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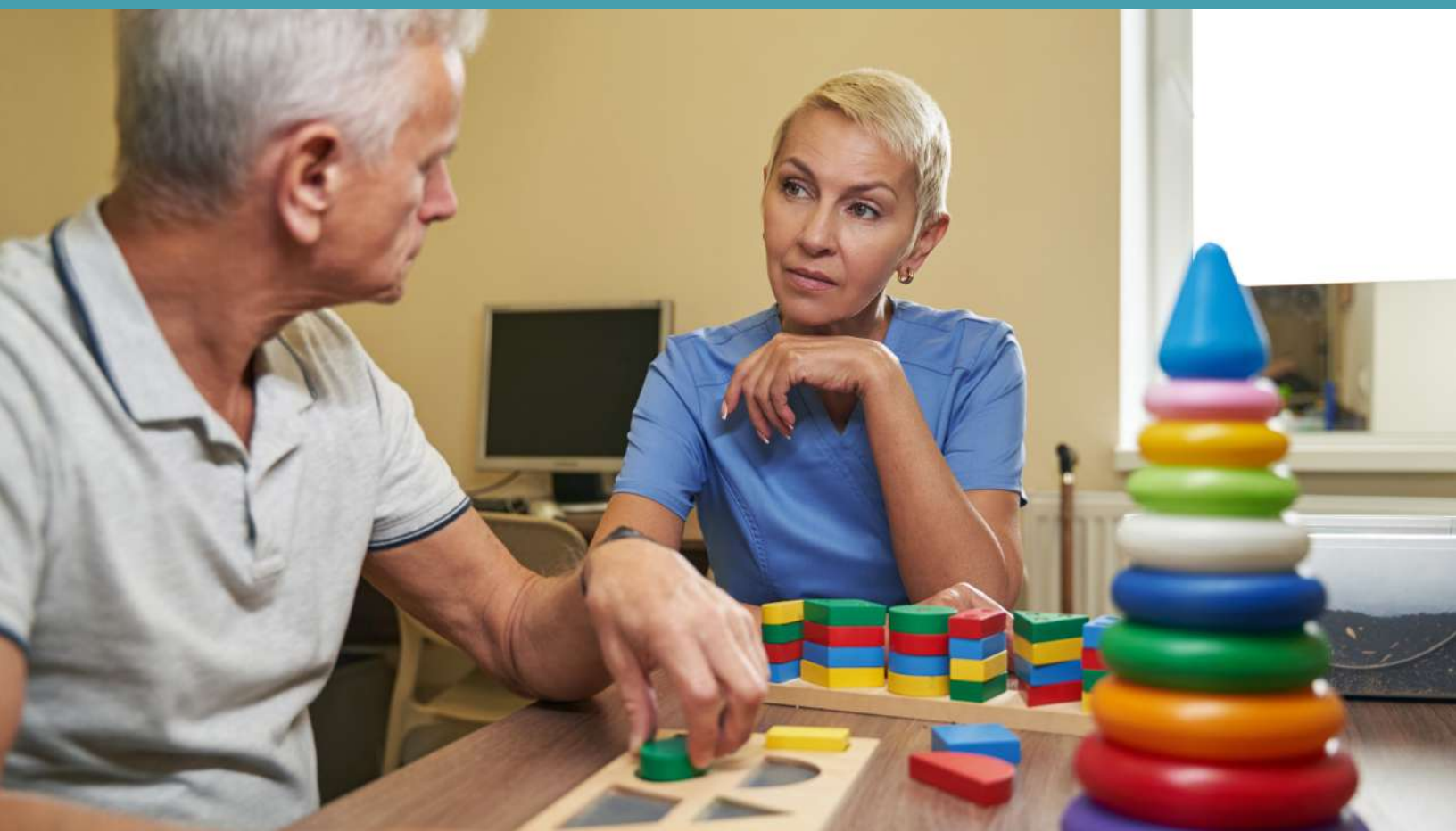
Dementia Care



Introduction

The CDC predicts that some form of dementia will impact 14 million Americans by 2060. This means the number of Americans with the disease will nearly triple in the next three decades. Dementia requires specialized treatment because it can have a widespread effect on an individual's ability to engage in ADLs, IADLs, leisure, socialization, and other meaningful activities. As a result, healthcare providers (especially occupational therapists) must be well-versed in the basics of the disease and how to effectively provide client-centered care to individuals with dementia.

OTs working in geriatrics are the most likely to encounter patients living with dementia. This is why all geriatric professionals and those who work exclusively with those who have dementia should possess a repertoire of intervention strategies to support these individuals and their caregivers. This will help maximize their quality of life, sustain their independence, and slow the progression of the disease.

Section 1: Dementia Background, Causes, & Risk Factors

1,2,3,4,5,6,17,18,19,20

Geriatrics is just one of the populations that occupational therapists can treat in a variety of settings. This specialty is also the practice area that has one of the highest needs for healthcare providers and caregivers, since seniors make up one of the largest age groups. As of 2019, there are 54.1 million individuals who are 65 years or older. Every day, more than 10,000 people across the nation turn 65. Individuals in this age group represent 16% of the population. These figures are expected to continue growing rapidly, especially in the next 30 years. The reason for this growth in the American population is due to lower birth rates in younger generations as well as a higher life expectancy that is partly attributed to advances in healthcare and medical technology.

With an ever-growing number of older adults, the country is also seeing a higher incidence of seniors with dementia. The most recent research shows that a total of 5.8 million people in the United States are living with a form of dementia. An overwhelming 5.6 million of these individuals are over the age of 65 with the remaining people holding a diagnosis of early-onset dementia. It is estimated that about 500,000 new cases of dementia are diagnosed in the United States each year. Most of these cases are Alzheimer's disease, which is the most common form of dementia.

Some people refer to dementia as one condition that causes memory loss, but it's actually a group of progressive, chronic diagnoses that causes impairment in at least two major cognitive functions. Memory, judgment, and information processing are among the most common and first mental functions affected. On a cellular level, dementia causes death of or damage to nerve cells in the brain. The symptoms someone with dementia might develop are also dependent on what brain lobe the injured cells are part of, the severity of the condition, and the type of dementia. Symptomatology might also vary based on the cause of dementia.

In most cases, dementia is caused by a co-occurring medical condition or injury that impacts brain function. This might be a recent or past occurrence, but it develops as a result of long-lasting damage to the brain. Some conditions that can lead to dementia include:

- Traumatic brain injury (TBI)
- Acquired brain injury (ABI), such as hemorrhage, oxygen loss, or ischemia
- Cerebrovascular disease
- Multiple sclerosis (MS) and amyotrophic lateral sclerosis (ALS)
- Untreated or late-stage Human Immunodeficiency Virus (HIV)
- Parkinson's Disease
- Huntington's Disease

There are instances where dementia symptoms might slightly improve if this medical condition is acute and able to be treated. However, symptoms of dementia will not entirely resolve and the progression will not stop, even with treatment.

While far less common, it is possible for dementia to develop as a result of certain inherited genes. Dementia with an early onset, which impacts individuals under the age of 65, is usually the only type caused by inherited genes. Other causes of dementia are specific to the condition subtype. For example, Alzheimer's disease and Lewy body dementia result from an abnormal buildup of proteins that form plaques and tangles in the brain. Vascular dementia results from cell death that starts with reduced blood flow within the brain and stems from narrowing blood vessels. Frontotemporal dementia also results from an abnormal buildup of proteins concentrated in the frontal and temporal lobes of the brain, but this subtype can also be inherited.

When a person inherits certain genes that lead them to develop dementia, this is an intrinsic risk factor for dementia that cannot be avoided or changed. Other intrinsic risk factors for dementia include:

- Age
    - A person's risk of dementia doubles every 5 years because it takes a while to develop; this makes adults in the oldest generation the most at risk
- Slower healing time
- Being a woman
    - This is partly due to their increased life expectancy; there is some research that suggests the possibility of sex hormones during menopause playing a part
- Individuals of South Asian, Black African, Black Caribbean, and Latinx descent
    - This is thought to be due to their increased risk of related conditions such as heart disease and diabetes
- Health concerns that involve the arteries and blood vessels
    - Hypertension
    - Diabetes
    - A weakened immune system
    - Atherosclerosis
    - High cholesterol
    - Traumatic brain injury
- High blood levels of an amino acid called homocysteine
- Other health concerns
    - Hearing impairment since this increases someone's risk of being socially isolated, which plays a part in their cognitive reserve
    - Depression

    - Down syndrome and other intellectual disabilities
    - Sleep apnea and other sleep-related disorders

In some instances, individuals can protect themselves from dementia by avoiding certain medical conditions or injuries and other lifestyle choices that contribute to the development of dementia. These are considered extrinsic risk factors for dementia because they are modifiable. Some extrinsic risk factors for dementia include:

- Living in a deprived area that has high levels of air pollution along with poor access to housing, healthcare, and education
- Heavy alcohol use and/or smoking
- Eating an unbalanced diet
- Deficiencies in folate along with Vitamins B6, B12, and D
- Being overweight
- Decreased cognitive reserve or the brain's resilience and sustained activity over time, which can be lowered by:
    - A low educational level
    - Non-complex jobs
    - Isolation from others

There are cases where other medical concerns can present like dementia. If the condition is acute, these dementia-like symptoms often resolve once the person receives treatment. However, the cognitive effects can't always be reversed in the instances of chronic conditions. There are also a range of medications that can cause dementia-like side effects. Some of the following conditions can present like dementia:

- Immune conditions and infections
    - Urinary tract infections
    - Rheumatoid arthritis
    - Neurosyphilis
    - Lupus

- Cyclical and chronic mood disorders such as depression
- Short- or long-term recreational drug use
- Age-related memory changes
- Mild cognitive impairment (MCI)
- Effects of chronic stress
- Operable brain abnormalities including tumors, subdural hematomas, and normal pressure hydrocephalus
- Vitamin and mineral deficiencies
    - Copper deficiency
    - Folic acid deficiency
    - Thiamine/Vitamin B1 deficiency
    - Vitamin B6 deficiency
    - Vitamin B12 deficiency
    - Vitamin E deficiency
- Delirium
- Thyroid disorders
    - Hyperthyroidism
    - Hypothyroidism
    - Hashimoto's thyroiditis
- Heavy metal exposure
- Hypoglycemia
- Liver cirrhosis
- Metabolic abnormalities and derangements
    - Addison’s disease

    - Cushing's disease
    - Hypercalcemia
    - Hypernatremia
    - Hyponatremia
- Side effects of certain medications
    - Sleeping pills
    - Anti-anxiety drugs
    - Anti-parkinson's drugs
    - Antidepressants
    - Anticonvulsants
    - Anticholinergics
    - Corticosteroids
    - Chemotherapy medications
    - Sedatives that are not in the benzodiazepine class
    - Statins and blood thinners
    - Antihistamines
    - Narcotics

Section 1 Personal Reflection

How can an occupational therapist help a patient boost their cognitive reserve to lower their risk for dementia?

Section 1 Key Words

Hypernatremia - A condition that results from too much sodium in the bloodstream

Hyponatremia - A condition that results from low levels of sodium in the bloodstream

Section 2: Normal Aging vs. Dementia Presentations

8,9,10,11,12,13,14,15,16

The body and brain both undergo many changes as a person ages. Some of these are typical while others might be characteristic of health concerns such as arthritis, hearing impairment, and dementia. In order for therapists to effectively treat patients with dementia, they must distinguish between age-related behaviors and functional changes and those associated with dementia.

As an individual ages, they might experience some of the following structural and functional changes:

Cardiovascular system

- Stiffening blood vessels
- More fatty deposits inside blood vessels
- Lower heart rate during exercise and activity
- Increased exertion on the heart due to difficulty pumping blood

Musculoskeletal system

- Shrinking bones
- Decreased bone density
- A drop in overall endurance
- Lower muscle strength and flexibility
- Difficulty swallowing due to esophageal rigidity

Metabolic system

- Larger spikes in blood glucose levels after eating
- Difficulty losing weight

Digestive system

- Slower gastrointestinal motility

- Increased constipation

Urinary system

- Decreased kidney efficiency in removing waste from the blood
- Less bladder elasticity
- More frequent urination urges
- Weakened bladder muscles
- Inability to completely empty the bladder
- Difficulty controlling bladder leaks

Skin and teeth

- Receding gums
- Dry mouth
- More skin tags, wrinkles, and age spots
- Increased vulnerability to tooth decay along with gum infections
- More brittle skin and nails
- Less sweating
- Tooth loss
- Slower hair and nail growth
- Thinning of the skin due to less fatty tissue below the top layer
- Drier skin due to decreased oil production
- Increased likelihood of bruising
- Decreased skin elasticity

Vision and hearing

- Decreased visual acuity when viewing nearby items
- Glare sensitivity

- Altered color perception
- Increased production of earwax
- Difficulty adjusting to light changes in the environment
- Clouding and stiffening of the lenses in the eye
- Difficulty hearing high pitch frequencies
- Slower reading speed
- Safety concerns related to driving at night
- Trouble discerning one sound from another in loud environments

Cognition

- Increased difficulty multitasking
- Mild memory loss, including trouble recalling names or certain words
- A decrease in brain cells
- Slowed reaction time
- Difficulty problem solving
- Increased distractibility
- Trouble learning new skills and concepts
- Impaired coordination

As you can see, there are many normal changes that someone experiences as they age. These changes often present themselves outwardly after the age of 50, but they usually begin on a cellular level as early as 30 years old. Many individuals begin to notice the most significant functional changes at or after 65 years old.

In terms of cognition, certain functions are impacted more than others. It's also important to note that two people can experience the same functional changes but have those characteristics hold different clinical significance. For instance, an individual who struggles with daily activities such as cooking, managing money, working, shopping, and scheduling appointments and has cognitive concerns might be diagnosed with early dementia. On the other hand, someone who has similar concerns related to their mental

function but is able to independently engage in these daily activities would be considered to have age-related functional changes.

Age-related changes most often affect a person's ability to multitask, sustain attention for extended periods, find words, retain information in their short-term memory, solve common or simple problems, and navigate familiar places. This is due to the shrinkage of specific brain areas, including the hippocampus (memory center), frontal lobe (governing executive functions such as memory and judgment), and temporal lobe (in charge of language processing). Conversely, there are certain brain functions that remain unchanged through the aging process. For example, a person's verbal reasoning, reading skills, and vocabulary knowledge typically do not decline over the course of the lifespan. There are some cases where these functions actually improve as a person ages.

Personality is another part of someone's presentation that typically remains constant throughout their life. This is why another major warning sign of dementia is drastic personality changes including uncharacteristic or strange behaviors, severe mood swings, laughing at inappropriate times, hysterical outbursts of crying, or unfounded anger. While these behaviors are often present with many cases of dementia, specific symptoms vary depending on the type of dementia. There are four common types of dementia: Alzheimer's disease, vascular dementia, Lewy body dementia, and frontotemporal dementia.

Alzheimer's Disease

Alzheimer's disease is the most widely known form of dementia. In fact, many people incorrectly use the terms Alzheimer's and dementia interchangeably though they each have different causes. Alzheimer's is caused by an excessive buildup of proteins in the brain. One protein that accumulates in those who have Alzheimer's is called amyloid. Amyloid forms large clumps called plaques while another protein called tau collects to form messy clusters called tangles. As we mentioned, there are other factors such as genetics and co-occurring medical conditions that can contribute to the development of Alzheimer's. However, the abnormal build-up of proteins is the primary mechanism behind this type of dementia. Researchers do not know what triggers the accumulation of these proteins, but they do believe amyloid and tau levels begin to build up several years before symptoms become apparent. These proteins impact neurons on a cellular level by impairing their ability to communicate with other cells in the brain. In particular, the protein buildup leads to a decrease in one neurotransmitter called acetylcholine. Acetylcholine is responsible for a range of bodily functions, one of which is control of

autonomic nervous system functions such as regulating heart rate, contracting muscles, dilating blood vessels, and more. Acetylcholine also governs a person's level of alertness and sensory abilities upon waking as well as their ability to learn, focus, retain new information, regenerate brain cells after an injury, and feel a sense of reward and enjoyment from certain activities. This deficit and the formation of plaques and tangles leads individuals with Alzheimer's to develop a range of symptoms.

In the early stages of the disease, someone with mild Alzheimer's might display the following symptoms:

- Short-term memory loss
- Impaired judgment
- Difficulty with problem solving
- Trouble planning basic events and tasks
- Rigidity of structure and routine
- Withdrawal from social activities
- Impaired visual processing and spatial awareness
- Getting confused about the current location or time
- Frequently getting lost or wandering
- Difficulty initiating and timing the completion of familiar daily tasks
- Chronic anxiety outside of situations that might warrant this feeling
- Misplacing items in strange places, such as putting keys in the refrigerator
    - Another related symptom is the inability to retrace recent actions to try and find these items

It's common for someone with moderate Alzheimer's to experience many of the symptoms characteristic of mild Alzheimer's but with increased severity. Moderate Alzheimer's also brings about some new symptoms. Regardless, these behaviors and symptoms have a greater impact on someone's function than those associated with mild Alzheimer's:

- Inability to learn new things

- Difficulty with reading, writing, and numbers (in terms of comprehension and expression)
- Increased disorientation and memory loss
- Impaired logical reasoning
- Making repetitive statements
- Difficulty sequencing multi-step tasks such as bathing or dressing
- Trouble with physical and mental organization
- Rigidity that has progressed to difficulty dealing with new situations or environments
- Limited attention
- Restlessness, wandering, anxiety, and sadness, especially in the evenings as part of sundowning
- Aggression, especially at inappropriate times
- Delusions and hallucinations
- Inability to recognize friends, family, and other familiar people
- Personality changes such as paranoia and frequent agitation

In cases of severe Alzheimer's, individuals will experience:

- Inability to talk or swallow
- Frequent skin infections and that may not fully heal
- Seizures
- Incontinence of bowel and bladder
- Impaired sleep cycles, leading to severe fatigue and difficulty remaining alert
- Non-verbal gestures in an attempt to communicate, such as grunting or moaning
- Failure to thrive or weight loss due to difficulty eating and regulating appetite

Vascular Dementia

This type of dementia results from conditions that cause damage to the blood vessels in the brain. Injuries such as ischemic stroke (a blood clot in the brain) and hemorrhagic stroke (when weak blood vessels rupture and lead to bleeding within the brain) have the potential to cause nutrient deficiency and oxygen loss, which are some of the leading causes of vascular dementia due to brain cell death. Vascular dementia can also result in individuals who have narrow or otherwise malformed blood vessels in the brain. These structural blood vessel issues can result from age or conditions such as hypertension, diabetes, and atherosclerosis.

The symptoms of vascular dementia are similar to those of Alzheimer's and include:

- Impaired focus and memory
- Urinary frequency and incontinence
- Improper judgment, planning, and response time
- Difficulty organizing thoughts and actions
- Depression, apathy, and withdrawal
- Agitation and restlessness
- Gait abnormalities

There are seven stages that detail the progression of vascular dementia. The first stage is often referred to as typical behavior since a person in stage one has vascular dementia on a cellular level (which may or may not be apparent through imaging and other testing), but they have not yet developed any symptoms. The second stage is characteristic of mild changes, which mostly entail increased memory loss and forgetfulness. The third stage is labeled a mild decline and will lead a person to demonstrate symptoms similar to those of mild Alzheimer's. It is at this point that family, friends, and others begin to notice a change in their loved one.

The fourth stage is a moderate decline, which involves similar symptoms to those displayed in the third stage but to a greater extent. Individuals who have stage four vascular dementia will likely need increased help with certain self-care and other daily activities at this level. In stage four, someone's mood and personality remain largely the same and they will still be able to do some things on their own or with very little help. The fifth stage of vascular dementia brings about a moderately severe decline, at which

point a person will need assistance with daily tasks throughout most of the day. Due to behaviors such as wandering, they will need constant supervision for their own safety.

The sixth stage of vascular dementia is severe decline. In addition to constant supervision and a high level of assistance for self-care tasks, individuals with stage six vascular dementia will demonstrate difficult behaviors. As a result, it's important for individuals and caregivers alike to receive support during this stage. In stage seven, individuals experience very severe decline, which means someone needs round-the-clock care and may also be bedridden.

Lewy body Dementia

Lewy body dementia is another progressive form of dementia that develops as a result of an accumulation of alpha-synuclein protein. This protein is naturally occurring in the brain, though its function is still not known. In terms of symptomatology, Lewy body dementia differs from other types of dementia in that the early signs include hallucinations, delusions, major fluctuations in sleep-wake cycles and levels of alertness, and personality changes such as irritability, depression, and anxiety. Changes in balance and coordination are also early (and ongoing) symptoms of Lewy body dementia.

Frontotemporal Dementia

This type of dementia is known to affect individuals far earlier than the other types, typically between the ages of 45 and 65. Frontotemporal dementia can have several causes: genetic mutations, an abnormal buildup of proteins in the frontal and temporal lobes, atrophy of the frontal and temporal lobes, Due to the location of the damage in the brain, symptoms associated with frontotemporal dementia include more specific symptoms such as:

- Impaired empathy and self-awareness
- Socially and sexually inappropriate behaviors
- Impulsivity
- Disinhibition
- Emotional withdrawal from others
- Frequent mood swings

- Repetitive movements and behaviors, such as clapping, toe tapping, etc.
- A major departure from typical eating habits and preferences
- Preference for mouthing and eating inedible objects

As you can see, many dementia symptoms are quite similar in the impact they have on a person's cognition. However, certain types of this condition - such as Lewy body dementia - have a more notable presentation than others especially at the beginning. This is because early Lewy body dementia causes someone to develop drastic personality changes and noticeable behaviors.

Section 2 Personal Reflection

How might the occupational therapy evaluation process differ for someone based on the type of dementia they are diagnosed with?

Section 2 Key Words

Apathy - A lack of enjoyment, interest, and motivation, in some cases

Atherosclerosis - A health concern that involves plaque buildup within the arteries

Hemorrhagic stroke - A brain injury that involves the rupturing of blood vessel(s) that can impact one or more lobes

Hippocampus - A part of the temporal lobe that governs memory and learning functions

Ischemic stroke - A type of stroke that results from a brain clot, which leads to oxygen loss and cell death

Section 3: Risks and Complications of Dementia [19,20,21]

Since dementia is a progressive condition, there is a good chance that someone with this disease will experience complications that place them at risk for further injury. These complications range depending on the severity and type of symptoms someone has. The risks commonly associated with dementia include:

- Malnutrition secondary to poor appetite and dysphagia

- Dehydration, which develops due to sensory changes that prevent someone from recognizing their thirst and communication deficits that get in the way of expressing thirst
- Pneumonia, which often stems from food entering the lungs due to dysphagia
- Choking as a result of dysphagia
- Bed sores that develop due to impaired mobility and an inability to change postures while seated
- Pulmonary embolism, which is when a blood clot forms in the lungs (usually due to lack of movement) and causes oxygen loss in one or more lobes
- Contractures that develop due to increased neuromuscular tone and worsen due to impaired mobility
- General safety concerns related to behaviors such as wandering
- Death from medical complications that are not treated in time
- Fractures and other injuries resulting from falls
- Stroke since the same vascular changes that can cause dementia can also lead to blood clots and brain hemorrhages
- Kidney failure since the vasculature of the kidneys changes is known to change in the same way that of the brain does with dementia
- Sepsis, which is a major bodily response triggered by infections that can lead to organ death if not diagnosed in time
- Heart disease, since impaired arteries and blood vessels can prevent the proper amount of oxygen and nutrients from getting to the brain
- Slowed healing of wounds, infections, and other curable or treatable conditions, which usually occurs since people with severe dementia often cannot report their feelings or symptoms such as pain

While these are usually considered effects of late-stage dementia, it is technically a possibility for anyone to experience these complications if they have certain symptoms. Many of these outcomes occur as a result of communication deficits (since this prevents

someone from reporting symptoms and getting help for them) and drastically impaired mobility, which causes a variety of muscular, skeletal, and cellular changes in the body.

The good news is that many of these complications are preventable if individuals have access to the right care and are being consistently monitored. Even in the event of being unable to report symptoms such as pain, swelling, or impaired sensation, individuals with dementia can get connected with treatment for related conditions. This is best done when caregivers and providers are diligent in reporting their observations and/or status changes to the individual's doctor. From there, certain tests can be done to make a diagnosis and provide the appropriate treatment.

Section 3 Personal Reflection

How can an occupational therapist and other healthcare professionals help prevent complications in individuals who have dementia?

Section 3 Key Words

Dysphagia - Difficulty swallowing, which is usually caused by muscular changes in the esophagus and throat; this can range from mild difficulty or pain while swallowing to complete inability to swallow and eat the traditional way

Section 4: Dementia Care Frameworks

22,23,24,25,26,27,28,29,30

There are many schools of thought of dementia care frameworks. However, a generally accepted framework follows a person-centered focus rather than a discipline-specific approach. Such person-centered efforts include aspects such as:

- Care coordination and transitioning between services
- Early detection and diagnosis
- Medical management
- Assessment planning
- The integration of therapeutic environments

- Supportive programming and education
- Ongoing self-care assistance
- Psychosocial monitoring and support

This is a good way to identify and prioritize the key aspects of a comprehensive care plan that should be used for anyone living with dementia.

There are also less formal frameworks that caregivers, friends, and family can use to guide the way they interact with and support people who have dementia. One example of such a guideline is the REACH framework. This is a simple reference that can be used to offer individuals with dementia more meaningful activities and opportunities. The REACH framework involves:

- Reminiscing - reminding those with dementia of their interests through movies, shows, photographs, objects, activities, stories, and more
- Emotional support - this helps soothe individuals with dementia who struggle with agitation, restlessness, and distress that comes along with an inability to express certain wants, needs, or emotions
- Activity - engaging those with dementia in both mentally- and physically-stimulating activities is important to support well-being and relieve emotional distress
- Community - integrating within their local environment and bonding with others around them can give individuals with dementia a sense of purpose and enjoyment while helping them feel less alone
- Healthy living - this can include specific changes in medication, diet, personal care, and activity engagement to better suit an individual's preferences and life changes

A physical therapist proposed a framework focused on improving outcomes and facilitating greater engagement. This framework emphasized four major pillars:

- Communication
    - Equally use verbal and non-verbal methods of interacting
    - Preserve dignity by avoiding patronizing elderspeak

    - Use a friendly voice to relay clear, short, simple phrases
    - Don’t forget to offer regularity in cue progression
    - Emphasize choices by presenting basic ‘yes’ and ‘no’ options
    - Maintain relaxed body language with a genuine smile
    - Be flexible around the client’s wants and needs
- Motor learning
    - Help clients acquire new skills by having them ‘do’
    - Keep all goals functional and important to the client and/or their family
    - Vary intensity for an added challenge
    - Use training specificity and part-whole training to your advantage
    - Grade difficulty appropriately to avoid the possibility of trial-and-error learning
    - Aim for repetitive practice to enhance skill retention
- Environment
    - Create a space that offers physical and emotional security
    - Incorporate as much familiarity into the environment as possible
    - Add environmental cues to improve task performance
    - Decrease visual and auditory distractions
    - Use calming music to create a relaxed atmosphere
- Relationship
    - Read non-verbal cues and surroundings at all times
    - Avoid person-specific triggers
    - Prioritize rapport and building a personal connection over activities
    - Remain positive

- Identify areas of importance for the client
- Utilize reminiscence in combination with empathic curiosity whenever possible
- Respect the version of reality that client believes

There are also several frameworks specific to the field of occupational therapy, which providers use to offer structure and support to the treatment they provide.

Allen's Cognitive Disabilities Model (CDM)

One of the most notable of these is the Allen's Cognitive Disabilities Model (CDM). This framework uses a series of tests to determine the cognitive levels of a person with dementia. These levels are intended to predict a person's abilities based on their cognitive skills. As a result, this framework is used by therapists to help structure treatments with appropriate therapeutic and functional activities that have task modifications to enable a person's success. The CDM rates someone's cognitive abilities based on six main levels. The first is ACL Level 1, which is known as automatic actions since a person's movements at this level are reflexive and involuntary. They can only respond to internal cues. Someone within this level is further rated based on their actions during the examination:

- 1.0 - withdrawal from painful input
    - Assistance needed: 24-hour nursing care, artificial feeding, and dependent for positioning
- 1.2 - some response to stimuli
    - Assistance needed: 24-hour nursing care, artificial feeding, and dependent for positioning
- 1.4 - location of stimulus
    - Assistance needed: 24-hour nursing care, standard diet, and help to initiate positional adjustments
- 1.6 - rolling in bed
    - Assistance needed: 24-hour nursing care, standard diet, and help to initiate positional adjustments

- 1.8 - can raise limbs
    - Assistance needed: 24-hour nursing care, placement of utensils in hands to eat a standard diet, and a clear, obvious path to get to the bathroom for bathing and toileting

At ACL Level 2, someone possesses what are known as **postural actions**. Due to severely impaired cognition, someone at this level only moves in response to proprioceptive cues that might be used to right themselves in relation to gravity. Someone within this level is further rated based on their actions during the examination:

- 2.0 - moving against gravity
    - Assistance needed: 24-hour nursing care for all transfers, the provision of food, and toileting tasks
- 2.2 - righting motions
    - Assistance needed: 24-hour nursing care to assist with weight-bearing limitations or nontraditional transfers (stand pivot or slide board), the provision of food, and toileting tasks
- 2.4 - wandering
    - Assistance needed: 24-hour nursing care for initiation and assist with all self-care tasks and to prevent injuries due to wandering and aimless movement
- 2.6 - purposeful walking
    - Assistance needed: 24-hour nursing care mainly focused on keeping a person's movements within a safe hallway, room, or other area, as well as assisting with bathing and toileting
- 2.8 - grasping
    - Assistance needed: 24-hour nursing care for locational assistance such as finding stairs, noticing thresholds, using grab bars, etc.

Someone who scores within ACL Level 3 will have **manual actions**. Cognition is still severely impaired, but someone at this level can spontaneously engage in movements that are purposeful after being given tactile cueing. Someone at Level 3 will be further rated based on the following actions:

- 3.0 - grasping objects
    - Assistance needed: 24-hour nursing care to initiate routines for self-care and to ensure quality of completion
- 3.2 - recognizing objects
    - Assistance needed: 24-hour nursing care to place relevant objects in front of the person for use during self-care and to ensure quality of completion
- 3.4 - continuing action with objects
    - Assistance needed: Supervision to place relevant objects in front of the person for use during self-care
- 3.6 - observing effects on objects
    - Assistance needed: Supervision to provide individuals with objects needed for self-care tasks and verbal reminders to finish the tasks, remove potentially dangerous items once done, and double-check completion
- 3.8 - use of objects
    - Assistance needed: Supervision to provide individuals with tools needed for self-care tasks, remove potentially dangerous items once done, and double-check completion

At ACL Level 4, someone retains their ability for **goal-directed actions**. Cognition is moderately impaired, but someone at this level is aware of cause-and-effect dynamics and can complete familiar tasks without concern. They struggle the most when coping with and solving new problems. Someone at Level 4 will be further rated based on the following actions:

- 4.0 - sequential events
    - Assistance needed: Close supervision related to dangerous objects and minor problem-solving; individual can do basic meal prep alone
- 4.2 - distinguishing different features
    - Assistance needed: Close supervision related to dangerous objects and minor problem-solving; individual can manage small amounts of money, walk short distances locally, and take a familiar bus

- 4.4 - achieving goals
    - Assistance needed: Can stay alone for parts of the day or live with someone who does daily checks; individual can manage small amounts of money and walk short distances locally
- 4.6 - personalizing
    - Assistance needed: Can live alone with daily assistance and manage small amounts of money; individual needs reminders to complete household chores and attend familiar social events
- 4.8 - memorization-based learning
    - Assistance needed: Can live alone with daily assistance with intermittent checks; can have a job or participate in regular, familiar community events with some structure

Someone with dementia who falls within ACL Level 5 will retain **exploratory actions**. Someone experiences mild cognitive deficits, impaired judgment, and impulsive decision-making at this level but this does not get in the way of someone learning new tasks with the help of trial-and-error. Someone at Level 5 will be rated based on the following actions:

- 5.0 - continual adjustments
    - Assistance needed: Can live alone with daily assistance with intermittent checks; can have a job or participate in regular, familiar community events with some structure
- 5.2 - discerning activity and task components
    - Assistance needed: Can live alone with daily assistance with intermittent checks (more for impulsivity rather than problem-solving); can have a job or participate in regular, familiar community events with some structure
- 5.4 - autonomous learning
    - Assistance needed: Can live alone and work a job that does not require precision or present any safety concerns
- 5.6 - following social norms and contexts

        - Assistance needed: Can live alone but needs outside perspective to identify environmental hazards; they can follow safety precautions once they are identified
- 5.8 - planning with others
        - Assistance needed: Can live alone but would benefit from assistance planning for the future and discussions about potential dementia complications

Someone who is graded at an ACL Level 6 demonstrates **planned actions**. A person at this level does not have any global cognitive deficits and does not require any supervision. In fact, they might not even hold a dementia diagnosis since there are no overt behaviors that would present as functional concerns. However, someone at this level might be covertly using the trial-and-error method to reason through new situations, which is the first indication of a cognitive impairment.

Cognitive-Behavioral Frame of Reference

This frame of references can be used on patients of any age with cognitive impairments, but it is especially suitable for those diagnosed with dementia. The Cognitive-Behavioral Frame of Reference identifies five components of a person's life: the environment, physiological responses, thoughts, behaviors, and emotions. Since each of these aspects are closely related, one is influenced by the other. This frame of reference involves continuous assessment, which begins with the therapist making theories and formulations about each of these components. As the therapist becomes aware of these observations, they are to make the patient aware so the process can become and remain collaborative. Due to this frame of reference's emphasis on the patient-provider relationship, it is not uncommon for therapists to use the Cognitive-Behavioral Frame of Reference in conjunction with a person-centered approach such as the Model of Human Occupation to maximize outcomes.

Dynamic Interactional Frame of Reference

This is another treatment approach that is used in cognitive rehabilitation for adults. As with many approaches, the Dynamic Interactional Frame of Reference analyzes the interaction between the person, the context, and the task they are engaging in. The components that are identified and addressed as part of this frame of reference include:

- Information processing: input, elaboration, and output
- Metacognition (knowledge of one's cognitive abilities)
- Motivation
- The impact of the environment on a person's information processing and adaptive abilities
- Identification of learning potential
- Task completion with analysis of:
    - Surface characteristics - quantity of items, postural adjustments needed, stimulus offered, etc.
    - Conceptual characteristics - skills used for certain tasks, purpose of task, personal meaning of task to patient

Based on the above factors (particularly the patient's potential for learning), therapists can begin to structure interventions that are most appropriate for the patient. For example, functional approaches and treatments are more ideal for patients whose learning potential is low. On the other hand, approaches that span multiple contexts are a better fit for patients who have an average or above-average potential for growth.

Cognitive Perceptual Frame of Reference

This is also referred to as the psychoeducational frame of reference since the basis of this model is to educate patients, their family, and caregivers about their condition. This is intended to improve the awareness of caregivers who are assisting their loving ones so they can respond to those with disabilities in a different way. In the case of patients who have dementia, psychoeducation can help caregivers better manage and respond to difficult behaviors such as irritability, isolation, aggression, and resistance to self-care tasks. Other topics of psychoeducation for caregivers of those with dementia include:

- Positioning to prevent pressure ulcers
- Body mechanics and safe lifting techniques to aid loved ones who are dependent or near dependent in transfers
- Environmental modifications to prevent falls and improve access within and outside of the home

- Temporal modifications to prevent behaviors such as restlessness and wandering from causing injury
- Sensory and communication strategies to minimize the frequency and/or impact of agitation, restlessness, or irritability
- Engaging in support groups to help cope with emotions related to caregiving
- The development of routines and strategies to help manage incontinence
- How to respond in the event of an emergency
- Steps to take to safely lift a loved one off the floor after they have fallen or otherwise been injured
- The importance of leading loved ones through consistent but structured exercises to help with restlessness, wandering, and difficulty sleeping
- Progression of the disease and what to expect as time goes on

Education can also prompt caregivers to provide the right type of structure and support for their loved one that facilitates function, maintains independence, and preserves the remaining abilities of someone with dementia.

For patients with mild dementia, psychoeducation serves the purpose of helping modify their behaviors and ways of thinking. For example, someone with mild dementia can regularly engage in activities that keep their mind and body active, including exercise, brain games, learning new skills, practicing existing hobbies with a new spin to challenge them, and more. In many cases, someone with mild dementia who is living alone may be able to add these activities to their daily routine with little to no reminders or complete them with intermittent help from a caregiver or therapist.

Section 4 Personal Reflection

What might be some of the first priority areas that a caregiver of someone with dementia will often need help managing?

Section 4 Key Words

Empathic curiosity - A personality trait that involves natural inquisition about someone else's feelings as well as the motives behind why that person feels the way they do

Model of Human Occupation - A person-centered treatment approach that is used to uncover how, why, where, and what occupations people engage in throughout their lives; the process of doing this involves breaking down the interactions someone has with their environment when engaging (or attempting to engage) in a certain activity

Reminiscence - The enjoyable act of being told a story about the past or telling a story about the past

Section 5: Occupational Therapy Evaluation Process for Dementia [31,32,33,34,35,36]

The evaluation process for someone with dementia typically begins with an occupational profile including a person's strengths, support systems, patient or caregiver goals, meaningful roles, and existing routines and occupations. This gives therapists a good starting point for the evaluation so they can look further into the patient- or family-identified goals. Therapists will also use this information to engage patients in activities that highlight their strengths followed by some slightly upgraded activities to determine the patient's capacity for participating in novel tasks.

The next part of the evaluation process involves administering assessments. There are a range of standardized assessments used to determine the baseline of someone with dementia, but non-standardized assessments can also be helpful in determining a person's performance abilities. For example, simply asking someone to complete a functional task such as putting on a jacket can give a therapist a range of information regarding the patient's motor planning, sensory function, gross motor skills, balance, range of motion, and strength. For this reason, it's important not to rely on the results of just one assessment when writing goals and creating a treatment plan.

The General Practitioner Assessment of Cognition (GPCOG) is a primary care assessment that many doctors use when first screening someone for dementia. This contains a few questions focused on orientation and some caregiver questions about their perception of the patient's abilities and memory. Another assessment is the Montreal Cognitive Assessment (MoCA). This is a general cognitive assessment intended to detect mild cognitive impairments (MCIs) and memory concerns related to dementia, stroke, multiple sclerosis, and more. The MoCA was considered a go-to assessment in the OT field for some time due to its brevity, ease of administration and scoring, and accessibility to all providers at no cost. However, there is now a fee to use it and

providers must take a specific training and certification program in order to administer it, so it's not as cost-effective now. The MoCA addresses foundational skills such as attention, orientation, spatial skills, and language.

The St. Louis University Mental Status Examination (SLUMS) and the Mini Mental Status Exam (MMSE) are both similar to the MoCA in that they are short assessments that don't require any tools to administer and they address similar foundational skills.

There are a range of other standardized assessments used on patients with suspected or diagnosed brain injuries, such as dementia and stroke. The following assessments are not performance-based:

- Confusion Assessment Method for the ICU (CAM-ICU) - Intended to help hospital workers test intensive care patients for the presence of delirium by asking patients to recall if they have seen pictures they were previously shown.
- Short-Blessed Test (SBT) - Another short test focused on orientation and recall.
- Routine Task Inventory (RTI) - This was developed with the help of the Allen's Cognitive Levels and involves the person, their caregiver, and their therapist rating their performance on a range of ADLs and IADLs.

The following assessments are functional, performance-based tests that can be used for patients with dementia. One disadvantage of these assessments is that their administration time is entirely dependent on how long it takes the patient to complete the task(s):

- Kettle Test - Patients are asked to physically make two hot drinks and therapists rate their ability to sequence and perform each of the task's 13 subcomponents focused on executive functioning and attention.
- Cognitive Performance Test (CPT) - This was initially developed based upon Allen's Cognitive Levels, but was revised to include an expanded set of functional abilities. The CPT requires providers to use a kit to guide patients through certain tasks.
- Executive Function Performance Test (EFPT) - This involves patients completing four tasks related to cooking, medication management, telephone use, and bill payment. Therapists can then determine a patient's impairments related to executive functioning, their ability to live alone, and their level of assistance.

- Test of Grocery Shopping Skills (TOGSS) - This timed test asks patients to find ten items within a grocery store with the help of a map. Therapists will assign points based on whether the patient found the correct item in the requested size at the lowest cost.
- Allen Cognitive Level Screen Assessment (ACLS) - A screening that involves patients completing three specific leather lacing tasks so providers can rate their functional cognition within one of six levels.
- Allen Diagnostic Module - A standardized assessment related to the ACLS that engages patients in 34 craft-based activities to determine their functional cognitive status. This can also be used to verify the results of the ACLS if providers need more information to devise a more accurate treatment plan.
- Erlangen Test of Activities of Daily Living (E-ADL) - This is a short performance-based test that helps providers assess the ADL abilities of individuals who have moderate to severe dementia. There is not much evidence supporting this test, so it's recommended that therapists use it in conjunction with other more reliable standardized tests or choose other assessment measures altogether.
- Dynamic Lowenstein Occupational Therapy Cognitive Assessment - This measure is intended for adults and older adults with any neurological deficits, so it can be helpful for patients with dementia, stroke, brain injuries, and other conditions. This has subtests for standard cognitive skill such as awareness and orientation along with praxis, visual-motor function, and visual perception.
- Independent Living Scales (ILS) - This assessment is used on older adults whose ability to live on their own may be in question. The test covers five scales in formative areas: money management; household maintenance and transportation; socialization; orientation and memory; and health and personal safety. This allows therapists to see how patients would respond to simulated scenarios that may come up over the course of independent living.
- Assessment of Motor and Process Skills (AMPS) - This test measures ADL performance along with skills such as problem solving, balance, functional mobility, coordination, attention, and working memory. Each task gauges if a patient is able to complete ADLs as well as their quality of completion. AMPS is suitable for use with kids, adults, or older adults with a range of diagnoses that impact motor and cognitive skills.

- Performance Assessment of Self-Care Skills (PASS) - This assessment requires patients to complete a variety of ADL, IADL, and functional mobility tasks, which are all rated for level of independence, safety, quality of completion, and efficiency of completion.

As you can see, there are a range of assessments that are appropriate for inclusion in the occupational therapy evaluation process for individuals with dementia. As with all populations, it's important for therapists to complete a combination of functional and client-centered assessments to get the most comprehensive perspective of each patient. This is the best way for occupational therapists to understand a patient's needs and create the most appropriate treatment plan.

Section 5 Personal Reflection

How might a therapist interpret results if a patient's scores are significantly different between the Allen Cognitive Level Screen Assessment and the Allen Diagnostic Module assessment?

Section 5 Key Words

Functional assessments - A type of test (sometimes standardized) that allows therapists to see how a patient completes certain tasks such as activities of daily living and instrumental activities of daily living; these are often called performance-based assessments because they focus on the quality of how someone completes activities

Standardized assessments - Assessments that present patients with a set group of tasks, questions, or activities designed to determine their strengths and weaknesses by comparing them to normative data that has been gathered from their peers

Section 6: Medical, Residential, and Rehabilitative Treatment for Dementia [37,38,39,40,41]

Patients with dementia will receive medical treatment based on the progression of their condition. This medical treatment often includes prescription medications to aid with symptoms management. Many pharmaceuticals will help slow the progression of memory loss and cognitive deterioration while managing certain difficult symptoms that

result from brain changes. Some medications that doctors may prescribe to address a patient's mental function include:

- Aducanumab (Aduhelm) - This medication is specific to dementia and provides someone with anti-amyloid antibodies given intravenously. These are intended to attack plaques that have accumulated in the brain and improve cognitive function.
- Cholinesterase inhibitors (Aricept, Evelyn, Razadyne) - Medications in this classification treat symptoms like impaired memory, poor judgment, limited ability for learning, and language deficits by preventing breakdown of the vital neurotransmitter acetylcholine. Aricept is beneficial for all stages of dementia while the other medications are more appropriate for those who have mild to moderate dementia.
- Glutamate regulators (Namenda) - These medications regulate the production and use of the most common neurotransmitter called glutamate, which helps the brain better process information. This category of medication is best for those with moderate to severe dementia.
- Cholinesterase inhibitor + glutamate regulator (Namzeric) - This medication combines two mechanisms and is intended to treat the symptoms associated with moderate to severe dementia.
- Orexin receptor antagonist (Belsomra) - Insomnia is a common symptom of dementia, which is why this medication is specifically FDA-approved for dementia-related insomnia in those with mild to moderate dementia.
- Antidepressants (Celexa, Prozac, Paxil, Zoloft, Desyrel) - While antidepressants are also used to treat primary depression, the above drugs can also treat dementia-related mood disorders.
- Anti-anxiolytics (Serax, Ativan) - Individuals with dementia can take these medications to ease behaviors such as resistance to certain activities, anxiety, and restlessness.
- Anti-psychotics (Clozaril, Abilify, Haldol, Zyprexa, Seroquel, Risperdal, Geodon) - Individuals with moderate to severe dementia will often experience more difficult behaviors, including agitation, aggression, hostility, hallucinations, and delusions. These behaviors typically respond best to antipsychotic medications. While these medications are effective in managing behaviors related to dementia, there is

evidence suggesting antipsychotics and benzodiazepines can promote and even speed up the progression of dementia. For this reason, doctors should recommend them in moderation and regularly monitor patients throughout the medication's course.

On the other hand, some medications aim to reduce the occurrence or frequency of complications related to dementia. For example, a patient with this condition who is largely immobile and spends the majority of their time in a bed or chair will be at an increased risk of urinary tract infections (UTIs). As a result, their primary care doctor might prescribe a low dose of antibiotics to be taken on a long-term basis to prevent these infections from developing or worsening.

Depending on their symptoms, an individual with dementia may live in a range of settings with the right kind of support. There are several options across the continuum of care:

Memory Care Unit

A memory care unit is a freestanding facility or a separate wing within an assisted living facility, skilled nursing facility, or retirement community. Memory care units are dedicated to providing services and support for individuals with progressive dementia (and other brain injuries) who cannot live alone or care for themselves and do not have the means for in-home care. This setting is considered the most restrictive environment, since most memory care units are locked for the safety of their residents. Memory care units usually offer the following services and amenities:

- 24/7 supervision and security
- Nursing care
    - Some memory care units have part-time nursing coverage while others have nurses present 24/7
- Medication administration
- Therapeutic recreation and social programming (often between 2 and 4 times each day)
- Private or semi-private sleeping accommodations
- Medical alert systems

- Access to PT, OT, and ST
    - Some memory care units have these providers on staff while others allow contracted agencies to come in when these services are needed
- Personal care assistance for ADLs, transfers, and functional mobility as needed
- Housekeeping, laundry, and meal preparation

While memory care units offer a range of services, they are usually the best fit for individuals with dementia who demonstrate behaviors that continually put their physical and emotional health at risk.

Long-term Care Facilities

A long-term care facility is usually a wing, ward, or floor of a skilled nursing facility that houses residents with physical or cognitive needs on a long-term basis. While individuals with dementia may live in long-term care facilities, this setting will not offer dementia-specific care. For this reason, this setting is not the best fit for individuals with severe dementia. Long-term care facilities offer these basic services to residents regardless of their needs:

- Access to PT, OT, and ST
    - Long-term care facilities do not provide specialty medical care so nurses are not required to be on staff
    - If a long-term care resident develops acute needs that require rehabilitation and nursing care, they may be seen by contract therapists and/or nurses who come into the facility for that purpose or therapists/ nurses who work in a different part of the facility (this is common for long-term care facilities that share a building with skilled nursing/rehabilitation)
- Medication administration
- Therapeutic recreation and social programming (often between 2 and 4 times each day)
- Private or semi-private sleeping accommodations
- Personal care assistance for ADLs, transfers, and functional mobility as needed

- Housekeeping, laundry, and meal preparation

Assisted Living Facilities

Independent (ILFs) and assisted living facilities (ALFs) are alternate housing communities with a range of amenities. Some individuals with dementia may start off in independent living facilities early in their diagnosis or before they are diagnosed and then transition to a different floor in the same facility as their condition progresses and they need more support. Independent living facilities are not all that different from life in an apartment building or condominium. Assisted living facilities, however, do offer the following services:

- Meal preparation (one to three times a day)
- Medication monitoring, if needed
- Personal care assistance for certain ADLs
- Home repairs, housekeeping, and laundry
- Emergency services
- Social and recreational activities

The difference between ALFs and skilled nursing facilities or long-term care facilities is that someone doesn't need to have a disability in order to benefit from an assisted living facility. This type of accommodation is suitable for adults of any age who do not need medical care but would like assistance with household management.

Home Care

Some individuals with dementia may be able to stay in their home and receive in-home services. Home health agencies (with the help of a companion or certified nurse's assistant and therapists) can provide a few hours of this care a week if the patient demonstrates a skilled medical need for rehabilitation or acute medical concerns. But this is typically on a short-term basis. If patients need round-the-clock care, they will often need to pay out-of-pocket for a live-in caregiver or someone who is with the patient during their waking hours.

Since they are not provided within an institution, there is more flexibility with home care services so they are provided purely based on what the patient needs. Family members

and patients can request for assistance with certain tasks but not others. For example, a patient with mild dementia might be able to complete their self-care and light housekeeping independently, but they may need assistance with medication management and heavy household chores.

Depending on the setting where a patient with dementia is treated, they might see several different service providers.

- Neurologist
    - These doctors specialize in disorders of the central nervous system (the brain and spinal cord) and typically play the biggest part at the start of someone's dementia. Patients are often referred to neurologists when they have suspected dementia, since these physicians will complete diagnostic testing for this condition. At this point, if necessary, they will also make referrals to other providers to further assist with the patient's care.
- Geriatric psychiatrist, behavioral neurologist
    - If a patient with dementia presents with behavioral concerns that have a major impact on their function or well-being, these doctors will often assume care. They will complete psychiatric, functional, and competency-based assessments periodically to monitor the progression of the disease. They might also perform imaging tests on the brain if a patient's symptoms are accelerating rapidly or other complications arise. Treatment options typically involve behavior management with one or more medications.
- Audiologist
    - Audiologists are healthcare professionals who assess and treat hearing disorders. Someone with cognitive concerns of any kind might behave differently if they have sensory changes (age-related or otherwise) such as hearing impairments. Audiologists can complete regular exams for those with hearing loss and look into other sources of hearing impairment.
- Optometrist
    - These doctors complete regular assessments and treatment for eye-related concerns. Similar to hearing, visual deficits are another sensory change that can be especially disorienting for someone with dementia, so regular

eye exams and prompt treatment of eye conditions is important for this population.

- Social worker
    - These professionals do not provide direct services, rather they coordinate support services that keep someone in their home or help them smoothly transition from their home to a residential care facility.
- Occupational therapist
    - OTs work with patients who have moderate to severe dementia to improve the ability to participate in ADLs. In patients with mild impairments, OTs might train patients in the use of assistive devices to help with memory loss and provide therapy to address IADLs such as laundry, cleaning, and meal preparation.
- Physical therapist
    - PTs will help patients with dementia build endurance, strength, and balance that might have been lost due to deconditioning. PTs can also work with OTs to develop positioning schedules for caregivers, family, and staff, which is crucial to prevent contractures.
- Speech therapist
    - STs can provide diet and texture recommendations to caregivers of patients with severe dementia to ensure they are getting adequate nutrition and can safely eat with or without assistance. STs can also address expressive communication deficits that might be present due to memory loss and other cognitive changes.
- Music therapist
    - Music therapists offer artistic opportunities for individuals with dementia to engage socially, improve their cognitive function, and better manage difficult behaviors. As with rehabilitation professionals, music therapy can be provided in small groups or individually.
- Dietitians

        - These professionals create specific diets for individuals with dementia who have limited nutritional intake, refuse to eat, have weight concerns (also called failure to thrive) or need to be tube fed due to severe dysphagia related to muscular changes in the throat and esophagus.
- Certified nurse's aide, home health aide
    - These providers work the most with individuals who have dementia, since they provide personal care assistance such as help with ADLs and household cleaning. If the person has severe dementia, they might need an aide 24/7. Others might only need one for a few hours each day.

Based on the severity of the disease, someone with dementia might have long-term goals in any of the following areas:

- Activities of daily living
    - Bathing
        - Patient will use a visual schedule to independently bathe twice per week.
        - Patient will increase tolerance for water temperature while bathing without demonstrating aggression.
    - Toileting
        - Patient will complete perineal care while remaining safely upright on the toilet.
        - Patient will recognize the need to use the toilet and alert their caregiver appropriately.
        - Patient will follow incontinence strategies with no more than 2 verbal cues to minimize accidents.
    - Grooming
        - Patient will demonstrate proper use of adapted tools (long-handled comb, hair brush, face wipes) to complete morning grooming.
        - Patient will complete evening grooming and hygiene with supervision only.

- Feeding
    - Patient will complete remaining motions necessary to feed themselves (elbow flexion to bring arm from bowl to mouth) once an eating utensil is placed in their hand.
    - Patient will consume dietary supplement (Ensure) once daily to receive sufficient nutrition with no more than 1 verbal cue.
- Dressing
    - Patient will choose age-appropriate upper body clothing and don/doff with no more than one visual cue.
    - Patient will assume a seated position before safely donning/doffing socks and shoes.
- Functional mobility
    - Patient will safely and independently move from the bedroom to the bathroom during morning ADL routine.
    - Patient will safely use a stepstool to retrieve clothing items from the middle shelf of their closet to pick out clothing to wear.

- Community mobility
    - Navigating public transportation
        - Patient will read street signs with 100% accuracy and supervision.
    - Transferring in and out of a vehicle, bus, etc.
        - Patient will safely clear two stairs while holding a unilateral hand rail to enter a bus.

- Work
    - Scheduling
        - Patient will utilize their digital calendar to schedule 85% of their appointments and meetings.

        - Patient will keep 75% of their appointments using a physical calendar.
    - Organization
        - Patient will create daily to-do lists with min A and adhere to those lists independently.
    - Time management
        - Patient will improve orientation to time with the help of a wristwatch, productivity timer, and environmental strategies to improve attention.
- Instrumental activities of daily living
    - Laundry
        - Patient will safely ascend and descend stairs once weekly to access washer and dryer while utilizing the laundry chute to better manage physical loads.
    - Household chores
        - Patient will complete light cleaning (vacuuming, dusting) with good use of energy conservation techniques.
    - Medication management
        - Patient will identify 5/5 medication and their purpose with min A from caregiver or nurse.
    - Money management
        - Patient will identify bills and coins with 85% accuracy in preparation for money exchange in stores
        - When in a store, patient will provide correct money for two items under $10.

Section 6 Personal Reflection

How would occupational therapy goals differ for an individual with mild dementia who lives with family versus someone with moderate dementia who resides in an independent living facility?

Section 6 Key Words

Antiepileptics - A class of medications that are used to treat seizure disorders

Assisted Living Facility (ALF): A supported living arrangement available to individuals who can benefit from assistance with household management, medication administration, and self-care but does not need specialty medical care

Benzodiazepines - A class of medications that lowers nervous system activity to manage health concerns such as anxiety, seizures, and insomnia; these are prescribed less often than antiepileptics and anti-anxiolytics due to their side effect of lethargy, which drastically decreases someone's alertness and functional abilities

Failure to thrive (FTT) - A global decline that can occur in children or older adults who have certain medical concerns; failure to thrive is diagnosed when someone experiences stunted physical growth or steady weight loss, dehydration, decreased physical activity, isolation or depression, and impaired immune system

Independent Living Facility (ILF) - A living arrangement available to individuals with or without disabilities who would benefit from or choose to receive assistance with household management but can still complete self-care tasks and medication management on their own

Long-Term Care (LTC) - A residential arrangement that helps individuals with physical or cognitive disabilities with household management as well as self-care and transfer assistance; LTC facilities do not offer specialty medical care so residents must not have any acute medical needs

Skilled Nursing Facility (SNF) - A healthcare institution where patients go on a short-term basis to receive medical care and rehabilitation services after an injury, surgery, or exacerbation of a chronic condition

Section 7: Occupational Therapy Interventions for Dementia [42,43,44,45,46,47,48,49,50]

There are a range of ways that occupational therapists can help individuals with dementia. The focus of OT often surrounds the management of difficult behaviors, the improvement of functional performance, the prevention of falls, and the promotion of a patient's overall well-being. OT interventions can fall under these three categories: remediation, maintenance, and modification.

The basis of evidence for each of these intervention types is strong. Kudlicka et al. completed a systematic review that looked at randomized controlled trials (RCTs) performed on individuals with confirmed cases of mild to moderate dementia. These participants were of all ages, various types of dementia, and were living with or without caregiver support. Some participants were receiving pharmacological treatment for dementia while others were not. These studies showed positive results from varying degrees of environmental modifications, skill remediation, and maintenance strategies to assist caregivers in preserving an individual's skills.

Another systematic review completed by Herke et al. specifically looked at RCTs that studied the impact of behavioral and environmental modifications on the feeding habits of individuals with dementia. Participants had all types of dementia, but their living situations varied (some were in residential facilities and some lived at home). The results suggested there were no significant improvements in the area of feeding, but that there is potential for environmental modifications to help those with dementia in other areas.

Woodbridge & Sullivan also completed a systematic review that assessed how modifications can assist the way a person with dementia engages within their environment. This review showed that very few studies looked at modifications for dressing and showering, but there was good evidence associated with the ones that helped with feeding, movement within the environment, and general engagement levels. A study by Bautrant et al. supported these findings. This 6-month study observed the frequency of behavioral and psychological symptoms (namely wandering, aggression, and yelling) exhibited by nursing facility residents with dementia before and after environmental modifications focused on temporal and spatial orientation. Results of this study showed that wandering and agitation were both significantly lower in the weeks following the modifications.

Environmental modifications are one of the first approaches many providers look toward because these can often make an immediate impact on the function of someone with dementia. Some evidence-based environmental modifications that can positively influence the occupational performance of an individual with dementia include:

- Label frequently-used items for clarity (depending on the person's abilities, words or pictures may be best)
- Remove small or loose throw rugs or add non-slip backing
- Organize, repurpose, and store items or loose wires that block walkways
- Use blackout curtains, shades, and task lighting to reduce glare and promote better sleep
- Install a gate at the bottom and top of stairways
- Get a temperature control sensor to prevent bath water from getting too hot
- Use light plastic plates that can easily be carried, with or without food on them
- Eliminate any decor that can pose a safety hazard (for example, fake fruit or plastic plants might be mistakenly eaten)
- Place simple but obvious decals or decorations on glass doors to prevent someone from walking through them
- Pad the corners of sharp furniture like tables and chair edges
- Store sharp objects (knives, razors, ice picks, etc.) and potentially dangerous items (blender, electric carver, household cleaners) under lock and key
- If they are able to take medications mostly on their own, place them in a talking, automatic, and/or locked pillbox; otherwise, place them under lock and key
- Facilitate independence and safety by supervising them while using an electric shaver
- Keep commonly-used items (cup, reacher, brush, remote control, phone, blanket, eating utensils) nearby
- Mount soap, shampoo, conditioner, and other hygiene products in dispensers on the wall of the shower or tub

- Install a medical alert button for emergencies
- Lock any doors that lead to outside to prevent wandering, but keep indoor entryways open (or remove the locks entirely) for easy access from the inside and outside
- Install grab bars near the toilet, in the tub or shower, just outside of the tub or shower, and next to the front door
- Utilize contrasting colors when possible to demarcate changes in flooring, furniture, and walls, but avoid any busy prints that may be distracting
- Post emergency numbers in large print and place them in a high-traffic place (on the fridge, by the nightstand, next to the phone, etc.)
- Put non-slip mats beside the bed, inside the tub/shower, and outside the tub/shower
- Add motion-sensor lighting to dim or dark areas of the home
- Add handrails to both sides of the stairs
- Place a table lamp or a light switch by the nightstand so it's within arm's reach of the bed
- Install automatic shut-off features, especially on stoves and ovens
- Label hot and cold knobs on any faucet
- Install child-proof locks on cabinets, refrigerator, etc. to prevent aimless rummaging
- Use signs or pictures as needed to help individuals better navigate places like residential facilities
- Do not move furniture or personal items within the home, as this can cause disorientation
- Install door alarms to allow for safety while wandering
- Mark elevation changes (such as thresholds and steps) with bright tape
- Install in-home cameras with motion sensors to help monitor someone overnight

- Use adaptive equipment to make ADLs and IADLs easier:
    - Handheld shower head to minimize noise and splashing
    - Talking clocks
    - Transfer turntables
    - Hospital beds with height-adjustable settings
    - Stair lift if ascending/descending stairs is too difficult and the person needs to access more than one floor
    - Long-handled sponges, safety plugs for use when bathing
    - Grip extensions for knobs, faucets, and dials throughout the home
    - A kettle tipper for someone who often boils water
    - Hoyer lift
    - One-way straws to improve ease of drinking without letting liquids go back down to the cup
    - Electric recliners
    - Trays to help transport or hold food and other items
    - Large-handled utensils
    - Talking, large-text phones with speed dial options
    - Curved-handle hair brushes and toothbrushes
    - Walker, cane, or wheelchair, depending on the level of assist someone needs
    - Whiteboards, diaries, calendars for orientation, lists, and reminders

In the realm of remediation, individuals with dementia can benefit from cognitive rehabilitation and cognitive training. Individuals with mild dementia are best suited for cognitive training, which entails guided practice of specific tasks that reflect certain cognitive and executive functions. Due to the nature of cognitive training, this tends to be completed via paper and pencil or on a computer since this offers a highly structured environment and task parameters. This also allows providers to isolate certain cognitive

processes and complete training in groups, if members would benefit from that mode of instruction. Goals for cognitive training are focused on certain cognitive domains rather than functional performance.

Cognitive rehabilitation, on the other hand, involves a more person-centered approach focused on helping those with dementia (and other progressive neurological conditions) and their loved ones to develop personally meaningful goals and individualized strategies to address these areas. Cognitive rehabilitation involves providers treating individuals on a one-to-one basis by addressing participation restrictions using groups of cognitive processes required to complete certain functional tasks. This intervention takes place in natural, real contexts and uses both restorative and compensatory approaches. Cognitive rehabilitation might also involve caregiver training with a psychoeducational tone.

While cognitive training may be useful for individuals with mild cases of dementia in certain circumstances, the majority of occupational therapists will use cognitive rehabilitation with dementia patients. This is more common since individuals are less likely to receive occupational therapy in the early stages of their condition. Occupational therapists might engage patients in a wide range of activities with a cognitive rehabilitation lens, but this is list is not all-inclusive:

- Gardening
- Spending time in nature
- Going to the park
- Having a picnic
- Play a favorite game or cards
- Watch a favorite sport, show, or movie
- Look at photos
- Get a manicure
- Make a collage
- Color a picture
- Engage in sensory stimulation with dough, putty, lotion, clay, etc.

- Create music with basic instruments like harmonicas and maracas
- Do a puzzle
- Watch live online videos of aquariums, zoos, meadows, other calming scenery, or possibly their favorite childhood place
- Read from their favorite book
- Fold laundry
- Go for a walk
- Sort objects such as coins, nuts, bolts, or items in a miscellaneous drawer of the house
- Spend time with pets and other animals
- Make a scrapbook
- Go for a drive
- Do some bird watching
- Chair exercises such as seated yoga
- Water exercises
- Watch old family videos or help create some with pictures
- Help them with light cleaning
- Encourage them to use their hands by untying knots, wiping down tables, or doing basic meal prep at the table (deshelling peas, peeling oranges, etc.)
- Read the newspaper together
- Make a family tree
- Encourage conversation about the past (family, jobs, friends, places they've lived, etc.)
- Eat a favorite food
- Painting

- Drawing
- Knitting or crocheting
- Bake or engage in simple cooking activities
- Practice holiday traditions (coloring Easter eggs, making holiday cards, decorating a pumpkin or a tree, singing holiday songs, etc.)

While many of these activities are leisure-based, therapists can incorporate practice for social interaction, coping skills, verbal expression, motor stillness, sensory regulation, fine motor coordination, activity tolerance, attention, behavior regulation, and more. Therapists can also use techniques such as visual scheduling to improve orientation of activities being performed and sequencing of motor tasks to improve independence. Therapists should keep in mind that all activities should be graded up or down based on the patient's abilities and they should be completed at a time when the patient is the most alert.

Maintenance is another important aspect of occupational therapy intervention for those with dementia. A therapy plan of care typically lasts 2-3 months at most, which is why a robust home program and caregiver training is necessary to help patients maintain functional gains after they are discharged. This type of intervention should help caregivers manage difficult behaviors, preserve remaining abilities, and promote overall well-being. Occupational therapists should provide caregivers with education on lifting techniques and body mechanics to prevent injury to themselves and the patient while they are in the later stages of dementia. Another helpful component for training is communication strategies to help manage difficult behaviors and disorientation. With mild dementia, some beneficial communication strategies include:

- Including the person in conversations
- Speaking directly to the person with dementia and use their name when possible
- Be patient when waiting for their responses to validate their feelings and help them form their thoughts into words
- Ask the person what they would like help with before automatically doing things for them
- Use gentle humor when and where it is appropriate

- Be understanding of feelings like frustration that commonly arise during this phase
- Ensure sensory aids such as glasses, contact lenses, and hearing aids are available and in working order before engaging the person
- Be mindful of a person's preferences for personal space
- Limit choices to make decisions easier and preserve independence

Patients with moderate dementia will likely need a bit more support in the way of communication:

- Limit distractions while someone is trying to communicate
- Speak slowly and clearly using familiar phrases, appropriate gestures, and visual cues
- Maintain eye contact
- Try to interpret what the person is saying based on context, but don't speak over them or prevent them from expressing themselves
- If they are getting agitated, step back and return to the topic later
- Use the person's name when communicating
- Be patient when waiting for their responses
- Ask one question at a time and stick to those that can be answered with "yes" or "no"
- Repeat phrases and questions as needed
- Don't disagree with delusional or fixed beliefs and thought patterns
- When engaging them in tasks, offer clear instructions provided one at a time
- Avoid using the word "don't" and instead ask them what you want them to do
- Ensure sensory aids such as glasses, contact lenses, and hearing aids are available and in working order before engaging the person
- Be mindful of a person's preferences for personal space

Caregivers and providers should use some of the following communication strategies with those who have late stage dementia:

- Approach someone from the front, identify yourself, and remain there when speaking to and interacting with them
- Request that the person use gestures to express themselves if they are struggling with words
- If they are getting agitated, step back and return to the topic later
- Use a variety of sensory cues (including appropriate touch, when indicated) to engage them
- Do your best to understand the feelings behind any difficult behaviors
- Avoid elderspeak or a patronizing tone of voice

Section 7 Personal Reflection

What caregiver training might be helpful for someone with dementia who wanders at night?

Section 8: Case Study #1

A 55-year-old woman was just diagnosed with frontotemporal dementia following brain damage that resulted from a car accident one year ago. Leading up to her diagnosis, she was working a full-time job as an administrative assistant and started displaying a lot of irritability at home. She has a 14-year-old son and a 17-year-old daughter who she cares for along with her husband. She was referred to occupational therapy due to increasing difficulty with home management.

1. What might be one of the first assessments an occupational therapist completes on this patient?

Section 9: Case Study #1 Review

This section will review the case studies that were previously presented in each section. Responses will guide the clinician through a discussion of potential answers as well as encourage reflection.

1. What might be one of the first assessments an occupational therapist completes on this patient?

   Since this patient is still working, it is appropriate for the occupational therapist to complete a standardized assessment focused on job performance such as the Worker Role Inventory. This patient might even benefit from a Functional Capacity Evaluation to determine if there are any physical or cognitive limitations present that prevent effective completion of job roles.

   Since the initial complaint was related to home management, the PASS is another good assessment. This will offer therapists a good view of the patient's engagement across all ADLs, IADLs, and functional mobility. Since the condition is frontotemporal dementia and it is considered early-onset, the patient will likely have a range of emotions related to coping and her performance skills. Therapists would also benefit from completing a person-centered assessment such as MOHO to focus on identifying the needs of the patient and her family.

Section 10: Case Study #2

A 75-year-old man living alone in a retirement community begins struggling with bathing and is withdrawing from his family members. His family contacted the doctor on his behalf and he politely declined to let this familiar provider in his home when he attempted to do a house visit. When confronted with the family member's concerns, the man denies any issues and begins to get agitated. The man is currently still driving and has high blood pressure, but otherwise has an unremarkable medical history.

1. From an OT's perspective, does it sound like this man might need an assessment to determine the presence of potential cognitive impairments?
2. What is the first assessment an OT should do to help this man?
3. What type of setting is most appropriate for this patient to get services?

Section 11: Case Study #2 Review

This section will review the case studies that were previously presented in each section. Responses will guide the clinician through a discussion of potential answers as well as encourage reflection.

1. From an OT's perspective, does it sound like this man might need an assessment to determine the presence of potential cognitive impairments?

   Yes, these are warning signs of cognitive changes and could be due to early stage dementia.

2. What is the first assessment an OT should do to help this man?

   The best initial assessment for this man is the ACL, which will indicate whether or not he is able to continue living on his own. Additional assessments that can be helpful are the AMPS to help determine if motor skills are playing a part in this man's difficulties. A driving safety assessment will also be helpful in knowing whether or not he can safely drive or needs to utilize other methods of transportation.

3. What type of setting is most appropriate for this patient to get services?

   From the information above, it sounds as if this man would be better served in an assisted living setting. That would allow him to receive support with ADLs such as bathing. He would also be able to benefit from transportation to and from appointments if it is determined he is unable to drive.

Section 12: Case Study #3

A 90-year-old woman who resides in her home recently fell. She currently has 15-20 hours of home care each week for grocery shopping, housekeeping, and to take her to appointments. This is given by a private caregiver and is paid for out of pocket by her family. She is independent in ADLs. She was hospitalized for 2 weeks following her fall, since she sustained a minor spinal fracture and briefly lost consciousness. She is now experiencing difficulty initiating and executing most self-care tasks, though her spinal fracture is considered medically healed.

1. How can the OT determine if this patient can safely return home?

2. What interventions would this patient benefit the most from?

Section 13: Case Study #3 Review

This section will review the case studies that were previously presented in each section. Responses will guide the clinician through a discussion of potential answers as well as encourage reflection.

1. How can the OT determine if this patient can safely return home?

   The OT should first complete a home assessment to determine if the patient can benefit from any environmental modifications that might help her achieve her prior level of functioning. The OT must also determine if there are major safety concerns that prevent the patient from continuing to live in her home alone. If it is within the family's ability to pay for more than 20 hours of care each week, that is a potential option. However, the OT must first complete a full assessment to determine if the patient has the physical ability to navigate the home independently with or without an assistive device.

2. What interventions would this patient benefit the most from?

   Since the patient was mostly independent before her injury, she would benefit from home modifications to prevent future falls. As a result of the recent brain injury, the patient is likely experiencing minor cognitive concerns so she will likely respond well to a visual schedule to help with ADL sequencing. Caregiver training will also be crucial to preserve remaining independence and be sure the patient is receiving just the right amount of help.

Section 14: Case Study #4

A 70-year-old woman who has been in an assisted living facility for 6 years has begun experiencing increased difficulty finding the dining hall each morning and night and getting back to her room after leaving for appointments. She lives with her husband who is on dialysis and has many physical health problems. She has family locally, but none are able to stop in and provide regular support for her. According to ALF staff, she needs more assistance with ADLs and struggles to request help when she needs it in the bathroom.

1. What might be the best living arrangements for this patient?
2. How might therapists be able to help this patient?

Section 15: Case Study #4 Review

This section will review the case studies that were previously presented in each section. Responses will guide the clinician through a discussion of potential answers as well as encourage reflection.

1. What might be the best living arrangements for this patient?

   Since this patient is already in an ALF, cannot navigate a familiar environment independently, and needs an increasing amount of support that she cannot obtain from family, a memory care unit is likely the safest option for her.

2. How might therapists be able to help this patient?

   Therapists can provide cognitive rehabilitation for this patient and address goals that are important to her, her husband, and her family. She is having difficulty expressing her needs, so her family can help with this part of the assessment and treatment plan formation. Therapists can also focus on preserving the relationship with her husband (identifying him, spending time with him during mutually enjoyable activities, and more) if she were to move to another care setting.

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