

Alzheimer's Disease and Related Dementias, 6 units (161)

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Contact hours: 6

Course price: \$39

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Course Summary

This course provides readers with the knowledge, skills, techniques, and strategies to care on a daily basis for family members and residents who have Alzheimer's disease or a related type of dementia, whether in the home, adult day care, or in an institutional setting such as a nursing home.

COI Support

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No commercial support was received for this activity.

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.

Course Objectives

When you finish this course you will be able to:

1. Describe three differences between Alzheimer's dementia and non-Alzheimer's dementia.
2. State the three National Institute on Aging and the Alzheimer's Association stages of dementia.
3. Identify three barriers that may contribute to a missed or delayed diagnosis of dementia.
4. In terms of onset, cause, and duration, distinguish among dementia, delirium, and depression.
5. List three common behavioral and psychological symptoms of dementia.
6. Identify five other common behaviors often attributed to dementia.
7. Explain the action of the two main classes of medications prescribed for Alzheimer's disease.
8. State three ways in which dementia affects a person's ability to complete activities of daily living.

9. Describe three ways in which exercise appears to positively impact in people with dementia.
10. Relate the three components that should be part of any activities program for anyone with dementia.
11. Discuss three ways in which stress can affect a caregiver's quality of life.

Alzheimer's and Other Types of Dementia

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

Dementia is the collective name for progressive, global deterioration of the brain's executive functions. It develops primarily in later adulthood and is a major cause of disability in older adults. Almost everyone with dementia is elderly but nevertheless dementia is *not* considered a normal part of aging.

Very early identification of dementia—before obvious symptoms appear—is an intense focus of research. Staging (used primarily in the research setting) and correctly diagnosing dementia is becoming increasingly important in the clinical setting. Understanding the difference between Alzheimer's disease and other types of dementia and differentiating dementia from delirium and depression is of critical importance.

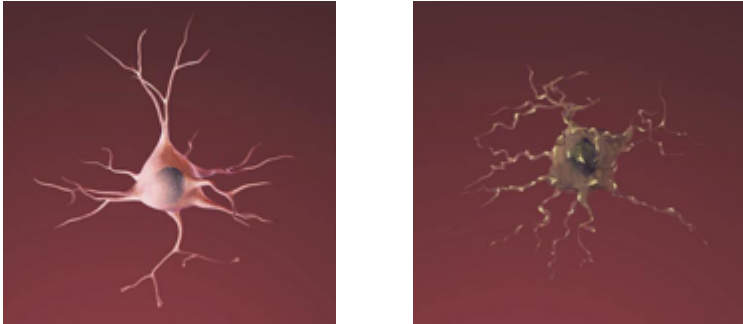
Once a person has been diagnosed with any form of dementia, management becomes a priority. Because dementia is progressive, patients and caregivers are faced with the challenge of managing an array of behavioral issues associated with dementia while providing more care as the disease progresses. Dementia is not an easy disease, either for the person experiencing the progressive loss of independence and control or for caregivers and family members. Education, collaboration, communication, and support are critical.

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 (Alzheimer's Disease International).

Although dementia is widespread in humans and occurs throughout the world, its exact cause is still unknown. In Alzheimer's disease, and likely in other forms of dementia, damage within the brain is associated with the formation of unwanted structures called **beta-amyloid plaques** and **neurofibrillary tangles**. It is also related to the degeneration and loss of nerve cells within the brain.

Degeneration of Cerebral Neurons



Left: A healthy nerve cell. Right: A dying nerve cell. Source: ADEAR, 2014.

We are learning that the changes associated with dementia occur over years, or even decades, before emotional, physical, or cognitive symptoms emerge. Eventually symptoms become obvious, and they lead to gradual and progressive decline (DeFina et al., 2013).

Alzheimer's Dementia

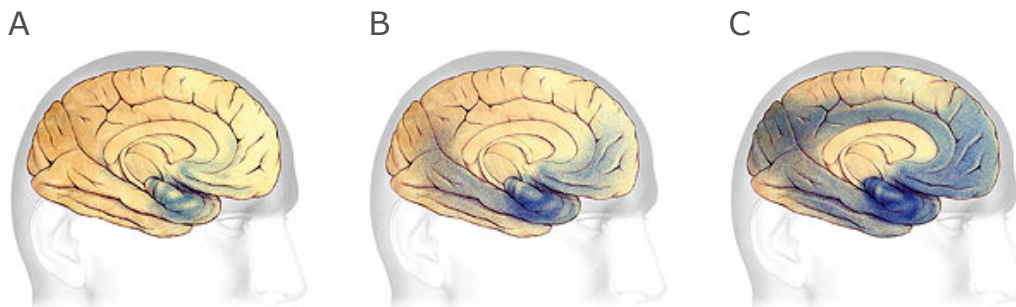
You likely already know that Alzheimer's disease (AD) is the most frequent and most studied cause of dementia in older adults. Its onset is gradual and progressive, meaning it gets worse over time. Memory problems are the most common early symptom of AD although language difficulties, apathy, depression, and vision and spatial difficulties can also be early symptoms. The latter two symptoms are less studied than memory changes but can be just as debilitating. Difficulties with vision and spatial awareness affect reading and comprehension of form and color, and can affect the ability to see contrast. This can make it difficult to detect motion and process visual information accurately (Quental et al., 2013).

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 the brain. In the earliest stage, before symptoms appear, plaques and tangles form in an area of the brain called the *hippocampus*, where new memories are formed (A). As the disease progresses, plaques and tangles spread to the front part of the brain; 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.



Different levels of contrast, with less contrast below (50%, 75%).
Source: Wikimedia Commons.

The Progression of Alzheimer's Disease

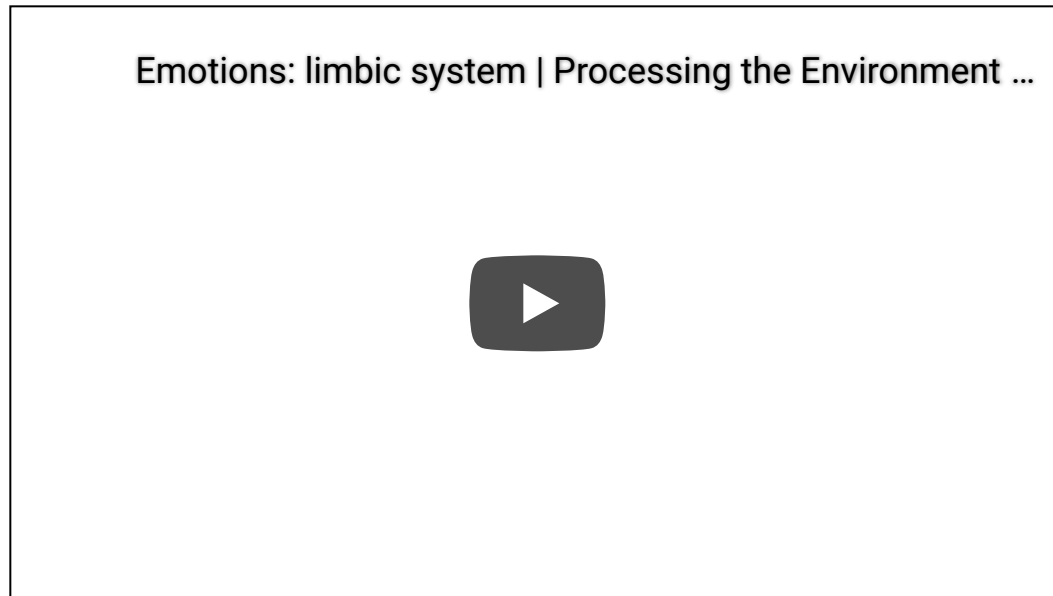


A: Plaques and tangles (shaded in blue) are beginning to form within the hippocampus. B: As the disease progresses, they spread toward the front and rear of the brain. C: In severe Alzheimer's, plaques and tangles cause widespread damage throughout the brain. Source: Courtesy of The Alzheimer's Association.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

Changes within the brain affect every aspect of a person's life. Memory is at the very core of who we are as a person. Difficulties with vision and spatial awareness affect our ability to move about safely in the environment. Because of these changes, walking on a busy street can be dangerous, driving is no longer safe, and avoiding obstacles is a challenge.

It turns out that memory loss isn't the only thing that happens in early Alzheimer's disease. In fact the hippocampus is just one part of a larger brain structure called the *limbic system*. This area of the brain is not only responsible for the formation of new memories; it is also involved with emotions. To understand why emotions and memory are so strikingly affected by Alzheimer's disease please view this clear, concise video.

Emotions: The Limbic System (10:31)



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

Non-Alzheimer's Dementia

Although Alzheimer's disease is the most common and well-known form of dementia, there are other causes and types of dementia that you are likely to encounter in your work. Some other common types of dementia include:

- Vascular dementia and vascular cognitive impairment
- Frontotemporal dementia
- Dementia with Lewy bodies
- Dementia associated with Parkinson's disease

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

Vascular Dementia and Vascular Cognitive Impairment

Vascular dementia and vascular cognitive impairment are caused by injuries to the vessels supplying blood to the brain. Damage can be due to multiple small strokes or to any injury to the small vessels within the brain. Generally, the first symptoms of vascular dementia are difficulty making decisions and impaired judgment. 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).

Vascular dementia is the second most common form of dementia after Alzheimer's disease, affecting approximately 20% of the dementia cases worldwide (Neto et al., 2015). Risk factors for developing vascular dementia and vascular cognitive impairment include heart rhythm irregularities, high blood pressure, diabetes, high cholesterol, smoking, and obesity. Vascular dementia also has been associated with a condition called *amyloid angiopathy*, in which amyloid plaques accumulate in the blood vessel walls, causing them to break down and rupture (NINDS, 2013).

Symptoms of vascular dementia and vascular cognitive impairment often begin suddenly and usually proceed in a step-wise progression. 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.

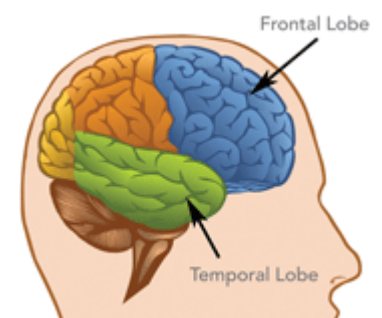
In vascular dementia, memory is less affected than in Alzheimer's but mood changes are more common. Cognitive impairment often seems "patchy" because of the many areas of the brain that are affected. Vascular dementia can be largely prevented if the underlying causes are identified and addressed.

Frontal-Temporal Dementia

Frontal-Temporal (frontotemporal) dementia begins in the frontal and temporal lobes of the brain. This contrasts with Alzheimer's dementia, in which damage begins in the hippocampus and then spreads to the front part of the brain. Frontotemporal dementia typically starts at an earlier age than Alzheimer's disease; it is a relatively common type of dementia in those under the age of 60.

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

Behavior is often referred to as "odd," "socially inappropriate," and "schizoid."



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

***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.

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

Dementia with Lewy Bodies

Dementia with Lewy bodies is one of the most common types of progressive dementia. It is caused by the buildup 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, 2015).

The central features of dementia with Lewy bodies are progressive cognitive decline, "fluctuations" in alertness and attention, visual hallucinations, and parkinsonian motor symptoms, such as slowness of movement, difficulty walking, or rigidity (stiffness). People may also suffer from depression (NINDS, 2015).

Difficulty sleeping, loss of smell, and visual hallucinations can precede movement and other problems by as much as 10 years. Because of this, dementia with Lewy bodies can go unrecognized or be misdiagnosed as a psychiatric disorder until its later stages (NINDS, 2013).

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* dementia with Lewy bodies is related to these other causes of dementia *or* that an individual can have more than one type of dementia at the same time. Dementia with Lewy bodies usually occurs in people with no known family history of the disease. However, familial cases have occasionally been reported (NINDS, 2015).

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.

Cognitive problems 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 disease 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.

Risk factors for developing Parkinson's disease dementia include the onset of Parkinson's-related movement symptoms followed by mild cognitive impairment and sleep disorders, which involves frequent vivid nightmares and visual hallucinations (NINDS, 2013).

Dementia with Lewy bodies and Parkinson's disease dementia are now recognized in the Diagnostic and Statistical Manual of Mental Disorders (DSM-5), 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 & McKeith, 2014).

Staging Alzheimer's Disease

In 2011 the National Institute on Aging and the Alzheimer's Association (NIA/AA) issued updated criteria and guidelines for the staging of Alzheimer's disease. **Staging** is an attempt to define the severity of a disease and understand its progression. Staging is not a diagnosis.

The NIA/AA guidelines describe Alzheimer's disease as occurring along a continuum, starting with healthy aging, then progressing to:

1. Preclinical Alzheimer's disease
2. Mild cognitive impairment
3. Dementia due to Alzheimer's disease

The NIA/AA guidelines also recognize for the first time the importance of **biomarkers** in identifying very early brain changes. Biomarkers are changes in sensory and cognitive abilities or substances in blood, cerebrospinal fluid, or urine. Biomarkers can indicate exposure to a substance, the presence of a disease, or disease progression over time (Lobello et al., 2012).

Magnetic resonance imaging (MRI), positron emission tomography (PET), amyloid imaging, and cerebrospinal fluid analysis are potential biomarkers and may aid in the identification of abnormal brain changes well before symptoms appear. These techniques are only useful, however, when large numbers of people are screened long before symptoms appear, which is currently impractical and even controversial.

Preclinical Alzheimer's Disease

Preclinical Alzheimer's disease is the stage in which pathologic changes have begun to appear in the brain but no cognitive or emotional symptoms are present. During the preclinical stage—currently used only in the research setting—amyloid buildup can be detected in some people using positron emission tomography (PET) scans and cerebrospinal fluid (CSF) analysis. It is unknown what the risk for progression to Alzheimer's dementia is for these individuals. These biomarkers are still being developed and standardized and are not ready for use by clinicians in general practice (NIA, 2011).

Mild Cognitive Impairment Due to Alzheimer's Disease

Mild cognitive impairment (MCI) is identified in the NIA/AA guidelines as the next stage of Alzheimer's disease progression. It is fairly common in older adults and does not necessarily indicate the presence of AD. It is characterized by a decline in cognitive function that falls between the changes associated with typical aging and changes associated with dementia (Lee et al., 2014).

The NIA/AA guidelines for mild cognitive impairment are largely for research, although they clarify existing guidelines for use in a clinical setting. The MCI stage is marked by symptoms of memory problems—enough to be noticed and measured—but not compromising a person's independence. People with MCI may or may not progress to Alzheimer's dementia (NIH, 2011).

Although mild cognitive impairment has been described as a transitional stage between normal cognitive aging and dementia, particularly Alzheimer's disease, community-based studies suggest that many individuals diagnosed with MCI do not progress to Alzheimer's disease and may even revert to normal. Nevertheless, receiving a diagnosis of mild cognitive impairment can be traumatic and it is important for clinicians to be able to provide their patients with information regarding the likelihood of progression to Alzheimer's disease (Lee et al., 2014).

Dementia Due to Alzheimer's Disease

The onset of dementia due to Alzheimer's disease is the third stage described in the NIA/AA guidelines and marks a period in which symptoms become more obvious and independent living becomes more difficult. This stage is referred to as the “dementia phase.”

Identifying Alzheimer's and Other Types of Dementia in the Clinical Setting

Currently, the identification and diagnosis of dementia in the clinical setting is mostly based on a clinician's suspicion of patient symptoms or caregiver concerns. Because the onset of dementia is gradual and the early symptoms of dementia are extremely common, cognitive or cognitive-related functional complaints may not be obvious during routine office visits unless they are directly assessed. To make matters more complicated, many individuals with subjective memory complaints often have normal cognition when tested (Lin et al., 2013). Unfortunately, patients with unrecognized impairment usually do not get tested for reversible causes of dementia, do not get counseling regarding the disease process or advanced care planning, and are not offered treatment (Cho et al., 2014).

Several barriers may contribute to a missed or delayed diagnosis of dementia, particularly in the primary care setting:

- Physician and patient lack of knowledge
- Physicians' concerns about over-diagnosis and labeling
- Lack of appropriate assessment tools
- Patient's refusal to be assessed for dementia
- Time and financial constraints (Lin et al, 2013)

Did You Know . . .

Compared to patients who see a geriatrician or neurologist, dementia patients followed up exclusively by primary care physicians are less likely to receive a specific dementia diagnosis and less likely to have their initial diagnosis change over time. They are also less likely to have neuroimaging or receive dementia medication (Cho et al., 2014).

Screening for Cognitive Impairment

Screening is a method for detecting dysfunction or disease before an individual would normally seek medical care. Screening tests are usually administered to individuals without current symptoms, but who may be at high risk for certain adverse outcomes. Screening has the potential to identify very early signs of dementia, which may allow early diagnosis and treatment. It also offers the chance to identify reversible causes of dementia (such as high blood pressure) and treat conditions that contribute to cognitive decline.

Screening tests for cognitive impairment in the clinical setting generally include asking patients to perform a series of tasks that assess at least one cognitive domain (memory, attention, language, and visuospatial* or executive functioning). Blood tests and radiology examinations are not currently used as screening tests but are often used after a positive screening result to confirm the diagnosis of dementia and determine its subtype (USPSTF, 2014).

***Visuospatial ability:** the ability to perceive and understand the special relationship between objects within the environment that are within our field of vision, including our own body's relationship to other objects.

In 2011 Medicare began covering the "detection of cognitive impairment" as a part of the annual wellness visit benefit, which is mandated by the Affordable Care Act. However, the recommendations issued by the Centers for Medicare and Medicaid Services (CMS) provide little guidance on recommended screening instruments or techniques, other than directing providers to use direct observation and consider information from informants (Lin et al., 2013).

A strong argument in favor of screening for cognitive impairment is that knowledge of the patient's cognitive status is important for the management of comorbid conditions. Cognitive impairment can affect the management of comorbid conditions and may lead to worsened outcomes of the comorbid conditions. Keep in mind that cognitive impairment may lead patients to report symptoms and health behaviors inaccurately, may decrease their ability to consent to treatments, may affect medication adherence, and may make followup of chronic conditions challenging (Lin et al., 2013).

Additionally, because the sensitivity of a clinician's diagnosis appears to be strongly related to dementia severity, most people with dementia are not diagnosed until the moderate to severe stages of the disease. Screening tests in all or targeted older adults may help identify patients with dementia or mild cognitive impairment that is otherwise missed (Lin et al., 2013).

Although no professional organizations explicitly recommend screening for dementia in asymptomatic adults, many groups have recommended assessing the cognitive abilities of older adults who present with cognitive or cognitive-related functional complaints (Lin et al., 2013).

The Alzheimer's Association has published guidance for the detection of cognitive impairment during the annual wellness visit and recommended an algorithm involving a health risk assessment, patient observation, and unstructured questioning. The Alzheimer's Association recommends the use of a brief structured assessment if signs or symptoms of cognitive impairment are present or if an informant is not available to confirm the absence of signs or symptoms (USPSTF, 2014).

Due to the many obstacles associated with screening for dementia, 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 (USPSTF, 2014).

Diagnosing Alzheimer's and Dementia

Diagnosis involves a thorough medical evaluation, medical history, and testing of mental status. Diagnostic tests are performed to rule out reversible causes of dementia such as drug interactions, depression, delirium, thyroid problems, alcohol and drug abuse, and vitamin deficiencies.

Diagnosis of Alzheimer's disease and other types of dementia is based on symptoms. This generally includes a gradual decline in mental capacity, changes in behavior, and the eventual loss of the ability to live independently. **As yet, there is no blood test or imaging technique that can definitively diagnose dementia.**

The National Institute on Aging and the Alzheimer's Association (NIA/AA) has published guidelines for the diagnosis of Alzheimer's disease. The diagnostic criteria are as follows:

1. A gradual, progressive decline in cognition that represents a deterioration from a previous higher level;
2. Cognitive or behavioral impairment evident in at least two of the following domains:
 - a. episodic memory¹
 - b. executive functioning²
 - c. visuospatial abilities³
 - d. language functions,
 - e. personality and/or behavior
3. Significant functional impairment that affects the individual's ability to carry out daily living activities
4. A situation in which symptoms are not better accounted for by delirium or another mental disorder, stroke, another dementing condition (ie, vascular dementia, frontal-temporal dementia) or other neurologic condition, or the effects of a medication (DeFina et al., 2013).

¹**Episodic memory:** a type of long-term memory associated with personal, individual events, places, people, time, and emotions (a person's remembrance of who, what, when, where, and why).

²**Executive functioning:** within the frontal lobe, the part of the brain that oversees or controls planning, attention, ethical behavior, memory, reasoning, problem solving, as well as other cognitive functions.

³**Visuospatial abilities:** the ability to perceive and understand the special relationship between objects within the environment that are within our field of vision, including our own body's relationship to other objects.

The Diagnostic and Statistical Manual of Mental Disorders 5 (DSM-5) contains updated criteria for diagnosing Alzheimer's disease that parallel the NIA-AA diagnostic guidelines. Clinicians should familiarize themselves with these revised criteria, listed within the Neurocognitive Disorders section of the DSM-5 because the criteria contained in the prior DSM-IV-TR are not reflective of the current state of the literature (DeFina et al., 2013).

Diagnostic criteria of Alzheimer's Disease, Vascular Dementia, and other Dementias

Alzheimer's disease

- Development of multiple cognitive deficits, with both memory impairment and one (or more) of the following cognitive disturbances:
 - Aphasia (language disturbance)
 - Apraxia (learned motor skills disturbance)
 - Agnosia (visuospatial/sensory disturbance)
 - Executive functioning (foresight, planning, insight anticipation)
 - Significant impairment in social or occupational functioning, representing a significant decline from a previous level of functioning
- Other diagnostic criteria: Hachinski Ischemic Score,¹ ICD-10; DSM-IV; ADDTC,² updated NINCDS-ADRDA.³

Vascular Dementia (NINDS-AIREN¹)

- Cognitive decline from previous higher level of function in three areas of function including memory
- Evidence of cerebrovascular disease by examination
- Evidence of cerebrovascular disease by neuroimaging
- Onset either abrupt or within three months of a recognized stroke

Vascular Dementia (Modified Hachinski Ischemia Score²: ≥ 4)

- Two-point items
 - Abrupt onset
 - History of stroke
 - Focal neurologic symptoms
- One-point items
 - Stepwise deterioration
 - Somatic complaints
 - History of hypertension
 - Emotional incontinence
- Other diagnostic criteria: ICD-10; DSM-5

Diagnostic criteria of Alzheimer's Disease, Vascular Dementia, and other Dementias

- | | |
|-----------------------------------|---|
| Frontal-Parietal Dementia | <ul style="list-style-type: none">▪ Behavioral or cognitive deficits manifested by either:<ul style="list-style-type: none">◦ Early and progressive personality change, with problems in modulating behavior; inappropriate responses/activities◦ Early and progressive language changes, with problems in language expression, word meaning, severe dysnomia▪ Deficits represent a decline from baseline and cause significant impairment in social and occupational functioning▪ Course characterized by gradual onset and continuing decline in function▪ Other causes (eg, stroke, delirium) are excluded▪ Gradual onset and progressive cognitive decline |
| Dementia with Lewy Bodies | <ul style="list-style-type: none">▪ Fluctuating in cognitive performance:<ul style="list-style-type: none">◦ Marked variation in cognition or function, or episodic confusion/decreased responsiveness◦ Visual hallucinations: Usually well formed, unprovoked, benign▪ Parkinsonism: Can be identical to Parkinson's Disease (PD), milder or symmetric |
| Parkinson's Disease with Dementia | <ul style="list-style-type: none">▪ Bradyphrenia (slowness of thought)▪ Executive impairment▪ Neuropsychiatric symptoms▪ Dysphonia |

¹Hachinski Ischemic Scale: Used to identify a vascular component once dementia has been diagnosed. Not a validated diagnostic tool.

²ADDTC: Alzheimer's Disease Diagnostic and Treatment Centers

³NINCDS-ADRDA: National Institute of Neurological and Communicative Disorders and Stroke and Alzheimer's Disease and Related Disorders Association (now known as the Alzheimer's Association).

Source: Modified from Beydoun et al., 2014.

Clinical Index to Predict Progression

To help clinicians better understand the progression of Alzheimer's disease, researchers at the University of California, San Francisco have developed a brief clinical index, which 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 eight 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) (Lee et al., 2014).

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 (Lee et al., 2014).

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 (Lee et al., 2014).

The 3 Ds: Delirium, Depression, and Dementia

Delirium and depression can cause cognitive changes that may be mistaken for dementia. Delirium can also be superimposed on dementia, particularly in older hospitalized patients. Clinicians and caregivers need to learn to distinguish the differences.

Delirium

Delirium is a neuropsychiatric syndrome with an acute onset and a fluctuating course. The term **delirium** literally means, “out of the track,” and was first used by Celsus, in the first century A.D. to describe either states of agitation or excessive somnolence.* Historically, this syndrome has been described under different names and classifications. Gradually the term *delirium* started to be more consistently used to designate reversible states of acute brain dysfunction associated with fever or medical/surgical conditions (Cerejeira & Mukaetova-Ladinska, 2011).

Somnolence: sleepiness or drowsiness, a desire to sleep for long periods of time during the day, falling asleep while working, during meals, or even in the middle of a conversation.

Delirium develops acutely—over hours or days—and is temporary and reversible. The most common causes of delirium, which are usually identifiable, are related to medication side effects, hypo- or hyperglycemia, 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. If severe enough, it can be detected during a clinical interview. In mild cases, impairment of attention can be uncovered only by formal cognitive testing (eg, naming the months in reverse order). Attention is impaired in early stages and throughout the course of a delirium episode, correlating with the severity of cognitive deficits (Cerejeira & Mukaetova-Ladinska, 2011).

A person experiencing delirium usually has difficulty with:

1. Orientation
2. Memory
3. Language and thought
4. Visuospatial abilities (Cerejeira & Mukaetova-Ladinska, 2011)

Specific deficits in visual perception have been described in people with delirium:

1. Illusions (misinterpretations of real sensory stimuli, as when the patient in a dark environment sees a threatening figure emanating from shadows on the walls)
2. Hallucinations (ranging from simple flashes or unstructured sounds to elaborate visions, that occur without corresponding sensory stimuli) (Cerejeira & Mukaetova-Ladinska, 2011).

Video: Patient Experience of Delirium (5:51)



Source: Northumbria Healthcare Foundation Trust, England, U.K.

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 (Hope et al., 2014).

Early diagnosis of delirium can lead to rapid improvement. Nevertheless, diagnosis is often delayed, and problems remain with recognition and documentation of delirium by healthcare providers. Although there are no definitive quantitative markers available to diagnose delirium, qualitative tools such as the Confusion Assessment Method (CAM) and modified Richmond Agitation and Sedation Scale have been validated. Unfortunately, these tools are underused and healthcare providers often simply record the patient's mental status in narrative (Hope et al., 2014).

Depression

Although it presents with an array of physical symptoms, **depression** is considered a disorder of mood. It is also called an *affective disorder* to signify that one of its key aspects is a disturbance of emotions or feelings (Diamond, 2015).

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 judged to be of clinical significance when they interfere with normal activities and persist for at least 2 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 affective symptoms 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 (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 3-year period (Vermeiren et al., 2015).

Causes of Depression in Those with Dementia

Depression has been associated with an increased risk of dementia in old age, but the mechanisms underlying this association are not well understood. Several possible mechanisms have been proposed: (1) depression is a prodrome* of dementia, (2) depression reduces the threshold for dementia, and (3) depression leads to damage to neural systems, particularly the hippocampus, which contributes to the development of dementia (Olazarán et al., 2013).

***Prodrome:** an early symptom that may indicate the presence of a disease.

Past or lifetime history of depression is known to increase the risk of developing both Alzheimer's disease and vascular dementia. This is true even when depression occurred more than 10 years before the onset of dementia. A history of depression nearly doubles the risk of developing dementia. This is further confirmed by a study that demonstrated increased plaque and tangle formation in the hippocampus of Alzheimer's patients who had a lifetime history of depression. Prolonged damage to the hippocampus due to hypercortisolemia* linked to depression has been proposed to underlie this finding (Muliyala & Varghese, 2010).

***Hypercortisolemia:** abnormal, high levels of circulating cortisol, often caused by stress and leading to a "fight or flight" response.

Vascular factors may play a role in depression and dementia. Cerebrovascular disease, hypertension, diabetes, and other vascular factors may cause both cognitive impairment and depression. However, this potential role of cerebrovascular disease and other vascular factors in the association between depression and dementia has barely been investigated (Olazarán et al., 2013).

Management of Depression

In the long-term care population, depression is both common and under-treated. Depressive illness is associated with increased mortality, risk of chronic disease, and the requirement for higher levels of supported care (Jordan et al., 2014).

Long-term care staff can play a key role in the detection, assessment, management, and ongoing monitoring of mental health disorders among those they care for. However, staff members usually receive little training in mental health and often hold misconceptions about disorders such as depression and the behavioral and psychological symptoms of dementia. As a result, they have demonstrated poor skills in managing residents with these disorders (Jordan et al., 2014).

Pharmacologic interventions are targeted at alleviating depressive symptoms primarily to improve quality of life and improve function (Nowrangi et al., 2015). Treatment of depression in patients with dementia has involved the use of tricyclic agents¹, SSRIs², and MAO inhibitors³ even though the evidence to support the effectiveness of these agents is weak (Muliya & Varghese, 2010).

1Tricyclic agents: used to treat depression, bipolar disorder, anxiety, obsessive-compulsive disorder, and other disorders of mood.

2SSRIs: selective serotonin reuptake inhibitors are used to treat major depressive disorders and anxiety disorders.

3MAO inhibitors: monoamine oxidase inhibitors are prescribed for the treatment of depression.

Randomized controlled trials have evaluated the use of imipramine (Tofranil), citalopram (Celexa), fluoxetine (Prozac), sertraline (Zoloft), and moclobemide with beneficial results. However, a recent multicenter, randomized placebo-controlled trial did not demonstrate efficacy for the treatment of depression with sertraline (Zoloft) in patients with Alzheimer's disease (Muliya & Varghese, 2010).

Antidepressant treatment may reduce cognitive decline in depressed older Alzheimer's patients. The use of cholinesterase inhibitors* with SSRI may improve activities of daily living and global functioning in patients with dementia. Non-pharmacologic management of depression involves both patient-focused interventions as well as family and caregiver support. In one study, treatment with donepezil (Aricept) delayed progression to Alzheimer's disease among depressed subjects with mild cognitive impairment (Muliya & Varghese, 2010).

***Cholinesterase inhibitor:** a drug that prevents the breakdown of acetylcholine, a chemical that helps with memory and thinking.

Comparing Dementia, Delirium, and Depression			
	Delirium	Depression	Dementia
Onset	Rapid, hours to days	Rapid or slow	Progressive, develops over several years
Cause	Medications, infection, dehydration, metabolic changes, fecal impaction, urinary retention, hypo- and hyperglycemia	Alteration in neurotransmitter function	Progressive brain damage
Duration	Usually less than one month but can last up to a year	Months, can be chronic	Years to decades
Course	Reversible, cause can usually be identified	Usually recover within months; can be relapsing	Not reversible, ultimately fatal
Level of consciousness	Usually changed, can be agitated, normal, or dull, hypo- or hyperactive	Normal or slowed	Normal
Orientation	Impaired short-term memory, acutely confused	Usually intact	Correct in mild cases; first loses orientation to time, then place and person
Thinking	Disorganized, incoherent, rambling	Distorted, pessimistic	Impaired, impoverished
Attention	Usually disturbed, hard to direct or sustain	Difficulty concentrating	Usually intact
Awareness	Can be reduced, tends to fluctuate	Diminished	Alert during the day; may be hyperalert

Comparing Dementia, Delirium, and Depression			
	Delirium	Depression	Dementia
Sleep/waking	Usually disrupted	Hyper or hypo somnolence	Normal for age; cycle disrupted as the disease progresses

Source: Adapted from Eliopoulos, 2010.

Depression vs. Grief

The diagnosis of dementia can cause grief related to actual or anticipated losses associated with the dementia diagnosis (Vroomen et al., 2013). Good support following the initial diagnosis helps people adapt and provides opportunities to develop coping responses.

Grief, like depression, can cause physical symptoms such as shortness of breath, headaches, fatigue, a feeling of heaviness, and a lack of energy. Psychological symptoms associated with grief include clinical depression, hypochondria, anxiety, insomnia, and the inability to get pleasure from normal daily activities. These issues can lead to self-destructive behaviors, such as alcohol or drug abuse.

Grief is often associated with the many losses experienced by a person with dementia:

- Loss of physical strength and abilities
- Increased confusion
- Loss of income and savings
- Loss of health insurance
- Changes in housing and personal possessions, including loss of pets
- Loss of self-sufficiency, privacy, and self-esteem
- Changes in social contacts and roles

The onset of dementia in a friend, spouse, or relative can also cause family members and caregivers to grieve due to:

- Loss of companionship
- Loss of income
- Loss of privacy and free time
- Changes in social roles
- Changes in routine

In the early stage of dementia, counseling, assessment of co-morbid conditions, information about dementia, caregiver training, and development of a care plan can help a person deal with grief. Unfortunately, these resources are often lacking.

In later stages, moving a loved one to a care home can be the cause of immense grief and loss for people with dementia and for their caregivers. People with dementia newly admitted to an institution are often disoriented and disorganized in their new environment and feel grief due to a loss of control over their lives (Vroomen et al., 2013).

When a loved one dies, family members, and especially spouses, experience a period of acute grief that generally includes intrusive thoughts,* intense emotional distress, and withdrawal from normal daily activities. When a spouse dies, in addition to grief, about 28% of surviving spouses experience major depression. This period, along with the chronic grief that follows, may vary in length and intensity from individual to individual and often resembles clinical depression (Monk et al., 2013).

***Intrusive thoughts:** unwanted, involuntary thoughts, images or ideas that can be obsessive, distressing, or upsetting.

This risk of depression appears to peak during the first six months of bereavement, although depressive symptoms can be present for up to two years. Even bereaved persons with minor depression may suffer, for they have a greater likelihood of functional impairment, poorer health, more physician visits and mental health counseling, and increased use of antidepressants than do non-bereaved individuals (Monk et al., 2013).

Neuropsychiatric Symptoms of Dementia

Behavioral and psychological symptoms of dementia (BPSD) or neuropsychiatric symptoms of dementia (NSP) occur in up to 90% of patients with dementia (Passmore, 2013). Neuropsychiatric symptoms can range from mild (depression, anxiety, irritability, apathy) to severe (agitation, aggression, vocalizations, hallucinations, disinhibition,* among others). Symptoms can persist or recur over time and are associated with patient 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.

Management of neuropsychiatric symptoms of dementia relies on the use of both pharmacologic and non-pharmacologic therapies based on treatments developed for other psychiatric disorders. Unfortunately, there has been a lack of progress in the development of effective treatments due to an incomplete understanding of the biological mechanisms underlying these symptoms. Because of this, treatment strategies are in response to behaviors and largely based on observation and experience rather than on an understanding of the underlying cause (Nowrangi et al., 2015).

Among the many neuropsychiatric behaviors associated with Alzheimer's disease and other types of dementia, depression,* apathy, agitation and aggression, and delusions and hallucinations (psychoses) are some of the most common. Challenging behaviors such as wandering, rummaging and hoarding, and sleep disturbances can arise and may or may not be related to neuropsychiatric changes.

*See Module 4: The 3 D's: Dementia, Delirium, and Depression for more on depression.

Non-Pharmacologic Approaches

There is growing evidence to suggest that the management of neuropsychiatric behaviors (particularly in long-term care) should shift from the traditional practice of medication-based symptom management to comprehensive non-pharmacologic approaches aimed at maintaining the physical and emotional comfort of the individual. Such non-pharmacologic interventions can be used with the individual or can be applied to the physical setting or built environment (Soril et al., 2014).

Non-pharmacologic treatments for the challenging behaviors associated with dementia include cognitive stimulation, cognitive training, behavioral interventions, exercise, music, aromatherapy, bright light therapy, animal therapy, and multi-sensory stimulation (Snoezelen*), among others. Non-pharmacologic interventions can also be aimed at caregivers and include education, support, case management, and respite care (Nowrangi et al., 2015).

***Snoezelen**: a Snoezelen or controlled multisensory environment room 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.

Video: Snoezelen Room (2:07)



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

Other studies have shown that staff education leads to reductions in behavioral outbursts and fewer episodes of restraint use. In a meta-analysis by Olazarán and colleagues, the majority of the studies reviewed showed positive effects for improvements in mood, behavior, and quality of life of persons with dementia while delaying institutionalization (Nowrangi et al., 2015).

One effective non-drug approach used to address challenging behaviors associated with dementia encourages caregivers to *problem solve*—to look for and understand the root cause of a behavior. Treatment can include solving problems within the environment, managing medication issues, and brainstorming with caregivers. The problem-solving approach encourages caregivers and healthcare workers to identify critical points for intervention based on observing the *antecedent*, *behavior*, and *consequence* (A, B, C) of a challenging behavior.

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

The ABC 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. The ABC method helps staff and caregivers understand when and how often a behavior occurs and offers the opportunity for discussion and planning.

In Norway, 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 healthcare workers described what they understood about—and how they responded to—challenging behaviors. Most regarded challenging behaviors as a symptom of dementia, including physical attacks, such as hitting, spitting, and pinching (Lykkeslet et al., 2014).

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

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.

Residents who wandered around or repeatedly said that they wanted to go home were also 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 course of 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 claimed 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 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.

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).

For pragmatic suggestions that healthcare workers can use when working with individuals who can no longer express themselves appropriately, see ATrain's course entitled *Dementia Care: Common Sense Guidelines*.

Dementia and Apathy

Apathy is described as a lack of interest or emotion and may be an early symptom of cognitive impairment, especially in frontal-temporal dementia. The prevalence of apathy increases with the severity of dementia. Apathy is different from depression although apathy and depressive symptoms may occur together (Volicer & van der Steen, 2014).

For a diagnosis of apathy, the diminished motivation must persist for no less than four weeks, and two of the following three dimensions should be present:

- 1.** Reduced goal-directed behavior
- 2.** Reduced goal-directed cognitive activity
- 3.** Reduced emotions (Rea et al., 2014)

Although apathy is a common behavioral symptom of neurodegenerative and other brain disorders it is one of the most under-recognized, under-diagnosed, and poorly managed aspects of these diseases (Leroi & Robert, 2012). It is the cause of distress for caregivers because it places the responsibility for day-in and day-out decisions on the caregiver. Over time, anger and conflicts inevitably follow between patients and caregivers. This makes apathy a risk factor for institutionalization (Rea et al., 2014).

Causes of Apathy

In Alzheimer's disease, apathy is associated with loss of nerve cells within specific parts of the brain. In the past, apathy was classified as a motivational loss not attributable to emotional stress, cognitive impairment, or consciousness reduction. Apathy has since been related to disconnection of certain brain circuits, including the amygdala,¹ which receives nerve impulses from various parts of the brain. This suggests that impaired cholinergic neurotransmission² is involved in apathy pathophysiology (Rea et al., 2014).

¹**Amygdala:** part of the limbic system, associated with memory, decision-making, and emotions.

²**Cholinergic neurotransmission:** a receptor is cholinergic if it uses acetylcholine as its neurotransmitter. The cholinergic system is involved in the regulation of memory and learning.

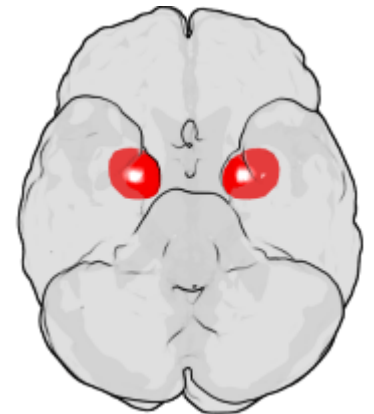
Management of Apathy

At present apathy accompanying Alzheimer's disease is a disorder not largely investigated and its treatment remains a challenge. Only a few treatments have been proposed, but so far there is no clear demonstration of the advantage of one treatment over others (Rea et al., 2014).

Four categories of drugs are currently used to treat apathy in people with Alzheimer's dementia. These include:

1. Cholinesterase inhibitors (inhibits the breakdown of acetylcholine)
2. Monoaminergic agents such as methylphenidate (Concerta, Methylin, Medikinet, Ritalin) and modafinil (Provigil)
3. Drugs such as the Ginkgo biloba extract Egb 76
4. Selective serotonin reuptake inhibitor citalopram (Celexa) (Rea et al., 2014)

Location of the Amygdala in the Human Brain



The figure shows the underside of a human brain, with the front of the brain at the top. The red areas show the approximate location of the amygdala in the temporal lobes of the human brain.
Source: Wikimedia Commons.

Agitation and Aggression

The terms *agitation* and *aggression* are often used in reference to behavioral symptoms associated with dementia. **Agitation** refers to observable, non-specific, restless behaviors that are excessive, inappropriate, and repetitive. This can include verbal, vocal, or motor activity (Burns et al., 2012).

Aggression involves physically or verbally threatening behaviors directed at people, objects, or self. Aggressive behaviors are generally perceived as a threat to the safety of those with dementia and to those around them, which includes family caregivers, staff, and other residents. Aggression is often described by specific acts such as:

- Verbal insults
- Shouting, screaming
- Obscene language
- Hitting, punching, kicking
- Pushing and throwing objects
- Sexual aggression (Burns et al., 2012)

Agitation and aggression occur in about 50% to 80% of nursing home residents with cognitive impairments (Ahn & Horgas, 2013). Men are more likely than women to engage in aggressive behaviors. *Cognitively* impaired people are more likely to engage in non-aggressive physical behaviors (such as pacing). *Functionally* impaired people are more likely to engage in verbally agitated behaviors (complaining, vocal outbursts) (Pelletier & Landreville, 2007).

Causes of Agitation and Aggression

Agitated and aggressive behaviors are a type of communication 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).

Physiologically, aggression may be related to a decrease in the activity of serotonin or reduced transmission of acetylcholine in the brain. Frontal lobe dysfunction has also been implicated. Aggression may also be related to underlying depression or psychotic symptoms (Burns et al., 2012).

Pain severity is associated with the frequency of agitated and aggressive behaviors. Nursing home residents with more severe pain are more likely to display these behaviors (Ahn & Horgas, 2013).

Management of Agitation and Aggression

To understand and prevent agitation and aggression, consider the antecedent: What precipitated the behavior? Observe the person and try to determine the cause of the agitation. Look for patterns. Use one of the many available rating scales—such as the Rating Scale for Aggressive behavior in the Elderly (RAGE)—to assess *aggressive* behaviors. For *agitated* behaviors rating instruments such as the Brief Agitation Rating Scale can be used to assess the different aspects of agitation (Burns et al., 2012).

Psychosocial and environmental interventions can reduce or even eliminate agitated or aggressive behaviors. Music therapy, massage, craniosacral therapy,* therapeutic touch, acupressure, and tactile massage have been shown to be successful for treating aggression. In addition, individual behavioral therapy, bright light therapy, Montessori activities, and individualized person-centered care based on psychosocial management is recommended (Burns et al., 2012).

***Craniosacral therapy:** a hands-on technique that uses soft touch to release restrictions in the soft tissue surrounding the central nervous system.

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).

Case

My mom Kimberly has dementia and my sister and I take turns staying with her at her home. She's a pretty quiet person but a couple of years ago she starting getting really agitated and angry in the evening—we blamed this on her dementia. It got so bad that we thought about sedating her but a nurse practitioner suggested we try to figure out what was causing her agitation using the problem-solving approach.

We watched her behavior carefully and finally figured out that she was getting really cold in the evening—even when it was warm outside. She didn't tell us she was cold but when we asked she said "I'm freezing."

Once we realized what was wrong, we ordered special heated slippers and also got an electric mattress pad so her bed is nice and warm when she goes to bed. It sounds simple but it took us a long time to figure it out because she doesn't complain. Now she's rarely—actually she's never—agitated or angry in the evening!

Family Caregiver, Santa Rosa, California

Delusions and Hallucinations (Psychosis)

Psychosis is a disturbance in the perception or appreciation of objective reality (Burns et al., 2012) and can include delusions and hallucinations. A **delusion** is a false idea or belief or a misinterpretation of a situation. **Hallucinations** are sensory events in which a person hears, tastes, smells, sees, or feels something that is not there.

Delusions and hallucinations can occur in people with dementia, with hallucinations particularly common in those with Parkinson's disease dementia and Lewy body dementia. In fact, the presence of recurrent visual hallucinations has been identified as one of the core features in the clinical diagnosis of dementia with Lewy bodies. Delusions and hallucinations can trigger other neuropsychiatric symptoms, such as agitation or aggression, which can lead to early nursing home admission (Vermeiren et al., 2015).

Causes of Psychosis

Delusions and hallucinations can be caused by health factors such as urinary tract infections, environmental factors such as poor lighting or sensory overload, or a reaction to certain medications. Changes in the brain can also contribute to these behaviors, especially changes related to sensory awareness, memory, and decreased ability to communicate or be understood.

People suffering from delusions and paranoia can become suspicious of caregivers or friends. Sensory deficits can contribute to delusions and hallucinations due to the distortion of sound or sight.

Visual hallucinations can occur in the moderate to severe stages of dementia and are particularly common in those with Lewy body dementia. While atypical antipsychotics are sometimes used off-label to manage hallucinations, in a person with Lewy body dementia antipsychotic medications can make hallucinations worse. In a person with new onset of visual hallucinations, the number one cause is medication side effects. For this reason, all medications should be carefully reviewed. This includes prescription and over-the-counter (OTC) medications, as well as herbal supplements.

Management of Psychosis

The first step in the management of delusions and hallucinations is to rule out delirium as a cause (see Module 4 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).

At present, antipsychotics are the primary pharmacologic treatment option used to alleviate depression and psychosis in Alzheimer's disease—although they may induce 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 of dementia in those 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. Finally, 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).

From a non-pharmacologic standpoint, psychotic behaviors can often be successfully managed by observing the behavior and listening to what the person experiencing the paranoia or delusion has to say. Is the feeling pleasant or frightening? If the hallucination elicits a fearful or negative response, address the person's need to regain comfort. For example, you may ask “What will make you feel safe or comfortable?”

When communicating with someone who is expressing paranoia or delusions, realize that even if their complaint is not true, it is real for that person. It is best not to argue; simply explaining the truth of the situation will not work. Do not agree with the person or further validate the paranoia or delusion, but respond to the person's emotion.

Decreasing auditory and visual stimuli can help in managing hallucinations. It may also be helpful to have the person evaluated for visual or hearing impairment. Delusions and hallucinations can be addressed using behavioral interventions or, in some cases, antipsychotic medication (Burns et al., 2012).

Here are some other suggestions for addressing hallucinations:

- Reduce stimulation in the environment—minimize violent or noisy TV, remove wall hangings, reduce noise, play relaxing music.
- Cover mirrors.
- Reduce glare from windows.
- Ensure adequate lighting.
- Review medications for potential side effects.

Other Challenging Behavioral Issues

Although many of the challenging behaviors seen in Alzheimer's disease and other types of dementia are associated with changes to the brain, other behaviors may be only partly related to dementia. Isolation, loneliness, frustration, constipation, pain, feeling too cold or hot, and boredom can lead to repetitive behaviors such as wandering, rummaging, and hoarding. A person may be over-medicated or be receiving medications with unwanted side effects. It is not uncommon for sleep to be disrupted, particularly with those living in a nursing facility. Many of these things would frustrate anyone—not only a person with dementia.

Wandering or “Walking About”

Wandering is a broad term encompassing a diverse set of behaviors. It 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 generally falls into two categories: goal-directed, in which residents attempt to reach an unobtainable goal (such as going home or to the store), and non-goal-directed, in which the resident wanders aimlessly. Wandering patterns vary and can include moving to a specific location, lapping or circling along a path or track, pacing back and forth, or wandering at random. Residents with Alzheimer's disease are more likely to wander than those diagnosed with other types of dementias.

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).

Causes of Wandering

People with Alzheimer's disease are more likely to wander than those diagnosed with other types of dementias. Wandering is more prevalent in men and in younger people with dementia. Those with frontal-temporal dementia have a greater tendency to pacing and lapping behaviors whereas those with Alzheimer's disease are more inclined to engage in random locomotion. Wandering in the form of restlessness, with a compelling need for movement or pacing, has been linked to side effects of psychotropic medications, particularly antipsychotics (Burns et al., 2012).

Wandering is often related to boredom, pain and discomfort, disorientation, and memory problems. People may wander out of habit or because they think something from their past needs to be done, such as going home after work, walking the dog, getting exercise, or searching for something they think they have lost.

A person's pre-dementia lifestyle may be a factor in whether they are likely to wander. Studies have indicated that people with the following characteristics are more likely than others to wander:

- Those with an active physical and mental interest in music
- Those who have an extroverted personality showing warmth, positive emotion, altruism
- Those who were very involved with social activities and were active in social-seeking behaviors
- Those who were physically active
- Those who experienced stressful events throughout their life, necessitating multiple readjustments
- Those who respond to stress by engaging in motor activities (Futrell et al., 2010)

Management of Wandering

Best practice in management of hospitalized older adults with dementia who wander involves:

- Identifying risk for wandering
- Providing appropriate supervision
- Reducing environmental triggers for wandering and
- Using individualized nursing interventions to address the causes of wandering behavior (HIGN, 2012)

Wandering can be a beneficial activity if there are safe places to wander, in and around a facility or home. Management of wandering should include a regular review of medications to make sure wandering is not the result of medication side effects, overmedicating, or drug interactions. The most important goal is to prevent a person from wandering into unsafe areas, other resident's rooms, or away from the facility. Additional strategies to manage wandering include:

- Redirecting to a purposeful activity
- Providing safe, looping wandering paths with interesting rest areas
- Providing regular exercise
- Engaging a person in simple chores such as folding laundry or assisting with dinner
- Reducing excessive noise levels
- Avoiding medications that increase fall risk
- Putting up visual barriers on exit doors such as stop signs
- Using electronic devices attached to the person's ankle or wrist that alert staff or family when someone has wandered out of a designated area
- Installing alarms on entryways into unsafe areas or to the outside
- Putting up physical barriers such as yellow tape to prevent wandering into unsupervised areas

Subjective barriers such as grid patterns on the floor in front of exit doors, camouflage, and concealment of doors and doorknobs may discourage a wanderer from exiting a building.

Did You Know . . .

The Alzheimer's Association has partnered with MedicAlert through the Alzheimer's Association Safe Return Program to provide 24-hour assistance for those who wander. They maintain an emergency response line and immediately activate local chapters and local law enforcement to assist with the search for someone who has wandered off. The program includes an ID bracelet and a medical alert necklace. For more information call 800 625 3780 or visit the Alzheimer's Association website (Alz.org).

Case

Mrs. Winkler has moderate dementia. A nursing assistant has wheeled her to the activities room and left her there. After about 20 minutes, Mrs. Winkler decides to leave the activities room. She heads down the hall and is stopped several times by staff, all of whom turn her back toward the activities room—usually with a reprimand.

As soon as the staff member is gone, Mrs. Winkler turns around and continues on her way. She stops near the elevator, where she sits for about 10 minutes watching people come and go. Several staff members pass her and sternly tell her not to get on the elevator. Each staff member leaves her in exactly the same place next to the elevator. Finally, when no one is looking, Mrs. Winkler wheels into the elevator. The door closes and the elevator takes off for the ground floor.

Antecedent: *Mrs. Winkler is a curious person and always liked walking around the city for exercise. She liked exploring the various neighborhoods. She was never one to sit around doing nothing. Mrs. Winkler can propel herself independently in the wheelchair but is no longer able to think logically or understand the consequences of her decisions. The elevator is interesting and looks like fun. People keep walking by and talking to her although she doesn't understand or remember what they are saying.*

Behavior: *The door to the elevator is an interesting visual cue. When a door opens, it is a common reaction to pass through it. The opening door cues Mrs. Winkler to wheel into the elevator. When the door opens on the ground floor, she wheels herself out of the elevator without knowing where she is. Her behavior is consistent with her personality and her previous habits.*

Consequence: *Once she gets into the elevator, Mrs. Winkler's inability to think logically puts her at great risk. If she were to exit the elevator next to a door that leads out of the building, she could wander into the street. People not familiar with her may be unaware she has dementia and is unable to exercise good judgment.*

Discussion: *Mrs. Winkler cannot understand the danger and does not remember the warnings to stay out of the elevator. One solution is to alter the environment. Move Mrs. Winkler to a place where she cannot see or hear the elevator. Try to determine the reason for her wandering. Review medications to make sure wandering is not the result of medication side effects, over-medicating, or drug interactions. People wander out of habit and because they are restless, bored, or, disoriented. Use the following suggestions to keep Mrs. Winkler out of the elevator:*

- *Redirect her to a purposeful activity.*

- *Provide a place where she can wander safely.*
- *Provide her with regular exercise.*
- *Engage her in simple, meaningful chores.*
- *Review her medications.*
- *Attach an electronic device to Mrs. Winkler's ankle or wrist that alerts caregivers when she has wandered out of a designated area.*
- *Paint a grid in front of the elevator to discourage her getting into the elevator.*
- *Place a plastic vertical PVC pole on the back of her wheelchair and a horizontal pole across the entrance to the elevator so that she is physically stopped from entering the elevator.*
- *Encourage a family member to take her for a stroll outside the building or for a ride in a car.*

Rummaging and Hoarding

Rummaging and hoarding refer to behaviors in which a person gathers, hides, or puts away items in a secretive and guarded manner. These actions are considered a type of obsessive-compulsive behavior. Rummaging and hoarding are not necessarily dangerous or unsafe but they can be frustrating for caregivers, residents, and family members.

Causes of Rummaging and Hoarding

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," confusion, 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.

Cognitive changes can contribute to the impulse to rummage and hoard. People may obsess about something they think has been misplaced. They may have a fear of being robbed or feel a need to protect their own possessions. Rummaging through familiar items may create a sense of safety and security.

Management of Rummaging and Hoarding

To address rummaging and hoarding behaviors, try to determine what triggers or causes the behavior and look at the consequences, if any. Put yourself in the other person's head—the reason for rummaging and hoarding may not be clear to you but there may be a perfectly good reason why someone with dementia is rummaging.

Rummaging through another person's belongings can be prevented by installing locks on drawers and closets. The rummaging impulse might be satisfied by creating a rummaging room or a bag or drawer of items that can be picked through. Placing restrictions on rummaging and hoarding can be frustrating for a person who enjoys these activities.

If possible, place important items such as credit cards or keys out of reach or in a locked cabinet. Consider having mail delivered to a post office box and check wastepaper baskets before disposing of trash. Other recommendations:

- Look for patterns.
- Get rid of poisonous items such as caustic liquids and poisonous plants.
- Label cabinets, doors, and closets with words or pictures to help the person find what they are looking for.
- Reduce clutter.
- Observe carefully to learn the person's hiding places.
- Check garbage for missing items.

Case

I used to work at a large nursing home in an urban area in northern California. One wing of the nursing home faced an alley where homeless people sometimes slept.

Unfortunately, the sliding glass doors in rooms 1 through 16 opened onto this alley and for some reason the doors were left unlocked day and night. Several residents with dementia began to complain loudly that they were losing things from their rooms. They spent a great deal of time obsessing about the lost items and rummaged all over the place, including in other residents' rooms looking for lost items. The staff, almost to a person, associated the rummaging and complaints with the residents' dementia.

After several months of trying everything from activities to antipsychotics, one of the occupational therapists noted during a staff meeting that several doors were ajar when she walked to the grocery store via the alley. She suggested we try locking the sliding glass doors in the residents' rooms. It turned out that several of the doors didn't even have locks on them and didn't even close properly.

The facility fixed the doors and added surveillance cameras in the alley. Sure enough the cameras revealed that someone had been entering the residents' rooms and stealing items. Once the doors were fixed and locked much of the complaining and rummaging subsided. It turns out, at least in this case, that items really were missing from residents' rooms.

Registered Nurse, Berkeley, CA

Sleep Disturbances

Sleep disturbances are very common among 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.

The symptoms of sleep disruption vary according to the type of dementia and may present with the following features:

- Increased sleep latency (difficulty getting to sleep)
- Nocturnal sleep fragmentation (waking often)
- Increased early-morning awakenings

- Decreased total sleep time
- Decreased sleep efficiency (how much time you are actually asleep)
- Decreased slow-wave and rapid-eye-movement (REM) sleep
- Nocturnal confusion (episodes of delirium or disorientation during sleep)
- Increased daytime napping and excessive daytime sleepiness
- Other behavioral and psychological symptoms such as agitation, verbally disruptive behaviors, hallucinations, and nighttime wandering (Burns et al., 2012)

Causes of Sleep Disturbances

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).

Medications used to treat the psychological and 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).

Management of Sleep Disturbances

Before treating sleep disturbances, look for potentially treatable causes such as pain, hunger and thirst, the need to urinate, infections, adverse drug reactions, and even noise. Some non-pharmacologic treatments that have been used successfully in nursing homes to treat sleep disorders include:

Light therapy

- High-intensity or ambient light in morning or evening
- Full-spectrum light box
- Melatonin with light therapy
- Bright light exposure during the day

Good sleep hygiene practices

- Get up at the same time every morning and go to bed at the same time every night

- Turn on music or radio at bedtime
- Provide a comfortable and warm bed
- Empty bladder before bedtime
- Limit daytime napping

Other Treatments

- Exercise during the day
- Individualized social activities
- Restriction or elimination of caffeine, nicotine, and alcohol
- Calm atmosphere
- Biofeedback (Deschenes & McCurry, 2009)

Challenging Behaviors and Adverse Drug Events

Older people are susceptible to adverse drug events due to chronic medical conditions, age-related physiologic changes, and polypharmacy. In people with dementia, functional impairment may make them more susceptible to adverse drug events, falls, fractures, and excess sedation. Despite these dangers, population-based research suggests that older people continue to take drugs with an unfavorable risk-to-benefit ratio. Despite guidelines advising against the use of drugs with sedative or anticholinergic properties in people with Alzheimer's disease, such drugs remain widely used in people with Alzheimer's disease (Gnjidic et al., 2014).

Among people with Alzheimer's disease in Europe, 23% used anticholinergic drugs with significant or moderate effects. In people with advanced dementia in institutional care in the United States, 28% used antipsychotics and 54% used antidepressants. Potentially inappropriate drugs, defined using the Beers Criteria,* were used by 20% of older adults with dementia living in the community in the United States (Gnjidic et al., 2014).

***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.

Several studies have emphasized the need to avoid drugs that affect cognition or induce delirium when treating patients with co-existing cognitive impairment. Memory loss, decline in intellectual function, and impaired judgment and language have a negative impact on decision making and often influence treatment adherence. These cognitive changes can also cause communication difficulties, which can affect a person's ability to report adverse effects. For this reason the use of drugs to treat non-dementia illnesses in older adults with severe cognitive impairment may lead to serious adverse effects, even when clearly beneficial drugs recommended by clinical guidelines are prescribed. These concerns represent barriers to pharmacologic treatment of complex patients with severe cognitive impairment and should be carefully evaluated by prescribing healthcare providers when treating older persons with this dementia (Colloca et al., 2012).

Rejection of Care

Because those with dementia may not understand the need for care, they may not cooperate with the caregiver and may actually actively resist caregiver's attempts to provide care. If the caregiver persists in trying to provide care, the person with dementia may become combative and may be called "abusive." In addition, depression may cause "abusive behavior" even in absence of rejection of care (Volicer & van der Steen, 2014).

Rejection of care can include rejecting an evaluation or rejecting specific aspects of care such as blood work, medications, or assistance with activities of daily living. It is not considered rejection of care if a patient's somnolence prevents the person from swallowing medications nor does it include aggressive behaviors intended to harm others. The prevalence of rejection of care increases with severity of dementia because of increased lack of understanding of caregiver's intent and may be present in up to 35% of nursing home residents (Volicer & van der Steen, 2014).

Using Restraints to Control Challenging Behaviors

A **physical restraint** is any device, material, or equipment attached to or near a person's body that can neither be controlled nor easily removed by the person, and that deliberately prevents or is deliberately intended to prevent a person's free body movement to a position of choice or a person's normal access to the body (Lai et al., 2011).

Restraint also includes using (or threatening) force to make a person do something that resists or restricts their movements, whether or not they resist (Nuffield Council on Bioethics, 2009). The prevalence of physical restraint varies from 5% to 56% as reported in existing literature (Lai et al., 2011).

The Omnibus Budget Reconciliation Act of 1987

The Omnibus Budget Reconciliation Act of 1987 (OBRA 87) established a resident's right to be free of restraints in nursing homes when used for the purpose of discipline or convenience and when not required to treat the resident's medical symptoms. Related regulations specify that uncooperativeness, restlessness, wandering, or unsociability are **not** sufficient reasons to justify the use of antipsychotic medications (Agens, 2010).

Use of restraints should be:

- Reserved for documented indications
- Time limited and
- Frequently re-evaluated for their indications, effectiveness, and side effects in each patient (Agens, 2010)

In most states the use of physical and chemical restraints on nursing home patients is illegal.

Types of physical restraints can include vests, straps, wrist ties, splints, mitts, belts, recliners, geri-chairs, lap boards, and bedside rails, among others. Several studies have demonstrated that carefully planned restraint-reduction programming can greatly reduce the use of physical restraining devices (Lai et al., 2011).

The use of physical restraints (including belts) can increase the risk of death or serious injury and can increase the length of a hospital stay. Their use may also indicate a failure to address the real needs of residents and patients. Both prolonged and short periods of physical restraint use are associated with pressure sores, loss of muscle strength and endurance, joint contractures, incontinence, demoralization, humiliation, feelings of low self-worth, depression, aggression, and impaired social functioning (Gulpers et al., 2010).

The use of physical restraints also creates an ethical dilemma by impinging on a person's autonomy. Their use is associated with increased instances of falling, the development of hospital-associated infections, and cognitive decline. Restraints also increase dependency in activities of daily living and walking (Lai et al., 2011).

Overall, in U.S. nursing homes, physical restraint use has steadily declined to about 1.7%, although antipsychotic use as a chemical restraint is still common, with nearly 25% of residents receiving some sort of antipsychotic medication (CMS, 2013). These statistics do not include side rails and bed rails.

A recent study has raised some troubling issues, indicating that restraint use is higher among black nursing home residents than among whites. The researchers looked at the use of five types of restraints: bed rails, side rails, trunk restraints, bed restraints, and chair restraints. The results indicated that some sort of restraint was used on 50% of black residents but on only 38% of white residents (Cassie & Cassie, 2013). The differences were particularly evident with bed rails, side rails, and trunk restraints.

Reducing Restraints in Clinical Practice

Many attempts have been made to reduce restraint use in clinical practice. Most interventions have used educational approaches, aiming to improve nursing staff knowledge and confidence to avoid physical restraints and to use alternative measures that target the resident's underlying problems (Gulpers et al., 2010).

In a small Dutch study involving thirty residents, education, institutional changes, and alternative interventions resulted in a significant reduction in the use of belt restraints. Belts were replaced with resident-centered interventions such as movement and balance training, lower beds, hip protectors, extra supervision, and monitoring devices (video camera, sensor mat, and infrared alarm systems) (Gulpers et al., 2010).

Other strategies have been used as an alternative to physical restraints. Reducing clutter, keeping hallways free of equipment and obstacles, and liberal use of rails, grab bars, and transfer poles in rooms, bathrooms, hallways, and common areas is recommended. A friendly, uncluttered, home-like environment provides a safe and effective alternative to physical restraints. Other suggestions related to the environment:

- Redesign the location of nursing stations so they are part of a home-like design.
- Provide pressure-relief wheelchair and chair cushions to improve comfort.
- Lower wheelchairs to allow self-propelling with feet.
- Provide comfortable, easy-to-access alternative seating.
- Install carpeting to reduce injury from falls.

Psychosocial policies and activities can also assist in reducing or eliminating the use of restraints. Establishing a routine, including a toileting schedule, will improve comfort and reduce anxiety. Regular exercise and comfortable places to rest and nap are important. Other psychosocial suggestions:

- Assess and treat hunger, thirst, and discomfort.
- Change medications or taper medications with adverse effects.
- Treat all underlying causes, including pain.

- Assess hearing and vision.
- Establish a nap schedule.
- Relieve impaction.

Pain in Those with Cognitive Impairment

The assessment of pain in people with cognitive impairment is a significant challenge. Cognitively impaired patients 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 patients are in pain and when they are experiencing pain relief. This makes cognitively impaired patients vulnerable to both under-treatment and over-treatment.

Pain management is a particular challenge for patients with advanced dementia and at the end of life. Although pain is not the main symptom of dementia, people with dementia often have pain because of chronic conditions such as arthritis or from diseases such as urinary tract infections. Pain perception is not diminished in Alzheimer's disease but may actually be increased. However, pain perception may vary according to the type of dementia; for example, those with frontal-temporal dementia may have an increased pain threshold and pain tolerance (Volicer & van der Steen, 2014).

Detection and diagnosis of pain in residents with advanced dementia is one of the most important factors in their total care. Nurses and other healthcare providers may feel uncertain about pain in residents with dementia, especially if the resident is unable to report when they are in pain. Patients with advanced dementia are less able to respond to pain scales, necessitating the use of observational scales in up to about half of patients. More than half of residents who were dying with advanced dementia experienced pain in the last week of life that was not satisfactorily managed (Volicer & van der Steen, 2014).

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

Total:

* Some institutions have developed policies in which a PAINAD score of four or greater must be addressed in the nursing care plan. Public domain.

Interventions and Treatments

Treatment seeks to improve quality of life and maximize function by addressing cognitive, mood, and behavioral impairments, as well as to treat any modifiable or reversible causes of impairment (USPSTF, 2013). In the management of Alzheimer's disease, a multimodal approach is necessary.

Pharmaceutical Interventions

Pharmaceuticals, primarily cholinesterase inhibitors, antipsychotics, and antidepressants are commonly used in older adults with dementia. These medications are generally used (1) to treat or slow the progression of symptoms associated with dementia, (2) to manage neuropsychiatric symptoms of dementia, and (3) as chemical restraints.

Increasing the Levels of Acetylcholine and Glutamate

Although there are no therapeutic interventions that can stop the progression or reverse the deterioration caused by Alzheimer's disease, there are four FDA-approved pharmaceuticals, currently prescribed, that may temporarily slow cognitive, functional, and behavioral decline:

Inhibit cholinesterase

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

Increase glutamate levels

4. Memantine (Namenda)

The first three medications work by increasing the levels of acetylcholine, a neurotransmitter in the brain involved in learning and memory. Cholinesterase inhibitors are indicated for the treatment of individuals in the mild to moderate stages of Alzheimer's disease (DeFina et al., 2013).

The fourth medication, memantine, works by increasing the levels of glutamate, another chemical implicated in learning and memory. This drug is indicated for the treatment of moderate to severe Alzheimer's disease. There is evidence that memantine may provide added benefits for individuals with Alzheimer's disease who are already taking donepezil (Aricept). Overall, the benefits of these drugs are limited, are effective for only a short period of time (about one year), and work in only about half of individuals for whom they are prescribed (DeFina et al., 2013).

Antipsychotics

Antipsychotics, also known as major tranquilizers and neuroleptics, are a group of drugs used to treat psychiatric conditions. They were first developed in the 1950s to manage psychiatric symptoms associated mostly with schizophrenia and bipolar disorder. There are two types of antipsychotics: the newer, atypical antipsychotics, also known as second-generation antipsychotics; and the older, typical antipsychotics, sometimes called first-generation antipsychotics.

The newer atypical antipsychotics were approved by Food and Drug Administration (FDA) in the 1990s for the treatment of schizophrenia. In short order, these medications began to be used for the treatment of behavioral and psychological symptoms of dementia, particularly for delusions, depression, and agitation.

The use of these drugs in people with dementia is fraught with controversy, partly because of serious side effects and partly because they have only a modest effect on the behavioral and cognitive symptoms of dementia. No atypical antipsychotic is FDA-approved for the treatment of any neuropsychiatric symptoms in dementia (Steinberg & Lyketsos, 2012).

For older people with dementia, antipsychotics may reduce aggression and psychosis, particularly among those most severely agitated. However, antipsychotics are associated with increased overall mortality, worsening cognitive impairment, hip fracture, diabetes, and stroke. Withdrawal of medication can reduce falls and improve verbal fluency, but aggressive behavior may return, particularly among those with the most severe symptoms (Jordan et al., 2014).

Attention to the misuse of antipsychotic drugs, particularly the newer atypical antipsychotic drugs, was brought to public attention by Lucette Lagnado, writing in the *Wall Street Journal* in December 2007. She reported that atypical antipsychotic drugs are often used off-label* in nursing facilities. Lagnado described several reasons for this, including the 1987 Nursing Home Reform Law's limits on the use of physical restraints, off-label marketing of antipsychotic drugs by drug companies, and insufficient staffing (Center for Medicare Advocacy, 2013).

***Off label:** the use of a drug in an unapproved age group, for an unapproved purpose, or in an unapproved manner.

Several large clinical trials have demonstrated an increased risk of mortality with the use of atypical antipsychotics in older adults 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 recommended 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).

A prescriber may choose to prescribe antipsychotic medications for behavioral and psychological symptoms associated with dementia and they may be effective in some cases. The prescriber must, however, disclose to the patient or family that the medication is being used off-label and obtain permission to use it for behavioral symptoms. Treatment seeks to improve quality of life and maximize function by addressing cognitive, mood, and behavioral impairments, as well as to treat any modifiable or reversible causes of impairment (USPSTF, 2013). Please review the following article and video for more information about the risks associated with antipsychotic use in elderly, demented patients.

Risks Run High When Antipsychotics Are Prescribed for Dementia
By 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>

**Video: Improving Antipsychotic Appropriateness in Dementia Patients:
Introduction to the Training and Toolkit (9:46)**

**Improving Antipsychotic
Appropriateness in Dementia
Patients:**

**Introduction to the
Training and Toolkit**

Ryan Carnahan, PharmD, MS, BCPP

Funded by AHRQ R18 HS19355-01

<https://www.healthcare.uiowa.edu/igec/iaadapt/>

Antipsychotics as Chemical Restraints

A chemical restraint is the intentional use of any medications to subdue, sedate, or restrain an individual. Traditionally chemical restraints have been used to restrict the freedom of movement of a patient—usually in acute, emergency, or psychiatric settings. Chemical restraints are typically prescribed for patients exhibiting dangerous, uncontrolled, aggressive, or violent behavior and should always be used for the shortest time possible.

In older adults with dementia, psychotropic agents such as anti-anxiety, antidepressant, and antipsychotic medications are commonly used to treat the behavioral and psychological symptoms associated with dementia. These medications, which affect mood, perception, consciousness, cognition, and behavior, can become a chemical restraint if used improperly and may be overused as a means of behavioral control in older adults with dementia (Peisah & Skladzien, 2014).

Non-Pharmaceutical Interventions

Researchers have begun to explore non-pharmaceutical interventions that may reduce toxins and prevent cell loss. Laser light therapy is one such intervention, and animal studies using infrared light treatment have documented positive results in mice with traumatic brain injury. More recently, researchers revealed a significant reduction of amyloid-B aggregates in neuroblastoma cells that were irradiated with intense 670 nm laser light, leading the authors to suggest that their approach might inspire a practical therapy for AD (DeFina et al., 2013).

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).

Nutraceutical Agents and Medical Foods

Nutraceutical agents, also called “functional foods,” are thought to have health benefits beyond their basic nutritional value. Numerous studies have demonstrated the effects of nutraceuticals from fruit or plant extracts in reducing oxidative damage* and promoting healthy aging in invertebrate models. The active ingredients in nutraceuticals that are generally produced by plants as “secondary compounds” appear to help plants overcome stressful conditions. The beneficial properties of nutraceuticals can be attributed to phytochemicals, such as flavonoids, anthocyanin glycosides, triterpenoids, and proanthocyanidin oligomers. Nutraceuticals made from fruits, spices, and teas are commonly consumed by humans in daily life (Dong et al., 2012).

***Oxidative damage:** a disruption of the body's ability to balance the production of free radicals and counteract their harmful effects with antioxidants.

Alpha GPC, phosphatidylserine, Huperzine A, and choline show promise as nutraceutical agents for enhancing cognitive performance and slowing cognitive decline. Alpha GPC, a naturally occurring form of choline, has shown promise in improving cognitive symptoms related to Alzheimer's disease, vascular dementia, and multi-infarct dementia.

Phosphatidylserine has been shown to improve age-related cognitive changes. Huperzine A (a natural cholinesterase inhibitor) has been linked to improved memory performance in elders with benign forgetfulness, as well as patients with Alzheimer's disease and vascular dementia. Cholinesterase inhibitors have been shown to have neuroprotective properties in patients with mild as well as moderate-to-advanced Alzheimer's disease (DeFina et al., 2013).

Medical foods were defined in 1988 as a special category of products intended for the specific dietary management of a disease or condition that has distinctive nutritional requirements, established by medical evaluation and based on recognized scientific principle (Thaipsisuttikul & Galvin, 2012).

Recently, there is the development of medical foods that are thought to have some promise in improving mental status: Axona, CerefolinNAC, and Souvenaid. Each works via a different mechanism of action, and all are prescriptive supplements. However, Souvenaid is not currently available for use in the United States (DeFina et al., 2013). Axona supplies ketone bodies as alternative energy source to neurons. Souvenaid provides precursors thought to enhance synaptic function. CerefolinNAC addresses the role of oxidative stress related to memory loss (Thaipsisuttikul & Galvin, 2012).

Preliminary studies of medical foods have largely been conducted in patients with mild Alzheimer's disease, so results cannot be generalized to all stages of Alzheimer's. The potential benefit of medical foods in mild cognitive impairment is also unclear. It is important to stress that the Food and Drug Administration does not require the same high level of testing to approve medical foods as it does for prescription medications. Medical foods are generally considered safe and have a minimal side-effect profile compared with drugs; however, careful use after a discussion about risks and benefits with the physician is still recommended. The prescription of medical foods should be considered as an adjunct to and not a replacement for current medication use (Thaipsisuttikul & Galvin, 2012).

Disease-Modifying Treatments

Ongoing research is aimed at finding disease-modifying treatments. A multifaceted approach is considered important, using a combination of drugs to target a number of factors associated with the disease process. For example, a phase II clinical trial of intravenous immunoglobulin (IVIG), an immunotherapy agent, was found to stabilize cognition and functioning in a small sample of Alzheimer's disease patients for three years. Another promising finding came from a pilot clinical trial of an intranasal insulin therapy for Alzheimer's disease in which participants who underwent treatment experienced memory improvement or maintained their current level of overall cognitive and functional performance (DeFina et al., 2013).

Dementia's Effect on Activities of Daily Living

The “small things” of care are particularly important in ensuring that care is genuinely supportive of the individual, and enhances that person's autonomy and well-being. The humanity with which assistance for everyday living is offered, especially help with eating and intimate care, is as crucial in helping the person retain self-esteem and dignity as the manner and tone in which a person is addressed; the care taken to ensure that they participate as much as they can or wish in any decision about their day-to-day life; the trouble taken about appropriate and attractive food and environments; and access to meaningful activity.

Nuffield Council on Bioethics

Activities of daily living (ADLs) are the tasks we do in our daily lives. Because ADL skills tend to worsen as dementia progresses, caregiver involvement naturally changes over time. ADLs are generally divided into two categories: basic ADLs and instrumental ADLs.

Basics ADLs are the skills needed to take care of personal needs such as eating, bathing, dressing, and toileting. **Instrumental ADLs** are the skills needed to function within society and within the community. The skills needed for ADLs decrease as dementia progresses.

When a person is no longer able to perform basic math calculations, a caregiver or financial advisor must oversee finances. When insight becomes limited and memory is significantly compromised, medical decision making and medication management will also shift to the hands of a caregiver. Pursuit of guardianship and capacity evaluations are not uncommon, especially when estate and legal issues need to be addressed (DeFina et al., 2013). Although there is often no clear demarcation between mild, moderate, and severe dementia, caregiver responsibilities increase as independence decreases.

When assisting someone with ADLs, encourage people to express their wishes. “No, I don’t want to!” means just that, even when spoken by someone with dementia. Keep these techniques in mind:

- Make eye contact and maintain a calm demeanor and voice.
- Repeat requests in the same words if needed. Rephrasing the request is confusing.
- Engage the resident. Offer simple choices, such as “Do you want orange juice or apple juice?”
- Be empathetic. Examples of empathetic responses include “You must be cold” or “Are you uncomfortable in that chair”?
- Problem solve by asking “What would help now?”
- Give the person physical space—do not crowd.
- Be aware of your body language and vocal tone.
- Be aware of the speed of your movements and speech.

Keep in mind that in different cultures, nonverbal gestures and eye contact may have different meanings. Western Europeans and North Americans of European ancestry generally associate direct eye contact with attentiveness and respect. In many Native American cultures, although eye contact is expected during the initial greeting, prolonged eye contact is considered disrespectful. Many consider it a sign of respect to keep their gaze turned down.

In Japanese culture, by contrast, people are taught not to maintain eye contact with others because too much eye contact is often considered disrespectful. Japanese children are taught to look at others’ necks because this way, the others’ eyes still fall into their peripheral vision (Uono & Hietanen, 2015).

ADLs in a Person with Mild Dementia

In the early stage of dementia most people are independent with basic ADLs. Most people with mild dementia will begin to need help with some instrumental ADLs—especially complex tasks requiring multiple steps or extensive planning. Basic ADLs such as eating, dressing, and bathing are likely still independent.

At this stage, a person will instinctively try to cover up confusion by turning to others for help with simple tasks. This is a natural response and denial, anger, and excuses are common defense mechanisms. There may be some loss of interest in hobbies and activities. Mood changes, such as depression and anxiety, can occur. Learning new tasks may be difficult and complex tasks may be left uncompleted. Faulty judgment and mild changes in personality become obvious to caregivers.

Those with mild dementia may need very little help, if any with basic ADLs. Nevertheless, it is good to keep certain core principles in mind:

Dressing

- Encourage choice in the selection of clothes.
- Assist as needed but allow resident to direct the activity.

Grooming

- Allow residents to groom themselves, provide tools if needed.
- Monitor progress and provide assistance as needed.

Eating

- Ask for food preferences.
- Ask the person to help with meal preparation and meal set-up.
- Provide adaptive utensils if needed.
- Provide assistance as needed.

Bathing

- Give choice as to when, where, and what type of bathing.
- Assist in the decision to bathe.
- Assist with bathing or shower as needed.
- Monitor for safety and comfort.

Toileting*

- Monitor and assist as needed.
- Encourage fluids even though more bathroom visits may be necessary.

*Be aware that some medications cause constipation while others increase or decrease the urge to urinate.

ADLs in a Person with Moderate Dementia

As dementia progresses to the moderate stage, instrumental ADLs such as work, medication management, and keeping track of personal finances become difficult or impossible. A person may begin to need help with basic daily activities. Mobility is often still good and, if so, safety becomes a concern for caregivers. Because of this, family caregiver responsibilities increase, causing stress, anxiety, and worry among family members and caregivers. In the moderate phase:

- Cooking, housework, and shopping require direct assistance.
- Basic ADLs require assistance for set-up and safety.
- Completing basic ADLs may be disrupted by behavioral and psychological symptoms such as anger, frustration, and difficulty communicating needs.

Keeping in mind that there is no clear delineation between mild and moderate dementia, it will become clear to caregivers that a person in the moderate stage of dementia will need more help with ADLs, especially instrumental ADLs. There is variability at this stage, depending on a person's physical capabilities and the type of dementia, but for some, walking, transferring, bed mobility, and basic ADLs may remain relatively independent. For others, especially those with physical limitations, more help may be required. In the moderate stage of dementia:

Dressing

- Provide comfortable clothes with elastic waistbands and Velcro closures.
- Limit choices but encourage participation in the choice of clothing.
- Assist closely but encourage independence.

Grooming

- Limit choices. ("Would you like lipstick today?" "Would you like to brush your hair?")
- Encourage as much independence as possible.

Eating

- Ask for food preferences.
- Set up the meal before serving.
- Open packages, uncover trays.
- Provide adaptive equipment as needed.
- Monitor closely.

Bathing

- Ask about bathing preferences.
- Initiate and monitor the activity.
- Provide direct assistance as needed, particularly in showers.

Toileting

- Ask regularly if the resident needs to eliminate.
- Provide close assist, particularly with transfers.
- Label bathroom door for easy identification.
- Provide toileting on a regular schedule.

ADLs in a Person with Severe Dementia

As dementia enters the severe stage, independence is gradually lost and caregivers must provide consistent direct care with most if not all ADLs. At this stage a person must be directly assisted with basic ADLs such as eating, bathing, transfers, and walking. Control of bodily functions may be inconsistent, requiring direct help with bathing and toileting. Family members may find it impossible to continue to provide care and may be forced to move their loved one to an assisted living or skilled nursing facility.

Safety issues and wandering require constant monitoring. If the person with dementia is still at home, tired and overworked caregivers must provide even more support with ADLs to maintain a safe environment. If in a skilled nursing or assisted living situation, the facility must provide enough staffing and equipment to create a safe environment.

As severe dementia progresses, balance and safety awareness go from bad to worse, requiring significant direct help with transfers and mobility. To prevent injuries from falls, it may be necessary to use bed and chair alarms or provide a one-on-one caregiver. Caregivers and healthcare providers must make difficult decisions to prevent injury and to provide a safe environment.

Once a person reaches the severe stage of dementia, the more complex instrumental ADLs have likely been completely taken over by a family member or caregiver. Basic ADLs will require a great deal of assistance to complete, depending on the person's physical capabilities. A person with severe dementia may still be able to walk independently. They may be independent or nearly so with bed mobility and transfers. Anything that requires planning, sequencing, or judgment will be severely impaired at this stage so close assistance will be needed for dressing, bathing, meal preparation, grooming, and toileting. If mobility is compromised, close assistance will be needed for all ADLs. In the severe stage of dementia:

Dressing

- Limit choices, select clothes and set them out.
- Choose comfortable clothing that is easy to wash.
- Use simple, one-step commands and gestures.
- Encourage as much independence as possible.

Grooming

- Provide as much assistance as needed.
- Move slowly, limit choices.
- Use one-step commands and gestures.

Eating

- Ask for food preferences.
- Fully set up meal before serving.
- Provide adaptive equipment as needed.
- Monitor closely and be ready to provide feeding assistance.
- Offer liquids on a regular schedule.
- Allow plenty of time to finish eating.

Bathing*

- Provide complete bathing care.
- Retain as much of resident's earlier bathing rituals as is reasonable.
- Use resident behavior as a guide.

Toileting**

- Expect both bowel and bladder incontinence requiring total care.

- Set up timed toileting schedule.

*Consider bathing habits (time of day, bath or shower); consider bed bath if more acceptable to resident.

**Goal is for resident to be clean and comfortable. Shower or tub bath is not necessary—a sponge bath may suffice.

Case

Mrs. Johnson has moderate dementia due to Alzheimer's disease 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. The caregivers usually have to change her diaper once or twice each night and occasionally need to change wet sheets if Mrs. Johnson takes her diaper off at night. They keep a spare set of sheets and a pad handy just in case.

Antecedent: One night Mrs. Johnson'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. Johnson again refuses the diaper and climbs into bed.

Behavior: Mrs. Johnson'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. Johnson while she is sleeping. A little while later she hears Mrs. Johnson getting up to go 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.

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 the caregivers are making a concerted effort to keep Mrs. Johnson clean and dry.

Discussion: Mrs. Johnson'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 doesn't like the new diapers she recently bought. They are too tight and chafe her mother's skin. She offers a 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.

Exercise, Physical Activity, and Dementia

As the population ages, health and social care services will come under pressure to provide services for older people with dementia as well as individuals with a wider range of other chronic diseases that are accompanied with physical impairments. In older adults with a neurodegenerative form of dementia, the on-going degeneration of brain tissue eventually leads to a loss of cognitive and physical functions (Telenius et al., 2015).

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. However, only a few studies have looked at the effect of physical activity in patients already suffering from Alzheimer's dementia. Several small studies were able to demonstrate significant cognitive benefits for patients with Alzheimer's dementia and also on quality of life and depression. Study limitations included sample size, lack of information on the use of psychotropic medication, nursing home setting, and discrepancies in contact time. Physical activity may induce neuroplastic changes in elders and thus exert a protective effect against cognitive decline; this may also occur in patients already suffering Alzheimer's dementia, thus inducing improvement of clinical symptoms (Holthoff et al., 2015).

Physical Activity

Physical activity is the movement of skeletal muscles, resulting in energy expenditure beyond the resting state. Physical activity, which includes exercise, is different from physical fitness. A person can be physically active without necessarily having good physical or aerobic fitness (Blondell et al., 2014).

Animal studies have demonstrated physical exercise effects on brain function over the lifespan. Activity in an enriched environment stimulates the brain on a physical and cognitive level and has the potential to affect brain plasticity. In humans, 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 (Holthoff et al., 2015).

In older adults with mild cognitive impairment, emerging evidence suggests that exercise training has cognitive benefits. For example, a 24-week, home-based physical activity program improved performance on the Alzheimer Disease Assessment Scale-Cognitive Subscale in seniors with probable mild cognitive impairment. Additionally, a six-month aerobic training program improved selective attention and conflict resolution, processing speed, and verbal fluency in senior women with amnesic mild cognitive impairment (Nagamatsu et al., 2013).

Preventing Loss of Independence Through Exercise (PLIÉ)

Currently available dementia medications are associated with small improvements in cognitive and physical function but have many adverse effects and do not stop or slow the disease course. In addition, several new medications that initially appeared promising have recently failed in Phase III clinical trials. Therefore, it is critically important to study alternative approaches that allow individuals with dementia to maintain physical function, cognitive function, and quality of life to the greatest degree possible throughout the disease process (Barnes et al., 2015).

A growing body of evidence suggests that “conventional” exercise programs such as 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. A recent meta-analysis identified 16 randomized, controlled trials of conventional exercise interventions in 937 individuals with dementia, finding evidence that exercise improves the ability to perform basic activities of daily living such as eating, dressing, bathing, using the toilet, and transferring from bed to chair. However, the effects of conventional exercise on other important outcomes such as cognitive function, mood, behaviors, and quality of life were less consistent (Barnes et al., 2015).

A handful of recent studies suggest that “complementary/alternative” forms of exercise such as tai chi, yoga, and dance may be effective for improving these other outcomes. For example, studies have found that tai chi and yoga are associated with improvements in cognitive function and quality of life as well as physical function in older adults with and without cognitive impairment. In addition, dance-based exercise programs are associated with reductions in problematic behaviors and greater enjoyment in individuals with dementia. Taken together, these studies suggest that different types of exercise may offer different benefits, and that a program that combines different approaches may result in greater improvements across multiple domains. In addition, it may be important to incorporate recent evidence from physical and occupational therapy studies, which suggest that a personalized, goal-oriented approach can lead to better outcomes in other settings (Barnes et al., 2015).

At the University of California, San Francisco, a recent pilot study developed 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 (eg, 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 a usual care 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): A Pilot Clinical Trial in Older Adults with Dementia (5:17)

UCSF PLIE: Preventing Loss of Independence through E...



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

How Dementia Affects Balance and Gait

Balance is the ability to automatically and accurately maintain your center of mass or center of gravity over your base of support. This happens because multiple systems interact flawlessly and automatically—coordinating, weighing, and modulating information from both the environment and the central nervous system. The onset of dementia leads to changes in sensory and motor systems, affecting their ability to coordinate input.

Balance is a central function in most ADLs. Reduced balance increases the risk of falling, and falls and fractures are common among residents with dementia. People with dementia have a two-fold increased risk of falls compared with non-demented older adults. In nursing homes, one-third of all falls result in injuries, and people with dementia are more often injured compared to non-demented residents. Acute trauma with soft tissue damage or fractures, hospitalizations, and immobilization can lead to pressure sores, pneumonia, and fear of falling. Fear of falling itself is a risk factor for inactivity and can create a vicious circle. Improvements in balance may potentially reduce the risk of falling and increase mobility through increased confidence (Telenius et al., 2015).

Dementia impairs judgment, alters visual-spatial perception, and decreases the ability to recognize and avoid hazards. Dementia aggravates age-related changes in sensory perceptions, which adversely affects a person's ability to adapt to changing environmental conditions (Eshkoor et al., 2014).

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. Cognitive processes related to prefrontal lobe function, such as attention and executive function, are associated with slower gait and gait instability. 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).

Walking involves complex processes that require the ongoing integration of visual, proprioceptive, and vestibular sensory information. Joint positions must be controlled, the terrain a person is walking on has to be considered, and the environment the person is moving in needs to be observed. Walking often must be integrated with another activity, such as watching for traffic or using a mobile phone—this is referred to as **dual-task walking** (Beurskens & Bock, 2012).

As we age, walking speed and stride length decrease, while lateral sway increases. Some of these changes are compensatory and act to stabilize posture, while others are dysfunctional and increase the risk of falls. Changes in gait have been attributed to cognitive decline—the critical role of cognition is supported by the fact that age-related gait changes are more pronounced in people with cognitive impairment and that they are accentuated under dual-task conditions (Beurskens & Bock, 2012).

Age-related deficits in walking can be partly compensated for using cognitive workaround strategies, replacing automated sensorimotor processing with conscious effort. This is a good example of neural plasticity, as it shows that deficits arising in one part of the nervous system can be overcome by engaging another part of that system. Those with reduced cognitive capacity have only limited ability to compensate in this way; they are more likely to walk unsteadily and their risk of falling is higher (Beurskens & Bock, 2012).

Activities for People with Dementia

Engaging people in regular cognitive, physical, and social activities is a promising dementia prevention strategy. This requires activity programs that combine the most beneficial dementia prevention activities, are acceptable to people, and result in long-term activity participation and lifestyle change (Dannhauser et al., 2014).

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 modifiable dementia risk factors such as physical and cognitive inactivity, obesity, hypertension, and diabetes (Dannhauser et al., 2014).

Stimulating cognitive activities are associated with reduced risk of cognitive decline in later life. The effects are particularly pronounced when cognitive activities are more complex. Social activities are also associated with reduced dementia risk. Socializing stimulates memory, attention, and executive processing (Dannhauser et al., 2014).

A number of studies have suggested that carefully designed activities can also have a positive effect on depression, confusion, and challenging behaviors.

Intellectual Stimulation/Cognitive Interventions

Cognitive rehabilitation was originally developed through work with younger brain-injured people, although it is easily applied to people with dementia. Cognitive therapists help individuals and their families identify goals and strategies aimed at improving cognitive function. Interventions address difficulties considered most relevant by people with dementia and their families (Bahar-Fuchs et al., 2013).

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

Cognitive training can involve guided practice on a set of standardized tasks designed to reflect particular cognitive functions, such as memory, attention, or problem solving. Tasks may be paper-and-pencil or computerized, or can focus on ADLs. The ability to adjust the level of difficulty in response to performance is one of the strengths of computerized programs (Bahar-Fuchs et al., 2013).

Cognitive training can be offered through individual or group sessions or facilitated by family members with therapist support. There is some evidence that cognitive training may enhance the effects of pharmacologic therapy and some studies have evaluated cognitive training in combination with acetylcholinesterase-inhibitors or other medications (Bahar-Fuchs et al., 2013).

Social Participation and Social Identity

Social participation is involvement in interpersonal interactions outside the home, including social, leisure, community activities, and work. Significant reduction of social interactions can lead to poor health outcomes and loneliness in later life. Interventions to increase social participation are indicated (Goll et al., 2015).

Reduced social participation, especially in older adults, may be related to the loss of social identity that a person previously derived from their profession, job, or membership in a group. There is evidence for a strong link between social identity and utilization of healthcare; for example, healthcare is more readily accepted when receivers share their social identity with the provider, and lack of shared social identity may lead to service refusal.

This suggests that an older man may not wish to attend a group populated mainly by women because this would challenge his male identity. Alternately, older people who identify as care providers may not want to attend a support group for fear they would become a care *recipient*. Moreover, widespread ageism may lead individuals to avoid groups of older people lest they become identified as “old,” and thus be stigmatized (Goll et al., 2015).

Lonely older adults may avoid social participation out of fear of rejection or exploitation by their peers. Social fears have been linked to loneliness and social isolation in working-age 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 that target maladaptive behaviors and cognitions, 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 into 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. Organizations can implement these practices in consultation with a mental health professional such as a clinical psychologist (Goll et al., 2015).

Lonely older adults avoid social opportunities for fear of invalidating their preferred identities. 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 emphasized their preferred social identities (eg, caregiver, Christian, educated person, sports fan). They avoided social situations that might contradict their preferred identities, and wished for (but could not find) opportunities that might provide identity reinforcement (Goll et al., 2015).

Society commonly associates youthfulness with valued traits such as independence, economic productivity, and usefulness, and aging with intensely negative characteristics such as dependency and uselessness. Efforts to maintain youthfulness and independence can be viewed as attempts to preserve valued identities. Attempts to maintain pre-existing social identities, which often involved being productive in some way, are important to older adults (Goll et al., 2015).

Social Interaction in an Adult Daycare Setting



Source: ADEAR, 2014.

Improving Communication

While memory problems are the most characteristic symptom of Alzheimer's disease, most individuals with dementia also experience progressive problems with communication. The deterioration of the individual's ability to communicate contributes considerably to the stress and burden of caregivers and is often classified among the most serious stressors that caregivers face. Poor communication between the caregiver and the care recipient can lead to conflicts, isolation, or depression in one or both of these individuals and may lead to earlier placement in institutions. Practices to enhance the verbal communication of individuals with Alzheimer's disease can help with these problems. Various methods have been proposed to improve caregiver-patient communication; these include memory aids, education and training of caregivers, and activity programs (Egan et al., 2010).

Memory Aids

Memory aids provide language support in the form of sentences, words, and images, and access to other semantic information stored in long-term memory. Written support can compensate for certain comprehension deficits that may appear when instructions are provided verbally. By offering visual cues, memory aids can also serve to remind individuals of the current task or topic of conversation, enabling better participation in the conversation. Cues also limit the number of choices and provide concrete topics for conversation. Socially, memory aids support the desire to communicate, another aspect of communication that often remains intact in individuals with dementia (Egan et al., 2010).

Memory aids generally consist of biographical information, photos of family members, and descriptions of important events in the life of the individual. By using images and phrases that are brief and simple, memory aids encourage patients' automatic communication abilities, with the goal of improving the structure and quality of communication with others (Egan et al., 2010).

Caregiver Education and Training

Caregiver education and training is another method used to improve communication between caregivers and care recipients. Recommended strategies include using close-ended or choice-based questions rather than open-ended ones, using direct and simple phrases, repeating key words and ideas in the conversation, noting a change in the topic of conversation, using direct contact, as well as using comments and nonverbal cues to preserve the quality and flow of the conversation (Egan et al., 2010).

Photos Used as a Memory Device



Photos of family member can be used to encourage memories. Source: National Institute on Aging.

Activity-based approaches can also increase communication. These interventions may be carried out individually or in groups and use very specific (eg, preparing a meal) or diverse activities to stimulate communication. Generally, the focus of these groups is on improving or maintaining functional skills, including communication (Egan et al., 2010).

One method for improving communication between caregivers and care recipients is **validation therapy**. Naomi Feil developed validation therapy through her work with patients she described as severely disoriented. Her work over the years has led to the increasing use of validation in dementia care as a way of demonstrating to the patient that their feelings, thoughts, and opinions are acknowledged and respected by the caregiver. A combination of validation and reminiscence is often useful in helping confused patients experience the joy of earlier life experiences and contributes to their quality of life (Zeman, 2015). A wonderful and effective demonstration of Feil's work can be viewed in the following video.

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



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

Dementia Care In and Out of the Home

Caregiving tends to emerge naturally from customary family transactions that involve support given and received before the onset of dementia. The need for care tends to escalate over time, from increased support for household, financial, and social activities, to personal care. For some, this will eventually develop into the need for almost constant supervision and surveillance. Important transitions in caregiving include the involvement of professional caregivers, institutionalization, and bereavement (ADI, 2013).

Family, the Cornerstone

In developed countries, the vital caring role of families and their need for support is often overlooked, while in developing countries the reliability and universality of the family care system is often *overestimated*.

Alzheimer's Disease International, 2013

All over the world, the family is the cornerstone of care for older people who have lost the capacity for independent living. In recent years, however, there has been tremendous growth in the paid, direct-care industry, which is playing an increasingly important role in sustaining the work of family caregivers. Family caregivers provide what is referred to as *informal care*. They are often cast into the role of caregiver unexpectedly and are largely unpaid or nearly unpaid. Overall, about half of people who need help with personal care have dementia, which creates a tremendous burden on family members (ADI, 2013).

The system of informal, unpaid care provided by family members is under tremendous pressure due to declining fertility rates and fewer young people willing to care for older adults. Changing attitudes and expectations among the young as well as increased workforce mobility mean that family members are not always living nearby their older adult relatives. The education of women—the majority of informal caregivers—has led to more workforce participation and less availability for informal care (ADI, 2013).

Most people with dementia live in the community, and for approximately 75% of these individuals care is provided by family and friends. More than 10 million Americans are caring for a person with Alzheimer's disease or another type of dementia. The largest group of those caregivers are spouses, followed by children and children-in-law, mostly female. The typical profile of a dementia caregiver is a middle-aged or older female child or spouse of the person with dementia (Brodaty & Donkin, 2009).

In the United States, at least 60% of unpaid caregivers are wives, daughters, daughters-in-law, granddaughters, and other female relatives, although male caregivers are becoming more prevalent. In 2008 men made up 40% of family caregivers in the United States, an increase of 21% from a 1996 study by the Alzheimer's Association (Brodaty & Donkin, 2009).

The challenges of providing home care have been well documented. Lack of support for family caregivers, lack of recognition and poor working conditions for home support workers, early hospital-to-home discharge policy, and poor system coordination are examples of the challenges faced by people living with dementia and their familial and formal caregivers. Furthermore, limited resources to implement and sustain home care and a shift of chronic care to community settings without the corresponding transfer of funds compound the difficulties encountered (Ward-Griffin et al., 2012).

Supporting Caregivers, Improving Outcomes

Providing care to a family member with dementia is often a stressful experience that can erode the mental and physical health of the caregiver. Caregivers not only develop feelings of burden but also show higher levels of psychiatric symptoms, depressive and anxiety disorders, decreased immune function, and even a higher death risk compared to non-caregivers or the general population. Therefore, the World Health Organization stresses the importance of caregiver support (Blom et al., 2015).

Reducing caregiver strain and improving outcomes for those with dementia is possible when caregivers receive education, training, support, and respite. Caregivers can reduce their stress by getting enough sleep, eating properly, seeing their own doctors, and sharing their feelings about their caregiving duties with co-workers, family, and friends.

Dementia Care Services Program

An innovative program in North Dakota called the Dementia Care Services Program trained consultants throughout the state to support individuals who care for people with dementia, offering emotional support, education, and referrals to local agencies that can help. After conducting an in-depth initial assessment, the consultants work with the caregivers to develop a care plan that lays out action steps to address key problems and subsequently check on their progress in following the plan (AHRQ, 2015a).

The consultants typically speak with the caregivers three times during the first six months and subsequently remain available to them for as long as they need support. Surveys of participating caregivers suggest 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 for the dementia patients they serve. These reductions have generated an estimated \$40 million in savings across the State, primarily due to the reductions in the likelihood of long-term care (AHRQ, 2015a).

Supporting Caregivers of Patients with Dementia



A dementia care consultant discussing resources with family members.

Source: AHRQ, 2015a.

Collaborative Care Model

Another innovative program established by Indiana University's Center for Aging Research, the Healthy Aging Brain Center uses a team-based collaborative care model to treat patients with dementia and support their caregivers. A multidisciplinary team conducts an initial diagnostic assessment, holds a family conference to communicate the diagnosis and develop an individualized care plan, and provides ongoing clinic- and telephone-based monitoring, care coordination, and support (AHRQ, 2015b).

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. Collectively, these improvements have generated significant cost savings (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 course consists of eight lessons and a booster session with the guidance of a coach, who monitors the progress of participants and evaluates their homework. Each lesson has the same structure and consists of information (text material and videos), exercises, and homework, with an evaluation at the start and end of each session. The elements of the course were presented in the following order: coping with behavioral problems (problem solving); relaxation; arranging help from others; changing non-helping thoughts into helping thoughts (cognitive restructuring); and communication with others (assertiveness training). The booster session is provided a month after participants finish the eight lessons, and it provides a summary of what has been learned (Blom et al., 2015).

After every lesson, participants sent their homework to a coach via secure software. The coach sent electronic feedback to caregivers on their homework within three working days. The feedback had to be opened before the next lesson can be started. Participants are automatically reminded to start with a new lesson or to send in their homework. 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).

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

Encouraging Independence Through Exercise

A growing body of evidence suggests that conventional exercise programs such as 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. A recent analysis of conventional exercise interventions in 937 individuals with dementia found evidence that exercise improves the ability to perform ADLs such as eating, dressing, bathing, using the toilet, and transferring from bed to chair (Barnes et al., 2015).

A handful of recent studies suggest that complementary and alternative forms of exercise such as tai chi, yoga, and dance may be effective in improving cognitive function, mood, behaviors, and quality of life. For example, studies have found that tai chi and yoga are associated with improvements in cognitive function and quality of life as well as physical function in older adults with and without cognitive impairment. In addition, dance-based exercise programs are associated with reductions in problematic behaviors and greater enjoyment in individuals with dementia. Taken together, these studies suggest that different types of exercise may offer different benefits, and that a program that combines different approaches may result in greater improvements across multiple domains. Physical and occupational therapy studies also suggest that a personalized, goal-oriented approach can lead to better outcomes in other settings (Barnes et al., 2015).

Dementia Care Programs

In the United States, long-term care service programs provide a great deal of care to those with dementia. About 8 million people are regularly served in adult daycare, home health, assisted living, nursing homes, and residential care communities. About one-third to one-half of the people served in these programs has a diagnosis of Alzheimer's disease or other type of dementia (Harris-Kojetin et al., 2013).

Adult daycare programs are designed to provide both respite for family caregivers and meaningful social and physical activity for older adults with dementia. Depending on the facility, services can include personal care, counseling, physical and occupational therapy and, in some cases, health services.

For long-term care facilities, there is a trend toward designing facilities as homelike as possible. This idea was pioneered in Sweden in the 1980s, where a homelike environment for people with dementia was tried for the first time. Today, similar concepts can be found all over the world, from Green Houses in the United States, to group homes in Japan, to small-scale living arrangements in the Netherlands, to German shared housing arrangements (Gräske et al., 2015).

All of these concepts challenge the traditional view, in which care is organized around nursing and medical tasks and the needs of the institution. Living arrangements in small and homelike settings are built around person-centered care, respecting residents' needs and choices. Daily routines include meaningful activities to encourage normal living while tasks focus on household chores such as cooking and baking (Gräske et al., 2015).

Family interactions and communication tend to change when a person enters long-term care. This is particularly true when work pressures are present, when the family member lives a long distance from the care facility, and when family members feel they have a limited role in the provision of care. The loss of in-depth communication, as well as social conversations, can result in the person with dementia feeling socially isolated and without the opportunity to express needs (Moyle et al., 2014).

One way to alleviate this stress is to encourage family members to become involved in a facility's dementia care program. Dementia care programs are multidisciplinary and multi-departmental programs designed to meet the daily needs of individual residents. The quality and success of a dementia care program is strongly influenced by the environment of a care facility and by the facility's philosophy of care, services available, and staff experience and training. 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 resident activities to share with the family
- Encourages residents to call and write to family members and friends
- Uses technology to keep families in touch with one another

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

The provision of care for this population is more complex than for residents needing just physical care; cognitive decline requires an additional level of support. This includes care plans designed to preserve the skills for ADLs and additional provisions for the socialization, stimulation, and safety of residents who wander or cannot call for help when needed. Additional training for staff members includes the causes of dementia and what to expect in the various stages of the disease (Zeman, 2015).

Good dementia care includes the recognition that there can be major differences in each person residing on a dementia unit. The type of dementia, the stage of dementia—and even the fact that several different dementias may exist in an individual at the same time—can be an issue. Additionally, most people with dementia are elders who may be suffering from multiple chronic diseases (Zeman, 2015).

The environment in which a person lives has a profound effect on their sense of well-being. Studies examining modifications to the built environment suggest that *purposeful design* can play an active role in promoting well-being and improved functioning. While no single definition of the built environment has been universally adopted, it is commonly understood as the constructed physical surroundings (interior and exterior) where an individual conducts activities of daily living—eating, bathing and sleeping—and interacts socially (Soril et al., 2014).

In her excellent book *Kisses for Elizabeth*, Stephanie Zeman offers dementia-care guidelines—not rules—based on commonsense. These guidelines go further to meet the needs of dementia patients than the OBRA regulations, which are inflexible and not directed at long-term care residents with cognitive disabilities (Zeman, 2015). Zeman suggests the following:

- 1.** Imagine yourself in the place of the person with dementia.
- 2.** Learn good dementia care communication skills.
- 3.** Don't argue with or say no to the person with dementia. Use diversion and distraction instead.
- 4.** Validate the feelings of the person with dementia.
- 5.** Consider the whole person, not just the dementia.
- 6.** Learn to use "feel-goods."
- 7.** Do not use reality orientation except for early-stage dementia.
- 8.** Encourage independence.
- 9.** Arrange for appropriate activities.
- 10.** Everyone needs to love and be loved.
- 11.** We all need something important to do each day.
- 12.** Don't be judgmental.
- 13.** Keep your sense of humor. Use it wisely.
- 14.** Religion is a comfort, even for people with dementia.
- 15.** Expect the unexpected. (Zeman, 2015)

Concluding Remarks

Dementia is a degenerative disease that slowly destroys a person's ability to live independently. There are many types of dementia, although Alzheimer's disease is the most common type. Delirium and depression can be confused with dementia and a thorough evaluation should rule out other causes of cognitive loss prior to making a diagnosis of dementia.

Although people with dementia often exhibit behaviors that are challenging for family and professional caregivers, the behaviors are caused by damage to the brain and are not intentional. Challenging behaviors can be caused by unmet needs and may be a means of communication. By carefully observing what comes directly before and after a behavior, the caregiver may be able to determine the underlying need and learn how to alleviate the challenging behavior.

People with dementia need to be treated with kindness and with the knowledge that they can still enjoy life. Physical and chemical restraints should be used only as a last resort. There are many proven alternatives to physical and chemical restraints that are the mainstays of individualized care.

Activities of daily living are disrupted in those with dementia. As dementia progresses, family members and caregivers must step in and assist with personal care and household management. Caregiver training is an essential component for anyone caring for a person with dementia. Family caregivers play a critical and often-overlooked role in the care of loved ones with dementia—especially in the early-to-moderate stages. Caregivers often experience stress, which does not abate simply by placing their family member in a care facility. In a facility, professional caregivers must be trained to view the person in the context of a family.

Facilities built around a philosophy of person-centered care can have a profound and positive effect on challenging behaviors associated with dementia. Providing a safe, clean, home-like environment in which residents and staff work together has been shown to improve outcomes in those with dementia.

Simply put, good dementia care must be flexible. Dementia is not a one-size-fits-all disease.

Resources and References

Resources

Brain Initiative, The

The BRAIN Initiative aims to accelerate the development and application of new technologies to produce dynamic pictures of the brain that show how individual brain cells and complex neural circuits interact at the speed of thought. These technologies will open new doors to explore how the brain encodes, stores, and retrieves vast quantities of information, and shed light on the complex links between brain function and behavior.

<http://braininitiative.nih.gov/>

CJE Senior Life

CJE Senior Life provides caregivers with educational materials and resources that are applicable to many different caregiving situations. They address the risk of caregiver burnout by sharing expertise in dealing with the older adult population.

www.cje.net/

Family Caregiver Alliance (FCA)

FCA provides information, education, services, research, and advocacy for families caring for loved ones with chronic, disabling health conditions. They provide caregiving tips in person and online, with resources listed by state.

www.caregiver.org

National Council of Certified Dementia Practitioners/ International Council of Certified Dementia Practitioners

National Council of Certified Dementia Practitioners is open to all healthcare professionals, front line staff and First Responders who qualify for CDP® certification and are interested in learning comprehensive dementia education, who value dementia education training, who are committed to ending abuse and neglect, and who value Certified Dementia Practitioner® CDP® certification.

www.nccdp.org

Nuffield Council on Bioethics

The Nuffield Council on Bioethics is an independent body that examines and reports on ethical issues in biology and medicine. It was established by the Trustees of the Nuffield Foundation in 1991, and since 1994 it has been funded jointly by the Foundation, the Wellcome Trust, and the Medical Research Council. Their comprehensive report *Dementia: Ethical Issues* is a must-read for healthcare and family caregivers.

<http://nuffieldbioethics.org/project/dementia/>

Share the Caregiving

Share the Caregiving is dedicated to educating the caregiving communities about the effectiveness of the Share the Care model. Share the Care encourages ordinary people to pool their efforts to help ease the burden on family caregivers and help those without family nearby.

<http://sharethecare.org/>

Strength for Caring (SFC)

SFC is a comprehensive website designed to provide family caregivers with a broad range of expert content and information, an emerging online community, daily inspiration, and much needed support.

<http://www.strengthforcaring.com/>

Today's Caregiver

Caregiver Media Group provides information, support, and guidance for family and professional caregivers. It publishes *Today's Caregiver* magazine, the first national magazine dedicated to caregivers, presents Fearless Caregiver conferences, and offers a website that includes newsletters, online discussion lists, articles from *Today's Caregiver*, chat rooms, and an online store.

<http://caregiver.com/>

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Post Test

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

1. Dementia is:

- a. A reversible pathophysiologic change in the brains of all older adults.
- b. The gradual degeneration of cells in the brainstem, considered a normal part of aging.
- c. Caused by cigarette smoking and overconsumption of aluminum-containing foods.
- d. A collective name for progressive deterioration of the brain's executive functions.

2. 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.

3. In early Alzheimer's disease, visual and spatial problems are common. This includes:

- a. An improved ability to identify form, color, and contrast.
- b. Difficulties with reading, problems in discriminating form and color, and an inability to perceive contrast.
- c. Decreased ability to smell, which can occur up to 20 years prior to the onset of other symptoms.
- d. Loss of judgment, inappropriate behaviors, and disinhibition.

4. 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.

5. Symptoms associated with frontotemporal dementia, a common type of non-Alzheimer's dementia include:

- a. Parkinson's-related movement symptoms.
- b. Loss of judgment rather than memory problems.
- c. Patchy cognitive impairment along with emotional problems.
- d. Visual hallucinations and loss of the sense of smell.

6. Preclinical Alzheimer's disease is:

- a. A decline in cognitive function that falls between the changes associated with typical aging and those fulfilling the criteria for dementia.
- b. A stage marked by a very high risk for progression to Alzheimer's dementia.
- c. The stage in which pathologic changes have begun to appear in the brain but no cognitive or emotional symptoms are present.
- d. A period in which symptoms become more obvious and complex tasks become more difficult.

7. Mild cognitive impairment:

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

8. Currently, Alzheimer's disease is typically diagnosed by:

- a. A test that shows the amount of beta-amyloid plaques in the blood.
- b. Biomarkers, which show abnormal substances in urine.
- c. A clinician's suspicion of patient symptoms or caregiver concerns.
- d. Magnetic resonance imaging.

9. The U.S. Preventive Services Task Force has recommended that, for the screening of cognitive impairment in older adults:

- a. Current evidence strongly supports it.
- b. All older adults should be screened using functional MRI.
- c. Cerebral spinal fluid analysis is strongly recommended.

d. Current evidence is insufficient to assess the benefits and harms of screening for cognitive impairment.

10. Diagnosis of Alzheimer's disease and other types of dementia is based on:

- a. Blood tests and imaging techniques that can definitively diagnose dementia.
- b. Noninvasive vascular tests and neuroimaging studies.
- c. The presence of headache, fatigue, dizziness, irritability, and difficulty concentrating.
- d. A gradual decline in mental capacity, changes in behavior, and the eventual loss of the ability to live independently.

11. Delirium:

- a. Generally lasts several months.
- 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.

12. Depression is characterized by:

- a. Short-term memory loss and the propensity to get lost in familiar places.
- b. Permanent damage to the brain tissue, leading to an inability to concentrate.
- c. Sleep disturbances lasting less than one month.
- d. Persistent and pervasive low mood and loss of interest or pleasure in usual activities.

13. 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.

14. The ABC, 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.

15. 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.

16. Agitated and aggressive behaviors are 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.

17. 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.

18. 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. Discuss the wanderer's behavior with the doctor.
- d. Restrain the person in a wheelchair.

19. Non-pharmacologic treatments that have been used to treat sleep disorders in people with dementia include:

- a. Physical restraints to keep a person in bed during the night.
- b. Light therapy, exercise during the day, and restriction or elimination of caffeine.
- c. Restricting exercise during the day and regular daytime napping.
- d. Reducing exposure to bright lights during the day.

20. Physical restraints in nursing home residents:

- a. Must be frequently re-evaluated for their indications, effectiveness, and side effects.
- b. Should be used only after a chemical restraint such as antipsychotic medication has been tried.
- c. Are very effective for the management of behavioral symptoms of dementia.
- d. Can be used at any time at the discretion of the nursing assistant, nurse, or physical therapist.

21. 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.

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

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

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

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

24. Nutraceutical agents such as such as huperzine A:

- a. Modify the course of dementia in older adults.
- b. May enhance cognitive performance and slow cognitive decline in those with dementia.
- c. Reduce toxins and prevent neurological cell loss.
- d. Should be strictly avoided by people with moderate to severe dementia.

25. When assisting a person who has moderate dementia with personal grooming, the best action is to:

- a. Give them something else to do as a distraction.
- b. Complete the task quickly so that the person does not have time to fight back.
- c. Do not allow the person to assist because it will take much longer to complete the task.
- d. Make the tools available, encourage participation, and allow simple choices.

26. In terms of ADLs, signs of moderate dementia can include:

- a. Losing car keys several times a day.
- b. The need for increased assistance with ADLs.
- c. Complete dependence on caregivers.
- d. Trying to cover up deficits by making up stories.

27. Your patient is in the moderate stage of dementia and has urinary incontinence. The best initial intervention is to:

- a. Show her where the bathroom is and tell her to use it regularly.
- b. Set up and assist her with a regular toileting schedule.
- c. Use a diaper or an adult brief and encourage her to urinate in the diaper.
- d. Remind her to use the bathroom as soon as she feels the urge.

28. Bathing at any stage of dementia is best managed by:

- a. Proceeding with bathing as scheduled regardless of the resident's wishes.
- b. Changing from a shower to a bed bath.
- c. Enlisting the assistance of a co-worker to prevent injury.
- d. Engaging the resident, allowing choices, and keeping the person comfortable.

29. Emerging evidence suggests that in people with mild to moderate dementia:
- a. Seated exercises provide the best improvements in activities of daily living and quality of life.
 - b. Exercise that combines different approaches may result in greater improvements in physical performance, cognitive function, and quality.
 - c. Exercise and physical activity has no effect on physical or cognitive performance.
 - d. Exercise is harmful.
30. Dual-task walking may be particularly affected by dementia. Dual-task walking is:
- a. Walking that must be integrated with another activity, such as watching for traffic or using a mobile phone.
 - b. Two people walking side-by-side.
 - c. A type of walking that should be avoided in people with dementia.
 - d. When a person stops walking to do a specific task such as using the phone or putting groceries away.
31. A person who is in the moderate to severe stages of dementia might enjoy:
- a. Listening to music that was popular when he was young.
 - b. Learning how to knit.
 - c. Reading books and discussing them with other residents.
 - d. Doing crossword puzzles if she enjoyed them earlier in life.
32. Your patient, who has mild to moderate dementia, sits in his room all day, and is reluctant to participate in group activities. The best way to get him involved is:
- a. Interview him about his experiences, hobbies, and interests.
 - b. Let him be—he probably doesn't like to participate in groups.
 - c. Take him to group activities even if he protests.
 - d. Tell him he must come to activities.
33. In developed countries, the caring role of families and their need for support is often overlooked while in developing countries:
- a. The reliability and universality of the family care system is often overestimated.
 - b. Family caregivers are universally available and respected.
 - c. Caregivers are generally paid for their work.

d. Caregivers provide care with a great deal of family support.

34. In the early stages of dementia, it is recommended that family members:

- a. Quit their jobs and provide 24/7 care.
- b. Receive early, specialized training about dementia.
- c. Take over as many tasks as possible so the person with dementia is well-cared for.
- d. Go on with your life and ignore any changes in their loved one.

35. Improving communication is a critical skill for caregivers of people with dementia. This can be accomplished using:

- a. Psychotropic medications.
- b. A regular sleep schedule.
- c. Memory aids, caregiver training, and family participation.
- d. Isolation, followed by light therapy.

Answer Sheet

Alzheimer's Disease and Related Dementias, 6 units

Name (Please print your name): _____

Date: _____

Passing score is 80%

1. _____
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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 three differences between Alzheimer's dementia and non-Alzheimer's dementia.

☐ 5 ☐ 4 ☐ 3 ☐ 2 ☐ 1

b. State the three National Institute on Aging and the Alzheimer's Association stages of dementia.

☐ 5 ☐ 4 ☐ 3 ☐ 2 ☐ 1

c. Identify three barriers that may contribute to a missed or delayed diagnosis of dementia.

☐ 5 ☐ 4 ☐ 3 ☐ 2 ☐ 1

d. In terms of onset, cause, and duration, distinguish among dementia, delirium, and depression.

☐ 5 ☐ 4 ☐ 3 ☐ 2 ☐ 1

e. List three common behavioral and psychological symptoms of dementia.

☐ 5 ☐ 4 ☐ 3 ☐ 2 ☐ 1

f. Identify five other common behaviors often attributed to dementia.

☐ 5 ☐ 4 ☐ 3 ☐ 2 ☐ 1

g. Explain the action of the two main classes of medications prescribed for Alzheimer's disease.

☐ 5 ☐ 4 ☐ 3 ☐ 2 ☐ 1

h. State three ways in which dementia affects a person's ability to complete activities of daily living.

☐ 5 ☐ 4 ☐ 3 ☐ 2 ☐ 1

i. Describe three ways in which exercise appears to positively impact in people with dementia.

☐ 5 ☐ 4 ☐ 3 ☐ 2 ☐ 1

j. Relate the three components that should be part of any activities program for anyone with dementia.

☐ 5 ☐ 4 ☐ 3 ☐ 2 ☐ 1

k. Discuss three ways in which stress can affect a caregiver's quality of life.

☐ 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 (ADRD 6 (161))

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

* Name: _____

* Email: _____

* Address: _____

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

* Country: _____

* Phone: _____

* Professional Credentials/Designations:

* 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**.

6 contact hours: \$39

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: _____