

Florida: Alzheimer's Disease and Related Dementias for Specialized Adult Day Care, Level Two

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Contact hours: 4

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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.

This training is for those of you who have direct contact with patients in specialized adult day care centers. It is designed to increase your awareness and understanding of Alzheimer's disease and related disorders.

Course Objectives

When you finish this course, you will be able to:

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.

Instructions for Mail Order

Once you've finished studying the course material:

1. Record your test answers on the answer sheet.
2. Complete the course evaluation.
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1. Adult Day Care

Adult day care centers were created to prevent isolation, depression, and undue cognitive and physical decline among community dwelling older adults. They help older adults to live at home or in the community as long as possible, by providing a supportive, professionally staffed environment which attends to nutritional, daily living, and social needs of adults with functional limitations within a group setting during the day (Ellen et al., 2017).

There are approximately 4,600 adult day service centers in the United States serving nearly 286,000 people (Caffrey and Lenden, 2019). In Florida, there are approximately 351 adult day care centers that provide therapeutic programs, social services, health services, and activities for adults in a non-institutional setting (AHCA, 2020). About one-third of regular adult day care clients have Alzheimer's disease or a related disorder (Harris-Kojetin et al., 2016).

In Florida, there are approximately 15-20 **specialized** adult day care centers, which are specifically designated to treat clients with Alzheimer's disease and other types of dementia. The specialized centers enroll a higher percentage of clients with dementia than do regular adult day centers and require specialized dementia training for their staff. A specialty license is also required to provide services as a **Specialized Alzheimer's Services Adult Day Care Center** (O'Keefe, 2014).

Adult day service centers provide non-residential coordinated services in a community setting for less than a day. There are three types:

1. social,
2. medical/health, and
3. specialized (providing programs for people with dementia)

Siegler et al., 2015

Did You Know . . .

Adult day care is a program of therapeutic social and health services as well as activities for adults who have functional impairments. Services are provided in a protective, non-institutional environment. Participants may utilize a variety of services offered during any part of a day, but for less than a 24-hour period.

The social model is designed for individuals who need supervision and activities but not extensive personal care and medical monitoring. The medical model provides more extensive personal care, medical monitoring, and rehabilitative services in addition to structured and stimulating activities (O'Keefe et al., 2014).

In general, adult day care clients are younger and more racially and ethnically diverse than users of other long-term care services. More than one-third of adult day care clients are non-white, about 17% are non-Hispanic black, and about 20% are Hispanic (Harris-Kojetin et al., 2016).

Most (about 2/3) of adult day care participants attend at least 3 days/week (Siegler et al., 2015) and most clients use transport services provided by the centers.

This course is for those of you who provide direct care to clients in a specialized adult day care center. It 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.

It discusses the areas of the brain associated with speech and language comprehension and describes how brain deterioration affects behaviors you may see in people with 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.

2. Understanding Brain Disease

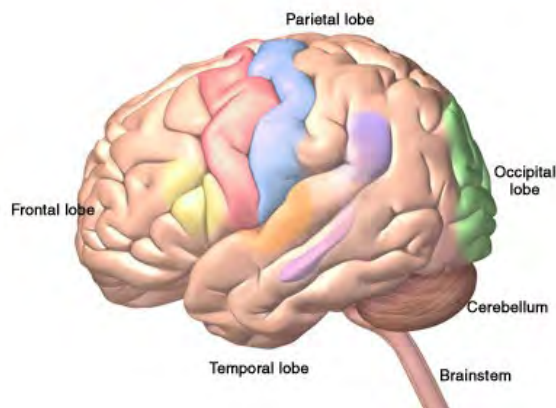
The ugly reality is that dementia often manifests as a relentless and cruel assault on personhood, comfort, and dignity. It siphons away control over thoughts and actions, control that we take for granted every waking second of every day.

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: Zygote Media. Used with Permission.

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.

Although Alzheimer's disease is the most common cause of dementia, it isn't the only cause. Frontal-temporal dementia—which begins in the frontal lobes and accounts for 5-10% of dementias—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). Dementia associated with Parkinson's disease shares a common etiology with Lewy body dementia.

In all, nearly twenty different types of non-Alzheimer's dementia have been identified. Determining if someone has dementia is important because some types of cognitive decline may be treatable or even reversible if the underlying cause is identified and treated (Sönke, 2013).

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 	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"> Behavior variant frontotemporal dementia Primary progressive aphasia Disturbances of motor function 	5–10%, prevalence thought to be underestimated
*Vascular dementia	<ul style="list-style-type: none"> Stepwise onset Similar to AD, but memory less affected, and mood fluctuations more prominent 	<ul style="list-style-type: none"> Any dementia related to cerebrovascular disease Most common cause is related to cerebral small vessel disease 	20–30%

	<ul style="list-style-type: none"> 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 	<ul style="list-style-type: none"> Single infarcts in critical regions, or more diffuse multi-infarct disease Considered a “group” of syndromes 	
Dementia with Lewy bodies (shares a common etiology with Parkinson’s disease dementia)	<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 	~5-10%
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-Stroke Dementia	<ul style="list-style-type: none"> ~2/3 experience cognitive decline Increased mortality compared to stroke patients without dementia 	<ul style="list-style-type: none"> History of stroke 	

*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.

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.

Alzheimer's Dementia

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

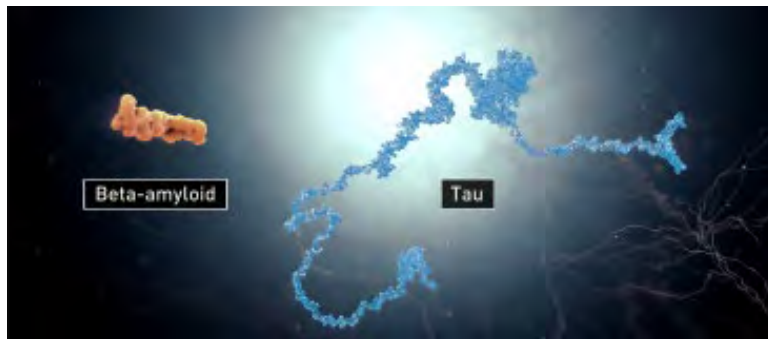
In Florida, there are 580,000 residents currently living with Alzheimer's disease (Alzheimer's Association, 2020a). By 2025, this number is expected to increase by more than 200,000.

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.

Did You Know . . .

Worldwide more than 50 million people live with dementia and this number is expected to **double** by 2030 and **triple** by 2050.

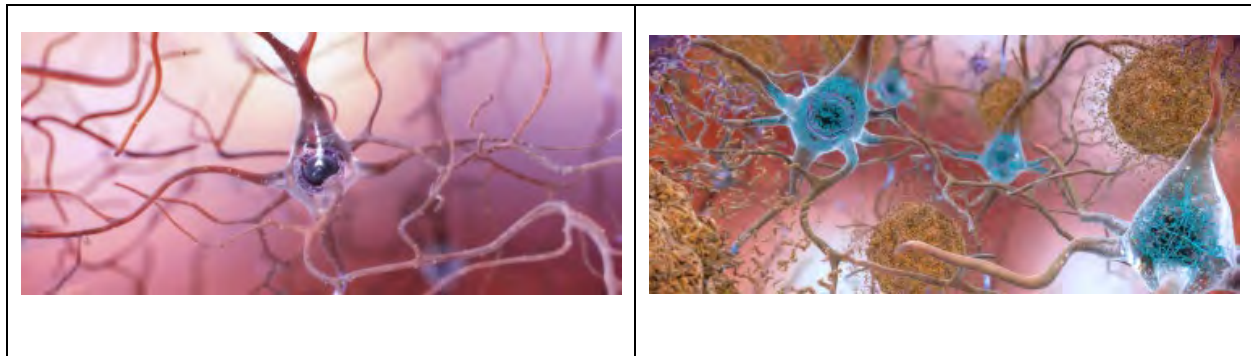
The exact cause of Alzheimer's dementia is still unknown. In Alzheimer's disease, and likely in other forms of dementia, damage within the brain is thought to be due to the formation of *beta-amyloid plaques*, the formation of *neurofibrillary tangles*, and degeneration neurons in the cerebrum.



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

Brain imaging techniques such as 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

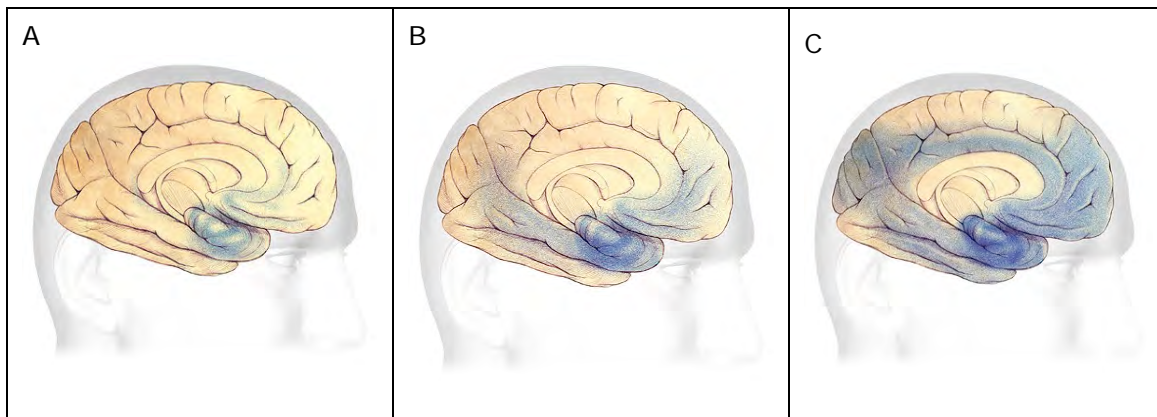


Left: A healthy neuron with many connections to other cells. Right: A dying nerve cell showing the nerve connections weakening and the main body of the cell deteriorating due to the presence of amyloid plaques and tau tangles. Source: Image courtesy of the National Institute on Aging/National Institutes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

In Alzheimer's, the progressive brain damage attributed to the formation of unwanted beta-amyloid plaques and neurofibrillary tangles is illustrated in the drawings below, which show the formation and spread of plaques and tangles (in blue). The blue areas represent damaged and dying nerve cells.

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 cognitive 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.

The Progression of Alzheimer's Disease



A: Plaques and tangles (shaded in blue) are beginning to form within the hippocampus. B: As the disease progresses, they spread towards the front and rear of the brain. C: In severe Alzheimer's, plaques and tangles cause widespread damage throughout the brain. Source: The Alzheimer's Association. Used with permission.

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). Vascular dementia 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 is a general term used to describe changes in cognition resulting from impaired blood flow to the brain. It can be caused by a stroke or a series of small strokes or any condition that causes brain damage or reduces blood flow to the brain. Generally, vascular dementia doesn't affect memory as much (or in the same way) as Alzheimer's, at least in its early stage. Symptoms are related to the part of the brain experiencing reduced blood flow.

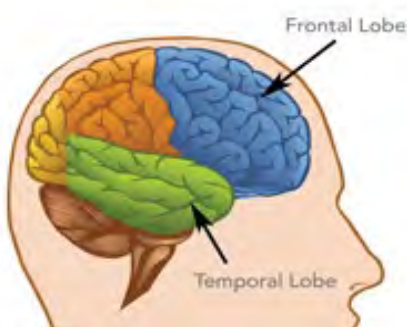
Vascular dementia can cause mood changes that are stronger than the mood changes you might see in someone with Alzheimer's. It can also affect judgment—but not as strongly as in someone with frontal-temporal dementia. It can be difficult to differentiate vascular dementia and Alzheimer's dementia because they can occur together. Cognitive changes can be gradual or occur in noticeable steps downward from a person's previous level of function.

Risk factors for developing vascular dementia include diseases or disorders that damage the vessels supplying blood to the brain. 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, 2020). Risk factors associated with vascular dementia include hypertension, heart rhythm irregularities, diabetes, high cholesterol, smoking, sleep-disordered breathing, and a sedentary lifestyle (UCSF, 2020).

Frontal-temporal Dementia

Frontotemporal dementia begins in the frontal and temporal lobes of the brain. It is believed to start at an earlier age than Alzheimer's disease and is a relatively common type of dementia in those under the age of 60. New research, however, is showing that frontotemporal dementia can start in older age. It is thought to be responsible for 5-10% of all cases of dementia (although its prevalence is likely underestimated). 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 behaviors. Damage to this part of the brain can lead to mood swings, disinhibition, inappropriate touching, loss of social decorum, loss of empathy in addition to language difficulties and problems with spatial orientation.



Damage to the brain's frontal and temporal lobes causes forms of dementia called frontotemporal disorders. Left source: National Institute on Aging. Right source: Alzheimer's Association, 2020 Used by permission.

Frontal-temporal dementia is usually categorized under three subtypes:

1. Behavior variant frontotemporal dementia (bvFTD)—changes in personality and behavior that can affect people in their early 50s and 60s. Affects judgement, empathy, foresight, and planning.
2. Primary progressive aphasia (PPA)—usually begins before the age of 65. Affects language skills, reading, writing, and comprehension.
3. Disturbances of motor function, muscle weakness or wasting, without behavioral or language problems.

(Alzheimer's Association, 2020c)

Because frontotemporal 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 frontotemporal dementia and Alzheimer's disease. It can also be confused with other psychiatric conditions such as late-onset schizophrenia.

Dementia with Lewy Bodies

Dementia with Lewy bodies (DLB) is another common type of progressive dementia. It accounts for up to 20-30% of all autopsy-confirmed dementias in older adults (Vermeiren et al., 2015).

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, 2019).

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, 2019).

Parkinson's Disease Dementia

Mild cognitive impairment is common in the early stages of Parkinson's disease and a majority of people with Parkinson's disease will eventually develop dementia. The time from the onset of movement symptoms to the onset of dementia symptoms varies greatly from person to person.

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.

Lewy body dementia and Parkinson's dementia are now recognized in the Diagnostic and Statistical Manual of Mental Disorders, where they are respectively coded as "Major and Mild Neurocognitive Disorder with Lewy Bodies" and as "Major and Mild Neurocognitive Disorder due to Parkinson's Disease" (Donaghy and McKeith, 2014).

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).

Functional Impairments

Dementia impairs judgment, alters visual-spatial perception, and decreases the ability to recognize and avoid hazards (Eshkoor et al., 2014). It also affects short-term memory and is thought to impair *working memory*, a type of memory that promotes active short-term maintenance of information for later access and use. The decline in working memory also affects language comprehension and visuospatial reasoning (Kirova et al., 2015).

When cognitive impairment is mild, studies indicate that lower attention/executive function or memory function may lead to a decline in gait speed. This is especially apparent when a person is walking and doing another task at the same time such as walking and talking, walking and crossing a busy street, or walking and carrying groceries—called “dual-task walking”. Slow gait speed may indicate deficits in the cognitive-processing speed or in executive and memory functions. The decline in cognitive function in people with mild cognitive impairment is not uniform, but rather depends on the type of cognitive impairment (Doi et al., 2014).

Because of these visual and perceptual changes, walking on a busy street can be dangerous, driving is no longer safe, and navigating around obstacles such as curbs, breaks in the sidewalk, stairs, and pets is a challenge. Visual and spatial difficulties also affect reading, comprehension of form and color, peripheral vision, and the ability to see contrast. This can make it difficult to accurately detect motion and process visual information (Quental et al., 2013).

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

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

Vascular dementia can cause impaired decision-making and judgment; mood changes are also common. Symptoms often begin suddenly and progress in a “step-wise” manner. This means the symptoms stay the same for a period of time, and then suddenly get worse, usually as a result of additional small strokes or other vascular damage. Mental impairment often seems “patchy,” because of the many different areas of the brain that are affected.

In the early stages of frontotemporal dementia, judgment and decision making are more affected than memory. There is a progressive change in behavior (mood changes, apathy, and disinhibition*), difficulties with language, and weakness or slowing of movement. People with frontotemporal 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.

The impulsive behavior and lack of judgment seen in people with frontotemporal dementia can cause inappropriate behaviors such as stealing, falling prey to internet or phone scams, excessive shopping, indecent exposure, and obsessive-compulsive behaviors such as pacing and hoarding.

Functional impairments associated with dementia with Lewy bodies include progressive cognitive decline, “fluctuations” in alertness and attention, visual hallucinations, and parkinsonian motor symptoms, such as slowness of movement, difficulty walking, or rigidity (stiffness) (NINDS, 2019). Nearly half of those with DLB also suffer from depression (Vermeiren et al., 2015).

Difficulty sleeping, loss of smell, and visual hallucinations can precede movement and other problems by as long as 10 years. Because of this, DLB can go unrecognized or be misdiagnosed as a psychiatric disorder until its later stages (NINDS, 2020).

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, 2020). Cognitive issues such as impaired memory, lack of social judgment, language difficulties, and deficits in reasoning can develop over time. Autopsy studies show that people with Parkinson’s dementia often have amyloid plaques and tau tangles similar to those found in people with Alzheimer’s disease, though it is not understood what these similarities mean.

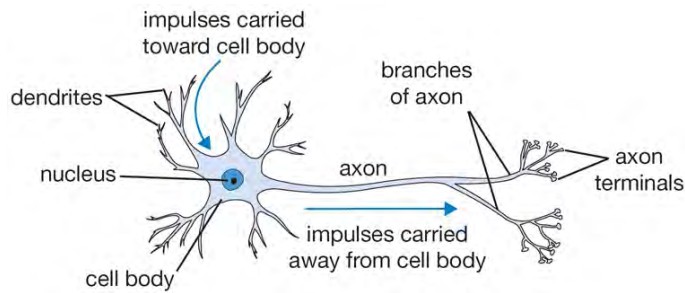
3. Normal Brain Functions and Normal Aging

Normal 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. Some of these changes are due to deconditioning, lack of exercise, and diet. But 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.

Normal Brain Changes with Age

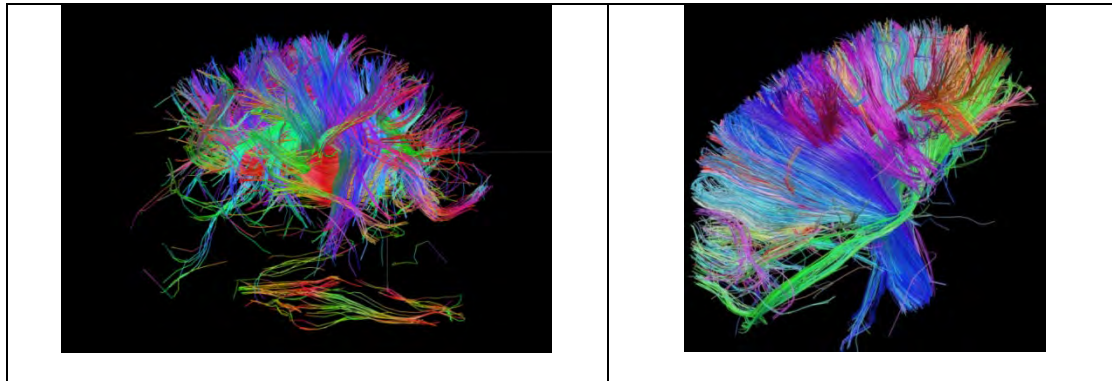
An aging brain—one not affected by dementia—experiences changes. Certain parts of the brain shrink a little although there is not a significant loss of nerve cells, as occurs in Alzheimer’s disease. Shrinkage typically is found in the prefrontal cortex and the hippocampus, areas of the brain important to learning, memory, planning, and other complex mental activities. There are also normal changes in neurotransmitters, which affect communication between nerve cells.

In certain brain regions, white matter (myelin-covered axons) is degraded or lost. This affects our brain’s ability to send and receive nerve impulses and to interact with neurons in other parts of the brain. When axons lose some of their ability to transmit a nerve signal efficiently, brain function is affected.



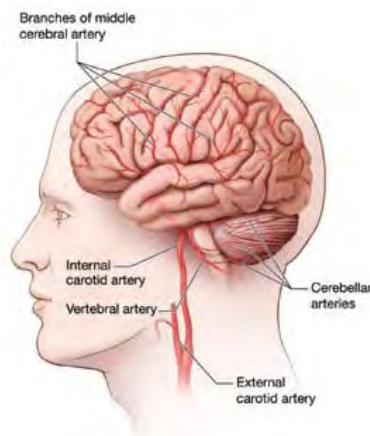
An illustration of a healthy neuron showing the nucleus, cell body, dendrites, and axons. Source: WPClipArt.com. Used with permission.

Because white matter connects the different regions of the brain, even a little loss or breakdown of myelin can affect cognition. You can see in the following images the massive amount of white matter within the human brain.



White matter fiber architecture of the brain. Measured from diffusion spectral imaging (DSI). The fibers are color-coded by direction: red = left-right, green = anterior-posterior, blue = through brain stem. Source: www.humanconnectomeproject.org. From <http://www.humanconnectomeproject.org/gallery/> L = row 12, #2 R=row 9, #3

As we age, changes in the brain's blood vessels can also occur. Blood flow can be reduced because arteries narrow and there is less growth of new capillaries.



The main arteries supplying blood to the brain. The brain receives blood through a vast network of arteries, arterioles, and capillaries. As we age, this network is less efficient than when we were young.

Due to these normal, age-related 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, 2019).

Cognitive training can counteract age-related structural and functional losses; memory training can increase the thickness of the cerebral cortex. Memory training has been shown to enhance activity in the hippocampus during memory retrieval in clients with mild cognitive impairment. Physical exercise has also been found to affect brain function positively (Zheng et al., 2015).

As we age, walking speed and stride length decrease, while lateral sway increases. But because of the flexibility of our brain—called neural plasticity—these age-related changes can be partly compensated for through conscious effort. In this way, deficits in one part of the nervous system can be overcome by engaging another part of that system (Beurskens & Bock, 2012).

Differentiating Normal Aging and Dementia

Someone with age-related changes can easily do 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. They know how to take care of themselves. 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 involves the impairment of memory and other cognitive functions (language, learned motor skills, visuospatial/sensory skills, executive functions). The impairments need to be sufficiently severe to affect social or professional life, and must not occur as a consequence of delirium, or be caused by another medical, neurologic, or psychiatric condition (Chertkow et al., 2013).

Mild Cognitive Impairment

Mild Cognitive Impairment (MCI) represents 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).

Although mild cognitive impairment has been described as a transitional stage between normal cognitive aging and dementia, particularly Alzheimer's disease, studies suggest that individuals diagnosed with this disorder do not always progress to Alzheimer's disease and may even revert to normal (Lee et al., 2014).

The onset of mild cognitive impairment has traditionally been associated with cognitive decline that affects social and occupational functioning and is accompanied by changes in behavior and personality (Chertkow et al., 2013). There are no tests that reliably indicate the presence of mild cognitive impairment; differentiating normal aging and mild cognitive impairment relies on screening, assessment, and client history (DeFina et al., 2013).

Cognitive Reserve and Cognitive Health

Cognitive reserve is a theoretical concept that suggests that individuals differ in their degree of resilience against age-related brain pathology. These differences are linked to the ability of an individual to recruit protective mechanisms associated with cognitive abilities built up over the lifespan, and actively compensate for damage caused by pathology (Evans et al., 2018).

Cognitive reserve highlights the brain's ability 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 in cognition are evident. People vary in cognitive reserve because of differences in genetics, education, occupation, lifestyle, leisure activities, or other life experiences. These factors may provide the ability to adapt to change and damage that occurs during aging.

For one individual, depending on a person's cognitive reserve and unique mix of genetics, environment, and life experiences, 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 (NIH, 2016).

Observational and some experimental evidence suggests that reserve can be built up through a combination of experiences throughout life, such as physical exercise, education, occupation, and participation in social and cognitively stimulating activities. These experiences may create a buffer against cognitive decline by enhancing brain processes such as neural connectivity and hence cognitive ability. This might protect an individual against the effects of disease pathology, compensate for damage, and recruit alternative neural pathways when required. This may reduce or delay the extent of impairment experienced and protect against the expression of pathological processes (Evans et al., 2018).

Cognitive health is a major factor in ensuring the quality of life of older people and preserving independence. Cognitive health is the development and preservation of a cognitive structure that allows older people to maintain social connectedness, an ongoing sense of purpose, and the ability to function independently, to successfully recovery from illness or injury, and to cope with any functional deficits. The key components of cognitive health are mental abilities and acquired skills, as well as the ability to apply these skills in purposeful activity (Clare et al., 2017).

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.

How Dementia Affects Cognition

Dementia is a syndrome, a collection or grouping of symptoms that can affect, damage, or destroy cells in the brain. Dementia is *progressive*, meaning it gets worse over time. Dementia can be the main cause of brain disease or it can develop as a result of accidents, tumors and cysts, concussions, cardiovascular disorders, uncontrolled diabetes, neurologic disorders such as Parkinson's disease, alcohol and drug abuse, and a number of other disorders and diseases.

Dementia affects cognition: thinking, memory, judgment, learning, language comprehension, attitudes, beliefs, safety awareness, morals, and the ability to plan for the future are all affected to some degree. Dementia also affects motor and sensory functions such as balance, spatial awareness, vision, pain processing, and the ability to modulate (control) sensory input.

Potentially Treatable Conditions

There are many conditions that can affect cognition, causing dementia-like symptoms; some of these conditions are reversible with appropriate treatment:

- Reactions to medications or interactions between medications
- Metabolic and endocrine abnormalities
- Nutritional deficiencies
- Infections
- Constipation
- Head injuries and subdural hematomas
- Poisoning from exposure to lead, heavy metals, or other poisonous substances
- Alcohol, prescription medications, and recreational drugs
- Brain tumors, space-occupying lesions, and hydrocephalus
- Hypoxia or anoxia (not enough oxygen)
- Autoimmune cognitive syndromes
- Epilepsy
- Sleep apnea (NINDS, 2020)

Delirium and depression 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.

Delirium

Delirium characteristically has an acute onset, fluctuating course, and the presence of an underlying medical condition, medication or psychoactive substance, or medication/substance withdrawal. Patients with behavioral and psychological symptoms of dementia can also have superimposed delirium as a cause for an abrupt worsening of their usual symptoms. History is the key to differentiating behavioral and psychological symptoms from delirium: in delirium, the onset of symptoms occurs over days to 1 to 2 weeks, while in behavioral and psychological symptoms of dementia, symptoms gradually worsen over several weeks to months (Cloak and Khalili, 2020).

Patients with delirium frequently have changes in the level of consciousness, such as periods of somnolence or extended periods of wakefulness, which are typically less prominent in behavioral and psychological symptoms of dementia. Visual hallucinations may be prominent in delirium, whereas delusions are more common in patients with behavioral and psychological symptoms of dementia. It can be challenging to distinguish Lewy body dementia from delirium, since patients with Lewy body may have visual hallucinations and fluctuations in the level of consciousness, but these symptoms will have a more gradual onset than in patients with delirium (Cloak and Khalili, 2020).

Patients with suspected delirium should have a thorough medical evaluation, beginning with history and physical and followed by targeted laboratory testing and imaging based on these findings; typically, comprehensive metabolic panel, CBC, urinalysis, cardiac enzymes, chest X-ray, and toxicology screens are performed routinely, with neuroimaging, lumbar puncture, blood gases, and EEG reserved for select cases. Unlike behavioral and psychological symptoms of dementia, symptoms related to delirium will resolve, albeit sometimes gradually, once the underlying cause is corrected (Cloak and Khalili, 2020).

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, metabolic changes, an unfamiliar environment, injury, or severe pain.

Inattention is the most frequent clinical finding in a delirium episode. Other symptoms include difficulty with:

1. Orientation
2. Memory
3. Language and thought
4. Visuospatial abilities
5. Deficits in visual perception such as illusions and hallucinations

Cerejeira and Mukaetova-Ladinska, 2011

Video: Patient Experience of Delirium (5:51)

<https://vimeo.com/31892402>

Source: European Delirium Association

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).

Depression

Depression is a disorder of mood involving a disturbance of emotions or feelings. The diagnosis of depression depends on the presence of two cardinal symptoms: (1) persistent and pervasive low mood, and (2) loss of interest or pleasure in usual activities. Depressive symptoms are clinically significant when they interfere with normal activities and persist for at least two weeks, in which case a diagnosis of a depressive illness or disorder may be made (Diamond, 2015).

Because of these complexities, diagnosing depression in patients with dementia can be difficult. Denial and cognitive impairment may compromise self-report of depressive symptoms. As a person's dementia progresses, the presentation of depression may alter, with non-verbal behaviors such as demanding behavior and clinging being more apparent than cognitive features. Moreover, autonomic symptoms such as poor concentration and anhedonia* are features of both depression and dementia (Dudas et al., 2018).

* **Anhedonia**: a reduction in, or complete lack of ability, to enjoy activities the person usually finds enjoyable.

Although depression can be hard to recognize in people with dementia, there is evidence that it is common and associated with increased disability, poorer quality of life, and shorter life expectancy. Many people with dementia are prescribed antidepressants to treat depression, but it is uncertain how effective they are (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—as two separate neuropsychiatric diseases. 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.

Along with apathy, depression is one of the most common mood disorders in Alzheimer's disease (Nowrangi et al., 2015). 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).

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).

Early Detection and Referral

The majority of patients with Alzheimer's disease experience neuropsychiatric symptoms during the course of their disease. This can include behaviors such as apathy, agitation, and psychosis, and are already highly prevalent in patients in the early stages of AD including those with mild cognitive impairment (Eikelboom, Singleton, van den Berg et al., 2019).

The majority of people with dementia currently do not receive a formal diagnosis. Only 20% to 50% of dementia cases in high income countries are recognized and documented in primary care, and this "treatment gap" is even greater in low- and middle-income countries. Early diagnosis of dementia is crucial since some treatments are more effective in the early stages, and earlier diagnosis and timely intervention provide health, financial, and social benefits (Ciblis et al., 2016).

Neuropsychiatric symptoms are very common in patients with mild cognitive impairment and Alzheimer's disease dementia and are associated with various disadvantageous clinical outcomes, including a negative impact on quality of life, caregiver burden, and accelerated disease progression. Despite growing evidence of the efficacy of (non)pharmacological interventions to reduce these symptoms, neuropsychiatric symptoms remain underrecognized and undertreated in memory clinics (Eikelboom, Singleton, van den Berg et al., 2019).

Ultimately, the most successful model of treatment for Alzheimer's disease will likely include early detection and control of physical factors (diabetes, hypertension, hyperlipidemia), followed by application of multifaceted, disease-modifying interventions to prevent the early and continued loss of neurons and to reduce the toxins that result in further cell deterioration (DeFina et al., 2013).

5. Mental Status Tests

Diagnosis of dementia is clinical in nature. Testing is usually done by a specialist, starting with a thorough history, a detailed medical and neurologic examination, and a formal mental status exam, including cognitive testing (Chertkow et al., 2013). The goal is to determine if there has been a cognitive change, and if so, whether it indicates the onset of dementia or the presence of a disease, infection, drug interaction, or anything else that may cause a cognitive change.

The American Psychiatric Association's Diagnostic and Statistical Manual of Mental Disorders (Fifth Edition) (DSM-5), defines dementia (also known as major neurocognitive disorder) as **a significant decline in 1 or more cognitive domains that interferes with a person's independence in daily activities**. The 6 cognitive domains identified in the DSM-5 are:

1. complex attention,
2. executive function,
3. learning and memory,
4. language,
5. perceptual motor function, and
6. social cognition.

(USPSTF, 2020)

Neurocognitive Screening

Screening is a method for detecting dysfunction before an individual would normally seek medical care. Ideally, screening identifies very early signs of dementia and refers clients who may need a more thorough cognitive assessment. Screening can also identify changes associated with reversible causes and treat conditions that may contribute to cognitive decline (Yang et al., 2016).

The Affordable Care Act directs clinicians to conduct an assessment of possible cognitive impairment in Medicare patients during their Annual Wellness Visit. As many as 29% to 76% of patients with dementia are unrecognized in the primary care setting. Screening usually involves asking patients to perform a series of tasks that assess at least one cognitive domain (USPSTF, 2020, February 25).

Neurocognitive Screening Tools

There are many screening tools that assess cognitive change, although no one tool is recognized as the best brief assessment to determine if a full dementia evaluation is needed (Alzheimer's Association, 2020b). Screening tests are not intended to **diagnose** mild cognitive impairment or dementia; a positive screening test result should lead to additional testing. This can include blood tests, radiology examinations, or a neuropsychologic evaluation to confirm the diagnosis of dementia and determine its subtype (USPSTF, 2020, February 25).

The most widely used tools are the *Mini Mental State Examination* and the *Montreal Cognitive Assessment*. 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).

The *Montreal Cognitive Assessment* is often used to assess mild cognitive impairment. 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.

Other screening instruments include the Clock Drawing Test, Mini-Cog Test, 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).

For non-clinicians, family, and friends, a mental status screen such as the *AD8 Dementia Screening Interview* can be useful. This tool looks at whether there has been a change or no change in:

- Judgment
- Interest in hobbies/activities
- Perseveration (repeating things over and over)
- Trouble learning how to use a tool or device
- Forgetting the month or year
- Trouble handling finances
- Trouble remembering appointments
- Daily problems with thinking or memory (Galvin et al., 2007)

Limitations of Neurocognitive Screens

Despite a large body of evidence examining cognitive screening instruments, most instruments have been tested in only a few well-designed studies. The tests most likely relevant to screening in primary care are very brief instruments, with an administration time of 5 minutes or less (USPSTF, 2020, February 25).

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 shows education and language/cultural bias (Yang et al., 2016) and both tools may be impractical as screening tools because they take at least 10 minutes to complete.

Other limitations of neurocognitive screening tools can be one or more of the following:

- Language barriers
- Cultural competence and cultural differences
- 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—whether something is normal for that person

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 (Saito et al., 2014). Because of these obstacles, the U.S. Preventive Services Task Force 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).

UCSF Brief Clinical Index

For clinicians, differentiating between the subtle cognitive declines associated with normal aging and those that signify early dementia can be difficult. To help clinicians better understand the progression of Alzheimer's disease, researchers at the University of California at San Francisco developed a brief clinical index. The index utilizes 8 items:

Gender,

Four questions regarding caregiver report of the patients' behaviors (stubborn/resists help and upset when separated) and functional status (difficulty shopping alone and forgets appointments), and

Three items focusing on ability to complete basic cognitive tasks (10-item list word recall, orientation to time and place and clock draw test).

Researchers the brief clinical index to predict whether 382 older adults diagnosed with a certain type of mild cognitive impairment would progress to probable Alzheimer's disease within 3 years. They also used other measures, including demographics, comorbid conditions, caregiver report of participant symptoms and function, and participant performance on individual items from basic neuropsychological scales. In this study, subjects had a mean age of 75 years and 43% progressed to probable Alzheimer's disease within 3 years.

Important predictors of progression included being female, resisting help, becoming upset when separated from a trusted caregiver, difficulty shopping alone, forgetting appointments, number of words recalled from a 10-word list, orientation, and difficulty drawing a clock. Fourteen percent of subjects with low-risk scores converted to probable Alzheimer's disease over 3 years, compared to 51% of those with moderate risk scores and 91% of those with high-risk scores.

Source: Lee et al, 2014

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 both social and relational. Needs go unmet and social interactions gradually become more stressful and tiring. This can cause frustration, conflict, and depression and may lead to earlier placement in a care facility. Dementia reduces a person's ability to communicate effectively, which makes it more difficult for caregivers to identify the needs of the person they are assisting (Pham et al., 2015).

Communication changes are related to the area of the brain affected by the disease. In Alzheimer's, damage begins in a part of the brain that is responsible for the formation of new, short-term memories, called the hippocampus. 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. Located next to the hippocampus is a part of the brain called the amygdala, which is involved with emotional control. As short-term memory declines, emotional control also weakens, further affecting a person's ability to communicate effectively.



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 traits that allow us to function in society: judgment, planning, moral reasoning, logical thinking, and social behavior. Although these functions are affected by a person's memories, the brain changes caused by frontotemporal dementia affect judgment, moral reasoning, and social control. 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 general, communication can be fraught with misunderstanding, frustration, and surprise—even for people without cognitive decline. A person experiencing cognitive decline due to frontal-temporal dementia gradually loses decision-making abilities, has difficulties with sequencing a task, is unable to explain or understand complex ideas, and loses the ability to communicate through written and spoken words. Because there is a loss of judgment and social control, caregivers and family members may be faced with embarrassing moments in public that can include inappropriate comments and behaviors.

So instead of losing short-term memory like people with Alzheimer's disease, a person with frontal-temporal dementia might start behaving in a way that is confusing to their friends and family. They might steal, even though they have never stolen in the past. They might make inappropriate sexual remarks or engage in inappropriate sexual behaviors, even though they have never done these things in the past.

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. As a result, communication problems are usually less specific than in other types of dementia. 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.

Vascular dementia can cause mood changes that are stronger than the mood changes you might see in someone with Alzheimer's. It can also affect judgment—but not as strongly as in someone with frontal-temporal dementia. It can be difficult to differentiate vascular dementia and Alzheimer's dementia because they can occur together. Cognitive changes can be gradual or occur in noticeable steps downward from a person's previous level of function.

In **Lewy body dementia**, abnormal clumps of alpha-synuclein (Lewy bodies) form throughout the cortex, brainstem, and midbrain. The location of these clumps 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. Arguing, explaining, agreeing, or validating the paranoia or delusion is usually ineffective. Emotional support, quiet touch, and redirection are more effective than verbal communication.

Areas of Brain Associated with Communication

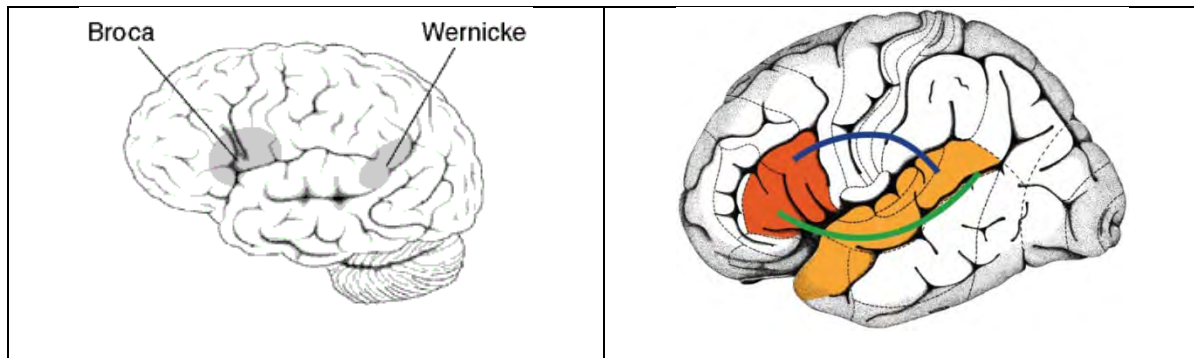
Certain parts of the brain are responsible for speech and language. These areas are mainly located in the left side of the brain. These brain regions and their connections form a network that provides the hardware for language in the brain. Without this network, we would not be able to talk to or understand 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 is also related to our emotions. 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.

How Dementia Affects Communication

Dementia affects our ability to communicate, as well as our ability to comprehend what others are trying to communicate. As dementia progresses, there is:

- A loss of ability to find the right word
- A tendency to describe objects rather than naming them
- An inability to finish sentences or express cohesive thoughts
- The loss of train of thought
- A tendency to revert to language of origin
- The need for longer periods of time to respond (Zeman, 2015)

A person with dementia:

- Has difficulty finding a word
- Creates new words for ones that are forgotten
- Repeats a word or phrase (perseveration)
- Has difficulty organizing words into logical sentences
- Curses or uses other offensive language
- Reverts to their original language
- Talks less than usual (Alzheimer's Society of Canada, 2019)

Managing Communication Challenges

Caregivers may fail to understand that good communication is a learned skill. Poor communication increases confusion and stress for the person with dementia and can also cause confusion and stress for the caregiver. The ability to communicate with people whose speech or hearing is impaired by cognitive decline is a skill that can be developed with practice. Several therapeutic interventions have been developed to work directly with people with dementia on an individual or group basis, and also indirectly with family and professional caregivers, to improve communication and quality of life for people with dementia (Pham et al., 2015).

Direct, simple phrases are recommended. Appropriate touch can signal the start of a conversation or a change in topic. Nonverbal cues such as simple hand signals can be helpful. Well-designed, meaningful individual or group activities can improve communication skills. The focus of group activities is on improving or maintaining functional skills, including communication.

A Physical Therapist Uses Sign Language

When I was younger, I took several classes in American Sign Language at the local community college. After graduating from PT school, I started working in stroke rehab and noticed that the signs I learned were helpful when communicating with people who were experiencing language deficits following a stroke. It didn't take me long to realize that simple signs also worked well for people in various stages of cognitive decline. Using simple, nonverbal cues was relaxing for me—it was quiet, direct, and successful!

Bella, PT, Miami

How you talk to a person influences how they respond. Techniques that improve communication and reduce agitation, confusion, fear, or anxiety include:

- Approaching from the front or side and sitting or kneeling at eye level
- Assessing a person's body language
- Monitoring your 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

(Zeman, 2015)

Communication habits of the caregiver affect the success or failure of interactions with a person experiencing cognitive changes. Poor communication can be a major driver of behavioral symptoms and increase agitation, confusion, fear, and anxiety. Communication habits to be avoided include:

- Speaking "down" to a person
- Using infantilizing words: "she's just like a baby"
- Using complex or lengthy explanations
- Speaking too quickly
- Speaking in an impatient voice
- Failing to allow time for the person to process what you are trying to communicate
- Rushing through any activity (Gitlin & Vause Earland, 2010)

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 90-years old woman who moved from Phoenix to live with her daughter in Santa Rosa, California following a brainstem stroke. She is struggling with mobility and also having 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 she was given a feeding tube due to swallowing problems. When she arrived in California, she was able to walk a few steps with a walker and 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 and has difficulty with memory and recall.

Timeline: Because of her improvement, Hallie's daughter feels her mother might enjoy the local adult day care program. The first time they attend, Hallie is withdrawn and refuses to participate in any activities—even drawing. The activities director, Celana, tries to engage Hallie in a conversation but she just smiles and asks where her mother is. Celana asks Hallie to tell her about her mother but she doesn't (or can't) answer. When Hallie's daughter comes to pick up her mom the day care center administrator reports that Hallie didn't participate in any activities and wouldn't budge from her recliner—even to use the bathroom. Celana feels that, with some gentle encouragement, Hallie will begin to participate in activities. She reports her observations and concerns to the facility administrator.

Intervention: The staff discuss Hallie's situation after the center closes that evening. The administrator asks Jenitra, 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 a nurse and the administrator rightly thinks that Hallie may be comfortable talking to a nurse. When Hallie arrives the next day, Jenitra, 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 without success.

Hallie is very quiet and seems confused. She asks Jenitra where she is and again asks for her mother. Jenitra 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. Jenitra asks her why and she says she is scared because she can't remember things. This provides staff members 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 day care, in a new living situation, and new to California. 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 is able to encourage 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 day care 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).

Behavioral and psychological symptoms can occur at almost any stage of Alzheimer's disease, and in some patients, these symptoms can even appear before memory deficits develop. The severity of the symptoms increases significantly 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 (depression, anxiety, irritability, euphoria, and apathy) to severe (agitation, aggression, vocalizations, hallucinations, impulsivity, psychosis, and disinhibition*). 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).

***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. Includes socially or sexually inappropriate behaviors.

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 be manifested in wandering, rummaging and hoarding, obsessive-compulsive behaviors, and sleep disturbances. Common causes of behavioral changes in people with dementia include:

- Brain changes, cell death
- Unmet physical needs (pain, discomfort, fatigue, boredom, lack of socialization, lack of meaningful activity)
- Challenging tasks (frustration due to inability to figure out or complete a task)
- Environmental issues (cold, heat, noise, uncomfortable chairs, too much or too little light)

Susan Howland, California Southland Chapter of the Alzheimer's Association

*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

Areas of the Brain Related to Behavioral Control

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 the thalamus, lentiform nucleus, and medial temporal cortex, 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. To understand why emotions, behavior, and memory are so strikingly affected by dementia, please view this video about the limbic system.

Video: Emotions: The Limbic System (10:31)

<https://www.youtube.com/watch?v=GDIDirzOSI8>

Source: The Khan Academy, 2013

Challenging Behaviors Associated with Brain Deterioration

Many challenging behaviors seen in people with dementia are associated with changes to the brain, although many are not. Dementia likely lowers a person's ability to cope with emotional frustrations such as excessive noise, boredom, and communication difficulties. But, in addition to changes in the brain, acute medical conditions, unmet needs, or pre-existing personality or psychiatric illness can have a profound effect on a person's well-being (Kales et al., 2015). Some of the most common of challenging behaviors in people with dementia are apathy, agitation and aggression, delusions and hallucinations, wandering, obsessive behaviors, and sleep disturbances.

Apathy

Apathy causes a lack of interest or emotion, loss of motivation, and blunting of emotions. It may be an early symptom of cognitive impairment, especially in someone with frontotemporal dementia, vascular dementia, or post-stroke.

Apathy is different from depression although apathy and depressive symptoms may occur together (Volicer & van der Steen, 2014). 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.

Apathy is often under-recognized, under-diagnosed, and poorly managed. It is the cause of distress for caregivers because it places the responsibility for day-in and day-out decisions on them. Over time, this can lead to anger and conflicts between patients and caregivers. This makes apathy a risk factor for institutionalization (Rea et al., 2014).

Agitation and Aggression

Agitation is observable, non-specific, restless behaviors that are excessive, (seemingly) inappropriate, and repetitive. This can include verbal, vocal, or motor agitation (Burns et al., 2012). Examples of agitation include becoming easily upset, repeating questions, arguing or complaining, hoarding, pacing, inappropriate screaming, crying out, disruptive sounds, rejection of care, and leaving home (Kales et al., 2015).

Aggression, on the other hand, involves physically or verbally threatening behaviors directed at people, objects, or self. Aggression includes verbal insults, shouting, screaming, obscene language, hitting, punching, kicking, pushing and throwing objects, and sexual aggression (Burns et al., 2012).

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 frontotemporal 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, helps to regulate 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 are often 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. These behaviors often occur during personal care tasks involving close caregiver-resident contact (Burns et al., 2012).

Pain is also associated with agitated and aggressive behaviors. Nursing home residents with relatively severe pain are more likely to display these behaviors. Agitation and aggression occur in about 50% to 80% of nursing home residents with cognitive impairments (Ahn & Horgas, 2013).

Delusions and Hallucinations (Psychosis)

Psychosis is a disturbance in the perception or appreciation of objective reality (Burns et al., 2012). This can include delusions* and hallucinations**.

***Delusion**: a false idea or belief or a misinterpretation of a situation.

****Hallucinations**: sensory events in which a person hears, tastes, smells, sees, or feels something that is not there.

Hallucinations are particularly common in people with Parkinson's disease dementia and dementia with Lewy bodies (DLB). In fact, the presence of recurrent visual hallucinations is one of the main features in the clinical diagnosis of DLB. Delusions and hallucinations can trigger other neuropsychiatric symptoms, such as agitation or aggression (Vermeiren et al., 2015).

Visual hallucinations have been studied using a special type of CT scan. A group of patients were examined and scanned for illusions, simple visual hallucinations, and complex visual hallucinations. The CT scans showed 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). These damaged areas of the brain caused:

- Problems recognizing shape, color, position in space, and movement
- Visual distortions
- Errors in visual processing (Heitz et al., 2015)

Delusions and hallucinations have also been associated with changes in the amount and availability of certain neurotransmitters within the brain. In particular, too much 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.

The first step in the management of delusions and hallucinations is to rule out delirium as a cause (see Module 3 for more on delirium). Another important factor is to determine if the claims by the person with dementia actually did occur (Burns et al., 2012).

With regards to psychosis, antipsychotics are the primary pharmacologic treatment option, although they may cause serious side effects, increase mortality rates—and their efficacy is “modest” at best. The administration of psychotropic medication has also been associated with a more rapid cognitive and functional decline, and not necessarily with improved neuropsychiatric symptoms (Vermeiren et al., 2015).

The pharmacologic treatment of neuropsychiatric symptoms in someone with dementia with Lewy bodies requires a cautious approach. All drugs with anticholinergic side effects, such as tricyclic antidepressants, low potency neuroleptics, antiparkinsonian anticholinergic drugs, and antispasmodics for bladder or gastrointestinal tract, should be avoided due to their potential to exacerbate psychotic symptoms. The administration of memantine (Namenda) may result in variable symptomatic side effects in patients with dementia with Lewy bodies, including worsening of psychosis or even an adverse drug reaction (Vermeiren et al., 2015).

Wandering or “Walking About”

Wandering has been defined as the inability of older adults with dementia to find their way while pursuing a need or goal. The behavior has also been referred to as a normal human activity that people engage in during their lifetime. Wandering is associated with terms such as “elopement”, “endangered”, and “getting lost” (Adekoya and Guse, 2019).

More than half of persons with dementia will “wander” into the community at some point during the course of their disease. In nursing homes, wandering is often referred to as “aimless walking” (Adekoya and Guse, 2019).

Wandering can include aimless locomotion with a repetitive pattern, hyperactivity, and excessive walking, as well as leaving a safe environment and becoming lost alone in the community (Rowe et al., 2011). Wandering is more common in people with Alzheimer's disease than other types of dementia (Burns et al., 2012).

The desire to move about can be related to boredom, pain and discomfort, or disorientation. The tendency for people with Alzheimer's dementia to wander may be related to memories and habits from the past, buried deep in long-term memory.

When healthcare workers perceive wandering as a problem and disruptive to their care routines, they may want to control or prevent the behavior. However, preventing residents from wandering could mean their losing the associated benefits of walking, including improved circulation and oxygenation and decreased risk of contractures (Adekoya and Guse, 2019).

Interventions for wandering have prevented the behavior using physical and pharmacological restraints. 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 option and include the use of electronic tagging and tracking devices, behavioral approaches, exercise, music therapy, aromatherapy, camouflage 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 day care, the management of wandering should, at a minimum include:

- Identifying risk for wandering,
- Providing appropriate staffing and supervision,
- Reducing environmental triggers for wandering, and
- Using individualized nursing interventions to address the causes of wandering behavior (Silverstein & Flaherty, 2018).

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 can arise 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.

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.

Of the estimated 5.8 million people in the United States living with Alzheimer's disease and related dementias, at least one-third have difficulty sleeping and approximately two-thirds of their estimated 18.5 million 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
- Sleep fragmentation (waking often)
- Increased early-morning awakenings
- Decreased total sleep time
- Decreased slow-wave and rapid-eye-movement (REM) sleep
- Episodes of delirium or disorientation during sleep
- Increased daytime napping and excessive daytime sleepiness
- Agitation, verbally disruptive behaviors, hallucinations, and nighttime wandering (Burns et al., 2012)

Medications can affect daytime alertness and can cause sleep disturbances. In particular, antidepressants, benzodiazepines, and non-benzodiazepines 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.

Inappropriate Behaviors

A person's ability to control and monitor inappropriate behavior is an important social skill. The ability to inhibit certain actions allows us to suppress actions inappropriate for the behavioral context (Mayse et al., 2015). The loss of this ability—disinhibition—results in a lack of restraint, disregard for social convention, impulsiveness, poor safety awareness, and an inability to stop strong responses, desires, or emotions.

Healthcare providers and caregivers may label a behavior as inappropriate when, in fact, the behavior is completely appropriate to the situation. For example, wandering is logical to a client 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.

Inappropriate or disinhibited behaviors are particularly common in clients with frontotemporal dementia. Disinhibition, impulsivity, and socially inappropriate behavior are core diagnostic features of this disorder, together with perseveration, hyperorality,* loss of empathy, apathy, and executive dysfunction including cognitive inflexibility (Hughes et al., 2015).

***Hyperorality:** the tendency to insert inappropriate objects in one's mouth.

Anxiety and COVID-19

An extended lockdown, as is occurring during the COVID-19 pandemic, with imposed self-isolation and change or deprivation of usual daily activities causes stress in both patients and caregivers. Factors triggering an increase of pandemic-related psychiatric disorders may be related to isolation, restrictions on movement, loss of social contacts and relationships, and loneliness. Anxiety and depression may arise from the rapid need to adapt to a new lifestyle and changes to day-to-day routines. In addition, increased alertness due to fear of contagion and grief or even mourning for the loss of family members or friends may undermine mental health wellbeing (Cagnin et al., 2020).

Changes in neuropsychiatric symptoms in people with dementia may exacerbate the psychological effects of lockdown in their caregivers, a situation which may further worsen behavioral symptoms, acting in a vicious loop. Lack of activities and cognitive and physical stimulation may cause delirium in individuals with dementia, contributing further to morbidity. There is also increase evidence that psychological symptoms due to stressor events can contribute to cognitive decline (Cagnin et al., 2020).

Employee Response to Inappropriate Behaviors

Direct care workers, as well as licensed staff, often lack dementia-specific training, which can effectively address inappropriate behaviors in their clients with dementia. Because clients in adult day care tend to be in an earlier stage of dementia, they generally need less assistance than people in other long-term care settings, particularly with eating, walking, and toileting (Harris-Kojetin et al., 2016). Nevertheless, employees in specialized adult day care will encounter challenging 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 reminding yourself that each person is worthy of respect—this is the basis for **person-centered care**. Also remember that there is usually a reason for the unwanted behavior—even if you don't understand that reason. Keep in mind the safety of the client, as well as the safety of staff. Follow these guidelines:

1. Use person-centered care as the basis for your interactions with all clients. This means treating clients and caregivers with dignity and respect.
2. Try to determine the cause of the behavior using the problem-solving approach.
 - **Antecedent**—what *caused* the behavior?
 - **Behavior**—what *is* the behavior?
 - **Consequence**—what are the *consequences* of the behavior?
3. Consider the safety of clients and staff.

Caregivers should be prompted to describe what they are seeing, rather than using generic terms such as “agitation” or “depression,” which can have different meanings to different observers. Other essential elements include the onset (i.e., acute, sub-acute, or chronic/progressive), frequency, timing, and trajectory of the disturbances, and any relationship to environmental changes or medication changes. There may be a temporal relationship with events such as a change in environment (e.g., moving from home to nursing facility), or symptoms might worsen in the evenings, following family visits, or when providing personal care (Cloak and Khalili, 2020).

Responding to Challenging Behaviors (6:36) Teepa Snow

<http://teepasnow.com/resources/teepa-tips-videos/challenging-behaviors/>

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 may be caused by any number of factors including fear, hunger, environmental issues, boredom, side effects of medications, loud noises, lack of exercise, or pain, among other things. In this example, Callie, a 96-year-old resident in an assisted living memory care unit with moderate to severe dementia, suddenly (and quietly) began to remove her clothes during a birthday party in the dining room.

Client Information: Callie was a resident in an assisted living facility memory care unit. Although she can walk with assistance, she usually prefers to sit quietly by herself in the living room. She rarely interacts with other residents and prefers simply to watch visitors come and go. Callie rarely smiles and 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: One weekend, on a very warm day in August, a family member arranged for a birthday party in the living room for her mother. All the residents were invited, including Callie, but the weekend staff forgot to take Callie to a quiet area. 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 resident 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 remainder 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 for 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. Staff members were reminded that Callie was 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 disturbances as 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 (e.g., distraction, giving patients clear instructions and simple choices, not rewarding the behaviors). 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 crossover study showed that training caregivers to deliver a protocol called *Bathing without a Battle* (available online at <https://bathingwithoutabattle.unc.edu/>) reduced agitation, bathing time, and antipsychotic use (Cloak and Khalili, 2020).

Engaging people in regular activities may be a dementia prevention strategy. Participation in specific physical, cognitive, and socially stimulating leisure activities during mid-life reduces the risk of dementia in later life by 28% to 47% (Dannhauser et al., 2014). This activity-associated risk reduction may be due to the positive effects that specific activities have on known modifiable dementia risk factors that cause an estimated 50% of dementia and include physical and cognitive inactivity, obesity, hypertension, and diabetes (Dannhauser et al., 2014).

Cognitively stimulating activities are also associated with reduced risk of cognitive decline in later life and more pronounced effects are related to increased complexity of activities and associated environments. Social activities are also associated with reduced dementia risk. Socializing robustly stimulates memory, attention, and executive processing (Dannhauser et al., 2014).

Person-Centered Care

Person-centered care is a philosophical approach that states that a person with dementia deserves kind and supportive treatment with the rights that we reserve for any other individual, namely dignity, respect, and autonomy. Person-centered care promotes inclusion of the person living with dementia and their caregivers in care and treatment decisions, with the aim of increasing positive outcomes for both (Handley et al., 2015).

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 in which the person living with dementia can experience relative well-being (Røsvik and Rokstad, 2020).

Person-centered care focuses on valuing the person, upholding personhood, meeting psychological needs, adopting the person's perspective, and ensuring a supportive social environment for people living with dementia. Existing approaches draw upon relationship-centered, rights-based, recovery, environmental, and family caregiver-based models to inform understandings of how best to achieve this (Rapaport et al., 2020).

Person-centered care has been shown to reduce agitation and improve quality of life in nursing home residents (Ballard et al, 2019). Interventions based on this approach have lowered the rate of neuropsychiatric symptoms, falls, and the use of psychotropic drugs in nursing home residents with dementia (van de Ven et al., 2014).

Person-centered care 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 in order to improve the quality of healthcare, especially long-term care.

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 patients with behavioral symptoms of dementia, helps establish priorities regarding the nature and urgency of interventions, characterize the symptoms, identify potentially reversible exacerbating factors, including environmental factors, medications, discomfort, substance use, and pre-morbid psychiatric disorders; and create a baseline for measuring the effectiveness of treatment. The goal of the physical examination is to confirm historical data and identify alternative or contributing psychiatric or general medical conditions (Cloak and Al Khalili, 2020).

The goal is to understand and supporting a client's history and needs by:

- Building relationships with clients and families
- Understanding their concerns and how illness has affected their lives
- Engaging in inter-professional collaboration
- Providing effective case management
- Developing good communication between clients and healthcare providers (Constand et al., 2014)

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 (Campenel & Brummett, 2010).

Identifying how a person with dementia might experience a lived space is important not only to compensate for their incapacities but also to facilitate their continuous engagement and activity in society. Among the central principals for the design of dementia-friendly environments are safety and security, simplicity, good structure, and familiarity (Førsund et al., 2018).

Simple, structured, and familiar environments orient people and support wayfinding. Familiarity is related to predictability and continuity; it is also important for creating a sense of being at home in addition to supporting social relationships, identity, autonomy, and privacy. These are important elements of the experience of lived space (Førsund et al., 2018).

A *therapeutic environment* is an environment that is supportive of individuals with dementia and their families. It 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 (Campenel & Brummett, 2010).

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 (Campenel & Brummett, 2010). Unfamiliar, chaotic, or disorganized environments have the opposite effect—they can 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. Examples include:

- Providing private spaces and a separate room or recess for sleeping or napping
- Providing easily accessed public spaces and places for semi-private interactions
- Keeping public spaces clean and getting rid of odors
- Providing sunlight, ventilation, and getting rid of dark nooks and crannies
- Providing views to the outside
- Replacing institutional, centralized nursing stations with smaller, residential-looking stations
- 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)

Although the following video from the Social Care Institute for Excellence explains 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>

Evidence-Based Intervention Programs

Well-designed interventions utilizing the skills of various team members have been shown to reduce or even eliminate agitated or aggressive behaviors (Burns et al., 2012). Staff education has been shown to lead to reductions in behavioral outbursts and fewer episodes of restraint use (Nowrangi et al, 2015).

“Multimodal” interventions are recommended, which means using 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.

Psychosocial and Environmental Interventions

Cognitive stimulation, music therapy, exercise, massage, therapeutic touch, acupuncture, and tactile massage have been shown to 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.

Cognitive Therapy

Cognition-based interventions typically involve a range of activities and discussions, can be conducted one-on-one or in groups, and are aimed at general enhancement of cognitive and social functioning. A Cochrane Review concluded that general cognitive stimulation and reality orientation consistently produced improvements in general cognition and, in some cases, in self-reported quality of life and well-being, primarily for people with mild to moderate dementia (Bahar-Fuchs et al., 2013).

Cognitive stimulation therapy (CST) is a treatment 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, while providing an optimal learning environment and the social benefits of a group. CST is the only evidence-based treatment recommended for people with mild to moderate dementia in the National Institute for Health and Care Excellence dementia guidelines based on the evidence that it can improve cognition in people with mild to moderate dementia over and above any medication effects (Binns et al., 2020).

Social Participation and Social Identity

People with dementia describe experiences of loss that threaten their autonomy and ability to contribute to society. They often have difficulties with orientation, loss of role function, and fear about the future, and need help from others.

Many studies have described challenges and sources of stress that people with dementia encounter. They report of loss of autonomy, control, and connection. They see themselves as “different” and no longer normal. Memory problems, other symptoms of dementia, and the unpredictable progression of the disease lead to worry and anxiety (Bjørkløf et al, 2019).

Needs change; the need to be looked after and to be taken care of increases, and new social and emotional needs arise. People report feeling stigmatized, embarrassed, or stupid. Dementia threatens people’s identity and sense of worth and changes their roles and the relationship to others. Taking part in social events and meaningful activities becomes more difficult. Consequently, some feel that they lack competency and may not be contributing as much as they would like, for instance in household and society (Bjørkløf et al, 2019).

Loss of social contact and meaningful activities lead to loneliness, isolation, emptiness, and boredom and many people feel it is necessary to adjust life expectations. The decline in function and abilities have great impact on daily life and some express that life loses purpose, and that happiness is gone. There is concern for the future and the unpredictable nature of the progression of dementia (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 be related to the loss of 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.” Widespread ageism may lead individuals to avoid groups for older people in case they become identified as “old” and thus stigmatized (Goll et al., 2015).

Some may try to uphold independent and youthful identities. They frequently emphasize their self-sufficiency, distinguish themselves from “old” people whom they described as dependent and decrepit, and may avoid opportunities for support in case this marked them as old and dependent. Some may avoid social situations that contradict their preferred identities and wish for opportunities that

instead provided identity-reinforcement (Goll et al., 2015).

Some older adults may avoid social participation out of fear of rejection or exploitation. Social fears have been linked to loneliness and social isolation in working-aged adults and in lonely older people. Loneliness can reflect a lack of perceived safety in social situations, which leads to cognitive and behavioral patterns that reinforce loneliness (Goll et al., 2015).

Talking therapies like Cognitive Behavioral Therapy (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. From: <http://www.nia.nih.gov/alzheimers/publication/2013-2014-alzheimers-disease-progress-report/caregiving-and-alzheimers>

The Benefits of Respite Care

Respite care provides short-term relief for primary caregivers. It can be arranged for just an afternoon or for several days or weeks. Care can be provided at home, in a healthcare facility,

or at an adult day center. Respite services charge by the hour or by the number of days or weeks that services are provided. Most insurance plans do not cover these costs. You must pay all costs not covered by insurance or other funding sources. Medicare will cover most of the cost of up to 5 days in a row of respite care in a hospital or skilled nursing facility for a person receiving hospice care. Medicaid also may offer assistance (NIA, 2017).

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.

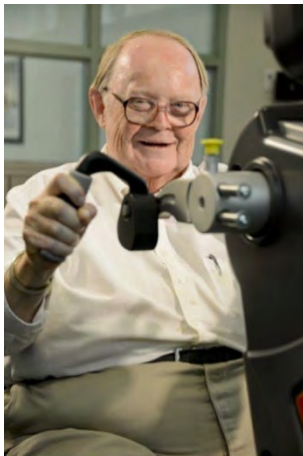
There is evidence that respite care reduces caregiver burden and depression and increases feelings of well-being. Caregivers receive a break, feel less hostile toward the care recipient, and use fewer negative coping strategies. When people with dementia attend a day care program, caregivers experience benefits from improved sleep patterns and report decreased behavioral problems in the care-recipient (Stirling et al., 2014).

Despite the benefits to the caregiver, day care services are underutilized. Some reasons include:

- Caregiver guilt
- Negative beliefs about care-recipient outcomes
- Financial costs of day care services
- Reluctance on the part of the caregiver to hand over responsibility for caregiving to the day care facility (Stirling et al., 2014)

Exercise and Physical Activity

Growing evidence suggests that lifestyle factors have a significant impact on how well non-demented people age, and 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 provide a protective effect against cognitive decline, and this 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.

A growing body of evidence suggests that 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. This evidence suggests that exercise improves the ability to perform basic activities of daily living such as eating, dressing, bathing, using the toilet, and transferring from bed to chair. However, the effects of conventional exercise on other important outcomes such as cognitive function, mood, behaviors, and quality of life were less consistent (Barnes et al., 2015).

At the University of California at San Francisco, a recent pilot study involved an integrative group exercise program for individuals with mild-to-moderate dementia. The program, called Preventing Loss of Independence through Exercise (PLIÉ), focused on training procedural memory* for basic functional movements such as sit-to-stand while increasing mindful body awareness and facilitating social connection (Barnes et al., 2015).

***Procedural memory:** a type of long-term memory that is responsible for storing information related to motor tasks such as walking, talking, cooking, and other learned tasks.

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 magnitude of improvement observed with PLIÉ was substantially larger than what has been observed with currently approved dementia medications (such as cholinesterase inhibitors and memantine) and affects a broader range of outcomes (Barnes et al., 2015).

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. In the area of mental health, it releases an automatic relaxation response, 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 amount of medications, and reduces physical pain (Klimova et al., 2019a).

For individuals with dementia, animal-assisted therapy:

- Contributes to slightly higher physical activity; people can pet the animal, or in better cases, they can 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. (Klimova et al., 2019a).



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

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. One of the care workers described her reaction to the behavior of a female client:

I do not think she always knows that she pinches us ... then we try to get away ... we pretend that nothing has happened and her behavior is a great challenge to us, because her inhibitions against hitting and kicking are very low.

Another care worker described her reaction to wandering. Residents who wandered around or repeatedly said that they wanted to go home were identified as a challenge. The caregivers regarded such behavior as a symptom of dementia that affected other residents. They noted that when one patient wants to go home, others also want to go home (Lykkeslet et al., 2014).

All the time she wants to go someplace, but does not know where. She puts on a lot of clothes and walks around ... if I tell her the truth about where she is, she becomes irritated, resigned, or offended.

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' behavior 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 told about how 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).

Mrs. Del Rio's at Night

Mrs. Del Rio has moderate dementia and lives at home with 24-hour care from family members and a caregiver. She is often incontinent of urine at night and has been wearing a diaper for the last year when she is in bed. Her daughters usually have to change her diaper once or twice each night and occasionally need to change wet sheets if Mrs. Del Rio takes her diaper off at night. They keep a spare set of sheets and a pad handy just in case.

Antecedent: One night, Mrs. Del Rio's daughter is helping her mom get ready for bed. She bends over to help her mother put on the diaper, but her mother gets very angry and shouts, "I despise that thing, I won't wear it" and pushes it away. Her daughter explains the need to wear the diaper at night to keep from peeing in her bed. She also gets angry at her mother, thinking of her own fatigue and lost sleep when faced with the prospect of stripping a wet bed in the middle of the night. Mrs. Del Rio again refuses the diaper and climbs into bed.

Behavior: Mrs. Del Rio's daughter is confused—her mother has never refused the diaper before. She is worried that her mother's dementia is getting worse. She checks back in about an hour and slips a diaper onto Mrs. Del Rio while she is sleeping. A little while later she hears Mrs. Del Rio getting up to the bathroom and goes in to help her. She has torn off the diaper and angrily throws it to the ground. "I despise that thing and I won't wear it" her mother yells. Her bed is also wet.

Consequence: When her mother wets the bed, her daughter awakens fully and has a hard time getting back to sleep. She already gets up 2 to 3 times per night to check on her mother and can't imagine losing even more sleep. Sometimes she awakens and finds her mom asleep in a wet bed and very cold. Her mother has frequent urinary tract infections, and her daughters are making a concerted effort to keep Mrs. Del Rio clean and dry.

Discussion: Mrs. Del Rio's daughter tries to figure out what has changed. Her mother is usually easy to deal with and understands the reason for the diaper. After a little thinking she realizes that her mother might not like the new diapers she recently bought. They are too tight and chafe her mother's skin. She offers a slightly larger, softer diaper to her mother who replies, "Yes, thank you—that's much better. I love you" as she happily pulls up the diaper and climbs back in bed. In the morning both the diaper and the bed are completely dry. Mrs. Del Rio never complains about the diaper again.

9. Physical Causes of Symptoms or Pain Indications

Understanding pain and other acute medical symptoms in people with dementia is a significant challenge. The prevalence of pain in people with dementia is high; there is good agreement in both large and small studies that about 50% of the people with dementia regularly experience pain. This is not surprising, considering that advanced age is an important risk factor for developing pain (van Kooten et al., 2015).

For this elderly population, pain represents a significant problem due to the high prevalence of musculoskeletal disorders, cancer, neuropathy, and other medical conditions for which pain is a major symptom (Schneider et al., 2020). Pain can be associated with arthritis, chronic neurologic conditions, and skin breakdown. Inactivity, uncomfortable beds and chairs, and lack of exercise contribute to discomfort and pain from these conditions.

Failing to address pain in people with dementia can lead to declines in cognitive functioning, as well as declines in the performance of activities of daily living; pain is one of the most cited reasons for a decrease in quality of life in dementia. Therefore, recognition and adequate treatment of pain in people with dementia should have high priority (van Kooten et al., 2015).

Key points about pain in people with dementia:

- People with dementia feel pain.

- Pain is **not** a normal part of aging.
- Pain may be difficult to assess.
- Pain is often caused by other medical conditions.
- Clients may be unable to tell you they are in pain or accurately describe the pain.
- Pain perception in a person with dementia may be increased compared to a person without dementia. (Volicer & van der Steen, 2014)

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, 36% had undetected illness that was associated with behavioral and psychological symptoms, including agitation, repeated questioning, crying out, delusions, and hallucinations (Kales et al., 2015).

Regular assessment should address uncomfortable physical symptoms, including pain, constipation, and urinary retention. Because pain is present in 46 to 56% of patients with dementia and the presence of pain is associated with increased behavioral and psychological symptoms, the past medical history should have a review for painful conditions (e.g., neuropathy, osteoarthritis, peripheral vascular disease), and caregivers should be asked about both the patient's self-report about pain and nonverbal signs of pain, because patients with dementia may demonstrate nonverbal signs of pain even though they do not report it (Cloak and Khalili, 2020).

The Pain Assessment in Advanced Dementia (PAINAD) scale or Face, Legs, Activity, Cry, Consolability scale (commonly used to assess pain in infants and children who are unable to self-report) are both reliable and valid tools for objectively evaluating and tracking pain. Most hospitals and some nursing homes use one of these instruments, and family caregivers can also be trained to use them (Cloak and Khalili, 2020).

Assessing Pain in Older Adults with Dementia

Undiagnosed and untreated pain is unacceptably high, with reported prevalence up to 32% in home-dwelling people with dementia and about 60% in nursing home patients with and without dementia (Husebo et al., 2016). The assessment of pain is fundamental to improve quality of life and reduce the risk of death in people with demented (Scuteri et al., 2020).

During a pain assessment, it is important to keep in mind that pain can appear in different forms (e.g., nociceptive pain, neuropathic pain, and central pain). Importantly, the occurrence of pain in dementia can lead to further complications in the patients' healthcare routine. At this moment, due to the COVID-19 emergency, many older adults with dementia and pain cannot travel to a hospital or clinic to receive their usual pain management routine (Scuteri et al., 2020).

Both physiologic and behavioral responses can indicate the presence of pain. *Physiologic* responses can include tachycardia, increased respiratory rate, and hypertension. *Behavioral* responses include splinting, grimacing, moaning or grunting, distorted posture, and reluctance to move. Underdiagnosed pain may induce behavioral and psychological symptoms like agitation, requiring the use of medications that can increase cerebrovascular accidents (Scuteri et al., 2020).

Healthcare providers may feel uncertain about assessing pain in clients with dementia. As verbal communication declines, pain detection and assessment become more difficult. Self-report is no longer a reliable means of reporting pain. Observable behaviors gain more and more importance as indicators of pain, namely facial responses, body movement/posture, and vocalization (Lautenbacher et al., 2018). Unfortunately, more than half of clients who were dying with advanced dementia experienced pain in the last week of life that was not satisfactorily managed (Volicer & van der Steen, 2014).

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, 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 fairly 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, ie, 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 specialist. The urologist put the daughters on the right track and fortunately they were able to use their own medical knowledge 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.

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 time frame for re-assessment should be directed by the needs of the client and the center's policies and procedures.

People experiencing cognitive impairment or dementia tend to voice fewer pain complaints but may become agitated or manifest unusual or sudden changes in behavior when they are in pain. Caregivers may have difficulty knowing when these people are in pain and when they are experiencing pain relief. This makes older adults with dementia vulnerable to both under-treatment and over-treatment.

The self-report of pain is typically viewed as the gold standard in pain assessment. In dementia, however, self-reports are limited by cognitive decline, which impairs the clients' ability to communicate about their pain. Dementia also causes a reduction in abstraction abilities, which reduces the clients' ability to comprehend and thereby use pain scales to indicate their pain (Oosterman et al., 2016). 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 patient self-reports.

In the absence of accurate self-report, observational tools must be used in both research and practice, based on the interpretation of behavioral cues to assess the presence of pain. This approach has resulted in a proliferation of pain assessment instruments developed to identify behavioral indicators of pain in people with dementia and other cognitive impairment (Lichtner et al., 2014).

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 in an overly loud voice "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 remained disoriented and very sleepy for the next 48 hours. Her pain was unaffected.

The most structured observational tools are based on guidance published by the *American Geriatrics Society*, which describe six domains for pain assessment in older adults:

1. Facial expression
2. Negative vocalization
3. Body language
4. Changes in activity patterns
5. Changes in interpersonal interactions
6. Mental status changes (Lichtner et al., 2014)

In people with dementia, these behaviors can overlap with other common behavioral symptoms or cognitive deficits such as boredom, hunger, discomfort, anxiety, depression, or disorientation. This increases the complexity of accurately identifying the presence of pain in patients with dementia and raises questions about the validity of existing instruments (Lichtner et al., 2014).

In a systematic review of reliability, validity, feasibility, and clinical utility of 28 pain assessment tools used with older adults with dementia, no one tool appeared to be more reliable and valid than the others (Lichtner et al., 2014). Because patient self-report often cannot be used in non-verbal older adults, the next best option is to question the person who is most familiar with the patient in everyday life; this is sometimes referred to as a “silver standard” (Lichtner et al., 2014).

Keeping these challenges in mind, three commonly used behavioral assessment tools can be used in assessing pain and evaluating interventions in cognitively impaired adults.

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.

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. These 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 sixty behaviors divided into four 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. It is unknown if a high score represents more pain than a low score. In other words, a patient who scores 10 out of 60 behaviors 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.

Advanced Dementia Scale (PAINAD)

Several observational scales for measuring pain in non-communicative patients have been developed. One commonly used scale is the Pain Assessment in Advanced Dementia (PAINAD). It is able to distinguish effect of analgesics and difference between various severities of pain (Volicer & van der Steen, 2014). This tool was developed by a team of clinicians at the E.N. Rogers Memorial VA Hospital in Bedford, Massachusetts and involves the assessment of breathing, negative vocalization, facial expression, body language, and consolability.

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

Treatment of dementia using medications mostly focuses on symptom management. There are no therapeutic interventions that have been found to stop the progression or reverse the deterioration caused by Alzheimer's disease.

People with dementia are more likely to take many 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. Although taking multiple medications may be necessary for the management of dementia and chronic diseases, 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 (Ruangritchankul et al., 2020).

Improper use of pain medications and polypharmacy increases the risk of drug interactions and developing adverse drug reactions in the elderly. The latter accounts for a great burden of disease in these patients including the need for hospital admission. A recent meta-analysis showed that among patients admitted to hospital because of adverse drug reactions, non-steroidal anti-inflammatory drugs were frequently related to these admissions. Optimal medical management and nursing care in pain treatment are thus essential to reduce morbidity and costs in older adults. Nevertheless, to implement appropriate pharmacologic pain management in practice remains a challenging task (Schneider et al., 2020).

Many studies have reported a high prevalence of polypharmacy and drug-related problems among older patients with dementia admitted to hospitals. Polypharmacy has been reported in 82–98% of this vulnerable population, potentially inappropriate medications in 22–96%, and drug-drug interactions in more than 40% (Ruangritchankul et al., 2020).



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Age-related pharmacokinetic and pharmacodynamic changes can pose higher risk for undesirable drug-related problems. Older people with dementia experience physiological changes that may increase their sensitivity to the neurological effects of medications, leading to 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. These medications are used in the hope of treating or slowing the progression of symptoms associated with dementia, to manage neuropsychiatric symptoms of dementia, and to treat other health conditions (Jordan et al., 2015).

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).

Whether to manage symptoms of dementia or co-morbidities:

- 25% to 50% of people with dementia receive antipsychotics
- One-third of care home residents receive antidepressants
- 10% to 20% of people with AD require anti-epileptics (Jordan et al., 2015)

FDA Approved Medications for Dementia

There are five FDA approved pharmaceuticals currently prescribed, which may temporarily slow cognitive, functional, and behavioral decline:

Cholinesterase Inhibitors

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

Increase Glutamate Levels

4. Memantine (Namenda [NMDA receptor agonist])

Combination

5. Namzaric (Aricept + Namenda)

The first three medications are cholinesterase inhibitors, which work by increasing the levels of acetylcholine, a neurotransmitter in the brain involved in learning and memory. Cholinesterase inhibitors are generally used for the treatment of individuals in the mild-to-moderate stages of Alzheimer's disease (Dou et al., 2018).

The fourth medication, memantine (Namenda), increases levels of glutamate, another neurotransmitter involved with learning and memory. Memantine is indicated for the treatment of moderate to severe Alzheimer's disease. Overall, findings have shown modest benefits for improving symptoms related to cognition, function, behavior, and clinical global changes (Dou et al., 2018).

The fifth medication, Namzaric, was approved by the FDA in 2014. It is a fixed-dose combination of memantine hydrochloride extended release (Namenda) and donepezil hydrochloride (Aricept). It is indicated for the treatment of moderate to severe Alzheimer's dementia in patients stabilized on memantine and donepezil. Namzaric is supplied as a capsule for once-daily oral administration. The capsules can also be opened to allow the contents to be sprinkled on food, to facilitate dosing for patients who may have difficulty swallowing (CenterWatch, 2020).

Side Effects

Although anti-dementia drugs have been widely adopted since they came onto the market in the mid-1990s, little research has been on the prevalence of adverse side effects. Most available studies have been funded by drug companies, and they may underestimate the adverse events that occurred because of, for example, reporting bias (Imai et al., 2020). Nevertheless, side-effects are widely reported, if mostly anecdotally.

Typical side effects that occur with the use of acetylcholinesterase inhibitors such as Aricept, Exelon, and Razadyne, include gastrointestinal symptoms such as vomiting and diarrhea and psychiatric symptoms such as excitability, insomnia, and hallucinations. Patients taking NMDA receptor antagonists such as Namenda sometimes experience adverse events such as dizziness and lightheadedness (Imai et al., 2020).

A nationwide survey of attending pharmacists in Japan found that the prevalence of adverse events caused by anti-dementia drugs exceeded 20%. The results suggest that adverse events resulting from anti-dementia drug therapy are more common than has been acknowledged to date (Imai et al., 2020).

The most common adverse event in both males and females was excitement/insomnia, occurring in close to half of patients. Poriomania*/violent behavior occurred in more than 20% of patients. Excessive mental excitement and uncontrollable physical movement is a frequent and marked adverse event in anti-dementia drug therapy. There is a previous report stating that excitement/insomnia associated with adverse events in anti-dementia drug therapy suggests that the dose being taken is not appropriate. Because acetylcholinesterase inhibitors are metabolized by the liver and NMDA receptor antagonists are excreted renally, in elderly patients in whom these functions are reduced, it is likely that the blood concentrations that are optimal for therapy could be exceeded, resulting in mental excitement (Imai et al., 2020).

***Poriomania**: an irresistible, impulsive desire of wander off or run away. Can be conscious or accompanied by retrograde amnesia.

Antipsychotics

Atypical antipsychotics are often used off-label to manage dementia-associated behavioral symptoms of dementia. The 2016 American Psychiatric Association practice guideline on the treatment of agitation or psychosis in patients with dementia recommends a patient-centered plan-of-care that incorporates nonpharmacologic and pharmacologic approaches. Antipsychotics are recommended as part of this approach when symptoms are serious, dangerous, or cause significant patient distress. Currently, no medication has been approved by the Food and Drug Administration for the treatment of dementia-associated neuropsychiatric symptoms, including agitation (Rubino et al., 2020).

Although there is only modest evidence suggesting clinical improvement from the use of antipsychotics in people with dementia, there is increased risk of adverse health outcomes and mortality. Antipsychotics can have a sedative effect, leading to adverse drug events, falls, fractures, and excess sedation. Nevertheless, these drugs remain widely used in people with Alzheimer's disease and other types of dementia.

Several large clinical trials have demonstrated an increased risk of mortality when antipsychotics are used by people with dementia. There is increased risk of cerebrovascular accident and greater rate of cognitive decline and mortality. Antipsychotics should be avoided for behavioral problems of dementia or delirium unless nonpharmacological options have failed or are not possible and the older adult is threatening substantial harm to self or others (Fixen, 2019).

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" (Fixen, 2019). 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:** In 1991 Beers and colleagues published an expert consensus document that attempted to establish criteria for identifying medications that are inappropriate for use in older adults. 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>

Best Practices in Adult Day Care

Adult day care staff should be aware of any medications a client is using that may affect cognition or lead to an adverse event. Older adults with dementia are susceptible to dehydration, which can affect drug absorption rates. Some medications can increase the risk of falls while others affect cognition. Weight loss and extremely low body fat 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 day care staff are allowed to "supervise self-administered medication" which means:

- Reminding participants to take medication at the time indicated on the prescription
- Opening or closing medication containers or assisting in the opening of pre-packaged medication
- Reading the medication label to participants
- Observing participants while they take medication
- Checking the self-administered dosage against the label of the container
- Reassuring participants that they have obtained and are taking the dosage as prescribed
- Keeping daily records of when participants received supervision
- Immediately reporting apparent adverse effects on a participant's condition to the participant's physician and responsible person (O'Keeffe et al, 2014)

Supervision of self-administered medication must not be construed to mean that a center shall provide such supervision to participants who are capable of administering their own medication (O'Keeffe et al., 2014).

No client who requires medication during the time spent at the center and who is incapable of self-administration can be admitted or retained unless there is a person licensed according to Florida law to administer medications. 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

People with cognitive decline often develop eating and swallowing problems, which can strongly affect nutrition. Difficulty swallowing, changes in appetite, and changes in eating habits occur as dementia progresses. Malnutrition and dehydration affect general health, worsen the frequency and seriousness of complications (especially infections) and can lead to a loss of independence. These symptoms are affected by cognitive decline, behavioral symptoms, and decline of daily activity (Kai et al., 2015).

Despite these issues, nutrition is an almost totally neglected area of focus 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).

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 (ADI, 2014). Malnutrition in older adults with dementia:

- Increases frailty, skin fragility, falls, hospitalization, and mortality.
- Tends to be progressive, with weight loss often preceding the onset of dementia with increases as the disease progresses (ADI, 2014)

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 responsible for the hospital admission of older adults in the United States and is associated with increased mortality and morbidity. 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).

Physiologic changes that affect nutrition and hydration include:

- Changes to the gastrointestinal system (impaired chewing ability, reduced function of salivary glands, impaired esophageal motility, decreased gastric secretion, reduced intestinal absorptive surface)
- Stomach feels full sooner
- Impairment of the central feeding drive
- Reduction of taste and smell (loss of sensitivity, decrease in the number of taste receptor cells, poor oral hygiene)

Risk Factors for Malnutrition and Dehydration

Risk factors for malnutrition and dehydration include:

- Illness
- Swallowing disorders
- Food and drug interactions
- Mouth problems (sores, ill-fitting dentures, mouth pain, weakness, tremors)
- Depression and loneliness, being housebound
- Lack of properly trained, individualized help
- Lack of oral care
- Unappetizing food and food served cold
- Cultural differences
- Skipped meals
- Reduced mobility
- Staff neglect

Signs and Symptoms of Malnutrition and Dehydration

The mechanisms underlying weight loss and undernutrition in dementia are only partly understood. Reduced appetite plays a role, as does the disruption of eating and feeding due to cognitive and behavioral problems. Changes in the central regulation of appetite and metabolism may also play a key role (ADI, 2014).

Signs and symptoms of **malnutrition** include:

- Weight loss and decreased muscle mass
- Lightheadedness and dizziness
- Inability to keep warm
- Constipation or diarrhea
- Difficulty swallowing
- Sore mouth or swollen and bleeding gums
- Recurrent infections
- Fatigue or weakness
- Bloated abdomen

Signs and symptoms of **dehydration** include:

- Thirst
- Dry skin
- Fatigue
- Sluggishness
- Dizziness
- Confusion
- Nausea

As dementia progresses—especially in the severe stage, a person may begin to refuse food and drink. Hand feeding can be stigmatizing, and some people may resist being helped in this way. Many people experience difficulties with swallowing, aspiration, choking, and chewing but failing to swallow.

Aversive, resistive behaviors can be related to:

- **Dyspraxia/agnosia:** unable to use utensils, unable to distinguish food from non-food
- **Resistance:** turns head away, blocks mouth with hands, bites caregiver, spits or throws food
- **Oral neuromuscular incoordination:** difficulty opening mouth, continuous tongue or mouth movements, chews without swallowing
- **Food preferences:** will only eat certain food or fluids (ADI, 2014)

Strategies for Addressing Malnutrition and Dehydration

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.

Promoting independent, pleasurable eating and drinking should focus on three levels:

1. **Environmental:** ritualizing the mealtime experience by creating a controlled stimulated environment.
2. **Social:** structuring effective mealtime social interactions.
3. **Individual:** individualizing eating assistance (Palese et al., 2018).

Ritualizing the mealtime experience can involve such things as ringing a bell to announce a mealtime, creating a home-like dining room, and maintaining a peaceful environment. A positive social experience involves ensuring good social interactions, balancing independence, and being aware of when, and in what order, each resident needs to be served. Individualizing eating assistance means knowing what each person needs, providing more assistance as more is needed, and addressing difficulties with utensils (Palese et al., 2018).

Direct interventions that address malnutrition and dehydration include modifying food and drink, providing food or drink-based supplements and social support, assisting with eating or drinking, and managing swallowing problems. **Indirect interventions** include modifying the dining environment or food service, and educational, behavioral, exercise, and multicomponent interventions (Abdelhamid et al., 2016).

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 dietitian services should be available (ADI, 2014).

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:

- 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 (Murphy and Holmes, 2015).

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

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

Source: Bournemouth University

Assistive Tableware

Assistive or adaptive tableware have been a mainstay in nursing homes and assisted living facilities for many years. Unfortunately, assistive tableware is not used as much as it could be, and users of assistive table settings can feel different and stigmatized (ADI, 2014).

A common strategy is to simplify the number of utensils by providing just a plate and spoon with pureed or diced food that can be eaten without needing to be cut up by the client. However, clients can push the food off the side of the plate when they are trying to pick it up. To address this, a plate with a high lip in its profile that helps to push the food onto the spoon is recommended (ADI, 2014).



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. From <http://www.eatwellset.com/#!features/cf1a>

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 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 similar to 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 a cup made from ceramic but from a mold with a double skin and an air-filled cavity between the inside and outside surfaces. This keeps the liquid warm while the outside of the cup remains cool (ADI, 2014).

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, in particular 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 (ADI, 2014).

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 of 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).

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.

Addressing Concerns about Malnutrition, Undernutrition, and Dehydration

Addressing nutritional needs of older adults with dementia requires consistency, diligence, knowledge, and patience. As we age, a thousand little things begin to change. As a person's dementia progresses, there will be a need for help with shopping and food preparation. 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, leading to the risk of malnutrition and dehydration.

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:

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.

(ADRC, 2018)

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.

Frequently, older adults do not meet the official recommendations for intake of fruits and vegetables. Many community-dwelling older adults lack at least one micronutrient and do not get enough protein in their diets. Fruits and vegetables are important sources of micronutrients, including vitamins E and C. Fiber, vitamins and micronutrients (iron, potassium, and calcium) and bioactive compounds (polyphenols, carotenoids, phytosterols) are frequently below recommended dietary allowances (Donini et al., 2013).

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). A higher protein intake is associated with higher muscle mass and a reduced loss of lean mass over time (Donini et al., 2013).

There is consistent evidence that macronutrient oral nutritional supplementation is effective in maintaining or improving weight among people with dementia. Supplements are well tolerated, with high levels of adherence under controlled clinical trial conditions (ADI, 2014).

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.

Person-Centered Care and Assistance with ADLs

Assistance with activities of daily living focuses on promoting independence and reducing the amount of help a caregiver must provide to the person needing assistance. Training, common sense, and appropriate assistive equipment are vital and can help the person you are caring for retain their independence as the dementia progresses.

Person-centered care, recognition of the perspectives of the person with dementia, and the creation of social environments that support well-being are important aspects of this type of care. 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. Because of the magnitude of its consequences, dementia-friendly or dementia-capable environments can help a person maintain independence in activities of daily living (Førsund et al., 2018).

For family caregivers, intimate knowledge of the preferences, likes, and dislikes of a family member is the basis for person-centered care. For professional caregivers, person-centered care means taking into account the opinions and concerns of the person with dementia as well acknowledging the contributions of family caregivers (Smebye & Kirkevold, 2013).

How to Assess if an Activity Is Meaningful

When caregivers understand how to provide meaningful activities that are matched to the abilities and interests of individuals with dementia, dramatic changes in agitation and reductions and improvement in overall symptoms can occur. In general, meaningful activities have these features (Mansbach et al., 2017):

1. Active participation
2. Activity content related to the interests and past roles of the participants
3. Activities that meet the basic psychological needs of identity and belonging

Whether an activity is meaningful can be assessed using a tool such as the Engagement in Meaningful Activities Survey. This 12-item survey asks participants, “The activities I do”:

1. Help me take care of myself
2. Reflect the kind of person I am
3. Express my creativity
4. Help me achieve something that gives me a sense of accomplishment
5. Contribute to my feeling competent
6. Are valued by other people
7. Help other people
8. Give me pleasure
9. Give me a feeling of control
10. Has just the right amount of challenge
11. Provide satisfaction
12. Help me express my personal values

(Eakman, 2012, Updated 2020)

Meaningful, Person-Centered Activities

People with dementia slowly lose the inability to create meaningful activities for themselves independently. To maintain quality of life and prevent development of behavioral symptoms, they must have the opportunity to continue to engage in activities that are adjusted to previous interests and the severity of their dementia (Volicer & van der Steen, 2014).

Meaningful activities should:

- Provide mental stimulation
- Reflect the past interests of the person with dementia
- Seek to maintain or slow the loss of skills without requiring the person to learn new ones
- Provide socialization, stimulation, and physical activity within the functional limits of the person with dementia
- Be sensitive to the cultural differences of those attending the activity
- Minimize failure (Zeman, 2015)



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 dementia care 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).

Supporting Independence in ADLs

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 (Harris-Kojetin et al., 2016). In general, about one-third of day care clients need help with toileting, about a quarter need help with eating, and about a third need help with medication management. Nearly half need some assistance with walking and about a third need help with transfers (Dwyer et al., 2014).

Assistive equipment and environmental design can 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 can reduce independence.

Familiarity also plays a role. In one example, Canadian researchers asked 27 older adults with mild, moderate, or severe dementia to test five faucet designs for ease of use. Although people with more severe dementia needed more help to turn the faucets on and off, all 3 groups needed more help with the less familiar design even though those faucets were considered to be better designed in terms of usability. The more familiar faucets correlated with lower levels of assistance from a caregiver, fewer operational errors, and greater operator satisfaction (Boger et al., 2013).



Faucets were ordered from least usable (left) to most usable (right) based on a human factors approach and most familiar (left) to least familiar (right) based on average years of exposure and commercial availability (Boger et al., 2013).

Routine and Structure in Adult Day Care

Often routines and schedules are related to the needs of staff or caregivers rather than the needs of the client. This is unfortunate because, for people with dementia consistent daily routines increase independence and can reduce the number and duration of challenging behaviors. A regular routine allows a person to know what to expect while giving caregivers a benchmark for evaluating a person's behavior.

When developing a schedule for someone with dementia:

- Plan the schedule carefully.
- Consider each person's capabilities and preferences.
- Try to continue familiar routines and schedules.
- Maintain mealtime routines.
- Maintain regular dental and healthcare appointments.
- Allow plenty of time.
- Note the effects of changes in routines.
- Consider issues that disrupt routines.

Although caregivers are responsible for maintaining a routine, they must be flexible and know when to make an adjustment. 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.

13. Validation 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 is implemented through the use of certain communication techniques, including using nonthreatening words to establish understanding; rephrasing the person's words; maintaining eye contact and a gentle tone of voice; 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 as having Alzheimer type dementia, are in the final stage of life, trying to resolve unfinished issues in order to die in peace. Their final struggle is important, and caregivers can help them. 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 the feelings lessen, people communicate more, and are less likely to withdraw into further stages of disorientation (VTI, 2020).

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, 2020).

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

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

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 the caregiver. A combination of validation and reminiscence helps confused clients experience joy from their earlier life and contributes to their overall quality of life (Zeman, 2015).

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 day care 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 might have stopped, knelt down beside Charles, offered her hand, and introduced her colleagues. She might have asked Charles if she could talk for a moment with her co-workers or 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 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.

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, 2015).

For most of us, being oriented to reality is essential. But reality orientation isn't helpful if the person is in the mid- to late-stage 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, 2015).

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.

Validation Therapy vs. Reality Orientation

Validation therapy and reality therapy differ in a number of 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. This in turn can improve self-esteem and reduce problem behaviors (Takeda et al., 2012).

Getting into Polly's Reality

Note: Please keep in mind that in this scenario, caregivers decided to use a “white lie” to encourage Polly’s participation in day care activities. Lying to a client is acceptable **only** as a last resort and if the truth leads to a poor outcome.

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 Peggy 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

Validation Therapy in Adult Day Care

Individuals' 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, 2015).

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), recommends the following guidelines when working with a person with dementia:

- Imagine yourself in the person's place.
- Avoid reality orientation except for early-stage dementia.
- Validate the person's feelings.
- Practice good communication skills and encourage independence.
- Avoid judgement, arguing or saying no.
- Consider the whole person, not just the dementia.
- Learn to use "feel goods" such as a hot bath, a cup of coffee, going to a movie, or even offering a piece of chocolate.
- Arrange for meaningful and important activities each day.
- Keep your sense of humor and use it wisely.
- Remember that religion can be a comfort.
- Expect the unexpected.

14. Safety: New and Proven Technologies

Cognitive decline, as well as sensory changes in vision, hearing, and proprioception* can 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 for older adults with dementia.

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

Technologies for aging are typically designed to support or enhance activities of daily living, personal health or safety, mobility, communication, and physical activity. Specific examples include vital signs monitoring and fall detection devices, mobile phones designed for seniors, and medication reminders (Peek et al., 2019).

Prevention

In recent years, interventions that include a combination of new technologies and more "traditional" care services have become increasingly popular in the field of dementia care. Because caregiver oversight constitutes the largest share of informal caregiving, new technologies for environmental safety and control can potentially reduce the time needed for supervision (Malmgren Fänge et al., 2017).

Did You Know

Leading causes of preventable death in the home and in the community include:

- Poisonings (37%)
- Firearms (29%)
- Falls (23%)
- Choking and suffocation (5%)
- Drownings (3%)
- Home fires (2%)

National Safety Council, 2020

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. As a person's dementia progresses, safety becomes more of a concern. Caregivers must (1) think prevention, (2) adapt the environment, and (3) minimize dangers.

Technologies that support people with dementia are often called "assistive technologies", and 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).

Safety in an Adult Day Care Center

Safety is a joint responsibility, shared by center operators, managers, healthcare workers, and volunteers. Safety policies and procedures must cover environmental safety, infection prevention, emergency procedures, handling of hazardous materials and chemicals, and creation of a disaster plan. The building's design must 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.

Because specialized adult day care centers have clients experiencing cognitive decline, safety policies and procedures must take into account needs and behaviors unique to that clientele. This means the center must have safety policies that address wandering, falls, aggressive behaviors, swallowing disorders, food preferences, and transportation safety, as well as staff training in these areas.

A day care center that provides services to people with dementia 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 (Tretteteig et al., 2017). Centers also contribute to safety by providing caregiver training and information about assistive equipment, transfer techniques, and safety planning in the home.

Technologies Related to Safety

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.

Computer-based technologies are increasingly being used to address safety concerns. Cameras, global positioning devices, text messaging, and wearable electronic devices that alert caregivers when a person is trying to leave a designated safe area can be useful.

Technologies recommended by dementia experts include:

- Analogue clock
- Personal management planners
- Pre-packaged medication system
- Electronic pill reminder
- Large number LED wristwatch
- Passive infrared beam to attract a person's attention and provide reminders
- Flood detectors
- Personal phone alarms
- Wireless remote key locator
- Internet mobile phone tracking device

(Dementia Australia, 2020)

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:

- Willingness to use
- Ease of learning
- Time to accept
- Willingness to keep
- Number of errors due to incorrect interactions
- Level of satisfaction (Abbate et al., 2014)

Despite the sophistication of healthcare technologies, little effort has been made to assess their usability and acceptability before deployment. 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 (Abbate et al., 2014).

Monitoring Wandering with a GPS Device

Wandering outside the home can put a person at risk of exploitation and injury and cause caregiver stress and anxiety. Often, however, the person does not wander 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 local shopkeepers, and the perception of autonomy afforded by “safe walking” (Milne et al., 2014).

One possible intervention to support safe walking is the use of electronic location devices such as Global Positioning System (GPS) navigation. In theory these devices can provide the exact coordinates of a person carrying a 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).

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 pro-active 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 falls prevention systems use are:

- **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.**

(Hamm et al., 2016)

Promising Practice for Older Adults

The Federal Highway Administration has developed a "Handbook on Designing Roadways for the Aging Population" which incorporates road design, retroreflective and larger signage, and engineering best practices to address functional challenges faced by older drivers and pedestrians. Florida, Iowa, and Michigan are currently leading the way in adopting these recommendations, part of a safe systems design approach for all road users.

National Safety Council, 2020

15. Caregiver Stress Management

In the United States, nearly 16 million caregivers provide almost *18 billion hours* of unpaid care to people with Alzheimer's and other dementias. Significantly, 85% of caregivers for elders in the United States are family members. Dementia profoundly affects these caregivers, who bear its emotional, physical, and financial burdens (Kahn et al., 2016).

Caregiving can be especially difficult for spouses, family members, and friends who may be in poor health and unable to take on the burdens of fulltime caregiving. Even trained healthcare providers can find it difficult to deal day in and day out with clients who have dementia.

Types and Causes of Stress

Although most caregivers are positive about the experience of caregiving, it is challenging to provide 24-hour care for a person with dementia. Thus, many caregivers suffer from stress and depression. A review of 37 studies on health consequences of being caregivers to family members with dementia found a majority of caregivers were over 60 years old and living in a state similar to chronic stress (Kabir et al., 2020).

Many spousal caregivers have health and well-being problems of their own, either pre-existing or arising from the role of caregiving activities, e.g. due to the tasks of caring and the distress associated with the role. Stress of a family caregiver may even reach a point that the person cared for may be transferred to a nursing home (Kabir et al., 2020).

Caregivers, especially those who are highly stressed, are at risk of depression and anxiety due to their caregiving role and related responsibilities. Many family caregivers report being highly burdened and having depressive symptoms. Depression may remain even after institutionalization or death of the care recipient. The intensity of caregiving is reported to be inversely related to the caregiver's quality of life. It can also cause a sense of isolation and loneliness (Kabir et al., 2020).

Did You Know. . .

It is generally accepted that the accumulated financial, physical, and psychological stress of caring for a person with dementia may increase a caregiver's risk of morbidity and mortality. Recent large, population-based studies however have suggested that morbidity and mortality rates for caregivers may be lower than for non-caregivers. This may be due to the physiological benefits of prosocial helping behaviors (Roth, Brown, Rhodes, and Haley, 2018).

Caring for an individual with dementia may be more stressful than caring for older adults with other serious disabilities. Research has identified associations between symptoms of dementia and reduced caregiver mental health, including anger, burden, anxiety, depression, guilt, and worry (Trapp et al., 2015).

Informal caregivers generally spend between five and 20 hours per day taking care of family members with dementia. Informal caregivers, like formal caregivers, also suffer from a gradually increasing physical, mental, and economic burden (Klimova et al., 2019b).

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. Caregiver burden increases the risk of depression and anxiety disorder, and 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).

How Stress Manifests Itself

For caregivers of people with dementia, stress can manifest in many ways. Caregivers may experience higher levels of psychiatric symptoms, depressive and anxiety disorders, poorer immune function, and even a higher death risk compared to non-caregivers or the general population (Blom et al., 2015).

Physical health problems related to caregiving, such as hypertension, cardiovascular disease, and sleep problems are also common. Social functioning problems include relationship challenges, greater family dysfunction, feelings of isolation, and inadequate social support. Health-related quality of life has been shown to be reduced in dementia caregivers (Trapp et al., 2015).

Family members can also become victims of stigma 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, because studies have suggested that caring for men with dementia is more arduous. Men with dementia tend to have more behavioral symptoms, such as disinhibition, aggression, and sexual inappropriateness, than women with dementia. These behaviors may be particularly stressful or embarrassing for caregivers and can increase their feelings of stress (Kahn et al., 2016).

Strategies to Reduce Caregiver Stress

In the early stage of dementia, family caregivers may not use healthcare or social services, which 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. Adopting a person-centered approach can help family caregivers deal with behavioral and cognitive changes and reduce a caregiver's sense of vulnerability and isolation (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, 2010

Recognizing that the caregiver is also a client can reduce caregiver stress improve outcomes—especially for caregivers of family members with dementia. Supporting and training caregivers can reduce caregiver illness and delay institutionalization.

Providing caregivers with the financial and emotional support needed to care for a family member with dementia has been shown to reduce caregiver stress. E-learning, especially web-based courses, provides a new form of healthcare learning, counselling, and assistance. It allows learners to study at their own tempo and enables greater access to personalized learning. To be effective, e-learning courses should be designed to meet the learner's needs in national, social, and cultural contexts (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 and exhibit little distress. 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).

The Role of Specialized Adult Day Care

Adult day care programs can play a key role in reducing caregiver burden by providing techniques for addressing 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 provide these benefits:

1. Facilitate 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 as well as increase wellbeing
4. Increase motivation for care and postponement of the need for residential care by offering information and support regarding dementia-related topics (Tretteteig et al., 2017)

Barbara and Jim

Barbara cares for her husband Jim 24/7 at home with very little help. She refuses to hire a caregiver and belittles her sister when she tries to help. Barbara is good at the medical side of caregiving but not so good at the emotional side. She is desperately in need of education, training, and respite. Barbara is in denial of her husband's dementia as well as her lack of knowledge. Her short temper, and her unwillingness to seek help has created a great deal of stress and, at times, abusive behavior toward Jim.

Friends and family have recommended that Barbara enroll her husband in adult daycare and that she attend a caregiver support group. She agrees to take her husband to adult daycare but refuses to attend a support group. When Barbara arrives to drop Jim off at the adult daycare center, Barbara meets Sana, the activities director at the center.

Sana just started a new job as an activity's director. She notes that Jim is cooperative and friendly but Barbara seems stressed out. Sana notices that Barbara is impatient with her husband and raises her voice in frustration when he doesn't get out of the car quickly enough. As soon as Jim is in Sana's hands, Barbara hops back into her car, waves, and speeds off.

Sana walks with Jim into the day care center and offers him a comfortable chair. When he sits down he turns to Sana and says urgently "Help me—she's trying to kill me!" This startles Sana and she's not sure what to do. Her first thought is that he has dementia and is probably just being paranoid. People with dementia have memory problems so maybe he doesn't really remember what happened 5 minutes ago. What should Sana do?

1. Pat Jim on the back and tell him you understand.
2. Wait until Barbara returns and tell her what Jim said.
3. Share this information with her supervisor.
4. Do nothing other than reassure Jim that he's safe and nothing bad will happen to him.

Sana remembers from her orientation that she is a mandated reporter, but since she is new to the job, she decides to discuss the situation with her supervisor first. Her supervisor is familiar with Jim's situation and tells Sana that APS is already involved.

The Role of Dementia Care Programs

Dementia care programs are multidisciplinary and multi-departmental programs designed to meet the daily individual needs of clients with dementia and their families. Friends and family members are encouraged to participate in a dementia care program. 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, services available, 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
- Plans activities that include family members
- Encourages family involvement in the planning of activities
- Informs family members about changes in 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

A dementia care program should include cues and themes to help clients remain oriented to their environment, electronic door security for safety, comfortable and familiar furniture, specialized foods and beverages, and regular personalized group and individual activities.

The effectiveness or even the existence of a good dementia care program is affected by several factors. Inequalities in care exist in rural communities, where access to memory care specialists, adult day care, and caregiver support groups is limited or absent. People from Black and minority ethnic groups often experience delays in receiving a diagnosis, which leads to inequalities in accessing post-diagnostic care (Giebel, 2020), support services, and care programs.

An innovative program in North Dakota called the Dementia Care Services Program trains consultants throughout the state to support individuals who care for people with dementia, offering emotional support, education, and referrals to local agencies. The consultants work with the caregivers to develop a care plan that addresses key problems. They typically speak with the caregivers three times during the first six months and remain available for as long as is needed (AHRQ, 2015a).

Participating caregivers report that the program has helped them feel more empowered, which in turn has led to reduced need for costly medical services and placements in long-term care facilities. These reductions have generated an estimated \$40 million in savings in North Dakota, primarily due to the reductions in the likelihood of long-term care use (AHRQ, 2015a).

Supporting Caregivers of Clients with Dementia



A dementia care consultant discussing resources with a client and her son. Source: AHRQ, 2015 From <https://innovations.ahrq.gov/node/8291>

When a Care Plan Fails

The care plan provides a road map for the care of an individual client. It must be flexible enough to reflect a person's changing needs, care goals, and end-of-life desires.

Ideally, a care plan is structured with input from family members or someone who knows the person well, but sometimes this is not possible, and the care plan is completed by a medical professional who knows little about the person's needs and preferences.

If the care plan is not regularly updated, it will fail to reflect and respect a person's needs as their condition declines. Some of the issues that contribute to the failure of a care plan as a living, changing reflection of a person's changing needs include:

- Poor communication (staff, caregivers, and family members)
- Failure to take into account cultural and language differences
- Inadequate training and high staff turnover
- Lack of regular care plan meetings
- Inconsistent assessment of a person's physical condition
- Failure to identify abrupt physical changes caused by inconsistent medication management
- Failure to identify abuse and neglect

Family members and caregivers must be on the lookout for signs that the care plan is not being followed. Some signs—such as bedsores—are obvious while others, such as malnutrition, lack of meaningful activities, lack of exercise, and verbal abuse are less obvious (and less provable).

The Role of Collaborative Care

A program established by Indiana University's Center for Aging Research, Healthy Aging Brain Center, uses a team-based care model to treat clients with dementia and support their caregivers. A multidisciplinary team conducts an initial diagnostic assessment, holds a family conference to discuss the diagnosis and develop an individualized care plan, and provides ongoing clinic- and telephone-based monitoring, care coordination, and support. The team also regularly collaborates with primary care providers to help them better manage their dementia patients' health problems. The model has improved health outcomes for patients with dementia, including reducing emergency department visits, inpatient use, readmissions, and medication problems, and improving blood sugar and cholesterol control (AHRQ, 2015b).

Mastery over Dementia

Another 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 demonstrated that caregivers' symptoms of depression and anxiety were significantly reduced after participating in the *Mastery over Dementia* program, compared to a minimal intervention in which caregivers received digital newsletters by e-mail (Blom et al., 2015).

The internet program consists of 8 lessons and a booster session with the guidance of a coach monitoring the progress of participants and evaluating the homework. Each lesson has the same structure and uses text and videos, exercises, and homework, with an evaluation at the start and end of each session. The program covers: coping with behavioral problems (problem solving); relaxation; arranging help from others; changing non-helping thoughts into helping thoughts; and communication with others (Blom et al., 2015).

After every lesson, participants send their homework to a coach and the coach sends feedback to caregivers. All participants in this study received feedback from the same coach, a psychologist employed by a healthcare agency with additional training in cognitive behavioral therapy and experience in the field of dementia (Blom et al., 2015).

For family caregivers themselves, internet support may have several advantages compared to face-to-face support. Caregivers can participate at the time that is suitable for them; they do not have to travel to a healthcare professional, which saves time; and support may be easier to accept because of the stigma still associated with seeking help from a mental healthcare provider (Blom et al., 2015).

Zarit Burden Inventory Scale

The *Zarit Burden Interview* (ZBI) is a scale used to measure caregiver burden. It is a self-administered, 22-item instrument that measures caregiver perceptions of the burden of providing care. The questionnaire addresses areas that caregivers commonly report as problematic, such as physical health, psychological well-being, finances, and their relationship with the patient. Responses to each item are structured on a five-point Likert scale ranging from 0 (never) to 4 (nearly always), with a total possible score of 0 to 88. Higher scores indicate an increased caregiver burden (Tsai et al., 2015). The ZBI Short Form was introduced in 2001 to create Short (12 items) and Screening (4 items) versions, making interviews easier to administer yet retaining results similar to that of the full version.

16. Concluding Remarks

No matter what 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 a challenge. Family caregivers are unpaid, largely untrained, and struggle to understand the ups and downs of cognitive decline. Understanding 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 them 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 can have a profound effect on the difficult behaviors often 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 managing pain and discomfort begins with proper assessment of pain and includes an understanding of polypharmacy and drug-drug interactions.

Purposeful, meaningful activities provide predictable and relaxing routines and schedules. A well-designed physical environment, easy-to-use assistive equipment, and other well thought out technologies can promote independence and 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 has not worked. There is no doubt that learning about cognitive decline and implementing a person-centered, thoughtful approach to care is urgently needed.

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18. Quiz

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 to multiple areas of the brain.

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. Impairments associated with Alzheimer's dementia can include:

- a. Disinhibition and loss of social control. Hallucinations, which can lead to suicidal thoughts.
- b. Inappropriate behaviors such as disrobing in a public area.
- c. Loss of ability to perform tasks such as balancing a checkbook or counting correct change.
- d. All of the above.

7. 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.

8. 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.

9. 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.

10. 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.

11. 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.

12. A limitation of most neurocognitive screening tools is:

- a. They are not designed as a tool for diagnosing dementia.
- b. They are self-administered.
- c. They require a neurologist to interpret.
- d. They are generally done at too young an age to be effective.

13. 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.

14. Dementia affects communication in which of the following ways?

- a. There is a sharp improvement in long term memory.
- b. There is a complete loss of the language of origin.
- c. There is an increase in vocabulary in an attempt to find new words for words that have been lost.
- d. There is a difficulty organizing words into logical sentences.

15. A communication habit that may increase a person's agitation and confusion is:

- a. Allowing time for the person to understand and process information.
- b. Introducing yourself each time you approach.
- c. Using patronizing or infantilizing phrases such as "she's just like a baby."
- d. Speaking slowly and clearly in short sentences.

16. In the early stage of Alzheimer's disease, damage to the limbic system can affect:

- a. The formation of new memories, spatial memories and navigation, and emotions.
- b. Judgment, moral behavior, and safety awareness.
- c. Sleeping, the sense of smell, and can cause hallucinations.
- d. Speech comprehension and the ability to form complex sentences.

17. Which of the following is a common behavioral symptom of neurodegenerative and other brain disorders and also one of the most under-recognized, under-diagnosed, and poorly managed aspects of these diseases?

- a. Depression.
- b. Apathy.
- c. Delirium.
- d. Delusions.

18. Agitated and aggressive behaviors can be a type of communication, often related to:

- a. Feelings of helplessness, loss of control, discomfort, pain, or fear.
- b. A lack of interest or emotion.
- c. Medication side effects, electrolyte disorders and dehydration, or metabolic changes.
- d. Degeneration of neurons in the part of the brain that controls circadian rhythms.

19. Delusions and hallucinations in people with dementia can be caused by:

- a. The inability to communicate discomfort.
- b. Boredom and memory problems.
- c. Degeneration of neurons in the part of the brain that controls circadian rhythms.
- d. Health factors such as urinary tract infections.

20. One way to address wandering in a person with dementia is to:

- a. Redirect the person to a purposeful activity.
- b. Verbally admonish the person to stop or else.
- c. Ask the client's doctor to tell the client to stop wandering.
- d. Restrain the person in a wheelchair.

21. Sleep disorders in people with dementia may be caused by:

- a. Too much social activity during the day.
- b. Degeneration of neurons in the part of the brain that controls circadian rhythms.
- c. Sleep disorders are rarely a problem in people with dementia.
- d. Too much exposure to bright lights during the day.

22. Healthcare providers and caregivers may label a behavior as inappropriate when, in fact, the behavior is completely appropriate to the situation.

- a. True
- b. False

23. 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.

24. Reduced social participation can be related to the loss of social identity derived from a profession, job, or membership in a group.

- a. True
- b. False

25. 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.

26. Emerging evidence suggests that 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 greater 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.

27. 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.

28. 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.

29. When assessing pain in a patient with severe dementia, be aware that:

- a. Smiling or an inexpressive facial expression may be an indication of severe pain.
- b. Repeated calling out, groaning, or crying is not usually related to pain.
- c. Pain significantly decreases in older patients with dementia.
- d. Being unable to console, distract, or reassure a patient may indicate the presence of severe pain.

30. 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.

31. 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.

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

- a. Modifying food and drink and 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.

33. 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.

34. Strategies for addressing malnutrition and dehydration in older adults with dementia include:

- a. Leaving the person alone, so they have privacy during mealtimes.
- b. Providing social support, assisting with eating or drinking, and managing swallowing problems
- c. Providing a cafeteria-style room for meals that also doubles as an activities room.
- d. Having meals away from the kitchen to avoid sad memories.

35. 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.

36. When assisting with ADLs, person-centered care:

- a. Encourages people with dementia to accept that they can no longer be independent with ADLs.
- b. Encourages caregivers to treat everyone the same.
- c. Can help a person with dementia maintain independence in activities of daily living.
- d. Is not a realistic approach to dementia care in most settings.

37. Meaningful, person-centered activities:

- a. Provide mental stimulation.
- b. Provide socialization, stimulation, and physical activity within the functional limits of the person with dementia.
- c. Are sensitive to the cultural differences of those attending the activity.
- d. All of the above.

38. 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. Stresses accepting the reality of the person living with dementia by focusing on the emotional content of a person's words or expressions.

39. Using validation therapy in adult day care means you:

- a. Consider the dementia first, not the whole person.
- b. Imagine yourself in the person's place and validate their feelings.
- c. Use reality therapy to orient your client to reality.
- d. Discourage independence and help as much as possible.

40. 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.

41. 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.

42. Caring for a person with dementia:

- a. Is easier than caring for someone with another disability.
- b. Is more stressful than caregiving for older adults with other disabilities.
- c. Can affect a caregiver psychologically but seldom affects their physical health.
- d. Decreases the risk of depression and anxiety.

43. For caregivers of people with dementia, stress:

- a. Can create feelings of burden, depression, and anxiety disorders.
- b. Is much less for female spousal caregivers.
- c. Can be relieved by getting plenty of sleep.
- d. Is not a big problem.

44. 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.

45. 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.

Answer Sheet

Name (Please print) _____

Date _____

Passing score is 80%

1. _____	21. _____	41. _____
2. _____	22. _____	42. _____
3. _____	23. _____	43. _____
4. _____	24. _____	44. _____
5. _____	25. _____	45. _____
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17. _____	37. _____	
18. _____	38. _____	
19. _____	39. _____	
20. _____	40. _____	

Course Evaluation

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

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

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

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

*The author(s) are knowledgeable about the subject matter. 5 4 3 2 1

*The author(s) cited evidence that supported the material presented. 5 4 3 2 1

*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?

_____ Yes, within the next 30 days. _____ Yes, during my next renewal cycle.
 _____ Maybe, not sure. _____ No, I only needed this one course.

*Would you recommend ATrain Education to a friend, co-worker, or colleague?

_____ Yes, definitely. _____ Possibly. _____ No, not at this time.

*What is your overall satisfaction with this learning activity? 5 4 3 2 1

*Navigating the ATrain Education website was: _____ Easy. _____ Somewhat easy. _____ Not at all easy.

*How long did it take you to complete this course, posttest, and course evaluation?

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 _____ Less than 30 minutes per contact hour

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_____ 18 to 30 _____ 31 to 45 _____ 46+

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