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FL: ADRD for Specialized Alzheimer's Adult Day Care, Level 2

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Contact hours: 4

Pharmacotherapy hours:0

Expiration date: August 28, 2020

Course price: \$35

Instructions

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This course has been approved by the Florida Department of Elder Affairs, Florida Policy Exchange Center on Aging. Approval number SAADC 8462.

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 1315.

Course Summary

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

COI Support

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No commercial support was received for this activity.

This course will be reviewed every two years. It will be updated or discontinued on August 28, 2020.

Criteria for Successful Completions

80% or higher on the post test, a completed evaluation form, and payment where required. No partial credit will be awarded.

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This course is accepted by the Georgia State Board of Physical Therapy.

- **FL ADRD: Specialized Alzheimer's Adult Day Care, Level 2**

Approved by the Florida Department of Elder Affairs, Florida Policy Exchange Center on Aging. Approval #SAADC 8462.

Course Objectives

When you finish this course you will be able to:

- Describe 2 differences between Alzheimer's dementia, vascular dementia, and frontotemporal dementia.
- List 3 ways in which normal cognitive changes that occur in older adults differs from cognitive changes seen in dementia.
- Relate three differences between dementia, delirium, and depression.
- Describe the purpose for a neurocognitive screening.
- Relate 3 ways in which dementia affects communication.
- Describe 5 challenging behaviors that might be associated with dementia.
- Define person-centered care.
- Describe 5 keys points about pain in older adult with dementia.
- Relate the 2 most common classes of medications used in older adults with dementia.
- List 5 factors for malnutrition and dehydration in older adults with dementia.
- Describe 3 features of a meaningful activity.
- Describe the three main components of validation therapy.
- List the two key features of safety technologies.
- Relate 5 ways to reduce caregiver stress.

Understanding Brain Disease

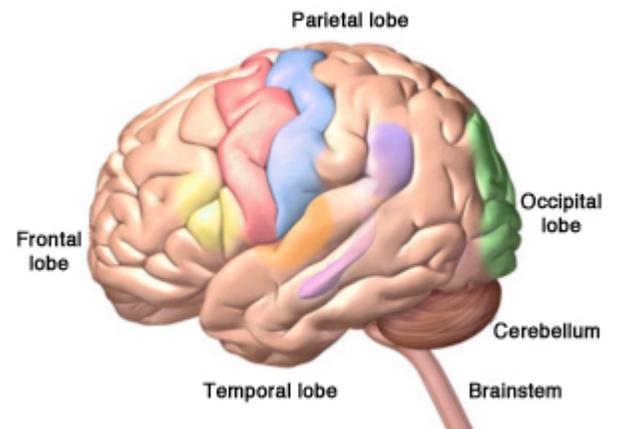
The ugly reality is that dementia often manifests as a relentless and cruel assault on personhood, comfort, and dignity. It siphons away control over thoughts and actions, control that we take for granted every waking second of every day.

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. Dementia is a syndrome, a collection or grouping of symptoms—the result of progressive deterioration and loss of brain cells and brain mass.

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 Brain Diseases

Different types of dementia affect different parts of the brain. Some start in a part of the brain that controls a specific function such as memory or emotions. 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.

In addition to Alzheimer's disease there are several other types of dementia:

- Vascular dementia
- Frontotemporal dementia
- Dementia with Lewy bodies
- Dementia associated with Parkinson's disease
- Post-stroke 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 are treatable and reversible if the underlying cause is identified and treated (Sönke, 2013).

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

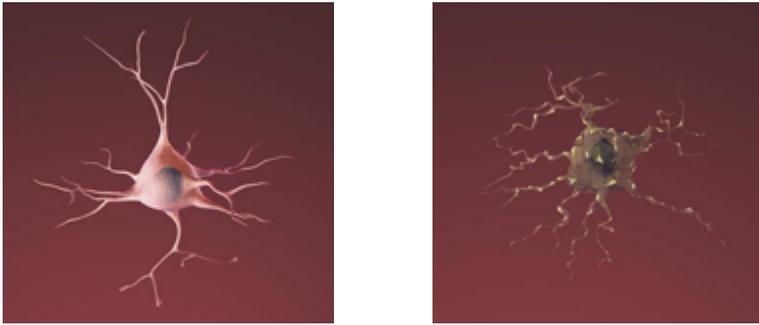
Alzheimer's disease (AD) is an irreversible, progressive, age-related brain disorder that affects as many as 5 million Americans age 65 and older. Along with heart disease and cancer, it is a leading cause of death for older people (ADEAR, 2014). Memory problems are a common early symptom of Alzheimer's 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.

Did You Know . . .

Worldwide more than 35 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. 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

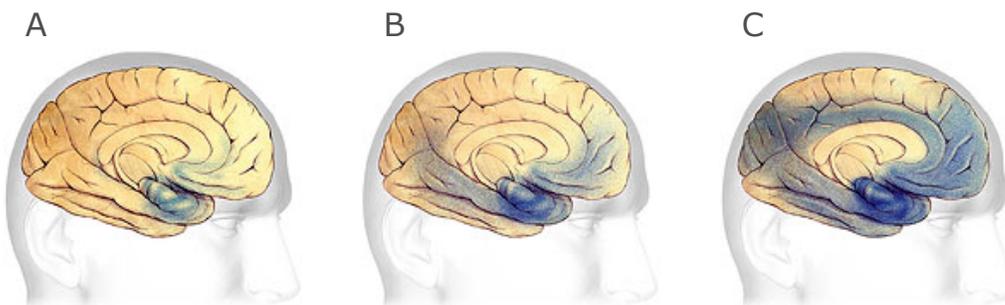


Left: A healthy nerve cell with many connections to other cells. Right: A dying nerve cell showing the nerve connections weakening and the main body of the cell deteriorating. Source: ADEAR, 2014.

In Alzheimer's, damage is thought to be associated with the formation of unwanted structures called *beta-amyloid plaques* and *neurofibrillary tangles* (plaques and tangles). The progressive brain damage associated with Alzheimer's dementia 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, 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.

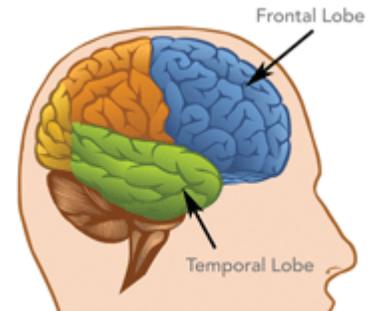
Vascular Dementia and Vascular Cognitive Impairment

Vascular dementia is one of the most common forms of dementia after Alzheimer's disease, affecting approximately 20% of the dementia cases worldwide (Neto et al., 2015). Risk factors for developing vascular dementia include diseases or disorders that damage the vessels supplying blood to the brain (heart rhythm irregularities, high blood pressure, diabetes, high cholesterol, smoking, small strokes, and obesity). 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, 2013).

Frontotemporal Dementia

Frontotemporal dementia begins in the frontal and temporal lobes of the brain. Although new research is showing that frontotemporal dementia can start in older age, the belief has been that it starts at an earlier age than Alzheimer's disease and is a relatively common type of dementia in those under the age of 60.

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.



Damage to the brain's frontal and temporal lobes causes forms of dementia called frontotemporal disorders. Source: National Institute on Aging.

Dementia with Lewy Bodies

Dementia with Lewy bodies (DLB) is another common type of progressive dementia. It accounts for up to 20% of all autopsy-confirmed dementias in elders (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, 2017).

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, 2017).

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.

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

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. The risk for cognitive impairment or decline is increased by a history of stroke. 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 (Eshkoo 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. 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).

Teepa Snow Aging Vision and Alzheimer's (2:49)

Vision Changes with Dementia



<https://www.youtube.com/watch?v=ZqbxFD2-lsQ>

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, 2017). 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, 2013).

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, 2013). 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.

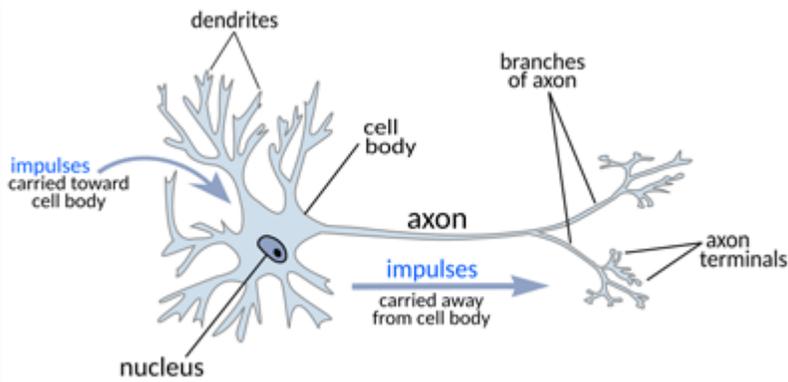
Normal Brain Functions and Normal Aging

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

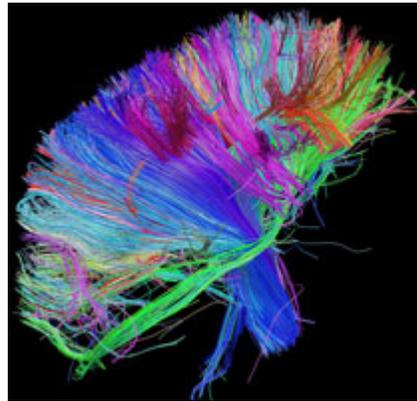
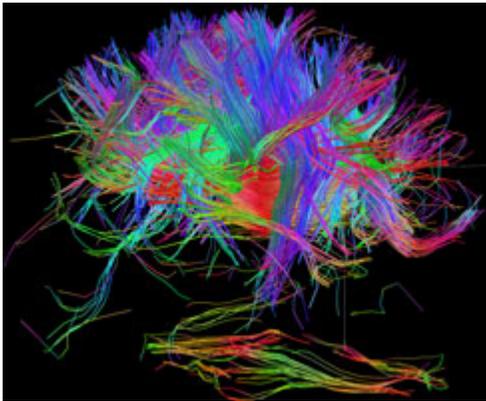
An aging brain—one not affected by dementia—experiences changes. Certain parts of the brain shrink a little although there is not a significant loss of nerve cells, as occurs in Alzheimer’s disease. Shrinkage typically is found in the prefrontal cortex and the hippocampus, areas of the brain important 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.

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.

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, 2016a).

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).

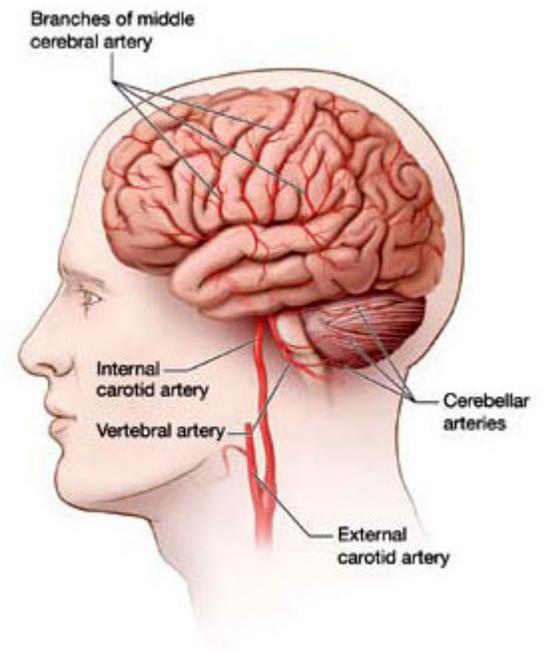
Differentiating Normal Aging and Dementia

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 Disorder

In some older adults, memory problems are more pronounced than those seen with normal age-related changes. This is referred to as *mild cognitive disorder*, also referred to as mild cognitive impairment. Although mild cognitive disorder has been described as a transitional stage between normal cognitive aging and dementia, particularly Alzheimer's disease, studies suggest that many individuals diagnosed with this disorder do not always progress to Alzheimer's disease and may even revert to normal (Lee et al., 2014).



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.

The onset of mild cognitive disorder 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 disorder; differentiating normal aging and mild cognitive impairment relies on screening, assessment, and client history (DeFina et al., 2013).

Cognitive Reserve

Cognitive reserve is the brain's ability to operate effectively even when some 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 a certain amount of tolerance and also the ability to adapt to change and damage that occurs during aging (NIH, 2016b).

At some point, 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, 2016b).

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 (NINDS, 2013):

- 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, 2013)

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 is a syndrome with an acute onset and a fluctuating course. It develops over hours or days and is temporary and reversible. 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>

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).

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 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).

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).

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 associated with cognitive change.

Neurocognitive Screening

Screening is a method for detecting dysfunction before an individual would normally seek medical care. It has the potential to identify very early signs of dementia and identify 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. Screening usually involves asking patients to perform a series of tasks that assess at least 1 cognitive domain (memory, attention, language, and visuospatial or executive functioning) (USPSTF, 2014).

Neurocognitive Screening Tools

Although there is no single cognitive assessment tool that is considered as a gold standard (Cordell et al., 2013), a variety of screening tools are available to assess clients for cognitive changes. No one tool is recognized as the best brief assessment to determine if a full dementia evaluation is needed (Alzheimer's Association, 2017).

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, 2014).

The Montreal Cognitive Assessment is used most often 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, 2014). 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
- 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

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 are impractical as screening tools because they take at least 10 minutes to complete.

Other limitations of screening tests 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, 2014).

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 have developed a brief clinical index that they used 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. The index utilizes 8 items that are readily obtainable in most clinical settings:

- 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 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 in an adult day care facility and notice or suspect a change in mental status, try to determine whether your client is operating at a 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.

Communication and Effects of Damaged Brain Cells

The deterioration of the person's ability to communicate is among the most serious stressors that clients and caregivers face. Poor communication can cause conflicts, isolation, and depression and may lead to earlier placement in institutions. Improving communication can help with these problems (Egan et al., 2010). Cognitive impairment in people with dementia reduces their ability to communicate effectively, which affects the ability of caregivers to identify their needs (Pham et al., 2015).

Communication changes may be related to the area of the brain affected by the disease. Because Alzheimer's affects the hippocampus, short-term memory is affected first. 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 when their next doctor's appointment is. Recall that Alzheimer's also affects emotional control, which can affect communication.

In frontotemporal dementia, because damage begins in the front part of the brain, memory is less affected. But the front part of the brain controls judgment, moral reasoning, logical thinking, and social behavior. A person with frontotemporal dementia, because they are gradually losing some of their social control, might make inappropriate sexual comments, make socially inappropriate remarks, and be frustrated when trying to make decisions or plans for the future.

In vascular dementia, because damage is widespread and not necessarily associated with a specific part of the brain, communication problems are usually less specific. There may be a slowness of thought, problems with attention and concentration, and difficulties with language. Complex, fast-paced conversations or quick changes in topic may be difficult to follow.

In Lewy body dementia, abnormal clumps of alpha-synuclein (Lewy bodies) are found 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.

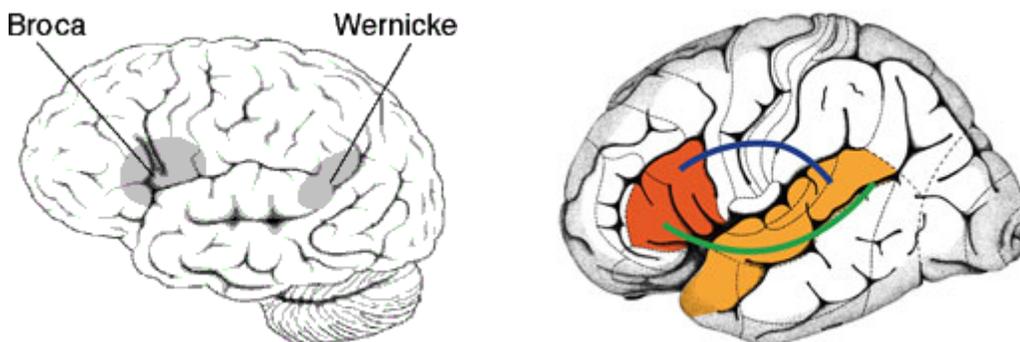
Areas of Brain Associated with Communication

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).

This loss or decline of language 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 is able to 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: The two 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 (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. A person with dementia can lose the ability to understand when you are expressing emotions such as frustration, anger, or even happiness; this is very likely to affect the 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 often:

- 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
- Talks less than usual (Alzheimer's Society of Canada, 2015)

Managing Communication Challenges

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).

Techniques such as close-ended or choice-based questions, using direct and simple phrases, repeating key words and ideas, signaling when a change in the topic has occurred, using direct contact, as well as utilizing comments and nonverbal cues, will improve the quality and flow of a conversation (Egan et al., 2010).

Activity-based approaches can also improve communication. These interventions can be carried out individually or in groups and use specific or diverse activities to stimulate communication. Generally, the focus of these groups is on improving or maintaining a number of functional skills, with communication being one (Egan et al., 2010).

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

- Approaching a person with dementia from the front or side

- Assessing the body language of the person with dementia
- Monitoring your body language, facial expression, and tone of voice
- Introducing yourself each time you approach
- Making sure the person with dementia can clearly see you
- Reducing distractions
- Sitting or kneeling next to the person at eye level
- Speaking slowly and clearly using short sentences
- Explaining what you are doing and why
- Allowing extra time for a response (Zeman, 2015)

Communication habits that can adversely affect communication and increase agitation, confusion, fear, or anxiety:

- Speaking “down” to a person
- Using infantilizing words
- Using overly complex or lengthy explanations
- Speaking too quickly
- Speaking in a stern or impatient voice
- Not allowing time for the person to understand and process information
- Rushing through a therapeutic activity (Gitlin and Vause Earland, 2010)

Angie Is Scared

Introduction: As mentioned earlier, 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: Angie had a brainstem stroke nearly 2 years ago and is not only struggling with mobility but also having difficulty expressing her needs and doesn't want to participate in any activities. She is a 90-year old woman who moved from Phoenix to live with her daughter in Santa Rosa, California following the stroke. Prior to suffering the stroke, she lived independently in Mesa, Arizona with her alcoholic son. In the hospital she was given a feeding tube, and when she arrived in California she was only 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 the 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, Angie is off her feeding tube, eating independently and enthusiastically, coloring intricate patterns in a coloring book, and 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, Angie's daughter feels her mother might enjoy the local adult day care program. The first time they attend, Angie is withdrawn and refuses to participate in any activities—even drawing. The activities assistant, Celana, tries to engage Angie in a conversation but she just smiles and asks where her mother is. Celana asks Angie to tell her about her mother but she doesn't (or can't) answer. When Angie's daughter comes to pick up her mom the day care center administrator reports that Angie 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, Angie will begin to participate in activities. She reports her observations and concerns to the facility administrator.

Intervention: The staff discuss Angie's situation after the center closes that evening. The administrator asks Jenitra, a registered nurse, to assess Angie in the morning—to spend some time with her and try to draw her out. When Angie arrives the next day, Jenitra, using her dementia-specific training, approaches Angie from the front, introduces herself, sits beside her, and offers her hand, which Angie takes. She tries to engage Angie in a general conversation without success. Angie is very quiet and seems confused. She asks Jenitra where she is and again asks for her mother. Jenitra makes sure Angie is comfortable, gently assesses her hearing and vision, and makes sure Angie is able to understand English. Finally, after some quiet back and forth, Angie 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 Angie 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. Angie is new to adult day care and the transition has been difficult for her. The adult day care center can address a new client's fears by making sure staff members support and educate Angie's family caregivers, provide a single point person to ensure continuity of care, use good communication techniques, and understand that people with memory problems are vulnerable to breakdowns in the continuity of care (Naylor & Keating, 2008).

Angie 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 Angie isn't very 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 Angie does better with one-on-one exercise.

Client Perspective: Angie 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 Angie to go again, telling her that they are having hamburgers for lunch. Angie says she is OK with that and agrees to attend adult day care again.

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). It is estimated that up to 90% of patients will eventually experience challenging behaviors associated with their dementia (Passmore, 2013).

Behavioral changes associated with dementia range from mild (depression, anxiety, irritability, and apathy) to severe (agitation, aggression, vocalizations, hallucinations, and disinhibition,* among others). Symptoms can be constant or come and go and are associated with client and caregiver distress, increased rates of institutionalization, and increased mortality (Nowrangi et al., 2015).

***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 of dementia 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.

*See Module 3: Treatable and Irreversible Dementias for more on depression.

Areas of the Brain Related to Behavior

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)



Source: The Khan Academy, 2013. <https://www.youtube.com/watch?v=GDIDirzOSI8>

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 neurobiologic 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 is a lack of interest or emotion and may be an early symptom of cognitive impairment, especially in the frontotemporal dementia. 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 involved in the regulation of memory and learning.

Apathy is one of the most under-recognized, under-diagnosed, and poorly managed aspects of dementia (Leroi & Robert, 2012). 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, 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 involved with the regulation of mood, memory, sleep, and cognition.

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”

The Alzheimer’s Association estimates that up to 60% of persons with dementia will “wander” into the community at some point during the course of their disease (Rowe et al., 2011). In nursing homes, wandering occurs in about half of residents with dementia (Ahn & Horgas, 2013).

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.

A person's pre-dementia lifestyle may be a factor in whether a person is likely to wander (Futrell et al., 2010). 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 supervision,
- Reducing environmental triggers for wandering, and
- Using individualized nursing interventions to address the causes of wandering behavior (Silverstein & Flahery, 2012).

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 very 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**: 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.

Studies have suggested that approximately one-quarter to one-third of those with Alzheimer's disease have problems with sleep, partly due to the degeneration of neurons in the part of the brain that controls circadian rhythms. Sleep apnea, restless leg syndrome, medical and psychiatric issues, and environmental and behavioral factors often predate the onset of dementia. Chronic pain also interferes with sleep and disturbed sleep reduces the pain threshold (Deschenes & McCurry, 2009). The symptoms of sleep disruption vary according to the type of dementia and may 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 used to treat behavioral symptoms of dementia, as well as those used to slow the progression of dementia, can negatively affect daytime alertness and can cause sleep disturbances. Short-term sleep disturbances in people with dementia are often treated with antidepressants, benzodiazepines, or non-benzodiazepines. There is limited evidence to support their long-term safety in cognitively impaired older adults (Deschenes & McCurry, 2009).

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.

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). In general, about 1/3 of day care clients need help with toileting, about 1/4 need help with eating, and about 1/3 need help with medication management. Nearly half need some assistance with walking and about 1/3 need help with transfers (Dwyer et al., 2014).

Nevertheless, employees in specialized adult day care will encounter inappropriate and 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.
 - **A**ntecedent—what *caused* the behavior?
 - **B**ehavior—what *is* the behavior?
 - **C**onsequence—what are the *consequences* of the behavior?

3. Consider the safety of clients and staff.

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.

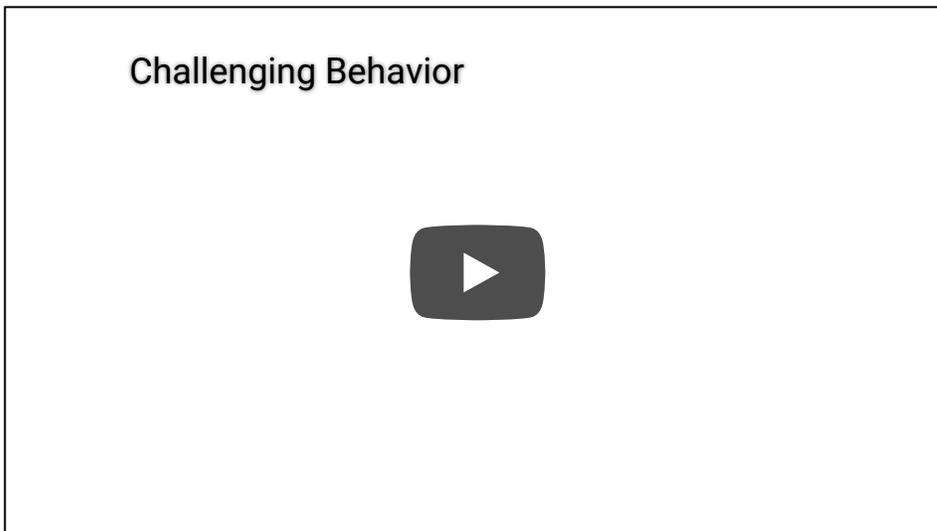
Staff members discussed the incident in a meeting the next day and agreed that they had forgotten to keep an eye on Callie as the birthday party got underway. Staff members were reminded that Callie was uncomfortable with noise and lots of activity but that overall, they did a good job diffusing the 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.

Video: Responding to Challenging Behavior (6:36)

Teepa Snow



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

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, 2013).

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).

Engaging people in regular activities may be a dementia prevention strategy. Regular 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 is probably 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). Its success depends not only on caregivers' skills and knowledge but also on adapting the entire care context to the clients' and caregivers' needs and preferences (Desrosiers et al., 2014).

Person-centered care may reduce unwanted behaviors and improve outcomes. 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 in America 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 and Needs

Considering a client's personal history and preferences will help caregivers design thoughtful interventions. A client's past medical and social history is essential to understanding their current needs. Sharing this information with the healthcare team allows the entire team to be aware of and sensitive to the client's needs (Constand et al., 2014).

Supporting a client's history and needs involves:

- 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

There is a profound and direct connection between their environment and how people feel and behave. Buildings thoughtfully designed for the care of people with dementia encourage community, maximize safety, support caregivers, cue specific behaviors and abilities, and redirect unwanted behaviors (Campernel & Brummett, 2010). This approach to dementia care considers the consequences of the built environment on the well-being of clients with dementia (Rijnaard et al. 2016).

The built environment is the constructed, physical surroundings (interior and exterior) where an individual eats, bathes, sleeps, and interacts socially. The environment has a profound effect on a person's sense of well-being and can play an active role in promoting well-being and improved functioning (Soril et al., 2014).

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 (Campernel & Brummett, 2010).

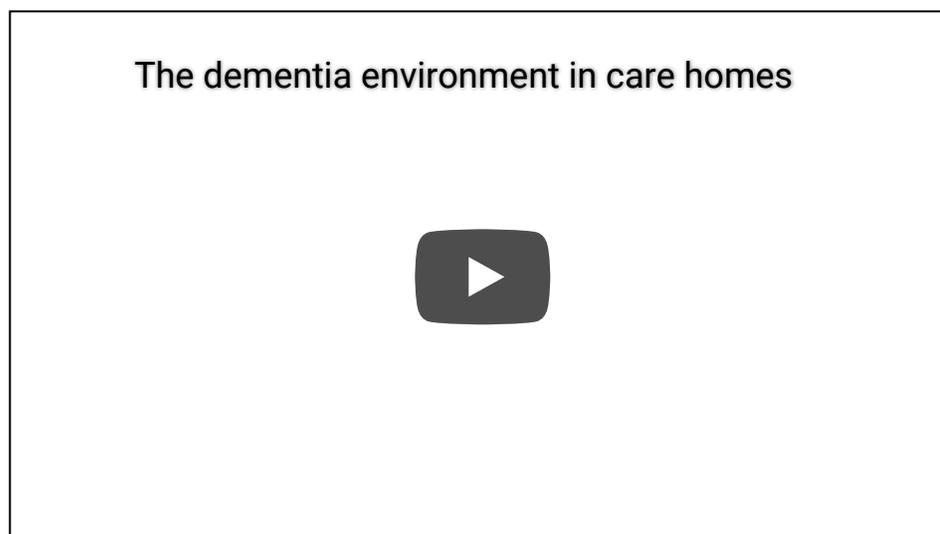
Homes or buildings thoughtfully designed for the care of people with dementia encourage community, maximize safety, support caregivers, cue specific behaviors and abilities, and redirect unwanted behaviors (Campernel & Brummett, 2010). Unfamiliar, chaotic, or disorganized environments have the opposite 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 (Nowranghi 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, acupressure, 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

Cognitive therapists help individuals and their families identify goals and strategies aimed at improving cognitive function. Interventions address difficulties considered most relevant by the person with dementia and his or her family. There is some evidence that cognitive training may enhance the effects of pharmacological therapy (Bahar-Fuchs et al., 2013).

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).

Social Participation and Social Identity

Social participation is involvement in interpersonal interactions outside the home, including social, leisure, and community activities and work. Reduction of social interactions can lead to poor health outcomes and loneliness (Goll et al., 2015).

Reduced social participation may 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).

In one study, participants sought to uphold independent and youthful identities. They frequently emphasized their self-sufficiency, distinguished themselves from “old” people whom they described as dependent and decrepit, and avoided opportunities for support in case this marked them as old and dependent. Participants avoided social situations that contradicted their preferred identities, and wished 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 by others. 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) might 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.

The Benefits of Respite Care

Respite care is an often overlooked intervention that benefits people with dementia as well as their caregivers. It provides caregivers with a break, reduces caregiver stress, and provides stimulation and social interaction for the person with dementia. Respite care can be anything from a few hours to a few weeks.

Numerous studies have shown that family caregivers experience high levels of strain, resulting in poor health outcomes and lower quality of life for caregivers, and earlier institutionalization for care recipients. Respite care can relieve the burden of caregiving and facilitate aging in place. In spite of this, many caregivers believe that respite care will have negative outcomes for care recipients (Stirling et al., 2014).

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 probably 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 is one of the most important protective factors 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 occur in clients already suffering Alzheimer's dementia, improving clinical symptoms (Holthoff et al., 2015).

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. Complementary and alternative forms of exercise such as tai chi, yoga, and dance may be effective for improving these other outcomes (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).

Video: Preventing Loss of Independence through Exercise (PLIÉ) (5:17)



<http://www.osher.ucsf.edu/research/current-research/preventing-loss-of-independence-through-exercise-plie/>

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 focused 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.

- **A**ntecedent—what *caused* the behavior?
- **B**ehavior—what *is* the behavior?
- **C**onsequence—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.

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).

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 in people with dementia.
- 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 actually be increased (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). Clients with dementia also have pain associated with chronic conditions such as arthritis, chronic neurologic conditions, and skin breakdown. Inactivity, uncomfortable beds and chairs, and lack of exercise contribute to discomfort and pain from these conditions.

Clinicians must learn to assess behaviors in the context in which they occur, and help families design a treatment plan and then evaluate its effectiveness. The extent to which caregivers are willing and able to implement strategies is important. This is particularly true with non-pharmacologic strategies that may not be fully understood, require changes in caregiver behavior, or are judged too stressful or complicated to be implemented by caregivers (Kales et al., 2015).

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 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 for Jenna. 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.

Assessing Pain in Adults with Dementia

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

Healthcare providers may feel uncertain about pain in clients with dementia, especially if the client is unable to report if they are in pain. Clients, especially those with advanced dementia are less able to respond to pain scales, necessitating the use of observational scales in up to about half of clients. Unfortunately, researchers reported 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).

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.

Cognitively impaired clients 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 clients are in pain and when they are experiencing pain relief. This makes the client 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:

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.

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. 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)

Combination

5. Namzaric

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 (DeFina et al., 2013).

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, the benefits of these drugs are limited. They are effective for about one year and in only about half of individuals to whom they are prescribed (DeFina et al., 2013).

The fifth medication, Namzaric, was approved by the FDA in 2014. It is a fixed-dose combination of memantine (Namenda) and donepezil (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, 2014).

Antipsychotics

There is particular concern over the use of antipsychotics in people with dementia, with only modest evidence suggesting clinical improvement but increased risk of adverse health outcomes and mortality (Jordan et al., 2015). Although people with dementia are more susceptible to adverse drug events, as well as falls, fractures, and excess sedation, these drugs remain widely used in people with Alzheimer's disease (Gnjidic et al., 2014).

Several large clinical trials have demonstrated an increased risk of mortality when atypical antipsychotics are used by people with dementia. All atypical antipsychotics now carry a black box warning from the FDA about this risk, and a similar warning applies to conventional antipsychotics. Atypical antipsychotics are also linked to a two- to three-fold higher risk of cerebrovascular events (Steinberg & Lyketsos, 2012).

The 2012 American Geriatric Society (AGS) Beers consensus criteria* for safe medication use in elders recommend **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" (Steinberg & Lyketsos, 2012).

***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.

For people with dementia, antipsychotics may reduce aggression and psychosis, particularly among those most severely agitated. However, in older people, antipsychotics are associated with increased overall mortality, worsening cognitive impairment, hip fracture, diabetes, and stroke (Jordan et al., 2014).

Several studies have emphasized the need to *avoid* drugs that affect cognition or cause delirium in clients with dementia. The use of drugs to treat non-dementia illnesses in older adults with dementia may lead to serious adverse effects, even when clearly beneficial drugs recommended by clinical guidelines are prescribed (Colloca et al., 2012).

Article: Risks Run High When Antipsychotics Are Prescribed For Dementia

Source: Scott Hensley, March 18, 2015

<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).

Malnutrition and Dehydration

People with cognitive decline develop various eating and swallowing problems, which along with the behavioral and psychological symptoms of dementia, can strongly affect nutrition (Koyama et al., 2016). 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 lead to a loss of independence. These symptoms are thought to be affected by cognitive dysfunction, psychiatric and neurologic 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
- Lack of properly trained, individualized help
- Lack of oral care
- Unappetizing food and food served cold
- Cultural differences
- Skipped meals
- Reduced mobility
- Being housebound
- 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:

- Unintentional weight loss
- 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
- Bloating abdomen

Signs and symptoms of **dehydration** include:

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

As dementia progresses—especially in the severe stage, aversive behaviors and feeding problems can occur. Difficulty swallowing, aspiration, choking, chewing but failing to swallow, and active resistance to hand feeding are common (Piva et al., 2012). Aversive behaviors include:

- 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

Providing and encouraging proper nutrition and hydration in people with dementia is an important part of their overall care. Malnutrition can be prevented or reduced with early intervention, which must be rapid and appropriate (Piva et al., 2012).

Direct interventions 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 dietician 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).

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 amount 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 easier. Designed by Sha Yao, Eatwell.com. Used with permission.

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 of its look 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 households. 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, and 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 as to 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 to 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 meal times (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. Food becomes less palatable as taste and smell decline. These changes affect the taste 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 are not likely to be able to meet nutritional needs.

Addressing Concerns about Malnutrition and Dehydration

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

Oral protein and energy supplements can be used in older people with undernutrition, or at risk of undernutrition. Their use is associated with significant weight gain, and a reduction in mortality for those who are undernourished (ADI, 2014). A higher protein intake is associated with higher muscle mass and a reduced loss of lean mass over time (Donini et al., 2013).

Studies have shown that older adults frequently do not meet the official recommendations for intake of fruits and vegetables and greater consumption is recommended. Many community-dwelling older adults lack at least one micronutrient and are not getting enough protein in their diets. Fruits and vegetables are important sources of micronutrients, including vitamins E and C. Fiber, vitamins (vitamins E, D, B1, B12, and folic acid) and micronutrients (iron, potassium, and calcium) and bioactive compounds (polyphenols, carotenoids, phytosterols) are frequently below recommended dietary allowances (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).

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 the amount of help a caregiver must provide to the person needing assistance. Anyone assisting a person with dementia will need to provide more help over time. Training, common sense, person-centered care, 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 has the following components:

- Personhood must be acknowledged in all aspects of care.
- Care and surroundings must be personalized.
- Shared decision making is an integral part of care.
- Behavior should be interpreted from the person's viewpoint.
- Personhood in people with dementia is increasingly *concealed* rather than *lost* (Smebye and Kirkevold, 2013).

In the context of assisting someone with ADLs, promoting independence is a priority. Although people with dementia experience a decline in decision-making abilities as the dementia progresses, they cannot be assumed to be incapable of making decisions on the basis of their diagnosis alone (Smebye et al., 2012).

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 as 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., 2016):

- 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 survey tool asks participants to rate (among other things) whether or not the activity:

- Gives me pleasure
- Expresses my creativity
- Challenges me
- Provides satisfaction
- Reflects the kind of person I am
- Expresses my personal values
- Provides a sense of accomplishment (Eakman, 2012)

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)

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.

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 as a result of 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.

Feil's model sought to classify the stage of dementia that an individual has reached according to cognitive and behavioral signs. Its development was the result of an attempt to provide practical solutions for difficulties experienced by patients and caregivers. Important features of validation therapy include: a means of classifying behaviors; provision of simple, practical techniques that help restore dignity; prevention of deterioration into a vegetative state; provision of an empathic listener; respect and empathy for older adults with Alzheimer's disease who are struggling to resolve unfinished business before they die; and acceptance of the person's reality (Takeda et al., 2012).

Validation therapy teaches that the experiences and personal truth of a person with dementia should be accepted and validated. 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, 2017)

Video: Gladys Wilson and Naomi Feil (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 down the hall 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, kneeled 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).

Reality orientation can be taught to caregivers and family members; it can be performed in the home and should be structured around the area in which the patient spends most time. For example, access to a window is recommended to facilitate orientation to the time of day and the weather. Other than environmental cues, familiar objects to the patients (family scrapbooks, flash cards, Scrabble games, a globe, and large-piece jigsaw puzzles) can be used to stimulate their memory in reality orientation (Takeda et al., 2012).

For most of us, being oriented to reality is essential. But reality orientation isn't helpful if the person has 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 a Client 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 of 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

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, a little creativity is required.

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 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.
- Validate the person's feelings.
- Learn good communication skills.
- Avoid 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.
- Avoid reality orientation except for early-stage dementia.
- Encourage independence.
- Arrange for meaningful activities.
- Love and be loved.
- Provide something important to do each day.
- Avoid judgment.
- Keep your sense of humor and use it wisely.
- Remember that religion can be a comfort.
- Expect the unexpected.

Safety: New and Proven Technologies

When caring for a person with dementia, safety can become a concern, especially as the dementia progresses. Because challenging behaviors can be unpredictable, a safety plan is recommended. Caregivers must (1) think prevention, (2) adapt the environment, and (3) minimize dangers (ADEAR 2015).

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. Facilities that serve people with dementia must have safety policies and procedures in place that include a systematic, explicit, and comprehensive process for managing safety risks that provides for goal setting, planning, and measurement of performance (National Safety Council, 2015).

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 with cognitive decline, safety policies and procedures must take into account needs and behaviors unique to a clientele with dementia. 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.

Day care centers can provide a *feeling* of safety for 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). Adult day care centers also provide training about safety 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.

Usability and Acceptance of Safety Technologies

For safety technologies to be useful they must be used—and for older adults with dementia, usability and acceptability are key issues. **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
- Interference with activities of daily living (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 follow 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).

GPS Program in Edinburgh, Scotland

In a small observational study in and around Edinburgh, Scotland, 12 caregiver/client pairs were given GPS devices, half of which set up “geo-fences” to alert the caregiver when the person with dementia left an area considered to be safe. In follow-up interviews, perceptions from caregivers and the people with dementia were generally positive:

- Participants said that walking was important and should be continued if possible.
- Caregivers said they felt reassured by having the GPS locator.
- Three participants expressed concern about being reminded of their condition and feeling watched but when interviewed at follow-up one person said she had come to feel reassured by the GPS.
- Some caregivers and care workers stated that without the GPS they would have had to limit the person’s freedom (Milne et al., 2014).



A view of Edinburgh, Scotland from Blackford Hill. Source: Kim Traynor by permission.

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

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).

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

Psychosocial interventions aimed at caregivers can reduce stress and illness and delay institutionalization of the person with dementia (Lee et al., 2014). Recognizing that the caregiver is part of the client can reduce caregiver stress improve outcomes. This is especially true for caregivers of clients with dementia.

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.▪ 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.

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 by providing information about caregiver burden as well as techniques for addressing behavioral challenges. Respite and support services can provide relief, reduce caregiver burden, and increase caregivers' motivation for their role as a caregiver. These benefits:

- 1.** Facilitate separation time, giving family caregivers time for undisturbed work, rest, or other pursuits.
- 2.** Seem to reduce behavioral problems and the need for assistance with ADLs.
- 3.** May 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 and her lack of knowledge, 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 go to a caregiver support group. She agrees to take her husband to adult daycare but refuses to attend a support group. When she arrives to drop Jim off at the adult daycare center, Barbara meets Sana, one of the activity aides at the center.

Sana just started a new job as an activities aide. She is asked to greet a new client named Barbara who is dropping off her husband Jim for the day. 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 your 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. 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

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.

The Role of Collaborative Care

Another innovative 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

Yet 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 used text and videos, exercises, and homework, with an evaluation at the start and end of each session. The program covered the following topics: 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 sent their homework to a coach and the coach sent feedback to caregivers. Participants were automatically reminded to start with a new lesson or to send in their homework if they were not active for a fixed period of time. 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.

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Post Test

Use the answer sheet following the test to record your answers.

1. 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.

2. In early Alzheimer's disease, visual and spatial problems are common. This includes:
 - a. An improved ability to identify form, color, and contrast.
 - b. 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.

3. Initial symptoms associated with frontotemporal dementia, a common type of non-Alzheimer's dementia 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.

4. Functional impairments associated with Alzheimer's dementia can include:
 - a. Hallucinations, which can lead to suicidal thoughts.
 - b. Disinhibition and loss of social control.
 - c. Loss of smell.
 - d. Loss of ability to perform tasks such as balancing a checkbook or counting correct change.

5. 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.

6. 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.

7. 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.

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

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

10. Neurocognitive screening is:

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

11. A limitation of most neurocognitive screening tools is:

- a. They are inaccurate as a tool for determining the presence of dementia.
- b. They take more than 10 minutes to complete.
- c. They require a neurologist to administer.
- d. They are generally done at too young an age to be effective.

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

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

13. 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.

14. 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.

15. 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.

16. 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.

17. 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.

18. 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.

19. 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.

20. 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.

21. 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.

22. 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 of life.
- c. Exercise and physical activity has no effect on physical or cognitive performance.
- d. Exercise is harmful.

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

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

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

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

25. When assessing pain in a patient with severe dementia, be aware that:
- Smiling or an inexpressive facial expression may be an indication of severe pain.
 - Repeated calling out, groaning, or crying is not usually related to pain.
 - Pain significantly decreases in older patients with dementia.
 - Being unable to console, distract, or reassure a patient may indicate the presence of severe pain.
26. The use of antipsychotics in older adults with dementia:
- Has been shown to be completely safe and effective.
 - Is particularly effective when used as a chemical restraint.
 - Is FDA-approved for the treatment of any neuropsychiatric symptoms in dementia.
 - Is associated with increased overall mortality and worsening cognitive impairment.
27. Malnutrition is:
- An inadequate diet in which either the quantity or quality of nutrients does not meet nutritional needs.
 - Fluid loss is greater than fluid intake or when there is an excessive loss of body fluid.
 - A behavioral and psychological symptom of dementia.
 - Is common in older adults with dementia living in the community but very uncommon in those living in nursing homes.
28. Strategies for addressing malnutrition and dehydration in older adults with dementia include:
- Leaving the person alone so they have privacy during mealtimes.
 - Providing social support, assisting with eating or drinking, and managing swallowing problems
 - Providing a cafeteria-style room for meals that also doubles as an activities room.
 - Having meals away from the kitchen to avoid sad memories.
29. When assisting a person who has moderate dementia using the philosophy of person-centered care, the best action is to:
- Do something to distract the person while you complete the ADL task.

- b. Complete the task quickly so that the person does not have time to disagree with you.
- c. Do not allow the person to assist because it will take much longer to complete the task.
- d. Encourage participation and shared decision-making.

30. An activity is meaningful when:

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

31. Toileting at any stage of dementia is best managed by:

- a. Proceeding with toileting as scheduled regardless of the client's wishes.
- b. Require all clients to use of adult diapers.
- c. Engaging the client, allowing choices, and keeping the person comfortable.
- d. Always enlist the assistance of a co-worker to prevent injury.

32. Validation therapy teaches:

- a. That the experiences and personal truth of a person with dementia should be accepted and validated.
- b. That the feelings and experiences of a person with dementia should be questioned rather than validated.
- c. That a person with dementia can no longer understand empathy.
- d. That in people with dementia, reality is so altered that their feelings are no longer valid.

33. 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.

34. 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.

35. 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.

36. 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.

37. 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.

38. 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.

39. 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

FL: ADRD for Specialized Alzheimer's Adult Day Care, Level 2

Name (Please print your name): _____

Date: _____

Passing score is 80%

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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:

a. Describe 2 differences between Alzheimer's dementia, vascular dementia, and frontotemporal dementia.

5 4 3 2 1

b. 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

c. Relate three differences between dementia, delirium, and depression.

5 4 3 2 1

d. Describe the purpose for a neurocognitive screening.

5 4 3 2 1

e. Relate 3 ways in which dementia affects communication.

5 4 3 2 1

f. Describe 5 challenging behaviors that might be associated with dementia.

5 4 3 2 1

g. Define person-centered care.

5 4 3 2 1

h. Describe 5 keys points about pain in older adult with dementia.

5 4 3 2 1

i. Relate the 2 most common classes of medications used in older adults with dementia.

5 4 3 2 1

j. List 5 factors for malnutrition and dehydration in older adults with dementia.

5 4 3 2 1

k. Describe 3 features of a meaningful activity.

5 4 3 2 1

l. Describe the three main components of validation therapy.

5 4 3 2 1

m. List the two key features of safety technologies.

5 4 3 2 1

n. 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

* This course contained no discriminatory or prejudicial language.

Yes No

* The course was free of commercial bias and product promotion.

Yes No

* As a result of what you have learned, do you intend to 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?

- 60 minutes (or more) per contact hour
- 50-59 minutes per contact hour
- 40-49 minutes per contact hour

- 30-39 minutes per contact hour
- Less than 30 minutes per contact hour

I heard about ATrain Education from:

- Government or Department of Health website.
- State board or professional association.
- Searching the Internet.
- A friend.
- An advertisement.
- I am a returning customer.
- My employer.
- Other
- Social Media (FB, Twitter, LinkedIn, etc)

Please let us know your age group to help us meet your professional needs.

- 18 to 30
- 31 to 45
- 46+

I completed this course on:

- My own or a friend's computer.
- A computer at work.
- A library computer.
- A tablet.
- A cellphone.
- A paper copy of the course.

Please enter your comments or suggestions here: _____

Registration Form

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

* Name: _____

* Email: _____

* Address: _____

* City: _____ * State: _____ * Zip: _____

* Country: _____

* Phone: _____

* Professional Credentials/Designations:

Your name and credentials/designations will appear on your certificate.

* License Number and State: _____

* Please email my certificate:

Yes No

(If you request an email certificate we will not send a copy of the certificate by US Mail.)

Payment Options

You may pay by credit card or by check.

Fill out this section only if you are **paying by credit card**.

4 contact hours: \$35

Credit card information

* Name: _____

Address (if different from above): _____

* City: _____ * State: _____ * Zip: _____

* Card type:

Visa Master Card American Express Discover

* Card number: _____

* CVS#: _____

* Expiration date: _____