swollen and bleeding gums affects chewing and swallowing. Malnutrition can cause constipation (or diarrhea), recurrent infections, fatigue and weakness, and a bloated abdomen.

Signs and symptoms of **dehydration** include thirst, dry skin, fatigue, and sluggishness. Other symptoms can include dizziness, confusion, and nausea.

As dementia progresses—especially a person approaches the severe stage, they may refuse food and drink. This can be especially stressful and concerning for caregivers. Hand feeding can be stigmatizing, and some people may resist being helped in this way. Many people experience difficulties with swallowing, choking, and aspiration. It is not uncommon for someone to chew food and hold it in their mouth, failing to swallow.

Aversive, resistive behaviors can be related to (ADI, 2014):

- Inability to use utensils or distinguish food from non-food (dyspraxia/agnosia).
- Turning the head away, blocking mouth with hands, biting caregiver, spitting or throwing food (resistance).
- Difficulty opening mouth, continuous tongue or mouth movements, chewing without swallowing (oral neuromuscular incoordination).
- Only willing to eat certain food or fluids (food preferences).

11.3 Strategies for Addressing Malnutrition and Dehydration

I was very frustrated that I wasn't able to find a microwave with controls my dad could see. The industrial look—gray numbers on a black background, plus a bunch of unnecessary functions made it nearly impossible for him to heat his coffee in the morning or heat up what we prepared him for lunch. Now, as I am aging, I realize that I also have trouble seeing the buttons on my microwave. There are a lot of people who don't have perfect vision—I hate that nobody seems to take this into account during the design.

Soana, Occupational Therapist, Miami

Encouraging proper nutrition and hydration, promoting independence in eating, and ensuring that eating is a pleasurable activity is an important part of a person's overall care. With good planning and proper training, malnutrition and dehydration can generally be prevented or reduced.

Clients with dementia take longer to eat, require prompting and encouragement, and may have problems with coordination and swallowing. Training, education, and support are needed for caregivers, particularly when aversive feeding behaviors and feeding difficulties occur. Basic information should be provided to families and training and dietician services should be available (ADI, 2014).

Promoting independent, pleasurable eating and drinking should focus on three levels (Palese et al., 2018):

1. **Environmental:** ritualizing the mealtime experience by creating a controlled stimulated environment.
2. **Social:** structuring effective mealtime social interactions.
3. **Individual:** individualizing eating assistance.

Despite the seriousness of malnutrition and dehydration in people with dementia, Jane Murphy and Joanne Holmes at the Burdett Trust for Nursing (Nutridignity in Dementia) point out that (Murphy and Holmes, 2015):

- There are no standardized interventions that address the maintenance of adequate nutrition.
- There is a lack of nutrition training, skills, and leadership to embed values and behaviors in care.
- There is poor recognition of the “meal experience” within the context of person-centered care.

Video: Professor Jane Murphy talks about nutrition in dementia care (2:23)

<https://www.youtube.com/watch?v=4z6IJx9LSDc>

Source: Bournemouth University

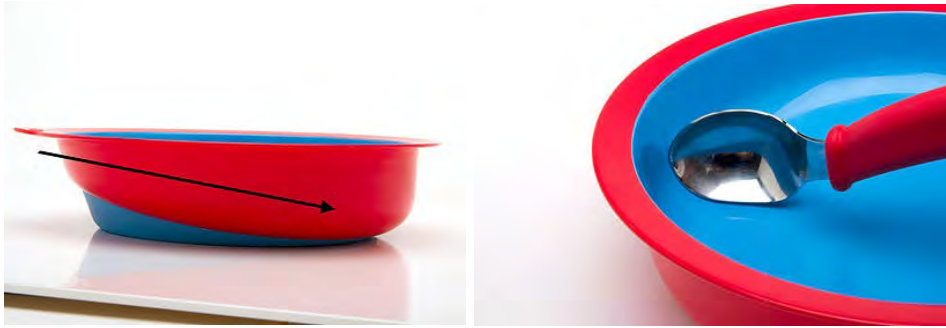
<https://www.bournemouth.ac.uk/research/projects/optimising-food-nutritional-care-people-dementia>

11.3.1 Assistive Tableware

Assistive or adaptive tableware is an important tool for people experiencing difficulties with eating and drinking. Unfortunately, it is not used as much as it could be, and users of assistive table settings often feel different and stigmatized.

The physical environment plays an important role in managing the challenges that patients with dementia experience with everyday activities. There is evidence that the use of high-contrast tableware increases liquid and food intake in patients with advanced dementia (Ocal et al., 2023). A variety of colors have been studied to find alternatives to standard, white tableware.

Well-designed assistive tableware should offer a range of matching items that form a complete set, can be used by people of all abilities, and resemble standard tableware. Color contrasts should feature prominently—for example royal blue plates provide a contrast both with a white table covering and food on a plate.



The slanted bottom hip lip of the plate can help users to gather food on one side without scooping. Spoon heads are designed to match the curvature of the bowls to pick up the food more easily. Designed by Sha Yao, Eatwell.com. Used with permission.

The same approach can be used with cups; for example, royal blue and white can be used to help those with low visual acuity or agnosia locate the handle and rim. The sides of the cup should be angled to reduce the need to tip the cup, a large handle will assure a good grip, and the top should be wide enough to allow a person's nose to fit inside the cup when tipped (ADI, 2014).



A cup with a weighted bottom is shown on the left. A cup with an easy-to-grip handle is shown on the right. Designed by Sha Yao, Eatwell.com. Used with permission.



An example of a complete set of assistive tableware. This tableware design applied research from Boston University. According to the study, colors help a person with dementia to reduce visual impairment and consume 24% more food and 84% more liquid. Designed by Sha Yao, Eatwell.com. Used with permission.

The standard “care cup” is one of the most disliked assistive tableware items because it looks like a baby product. Its purpose is to help clients with reduced strength and dexterity grip both sides of the cup without spilling the liquid or burning their hands, as they might with a ceramic mug. An alternative approach is using a ceramic cup with a double skin and an air-filled cavity between the inside and outside surfaces. This keeps liquids warm while the outside of the cup remains cool (ADI, 2014).

11.3.2 Red Plate Study

A 2004 study by Tracy Dunne found that using high-contrast red tableware instead during meals for patients with advanced dementia increased food intake by 25%. Liquid intake increased by more than 80% (Dunne et al., 2004).

11.3.3 Modifications to Mealtime Environment and Routine

The last 30 years have seen a gradual transition to flexible, individualized, and person-centered care that more closely resembles a household. For people with dementia, it may be particularly important to have a dedicated dining room, the use of which is limited to meals and food. This should look like a dining room in a home, with recognizable furniture such as dining tables and sideboards (ADI, 2014).

Large communal dining areas should be avoided, especially for clients with dementia. Large dining spaces can be noisy and confusing, with too much sensory distraction, which do not provide the sensory cues that orient a person with dementia to mealtime. Smaller dining rooms have a more intimate and familiar ambience and reduce confusion about the function of the room. Smaller dining rooms, bright and welcoming colors, and other residential features seem to be associated with increased food intake (ADI, 2014).

“Eat-in-kitchens” linked to dining areas help involve clients in meal preparation. Kitchens evoke feelings of warmth, comfort, and security. Linking the eating area to a kitchen stimulates all the senses with the smell and sound of cooking, cueing that a meal is about to take place. Food preparation smells stimulate the appetite of people with dementia and remind them of mealtimes (ADI, 2014).

11.4 Dietary Restrictions and Challenges

In older adults with dementia, dietary restrictions and challenges associated with changes in eating behavior can cause significant issues for caregivers. As food becomes less palatable and senses decline, these changes affect the taste, smell, and texture of food. Swallowing difficulties can lead to coughing and aspiration, turning eating into an unpleasant chore.

For people on restricted diets due to high blood pressure or diabetes, salt and sugar may be restricted, making food bland and tasteless. For people with swallowing difficulties or those at risk for aspiration, thickened liquids and chopped-up food may be unfamiliar and unsatisfying. People living in areas without easy access to a good grocery store, people with mobility issues, or those unable to afford good quality food may not be able to meet nutritional needs.

11.5 Addressing Concerns about Malnutrition, Undernutrition, and Dehydration

It is sometimes difficult for caregivers and family members to recognize that as we age, food preferences change, activity levels decline, and meals become less social. For a person experiencing the cognitive and sensory changes associated with dementia, these changes are magnified.

Researchers at the *Ageing and Dementia Resources Centre* at Bournemouth University have developed 6 person-centered care recommendations designed to address these concerns, while supporting staff, caregivers, and people with dementia (ADRC, 2018):

1. Offer a variety of different, nutritional foods and drinks, available throughout the day, that account for cultural, religious, and food preferences of each individual.
2. Monitor and screen regularly for dehydration and undernutrition.
3. Encourage meals with family members, care staff, and other residents.
4. Encourage participation in meaningful activities, meal planning, and food preparation.
5. Keep care consistent.
6. Provide accurate and trusted information about nutrition.

In adult day care centers, clients are required to be offered refreshments throughout the day. The refreshment, as well as meals, must adhere to the USDA dietary guidelines. Lunch and snacks must come from USDA food groups and be supplied by an approved vendor. Adequate hydration must be provided (at least 3x/day) and beverages must be provided outdoors and in hot areas where dehydration may be an issue.

Oral protein and energy supplements can be used in older people with *undernutrition*, or at risk of undernutrition. Their use is associated with significant weight gain, and a reduction in mortality for those who are undernourished (ADI, 2014). Fruits and vegetables are important sources of micronutrients, including vitamins E and C. Fiber, vitamins, and micronutrients and bioactive compounds are often below recommended dietary allowances.

12. ADLs, a Purposeful Life, Routines, and Schedules

Activities of daily living (ADLs) are the tasks we do during our daily lives. They are usually divided into two categories: **basic** ADLs and **instrumental** ADLs. Basic ADLs are the skills needed for eating, bathing, dressing, and toileting. Instrumental ADLs are the skills needed to function within society and within the community.

In adult day programs, clients tend to need less assistance with ADLs than people in other long-term care settings, particularly with bathing, dressing, and toileting. In general, about 37% of daycare clients need help with bathing and 22% need help with eating. A little more than a quarter of participants in adult day programs need help with transfers (Singh et al., 2022).

12.1 Person-Centered Care and Assistance with ADLs

In the context of assistance with ADLs, person-centered care means that a person with dementia deserves to be treated with dignity and respect. Promoting autonomy and independence and including the person you are assisting in care and treatment decisions are key practices.

Caregivers should focus on reducing the amount of (unnecessary) help they provide. This takes practice and patience because an older adult with dementia needs plenty of time to complete their ADLs. Training, common sense, proper seating, and appropriate assistive equipment are vital and can help a person with cognitive and physical declines retain their independence as the dementia progresses.

12.2 Supporting Independence in ADLs

Dementia-friendly or dementia-capable environments help a person maintain independence in activities of daily living (Førsund et al., 2018). Assistive equipment and environmental design play an important role in supporting independence and reducing the amount of assistance required for ADLs. Equipment that is well-designed and readily available supports independence, while poorly designed equipment, cluttered hallways, improper seating, and lack of well-designed resting areas reduce independence.

12.3 Meaningful, Person-Centered Activities

Living with dementia involves enduring the loss of mental and physical abilities, which leads to difficulties in handling everyday living, maintaining meaningful activities, and taking part in social life. To maintain quality of life and reduce challenging behaviors, a person with dementia must have the opportunity to participate in activities that are adjusted to interests and to the severity of their dementia.

Meaningful activities should provide socialization, stimulation, and physical activity within the functional limits of a person's abilities. When designing an activity, be sensitive to the cultural differences of those attending the activity. Activities should (Zeman, 2015):

- Provide mental stimulation.
- Reflect the interests of the person with dementia.
- Maintain or slow the loss of skills without requiring the person to learn new ones.
- Minimize failure.



The author's mother helping with gardening—an activity she had done her entire life. She could no longer walk safely but was eager to help in any way she could. Source: Author.

For staff, any contact with the person who has dementia is an opportunity for positive, meaningful interaction. Reminiscing, singing old songs, talking about shared interests, encouraging the client to help with minor chores, and breaking tasks down to allow the person to complete them, can all be enjoyable and stimulating activities and should be a regular part of the day (Zeman, 2015).

12.4 How to Assess if an Activity Is Meaningful

Providing meaningful activities that are matched to the abilities and interests of individuals with dementia can lead to dramatic reductions in agitation and other challenging behaviors. In general, meaningful activities have these features (Mansbach et al., 2017):

1. Active participation.
2. Content is related to the interests and past roles of the participants.
3. Activities meet the psychological needs of identity and belonging.

The *Engagement in Meaningful Activities Survey* is a useful tool for assessing if an activity is meaningful to a person for whom you are caring. The survey asks participants, "Does this activity" (Eakman, 2012, Updated 2020):

1. Help me take care of myself?
2. Reflect who I am as a person?
3. Express my creativity?
4. Provide me with a sense of accomplishment?
5. Contribute to my feeling competent?
6. Help other people?
7. Give me pleasure?
8. Give me a feeling of control?
9. Have the right amount of challenge?
10. Provide satisfaction?
11. Help me express my personal values?

12.5 Routine and Structure in Adult Day Care

In many instances, routines and schedules are built around the needs of staff and caregivers rather than the needs of the person with dementia. This is unfortunate because consistent daily routines that align with a person's abilities promote independence and can reduce the number and duration of challenging behaviors. The person with dementia knows what to expect while giving caregivers a benchmark for evaluating their behavior.

Although caregivers are responsible for maintaining a routine, flexibility is essential. For example, if someone does not want to participate in an activity or eat at the scheduled time, it is best to be flexible and allow the person to rest or eat later.

When developing a schedule for someone with dementia, plan carefully, allow plenty of time, and consider each person's capabilities and preferences. Additionally:

- Continue familiar routines and schedules.
- Maintain mealtime routines.
- Maintain regular healthcare appointments.
- Note the effects of changes in routines.
- Consider issues that disrupt routines.

Daily routines, whether in a facility or in the home should always consider a person's need and abilities. Failing to understand a person's cognitive and physical changes is a common caregiver behavior and often leads directly to all sorts of challenging behaviors, frustration, and anger.

For example, a person who recently had a brainstem stroke is experiencing increased tone and stiffness in her legs and trunk. This means all her joints are stiff and her movements are slower than they were before the stroke—a common side-effect of this type of stroke. All her basic activities of daily living are affected—moving in bed, sit-to-stand, transfers, and gait. Caregivers can be easily frustrated if they fail to understand how this person's abilities have changed.

Luella Wants to Brush Her Teeth

Introduction: Aligning caregiving with a person's abilities can be difficult in older adults with dementia. Caregivers and healthcare providers must learn to identify, assess, and address the changes in a person's abilities as cognition changes and make appropriate adjustments.

Client Information: Luella has moderate to severe dementia. She lives at home with 24-hour care and attends an adult day care program 3 times each week. Luella has always been active and eagerly exercises at the day care center. Recently, because of declining strength and balance, she has needed more assistance with basic activities. She never asks for help and, despite changes in her abilities, she tries to do everything herself.

Timeline: For Luella, doctor's appointments have always been drama free. She used to get ready quickly and be ready to depart on time. She always, always brushed her teeth before an appointment. Recently, she has required a caregiver to stand next to her at the sink while she brushes her teeth, which takes at least 15 minutes and frustrates her daughter.

One day, her daughter was running behind and tried to get her mother to get in the car without brushing her teeth. This caused a huge argument during which her mother sat on the floor and put her feet on the door to the garage and refused to move. The solution was to help her up and stand beside her while she brushed her teeth. Once she was in the car, she turned to her daughter and said, "hurry up, we're going to be late".

Discussion: Luella's daughter was having trouble with her mother's declining abilities and thought she could talk her mother into going before she was ready. In this case, her mother's abilities were changing but her needs were not. She had always been able to get ready for an appointment without much help while her daughter finished chores and got everything else ready to go. Eventually, her daughter realized that it was taking much, much longer for her mother to get ready for an appointment and she started preparing things more than an hour ahead of time.

Client Perspective: Luella was perfectly happy with the outcome of this recent disagreement. In fact, she didn't even remember anything had happened. She got what she wanted and got to her doctor's appointment with minutes to spare. Luella didn't have much of an idea of how much pressure was on her daughter to keep things running smoothly. She told her daughter, "You worry too much."

13. Validation Therapy and Reality Therapy

Validation therapy is a type of interactive cognitive therapy developed by Naomi Feil for use in older adults with cognitive disorders and dementia. It arose from Feil's experience as a young adult watching what she felt was the failure of reality therapy in this patient population. She developed validation therapy as a method of working with patients she described as severely disoriented.

Validation therapy focuses on accepting the reality of the person living with dementia by focusing on the emotional content of a person's words or expressions. The aim is to reduce negative feelings and enhance positive feelings. Validation therapy uses certain communication techniques, including a gentle tone of voice; nonthreatening words to establish understanding; rephrasing the person's words; maintaining eye contact (where culturally appropriate); responding in general terms when meanings are unclear; and using appropriate touch (Scales et al., 2018).

Validation theory explains that many (very) old, disoriented people, who are often diagnosed with Alzheimer's-type dementia, are in the final stage of life, trying to resolve unfinished issues to die in peace. Their final struggle is important, and caregivers can help them (VTI, 2023).

Validation techniques offer disoriented older adults an opportunity to express what they wish to express, whether it is verbal or non-verbal communication. When disoriented older adults can express the things that may have been suppressed for many years, the intensity of their feelings lessens, they communicate more, and are less likely to withdraw into further stages of disorientation (VTI, 2023).

Validation therapy states that:

1. Very old people struggle to resolve unfinished life issues before death.
2. Caregivers should use a basic, empathetic attitude that respects and values very old people without judgment.
3. Caregivers should use specific techniques for individual as well as group work, based on the needs of the individual and his or her phase of resolution (VTI, 2023).

Video: Gladys Wilson and Naomi Feil (5:46)

<http://www.youtube.com/watch?v=CrZXz10FcVM>

13.1 Situations in Which Validation Therapy is Useful

The use of validation in dementia care is a way of demonstrating to the client that their feelings, thoughts, and opinions are acknowledged and respected by a caregiver. A combination of validation and reminiscence helps confused or disoriented clients experience joy from their earlier life and contributes to their overall quality of life (Zeman, 2012).

Validation therapy is useful in any situation in which a caregiver, family member, or professional must interact with a person with dementia. Because validation therapy provides techniques for approaching and communicating with a person with dementia, it is particularly helpful in preventing a reaction in the person with dementia that might escalate into an unwanted behavior. It is also useful for calming and diffusing challenging behaviors.

Charles Lashes Out at Frances

Frances, a physical therapist working in a specialized adult daycare center, was wheeling her client Charles to the activities room. Charles was quiet and relaxed as they moved down the hall. About 50 feet from the activities room, Frances was stopped by two co-workers who engaged her in a conversation about another client. All three were standing behind Charles, talking animatedly. Frances placed her hand on Charles's shoulder to reassure him and he angrily pushed it away, yelling in a loud voice "Stop that!" When one of Frances's co-workers tried to calm him down, Charles yelled again and tried to hit the woman.

If Frances and her co-workers were familiar with validation therapy or another dementia-specific communication technique, they could have prevented this incident entirely. Instead of ignoring Charles and talking over him, the physical therapist should have stopped, kneeled beside Charles, offered her hand, and introduced her colleagues. She should have asked Charles if she could talk for a moment with her co-workers and included him in the conversation, while reminding her colleagues that nobody likes having people stand over them. If Charles seemed uncomfortable, she could have asked her colleagues to wait until she and Charles had finished what they were doing and continued the conversation after Charles was seated at the activities table.

This is a situation that didn't need to cause Charles discomfort. If Frances and her co-workers had been respectful of Charles and validated his needs and preferences, they could have avoided upsetting him and modeled good practice for their colleagues.

13.2 Reality Therapy

Reality therapy or reality orientation is based upon the idea that a person who has lost contact with reality can be guided back to reality and that this process will help a person accept and deal with the reality of their situation. Reality therapy is intended to support a client's own insights into the truthfulness of their situation.

For people who are confused or disoriented, reality therapy is designed to improve cognitive and psychomotor function. It is often employed to help clients focus on their immediate surroundings. With this technique, caregivers actively and repetitively present information needed to orient clients to the time and day, as well as their environment and the people around them. This process is most helpful for the person in early stages of dementia (Zeman, 2012).

Reality orientation isn't helpful for a person in the mid- to late-stage of dementia. Short-term memory loss and cognitive deficits make it impossible to remember or even understand much of this information. Trying to get the individual to focus on reality when significant confusion and cognitive loss are present can increase confusion and cause agitation (Zeman, 2012).

13.3 Validation Therapy vs. Reality Orientation

Validation therapy and reality therapy differ in several ways. Validation therapy deals with a person's feelings. It is not intended to improve a person's cognition or to delay cognitive decline. It is intended to draw people out, encourage communication, and validate a client's personal truth. When used consistently, validation therapy can reduce the number and intensity of challenging behaviors, decrease the use of drugs used to treat these behaviors, and provide comfort to the person with dementia.

Reality orientation on the other hand, is intended to reduce cognitive decline using repetitive activities that reinforce name, date, place, and time. It is based on the belief that continually and repeatedly telling or showing certain reminders to people with mild to moderate memory loss will result in an increase in interaction with others and improved orientation (Takeda et al., 2012).

13.4 Joining Clients in Their Own Reality

When a person with dementia has a delusion or hallucination or another type of challenging behavior, "getting into their reality" may allay fears, address a problem behavior, or help the caregiver figure out its cause. This often leads to simple, commonsense solutions. It also helps improve the quality of life for the individual by fostering trust in the caregiver and reducing dependence on medications to manage negative behaviors.

Getting into Polly's Reality

Introduction: For older adults who are still able to participate in activities, specialized adult daycare is a good option. It provides respite for family caregivers while offering activities and socialization for clients with dementia. But, sometimes, success requires a little creativity.

Client Information: Polly is 75 years old and lives at home with her husband, Mel, who still works fulltime as a lawyer. She has moderate dementia, is independent in all basic activities of daily living but is no longer able to drive, shop, or manage complex tasks without the help of her husband. Polly had worked as a secretary in a law office for almost twenty years. When she retired, still wanting to keep busy, she took a part-time job at a nursery school and volunteered at the local animal shelter. Polly described herself as a "people person."

Timeline: A specialized adult daycare center in Ohio did its part to help Mel when he called and asked about admitting his wife to their program. Mel believed Polly would do well there. Visiting the next day, he was impressed. Polly could stay at the center for the whole time he was at work, and professionals would make sure she was safe, had a good lunch, a nap if she needed one, and activities she would enjoy. It seemed like the ideal solution, and Mel thought it would allow him to remain employed for another year or two.

Polly, however, had other plans. She did not like the idea of a day care center, and especially the people she imagined were staying there. She told Mel she was "not one of them." She refused to consider it and decided she wanted to go back to work instead. She told Mel she needed to be around people, enjoy her job, and have things "like they used to be."

Intervention: Not knowing what else to do, Mel called the daycare center for suggestions, and they gave him an idea. That evening, Mel explained to Polly that her previous employer had hired another person. Her old job was gone, but if she was interested, he found another job for her. He told her he thought she would like it because she could be around a lot of other people.

The following day he took Polly to the daycare center. Mel explained that it was a place for people who had problems with their memory, and they were looking for help. The director greeted them and told Polly they wanted to hire her because they needed someone to help the staff keep the people there happy and engaged in activities. Her job would include talking to them, helping to set the table for lunch, handing out snacks, accompanying others to activities, and helping with pet therapy.

Polly was given a tour of the center and was treated as if she were a prospective employee. On the tour she saw the attendees in various activities including group exercise, a reminiscence circle, and flower arranging. She also met the pet therapist, who was bringing in two beautiful dogs that Polly admired.

Discussion: Mel was pleased that the center had recognized Polly's need to "work" and their willingness to use that to encourage her interest in attending the daycare program. Of course, they knew that no real demands or expectations would be placed on Polly and that she would be encouraged to make friends and enjoy the activities. They waited to see what Polly's decision would be.

Client Perspective: Polly did decide to take the "job" at the center. For a few weeks, she managed to hang on to the idea that she was there to work with the other people who had dementia. But gradually, Polly just enjoyed going to the center to see her "friends."

Source: Adapted from *Kisses for Elizabeth: A Common Sense Approach to Alzheimer's and Dementia* (2012), by Stephanie Zeman, RN, MSN. Used by permission.

13.5 Validation Therapy in Adult Day Care

An individual's physical and mental condition is only part of what makes them tick. The roles they fill in contemporary life as well as their culture, ethics, spiritual beliefs, education, and the choices they made in earlier life are unique to each person. Commonsense dementia care addresses the needs of the person with dementia, not just the dementia in the person we care for (Zeman, 2012).

For healthcare providers working with a client with dementia, Stephanie Zeman, in her book *Kisses for Elizabeth: A Common Sense Approach to Alzheimer's and Dementia* (2012), includes many commonsense recommendations. First and foremost, consider the whole person—not just the dementia. Practice good communication skills and encourage independence. If you can, imagine yourself in the person's place, have a good sense of humor (and use it wisely). Most importantly, expect the unexpected.

Additionally:

- Avoid reality orientation except for early-stage dementia.
- Validate the person's feelings.
- Avoid judgement, arguing or saying no.
- Learn to use "feel goods" such as a hot bath, a cup of coffee, going to a movie, or offering a piece of chocolate.
- Arrange for meaningful and important activities each day.
- Remember that religion can be a comfort.

Joining Rose in Her Own Reality

Rose was upset at noises she heard during the night. She was convinced that animals were living in the ceiling of her room and would hurt her. Because she was so frightened by this, Rose started sleeping in a recliner by the nurses' station.

When I heard about this, I asked a staff member "put yourself in Rose's place and listen for the noise" by staying in her room for a while. Surprisingly, around midnight the staff member heard scratching noises from above.

An investigation of the noise discovered a tree branch was scraping the roof of the one-story facility when it was windy. It was removed the next morning, but Rose was still frightened and would not go into her room. No amount of explanation or "reasoning" with her would help. In her mind, she was in danger from the animal in her room.

Once again, we thought about what we needed to do for Rose. We even considered changing her room, but eventually the staff decided to "get rid of the animal." They brought in a ladder and a paper bag. Removing a ceiling tile, one of the housekeeping staff climbed up and made some banging noises. Inflating the bag, and twisting the top, he came down the ladder with the "animal" in tow. Rose, who had been watching from the door, was relieved, and since the noise from the branch was gone, the "animal" never came back.

14. Safety: New and Proven Technologies

Cognitive decline, as well as sensory changes in vision, hearing, and proprioception* increase the risk of accident and injury in older adults with dementia. Increasingly, technology has become a potential resource for improving safety and supporting independence.

***Proprioception:** a sense or understanding of the position and movement of our bodies in space.

Assistive technologies are fast becoming a fundamental pillars of health strategies. They include any product or technology-based service that enables people of all ages with activity limitations in their daily life, education, work, or leisure (Pappadà et al., 2021).

For people with dementia, assistive technologies—such as GPS devices—can increase autonomy and reduce the risks associated with wandering. They can also support and sustain people's cognitive abilities—those required to accomplish necessary daily activities (Pappadà et al., 2021).

Assistive technologies and devices can delay institutionalization or reduce the number of severe clinical cases requiring admission to care homes. Technology can also be useful when a person with dementia is admitted—it can allow for easier communication between residents and relatives and help a person overcome social barriers (Pappadà et al., 2021).

14.1 Prevention

Many caregivers (as well as healthcare providers and workers) fail to recognize the importance of prevention when caring for older adults living with dementia. Creating a safe environment supports person-centered care, encourages independence, and reduces caregiver burden.

Safety is a joint responsibility, which should cover environmental safety, infection prevention, emergency procedures, handling of hazardous materials and chemicals, and creation of a disaster plan. The building's design should include safety features such as grab bars, ramps, wandering paths with ample seating, standing stations for exercise and stretching, and features that encourage independence while also ensuring safety.

Preventable deaths can be cause by poisonings, falls, choking, drowning, and home fires. For someone with dementia, isolation, decreased mobility, and polypharmacy are also safety concerns. Medication management is often overlooked as a safety issue even though many medications affect balance, cognition, and judgement. Medical issues such as urinary urgency, constipation, skin breakdown, anxiety, and depression can lead to injuries and accidents if not properly managed.

14.2 Elements of a Safe Environment

Safety is the ability to keep a person safe from harm. A **safe environment** is one in which a person is protected from anything that is likely to cause injury. Caregivers must (1) think prevention, (2) adapt the environment, and (3) minimize dangers.

Specialized adult day care centers must consider the safety needs unique to a clientele experiencing cognitive decline. This means the center must address wandering, falls, aggressive behaviors, swallowing disorders, food preferences, and transportation safety. Centers can also enhance safety by providing caregiver training and information about assistive equipment, transfer techniques, and safety planning in the home.

A day care center can provide a *feeling of safety* for clients and their family members. In a Norwegian study involving 17 family caregivers of people with dementia who attended an adult day care program, caregivers described the center as a service that represented something safe and routine for the person with dementia. Family caregivers reported feeling a sense of relief and shared responsibility because the day care center addressed social and nutritional needs, while providing physical activity, structure, and variety for the person with dementia. Caregivers reported feeling safe because staff knew their loved one's situation and condition and provided information about other relevant resources in the community (Tretteteig et al., 2017).

14.3 Technologies Related to Safety

Technologies that support a safe environment for people with dementia can be grouped into three overlapping categories:

1. Devices used for prompts and reminders.
2. Devices that support communication and reminiscence.
3. Devices used to monitor activity, movement, and location.

Care homes tend to favor technologies used "on" residents, primarily to enhance safety and help with care. These technologies include systems that incorporate wearable or environmental sensors to detect bed occupancy, falls, entry and exit through doorways, and provide location monitoring, activity, or physiological changes. These items alert staff when assistance is needed and provide data for analysis. There is growing interest in video technology, partly to address fears of malpractice, but also to record unwitnessed incidents such as falls or altercations between residents (Hall et al., 2019).

For people with dementia, technologies related to safety can be something as simple as a grab-bar or a safety razor. In a healthcare center—as well as in the home—safety technologies might include rails, barriers, alarms, gait belts, non-skid surfaces, comfortable seating systems, walkers, canes, and wheelchairs. Global positioning devices, phone tracing devices, text messaging, and wearable electronic devices can be useful.

In care homes, video monitoring—combined with bed sensors—can reduce intrusive nighttime check-ups from healthcare workers by avoiding sudden and unnecessary awakenings. These devices have positive quality of life-related outcomes and high levels of acceptance from people with dementia, their caregivers, and staff members (Pappadà et al., 2021).

Smart phones have a wide variety of applications that can be used to improve safety. Alarm reminders can be set for medications, voice activation can be used for phone calls, and the phone can be used as a personal planner. But smart phones are expensive, complicated, easily misplaced, and useless if a person refuses or is unable to use the device.

A person's experience and preferences affect the usefulness of any electronic device. For example, most older adults grew up with analog clocks (clocks with hands) and may be most comfortable with this style of clock. TV controls are increasingly complicated—especially for a person with visual impairment.

For medication management, a pre-packaged medication system and electronic pill reminder may be useful, especially in the early and moderate stages of dementia. Other medication safety devices include (Dementia Australia, 2022):

- boxes with separate flip-top pill compartments labelled with the time and day of the week
- automatic pill dispensers with visual and sound prompts
- Webster-Paks® available from pharmacies
- medication management mobile phone apps



A Webster-Pak®. Used by permission.

14.3.1 Usability and Acceptance of Safety Technologies

Usability and acceptability are key issues when considering a new technology intended to be used by older adults with dementia. **Usability** is the level at which a device can assist users without interfering with their normal activities of daily living (Abbate et al., 2014).

In the context of dementia care, **acceptability** is the degree to which a technology is pleasing and agreeable to the user. Usability and acceptability are related to how easy it is to use the technology and whether a person is willing to use the object. Additionally, usability and acceptance are related to:

- time to accept
- willingness to keep
- number of errors due to incorrect interactions
- level of satisfaction (Abbate et al., 2014)

To be useful, the design of safety devices must consider the users' needs, fears, mental models, self-learning ability, social behavior, lifestyle, and fashion tastes. Despite this, little effort has been made to assess their usability and acceptability of new technologies before deployment (Abbate et al., 2014).

14.3.2 Monitoring Wandering with a GPS Device

Wandering outside the home can put a person at risk of exploitation and injury and increase caregiver stress and anxiety. Often, however, a person who wanders does not go far from home, may be in familiar territory, can find their way home, and may be at relatively low risk. Locking people inside a home or facility must be balanced against the potential benefits of physical exercise, social contact, informal supervision by neighbors, and the perception of autonomy afforded by "safe walking" (Milne et al., 2014).

The rapid growth of information and communication technologies has created new opportunities for safety interventions. Locator devices using Global Positioning System (GPS) navigation may promote safe walking while simultaneously balancing an individual's autonomy and safety (Neubauer et al, 2022).

In theory these devices can provide the exact coordinates of a person carrying the GPS device. Safe areas and times can be set up that allow the person to move around through familiar areas but will set off an alert if a geo-temporal limit (or "geo-fence") is breached. Additional services such as an operator to phone the person and using GPS to guide them home have also been described (Milne et al., 2014).

The adoption rate of these devices is relatively low. Abandonment of the devices is a concern as well as privacy, cost, and device complexity, which can pose barriers to their use among older adults. The legal repercussions of technologies that collect, store, and upload data have not been considered or addressed. Locator devices, for example, place users at risk of their information being publicized, which in turn can put vulnerable users, such as persons with cognitive decline, at greater risk for elder abuse (Neubauer et al, 2022).

14.3.3 Using Technology to Prevent Falls

Technology-based interventions have been deployed in a wide range of falls prevention contexts and include diagnosing and treating fall risks, increasing adherence to interventions, detecting falls, and alerting clinicians in case of falls. Technology also has the potential to play a role in enabling older adults to self-assess, giving them the opportunity to perform self-assessments (Hamm et al., 2016).

Pre-fall prevention interventions are technology applications that focus on supporting patients who have not yet experienced a fall but may be at risk of falling. They take a proactive approach via the development of applications, which support the delivery of targeted physical activities, exercises, and education programs that increase awareness of fall risks and help develop strategies to identify and overcome environmental fall hazards and the complications that may arise after having a fall (Hamm et al., 2016).

Post-fall prevention interventions are applications of technology which focus on individuals who have already experienced a fall and aim to help assess and deliver interventions to reduce the future risk of repeated falling episodes. Interventions share similarities with the pre-fall program emphasizing applications that support the delivery of exercise and education programs with a view to overcoming intrinsic and extrinsic fall risk factors (Hamm et al., 2016).

Technology platforms that support falls-prevention systems use are (Hamm et al., 2016):

- **Game consoles:** self-contained platforms in which specific game applications are utilized by falls prevention systems to deliver falls prevention related games.
- **Nintendo Wii and Microsoft Kinect:** for intervention types such as physical activities, game consoles and sensor devices such as are often used.
- Desktop computers.
- **Smart phones:** with integrated sensors and communication features.
- **Tablets:** which includes inertia measurement units, sensors (accelerometer, gyroscope, GPS), camera and touchscreen display.
- Virtual reality devices.

15. Caregiver Stress Management

In the United States, nearly 16 million caregivers provide more than *17 billion hours* of unpaid care to people with Alzheimer's and other types of dementia. Significantly, the vast majority of caregivers for older adults in the U.S. are family members. Dementia profoundly affects these caregivers, who bear its emotional, physical, and financial burdens (CDC, 2023, June 30).

15.1 Types and Causes of Stress

Although most caregivers are positive about the experience of caregiving, providing 24-hour care for a person with dementia is challenging. A review of 37 studies on the health consequences of being caregivers to family members with dementia found that most were living in a state similar to chronic stress (Kabir et al., 2020).

Many spousal caregivers have health problems of their own due to the tasks of caring and the distress associated with the role. As a result, caregivers are at high risk of depression and anxiety. Depression can remain even after institutionalization or death of the care recipient. The intensity of caregiving can also cause a sense of isolation and loneliness (Kabir et al., 2020).

The term *caregiver burden* is often used to describe this phenomenon, which is defined as the degree to which a caregiver's emotional or physical health, social life or financial status has suffered as a result of caring for their relative. Informal caregivers of people with dementia living at home experience care as more burdensome compared to informal caregivers of recently institutionalized people with dementia (Tretteteig et al., 2017).

15.2 How Stress Manifests Itself

Due to the progressive course of dementia, the likelihood of physical, social, financial, and mental health challenges increase. The risk for depression, anxiety, increased perceived burden, and a reduction in the caregiver's quality of life are common. Caregiver mental health issues increases the likelihood of a family member with dementia being moved to a residential facility. Although this can reduce the demands of daily caregiving, it can lead to feelings of guilt, anxiety, depression, and financial strain. Certain factors increase caregiver vulnerability (Wiegelmann et al., 2021):

- **Socio-demographic factors** such as female gender, spousal relationship, cohabitation, lower income, and financial inadequacy.
- **Disease-related factors** such as frontotemporal dementia, duration of caregiving, neuropsychiatric symptoms, behavioral problems, and impairment in basic daily activities.
- **Caregiver factors** such as high level of neuroticism, high expressed emotion, low confidence in caregiving role, feelings of being trapped and emotion-based, confrontative coping strategies.
- **Relationship factors** such as poorer relationship quality and low levels of intimacy.

For the caregiver, physical health problems related to caregiving, hypertension, cardiovascular disease, and sleep problems are common. Relationship challenges, greater family dysfunction, feelings of isolation, and inadequate social support add to the stress of caregiving (Trapp et al., 2015).

Family members can also become stigmatized and may experience feelings of shame about the disease. The feeling of stigma experienced by clients and caregivers is an important and potentially modifiable contributor to caregiver burden (Kahn et al., 2016).

Female spousal caregivers may suffer more stigma, as well as burden. Studies have suggested that caring for men with dementia is more arduous than caring for women with dementia. Compared to women with dementia, men with dementia tend to have more behavioral symptoms, such as disinhibition, aggression, and sexual inappropriateness. These behaviors are particularly stressful or embarrassing for caregivers and can increase their feelings of stress (Kahn et al., 2016).

15.3 Strategies to Reduce Caregiver Stress

In the early stage of dementia, family caregivers often do not use healthcare or social services that can provide early support and training. Understanding how to navigate the healthcare system, getting emotional support, and learning coping strategies can significantly reduce caregiver stress (Kabir et al., 2020).

Did You Know. . .

Dementia patients have higher rates of behavioral symptoms and mortality when cared for by families who are stressed, use emotion-based coping (e.g., wishing the disease would go away), or negative communication strategies.

Gitlin and Vause Earland

A Biobehavioral Home-Based Intervention and the Well-being of Patients with Dementia and Their Caregivers

Most healthcare providers and professional caregivers fail to recognize that the caregiver is also a client. Supporting and training caregivers reduces caregiver illness and delays institutionalization—especially for caregivers of family members with dementia.

Providing caregivers with the financial and emotional support needed to care for a family member with dementia has been shown to reduce caregiver stress. Web-based courses can provide education, counselling, and assistance, allowing caregivers with a busy schedule to study at their own pace. Online courses should be designed to meet the learner's social and cultural needs (Klimova et al., 2019b).

Reducing Caregiver Stress	
Things to Do	Things to Avoid
<ul style="list-style-type: none"> • Join a support group to discuss your feelings. • Set limits on caregiving time. • Become an educated caregiver. • Discuss your situation with your employer. • Accept changes as they occur. • Make legal and financial plans. • Join an online support group. • Take regular breaks (respite). 	<ul style="list-style-type: none"> • Avoid isolating yourself. • Don't try to be all things to all people. • Don't expect to have all the answers. • Don't deny your own fears about dementia and aging. • Avoid negative communication habits.

Despite the difficulties of caring for a person with dementia, many caregivers report a variety of positive experiences related to caregiving. Resilience, effective coping, and adaptation when faced with loss, hardship, or adversity have been identified as protective factors against caregiver stress. Similarly, optimism—a general positive outlook on life—has been associated with improved dementia caregiver mental health (Trapp et al., 2015).

15.3.1 The Role of Specialized Adult Day Care

Adult day care programs play a role in reducing caregiver burden by providing education and techniques for dealing with behavioral challenges. These programs offer respite and support services, which can provide relief, reduce caregiver burden, and increase caregivers' motivation for their role as a caregiver.

Adult day care programs (Tretteteig et al., 2017):

1. Provide separation time, giving family caregivers time for undisturbed work, rest, or other pursuits.
2. Reduce behavioral problems and the need for assistance with ADLs.
3. Reduce care demands, stress, and depression.
4. Increase motivation for care.
5. Offer information and support, potentially postponing the need for residential care.

15.3.2 The Role of Dementia Care Programs

Dementia care programs are multidisciplinary and multi-departmental programs designed to meet the needs of clients with dementia and their families. The quality and success of a dementia care program is influenced by the environment of a care facility and by the facility's philosophy of care, available services, and staff experience and training. They usually include support groups for family members, friends, and caregivers.

A well-designed dementia care program allows and encourages families to visit at any time and plans activities that include family members. A good dementia care program:

- Encourages family involvement in the planning of activities.
- Informs family members about changes to their loved one's condition.
- Keeps a log of client activities to share with the family.
- Uses technology to keep families in touch with one another.

In many areas, lack of access to memory care specialists and caregiver support groups means caregivers may be unaware of services available in their communities. People from rural communities, and Black and minority ethnic groups often experience inequalities in accessing post-diagnostic care, support services, and care programs.

Supporting Caregivers of People with Dementia



A family member having a discussion with her mother. Source: AHRQ, 2019. Public domain.

15.3.3 Collaborative Care

Collaborative care models use multidisciplinary teams to integrate medical and psychosocial approaches to healthcare for people living with dementia. Care coordination functions are assigned to specific care coordinators. Collaborative care is usually organized within a healthcare system but may be provided through services either in the community or in residential facilities (Butler et al., 2020).

Dementia Care Management is a type of collaborative care that aims to improve care after a dementia diagnosis. This approach can reduce caregiver burden, improve quality of life for the person living with dementia and their caregivers, and reduce the risk of institutionalization (Mühlichen et al, 2022).

15.3.4 Mastery over Dementia

Caregiver mastery is defined as a positive view of one's ability and ongoing behavior during the caregiving process. A high level of mastery is a buffer to caregiver stress. High caregiver mastery also promotes better health outcomes in people for whom they are caring. For example, family caregivers' mastery was related to higher survival rate in persons living with cancer and poor family caregiver mastery was related to increased anxiety symptoms in adolescents with epilepsy. Unfortunately, there is little information on how caregiver mastery is related to people living with dementia (Hwang and Hodgson, 2021).

An innovative caregiver support program, *Mastery over Dementia*, looked at the effectiveness of internet-based training to reduce anxiety and depression among family members caring for a person with dementia. The results showed that caregivers' symptoms of depression and anxiety were significantly reduced after participating in the program, compared to a minimal intervention in which caregivers received digital newsletters by e-mail (Blom et al., 2015).

For Black Americans, caregiving can be more complex. Black Americans have more than double the prevalence of Alzheimer's disease and related dementias compared to non-Hispanic white Americans, which suggests a disproportionate burden of dementia caregiving on Blacks when compared to caregivers from other racial groups (Bonds Johnson, et al., 2022).

Despite this disproportionate burden of dementia caregiving within Black communities, dementia caregiver interventions are rarely culturally sensitive or culturally relevant. For example, few interventions account for caregiving networks encompassing more than one caregiver, caregiver co-residence, and pooling of financial resources that are common in the informal care provided to Black older adults (Bonds Johnson, et al., 2022).

In addition, dementia caregivers typically spend more hours providing care and report greater emotional, physical, and financial challenges. Thus, Black dementia caregivers must learn to cope with the challenges they face in societal institutions shaped by racism and discrimination while upholding their cultural values (Bonds Johnson, et al., 2022).

15.4 Measuring Caregiver Burden

One of the most popular instruments for measuring perceived caregiver burden is the *Zarit Burden Interview* (ZBI). It was originally composed of 29 items assessing psychological well-being, finances, relationship of the caregiver and person the person for who they are caring, and social life; it was later reduced to 22 items. This tool has been validated in caregivers of patients with dementia, schizophrenia, informal caregivers, older adults, and oncology patients (Domínguez-Vergara et al., 2023).

The questionnaire addresses areas that caregivers commonly report as problematic, such as physical health, psychological well-being, finances, and their relationship with the patient. Several short versions of the ZBI have been developed, using various methods, ranging from single-item to 18-item versions.

When comparing the various versions, the original ZBI has good utility in identifying probable depression in caregivers. The 6-item version emerged as the most optimal short version in having the least number of items yet demonstrated comparable diagnostic utility as the original 22-item version (Yu, Yap, and Liew, 2019).

16. Concluding Remarks

No matter the setting—at home, adult day care, assisted living, or in a skilled nursing facility—caring for a person experiencing the onset and progression of dementia can be stressful and challenging. Family caregivers are unpaid, largely untrained, and struggle to understand the ups and downs of cognitive decline. Knowing a little bit about the brain changes that occur with dementia and learning the difference between treatable and irreversible aspects of dementia can reduce caregiver stress.

For professional caregivers, learning about dementia will help them in their jobs and help you educate family members. Learning about the physiology of brain deterioration and how the changes affect a person's behavior, and their ability to communicate and participate in social activities is a must for professional caregivers.

Without a doubt, dealing with behavioral symptoms of dementia is one of the most difficult aspects of family and professional caregiving. Interventions based on person-centered care, meaningful activities, and appropriate physical activity have a profound effect on reducing the challenging behaviors associated with dementia.

Because such a high percentage of people experiencing cognitive decline also have acute and chronic pain, caregivers must understand how pain affects older adults. This is especially true for people with dementia, who often have trouble explaining or describing what they are feeling. Pharmacologic and non-pharmacologic methods for management of pain and discomfort begins with proper assessment and includes an understanding of polypharmacy and drug-drug interactions.

Purposeful, meaningful activities are predictable and relaxing. A well-designed physical environment, easy-to-use assistive equipment, and other well thought out technologies promote independence and can significantly reduce stress for people with dementia and their caregivers.

Common sense, education, and respect for caregivers will improve the way we have been approaching the care of people with dementia. Much of what we have accepted in the past—antipsychotics, restraints, and warehousing of older adults with dementia simply does not work. There is no doubt that learning about cognitive decline and implementing a person-centered, thoughtful approach to care is urgently needed.

[Continue to next page for references]

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[Continue to next page to begin quiz]

Quiz: FL Specialized ADC, Level 2 (345)

1. **Adult day-care centers provide therapeutic programs, social services, health services, and activities for adults in a non-institutional setting.**
 - a. True
 - b. False
2. **Dementia is:**
 - a. A reversible pathophysiologic change in the brains of all older adults.
 - b. The gradual degeneration of cells in the brainstem, considered a normal part of aging.
 - c. Caused by cigarette smoking and overconsumption of aluminum-containing foods.
 - d. A collective name for progressive deterioration of brain cells and brain mass.
3. **In Alzheimer's disease, damage is thought to be related to:**
 - a. Exposure to aluminum, male gender, and inflammation within the damaged parts of the brain.
 - b. The formation of beta-amyloid plaques, neurofibrillary tangles, and loss of nerve cells within the brain.
 - c. Inflammation that starts in the peripheral nervous system, exposure to lead, and degeneration of brainstem neurons.
 - d. Female gender, old age, and loss of the sense of smell.
4. **Initial symptoms associated with frontotemporal dementia, a common type of non-Alzheimer's dementia, can include:**
 - a. Loss of judgment, perhaps in addition to memory problems.
 - b. Parkinson's-related movement symptoms.
 - c. Patchy cognitive impairment along with emotional problems.
 - d. Visual hallucinations and loss of the sense of smell.
5. **In early Alzheimer's disease, visual and spatial problems are common. This includes:**
 - a. An improved ability to identify form, color, and contrast.
 - b. Decreased vision, which can occur up to 20 years prior to the onset of other symptoms.
 - c. Difficulties with reading, problems in discriminating form and color, and an inability to perceive contrast.
 - d. Loss of judgment, inappropriate behaviors, and disinhibition.
6. **A normal, age-related cognitive change might be:**
 - a. A modest decline in the ability to learn new things and retrieve information.
 - b. An inability to form new memories.
 - c. An acute, reversible change of consciousness.
 - d. A deep depression lasting more than 2 weeks.

7. Mild cognitive disorder:

- a. Is uncommon in older adults.
- b. Will eventually progress to Alzheimer's disease.
- c. Does not necessarily indicate the presence of Alzheimer's disease.
- d. Compromises a person's ability to function independently.

8. Delirium:

- a. Generally lasts several months and can cause dementia.
- b. Has a sudden onset, a fluctuating course, and can be associated with infections.
- c. Is usually permanent and leads to eventual death.
- d. Is characterized by a normal level of consciousness.

9. Depression in people with dementia:

- a. Develops acutely—over hours or days—and is temporary and reversible.
- b. Causes a sudden and global impairment in cognition.
- c. Is associated with increased mortality, risk of chronic disease, and the need for higher levels of supported care.
- d. Is not reversible and is ultimately fatal.

10. Neurocognitive screening is:

- a. A method for detecting cognitive impairment before an individual would normally seek medical care.
- b. A method for detecting high blood pressure before a person has a stroke.
- c. A comprehensive neurological test conducted only by a neurologist.
- d. A test to determine the IQ of children between the ages of 4 and 7.

11. A limitation of most neurocognitive screening tools is:

- a. They are inaccurate as a tool for determining the presence of dementia.
- b. Language barriers and cultural differences.
- c. They require a neurologist to administer.
- d. They are generally done at too young an age to be effective.

12. Improving communication is a critical skill for caregivers of people with dementia. Poor communication:

- a. Is usually only a problem for the person with dementia.
- b. Is usually not a problem for family caregivers.
- c. Affects a person's ability to interact and communicate with others.
- d. Generally does not affect a person with dementia very much.

- 13. A communication habit that may increase a person's agitation and confusion is:**
- Allowing time for the person to understand and process information.
 - Introducing yourself each time you approach.
 - Using patronizing or infantilizing phrases such as "she's just like a baby."
 - Speaking slowly and clearly in short sentences.
- 14. In the early stage of Alzheimer's disease, damage to the limbic system can affect:**
- The formation of new memories, spatial memories and navigation, and emotions.
 - Judgment, moral behavior, and safety awareness.
 - Sleeping, the sense of smell, and can cause hallucinations.
 - Speech comprehension and the ability to form complex sentences.
- 15. Agitated and aggressive behaviors can be a type of communication, often related to:**
- Feelings of helplessness, loss of control, discomfort, pain, or fear.
 - A lack of interest or emotion.
 - Medication side effects, electrolyte disorders and dehydration, or metabolic changes.
 - Degeneration of neurons in the part of the brain that controls circadian rhythms.
- 16. Delusions and hallucinations in people with dementia can be caused by:**
- The inability to communicate discomfort.
 - Boredom and memory problems.
 - Degeneration of neurons in the part of the brain that controls circadian rhythms.
 - Health factors such as urinary tract infections.
- 17. One way to address wandering in a person with dementia is to:**
- Redirect the person to a purposeful activity.
 - Verbally admonish the person to stop or else.
 - Ask the client's doctor to tell the client to stop wandering.
 - Restrain the person in a wheelchair.
- 18. Sleep disorders in people with dementia may be caused by:**
- Too much social activity during the day.
 - Degeneration of neurons in the part of the brain that controls circadian rhythms.
 - Sleep disorders are rarely a problem in people with dementia.
 - Too much exposure to bright lights during the day.
- 19. Healthcare providers and caregivers may label a behavior as inappropriate when, in fact, the behavior is completely appropriate to the situation.**
- True
 - False

20. Person-centered care:

- a. May increase unwanted behaviors, especially agitation and aggression.
- b. Tends to increase the rate of neuropsychiatric symptoms, falls, and the use of psychotropic drugs.
- c. States that a person with dementia deserves kind and supportive treatment with the rights that we reserve for any other individual.
- d. Is used only after pharmaceutical methods have failed.

21. Respite care is an often-overlooked intervention that benefits people with dementia as well as their caregivers. It:

- a. Provides caregivers with a break.
- b. Reduces caregiver stress.
- c. Provides stimulation and social interaction for the person with dementia.
- d. All of the above.

22. For people with mild to moderate dementia:

- a. Seated exercises provide the best improvements in activities of daily living and quality of life.
- b. Exercise that combines different approaches may result in improvements in physical performance, cognitive function, and quality.
- c. Exercise and physical activity has no effect on physical or cognitive performance.
- d. Exercise is harmful.

23. The problem-solving approach to challenging behaviors in people with dementia encourages caregivers to use the following approach to address problem behaviors:

- a. Approach those with dementia cautiously, stop the behavior, and consider how to prevent the behavior from happening again.
- b. Arrest or stop the behavior by whatever means necessary, begin the process of documenting the behavior, and help the person misbehaving understand the consequences of their behavior.
- c. Approach the person misbehaving assertively, beware of violence, and call for help.
- d. Look for the cause of a behavior, identify the behavior, and consider the consequences of the behavior.

24. Assessing pain in cognitively impaired adults presents certain challenges because:

- a. They rarely show changes in behavior as a result of pain.
- b. Their pain cannot be reliably assessed using a behavior pain scale.
- c. They tend to voice fewer pain complaints than younger adults.
- d. They do not feel pain as acutely as younger adults.

25. The use of antipsychotics in older adults with dementia:

- a. Has been shown to be completely safe and effective.
- b. Is particularly effective when used as a chemical restraint.
- c. Is FDA-approved for the treatment of any neuropsychiatric symptoms in dementia.
- d. Is associated with increased overall mortality and worsening cognitive impairment.

26. Malnutrition is:

- a. An inadequate diet in which either the quantity or quality of nutrients does not meet nutritional needs.
- b. Fluid loss is greater than fluid intake or when there is an excessive loss of body fluid.
- c. A behavioral and psychological symptom of dementia.
- d. Is common in older adults with dementia living in the community but very uncommon in those living in nursing homes.

27. Malnutrition and dehydration can generally be prevented or reduced:

- a. By providing food or drink-based supplements and social support.
- b. With good planning and stern, consistent, and repetitive orders from caregivers.
- c. When caregivers encourage the person with dementia to handle their own nutritional needs.
- d. When caregivers spoon-feed the person they are caring for.

28. When making modifications to the mealtime environment:

- a. Avoid using a dedicated dining room and provide a lot of food choices.
- b. Large communal dining areas should be avoided, in particular for clients with dementia.
- c. Keep clients with dementia away from the area where food is being prepared.
- d. Do not link the eating area to the kitchen.

29. When assisting a person who has moderate dementia using the philosophy of person-centered care, the best action is to:

- a. Do something to distract the person while you complete the ADL task.
- b. Complete the task quickly so that the person does not have time to disagree with you.
- c. Do not allow the person to assist because it will take much longer to complete the task.
- d. Encourage the person to do as much as they are able and provide choices.

30. An activity is meaningful when:

- a. It allows for active participation.
- b. Activity content is related to the interests and past roles of the participants.
- c. Activities meet the basic psychological needs of identity and belonging.
- d. All of the above.

31. Validation therapy:

- a. Trains a person with dementia to understand the reality of their situation.
- b. Is not useful when used with people who are disoriented.
- c. Relies on verbal communication to increase the intensity of a person's repressed feelings.
- d. Focuses on accepting the reality of the person living with dementia by focusing on the emotional content of a person's words or expressions.

32. In an adult day care center, safety is:

- a. Not a concern because people only come in during the day.
- b. The responsibility of the department of health.
- c. A joint responsibility, shared by the center operators, managers, healthcare workers, and volunteers.
- d. Improved if all doors to the outside are kept locked.

33. For people with dementia, safety technologies:

- a. Must be completely hidden.
- b. Can be cumbersome as long as it does the job.
- c. Generally are not accepted and not recommended.
- d. Must be easy and satisfying to use.

34. Caring for a person with dementia:

- a. Is easier than caring for someone with another disability.
- b. Is less stressful than caregiving for older adults without dementia.
- c. Can affect a caregiver psychologically but seldom affects their physical health.
- d. Can increase a caregiver's risk of depression and anxiety.

35. Specialized adult day care programs can reduce caregiver stress by:

- a. Providing family caregivers with separation time.
- b. Reducing care demands, stress, and depression.
- c. Increasing motivation for care and postponement of the need for residential care.
- d. All of the above.

36. In the *Mastery over Dementia* program:

- a. Caregivers are given material to read but no direct support.
- b. There was no reduction in caregiver stress after participating in the program.
- c. Caregivers' symptoms of depression and anxiety were significantly reduced after participating in an internet support program.
- d. Caregivers can earn a master's degree in dementia caregiving.

[Continue to next page for answer sheet]

Answer Sheet: FL Specialized ADC, Level 2 (345)

Name (Please print) _____

Date _____

Passing score is 80%

1. _____	19. _____
2. _____	20. _____
3. _____	21. _____
4. _____	22. _____
5. _____	23. _____
6. _____	24. _____
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12. _____	30. _____
13. _____	31. _____
14. _____	32. _____
15. _____	33. _____
16. _____	34. _____
17. _____	35. _____
18. _____	36. _____

[Continue to next page for course evaluation]

Course Evaluation: FL Specialized ADC, Level 2 (345)

Please use this scale for your course evaluation. Items with asterisks * are required.

1 = Strongly agree 2 = Agree 3 = Neutral 4 = Disagree 5 = Strongly disagree

*Upon completion of the course, I was able to:

- | | | | | | |
|------------------------------------------------------------------------------------------------------------------------------|-----|----|---|---|---|
| 1. List the 3 overall services provided by an adult day care facility. | 1 | 2 | 3 | 4 | 5 |
| 2. Describe 2 differences between Alzheimer's dementia, vascular dementia, and frontotemporal dementia. | 1 | 2 | 3 | 4 | 5 |
| 3. List 3 ways in which normal cognitive changes that occur in older adults differs from cognitive changes seen in dementia. | 1 | 2 | 3 | 4 | 5 |
| 4. Relate 3 differences between dementia, delirium, and depression. | 1 | 2 | 3 | 4 | 5 |
| 5. Describe the purpose for a neurocognitive screening. | 1 | 2 | 3 | 4 | 5 |
| 6. Relate 3 ways in which dementia affects communication. | 1 | 2 | 3 | 4 | 5 |
| 7. Describe 5 challenging behaviors that might be associated with dementia. | 1 | 2 | 3 | 4 | 5 |
| 8. Define person-centered care. | 1 | 2 | 3 | 4 | 5 |
| 9. Describe 5 key points about pain in an older adult with dementia. | 1 | 2 | 3 | 4 | 5 |
| 10. Relate the 2 most common classes of medications used in older adults with dementia. | 1 | 2 | 3 | 4 | 5 |
| 11. List 5 risk factors for malnutrition and dehydration in older adults with dementia. | 1 | 2 | 3 | 4 | 5 |
| 12. Describe 3 features of a meaningful activity. | 1 | 2 | 3 | 4 | 5 |
| 13. Describe the purpose for a neurocognitive screening. | 1 | 2 | 3 | 4 | 5 |
| 14. List the 2 key features of safety technologies. | 1 | 2 | 3 | 4 | 5 |
| 15. Relate 5 ways to reduce caregiver stress. | 1 | 2 | 3 | 4 | 5 |
| *The author(s) are knowledgeable about the subject matter. | 1 | 2 | 3 | 4 | 5 |
| *The author(s) cited evidence that supported the material presented. | 1 | 2 | 3 | 4 | 5 |
| *Did this course contain discriminatory or prejudicial language? | Yes | No | | | |
| *Was this course free of commercial bias and product promotion? | Yes | No | | | |
| *As a result of what you have learned, will make any changes in your practice? | Yes | No | | | |

If you answered Yes above, what changes do you intend to make? If you answered No, please explain why.

*Do you intend to return to ATrain for your ongoing CE needs?

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Please enter your comments or suggestions here:

[Continue to next page for registration and payment]

Registration and Payment: FL Specialized ADC, Level 2 (345)

Please answer all of the following questions (* required).

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