FL: ADRD for Specialized Alzheimer's Adult Daycare, Level One

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

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

Course Objectives

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

- Give 3 examples of normal changes in thinking that occur as we age.
- Describe 3 characteristics associated with dementia.
- Relate 3 ways in which dementia can affects general conversations.
- Relate the 3 components that should be part of individual and group activities for clients with dementia.
- Describe 3 ways in which stress can affect a caregiver's quality of life.
- Describe 3 issues family caregivers face as their loved one transitions from mild to moderate to severe dementia.
- Identify 3 common behavioral and psychological symptoms of dementia.
- Describe how mild, moderate, and severe dementia affects a person's ability to complete basic activities of daily living.
- Identify 3 philosophical concepts that are important in the design of a therapeutic environment for those with dementia.
- Identify common ethical conflicts that may arise when caring for clients with dementia.

Instructions for Mail Order

Once you've finished studying the course material:

1. Record your test answers on the answer sheet.
2. Complete the course evaluation.
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1. Understanding Alzheimer's Disease and Related Disorders

Although dementia has probably been around since humans first appeared on earth, it is only as we live longer that we have begun to see its widespread occurrence in older adults. The most common type of dementia is Alzheimer's disease, but there are other types and causes of dementia. In fact, new research is suggesting that "pure" pathologies may be rare and most people likely have a mix of more than one type of dementia.

Worldwide more than 50 million people live with dementia and because people are living longer this number is expected to triple by 2050 (ADI, 2019). In Florida, there are more than 500,000 residents currently living with Alzheimer's disease and by 2025, this number is expected to increase by more than 200,000.

For those of you working in adult daycare, it is very likely you will have contact with clients experiencing cognitive changes. Many will also have chronic conditions and recent hospitalizations. A major goal of adult daycare is to reduce the risk of hospitalizations and readmissions and manage chronic conditions among their participants (Caffrey and Lendon, 2019). Before getting into how the brain works and how it is affected by dementia, let's learn a little about adult daycare.

Adult Daycare

There are approximately 4,600 adult day service centers in the United States serving nearly 286,000 people (Caffrey and Lenden, 2019). Adult day service centers provide non-residential coordinated services in a community setting for less than a day. There are three types:

1. Social,
2. Medical/health, and
3. Specialized (providing programs for people with dementia) (Siegler et al., 2015)

> Adult daycare is a program of therapeutic social and health services as well as activities for adults who have functional impairments. Services are provided in a protective, non-institutional environment. Participants may utilize a variety of services offered during any part of a day, but for less than a 24-hour period.
>
> The social model is designed for individuals who need supervision and activities but not extensive personal care and medical monitoring. The medical model provides more extensive personal care, medical monitoring, and rehabilitative services in addition to structured and stimulating activities.
>
> O'Keefe et al., 2014

In Florida, there are approximately 351 adult daycare centers that provide therapeutic programs, social services, health services, and activities for adults in a non-institutional setting (AHCA, 2020). About one-third of adult daycare clients have Alzheimer's disease or a related disorder (Harris-Kojetin et al., 2016).

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

In general, adult daycare clients are younger and more racially and ethnically diverse than users of other long-term care services. More than one-third of adult daycare clients are non-white, about 17% are non-Hispanic black, and about 20% are Hispanic (Harris-Kojetin et al., 2016). Most (about 2/3) of adult daycare participants attend at least 3 days/week (Siegler et al., 2015) and most clients use transport services provided by the centers.

This course is for those of you who have direct contact with clients in a specialized adult daycare center. It discusses Alzheimer's disease and other common types of dementia from the perspective of both workers and clients. It includes information on how dementia affects the brain and how Alzheimer's disease differs from other types of dementia. It describes behaviors you will see in people with mild, moderate, and severe dementia and discusses communication issues at different stages of dementia.

The course includes with activities you can do with your daycare clients and provides information on how to assist with their activities of daily living. We also include information about family issues, caregiver stress, and share some innovative ideas about "therapeutic environments." We conclude with a discussion of ethical issues you may encounter.

2. How the Brain Works

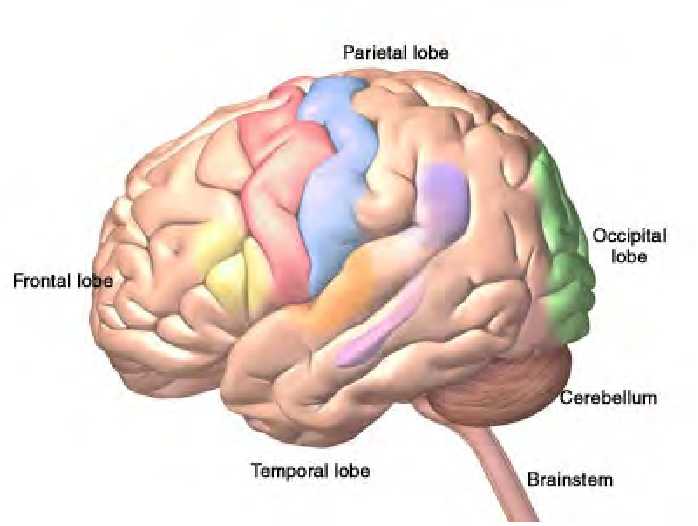
The brain is a communications center consisting of billions of neurons, or nerve cells. It is the most complex organ in the body. This three-pound mass of gray and white matter is at the center of all human activity—you need it to drive a car, to enjoy a meal, to breathe, to create an artistic masterpiece, and to enjoy everyday activities. The brain regulates your body's basic functions; it enables you to interpret and respond to everything you experience and shapes your thoughts, emotions, and behavior (NIDA, 2018).

Networks of neurons pass messages back and forth among different structures within the brain, the spinal cord, and the nerves in the rest of the body (the peripheral nervous system). These nerve networks coordinate and regulate everything we feel, think, and do (NIDA, 2018). Dementia interrupts the efficient function of these networks, affecting every aspect of a person's life.

Alzheimer's disease and other types of dementia damage the brain. The most significant and obvious damage occurs in the critically important part of the brain called the cerebrum. The cerebrum fills up most of our skull and is divided into four lobes:

1. **Frontal lobes**: reasoning, judgement, motor control, planning, decision-making
2. **Temporal lobes**: memory and emotion, hearing, language
3. **Parietal lobes**: sensation, touch, temperature, pressure, pain
4. **Occipital lobes**: visual processing, depth, distance, location of objects

The Human Brain



The four lobes of the cerebrum, plus the cerebellum and the brainstem. Alzheimer's disease starts in the hippocampus, located in the temporal lobe. ©Zygote Media Group, Inc. Used with permission.

The cerebrum allows us to think, form memories, communicate, make decisions, plan for the future, and act morally and ethically. It also controls our emotions, helps us make decisions, and helps us tell right from wrong. The cerebrum also controls our movements, vision, and hearing.

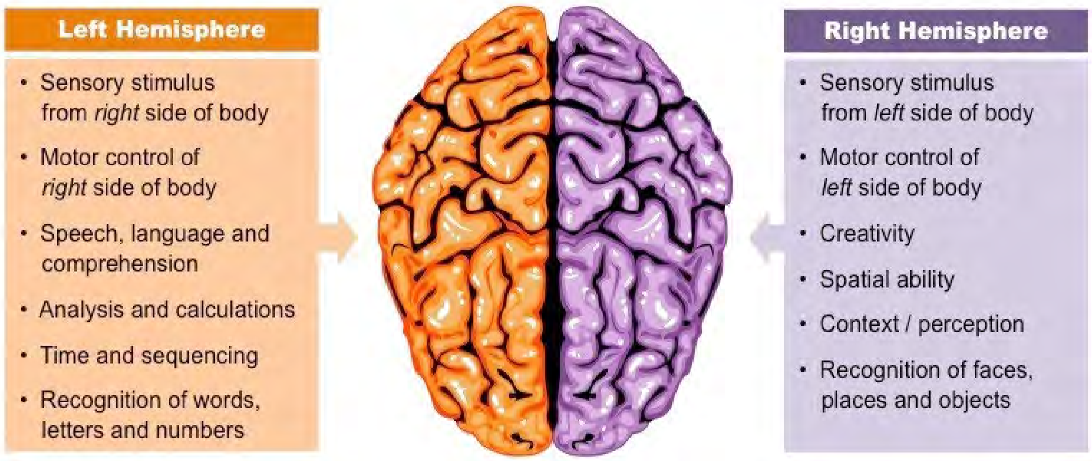
When dementia strikes, brain cells in the cerebrum begin to shrink and die. As the damage progresses, brain cells are no longer able to communicate with one another as well as they did in the past. Not surprisingly, as more and more brain cells are damaged, connections are lost, pathways are disrupted, and eventually people with dementia lose many brain functions.

Because the right and left sides of each lobe differ in function, the location of the deterioration is important to understand. For example, damage in the left frontal and temporal lobes can affect the so-called language centers, causing difficulties with speech and language comprehension, while damage to the right hemisphere can cause problems with spatial perception and identifying objects by touch.

The parietal lobes provide another example of the differences between the right and left sides of this part of the brain. Several portions of the parietal lobe are important to language and visuospatial processing; the left parietal lobe is involved in symbolic functions in language and mathematics, while the right parietal lobe is specialized to process images and interpretation of maps (i.e., spatial relationships) (Lumen Learning, n.d.).

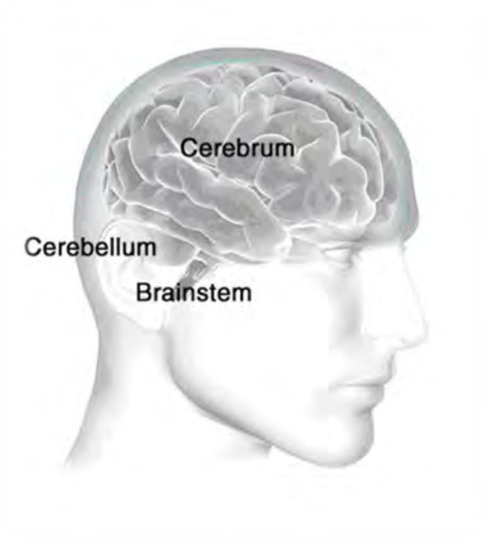
it is easy to exaggerate the differences between the functions of the left and right hemispheres; both hemispheres are involved with most processes. Additionally, neuroplasticity (the ability of a brain to adapt to experience) enables the brain to compensate for damage to one hemisphere by taking on extra functions in the other half, especially in young brains (Lumen Learning, n.d.).

Hemispheres of the Brain



Source: Cornell, B. 2016. BioNinja. Reprinted by permission.

In addition to the cerebrum, the human brain has two other important parts: the **cerebellum** and the **brainstem**. Touch the back part of your head just below the occipital lobes. The cerebellum is right there. It is involved with coordination and balance.



Three Main Sections of the Human Brain

Now move your hand a little down and stop before your get to your spine. The brainstem is right there—at the back of the head, above your spine. It connects the brain to the spinal cord. The brainstem oversees automatic functions such as breathing, digestion, heart rate, and blood pressure. Although it is possible for the brainstem and cerebellum to be damaged by stroke or traumatic injury, they are generally not affected by dementia.

The cerebellum and brainstem are at the back of your head below the cerebrum. Source: NIH. Used with permission

Defining Dementia

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

Alzheimer's disease is the most common type of dementia and is responsible for 60% to 80% of all cases. AD typically starts in an area of the brain called the hippocampus—the part of the brain responsible for new, short-term memories. The hippocampus is part of the brain's limbic system and is responsible for the formation of new memories, spatial memories and navigation, and is also involved with emotions.

Damage to the hippocampus can cause a person with dementia, particularly someone with Alzheimer's disease, to forget something that happened just a moment ago. Although most types of dementia start in one part of the brain, eventually the entire brain will be affected.

Alzheimer's disease isn't the only cause of dementia and, unfortunately, there is no way to know for sure what type of dementia a person has. Early diagnosis remains a key focus and goal of research.

Diagnosis of AD is most often based on a combination of medical history and detailed physical, neurologic, and neuropsychological exams. Brain imaging can be used but early preclinical dementia is difficult to diagnose accurately using these methods. In recent years, a number of soluble components in cerebrospinal fluid (CSF) and blood have been identified as potential, useful biomarkers* for AD (DeMarshall et al., 2019).

***Biomarkers**: A measurable substance that may indicate the presence of a particular biologic state, a clinical disease, an environmental exposure, or disease susceptibility.

Measuring biomarkers for brain diseases in blood is the focus of intense research although there are a number of challenges. Because of the blood-brain barrier, biomarkers are generally present at relatively low concentrations in blood taken from the brain. In addition, some biomarkers related to AD pathology are expressed in non-cerebral tissues, which may confound their measurement in the blood. Blood may also contain antibodies, which can give falsely high or low results. This is less of a problem in CSF because antibody levels in CSF are much lower. Finally, the biomarker of interest may be degraded by various substances in blood plasma (Zetterberg & Burnham, 2019).

Recently, a blood test has been developed that measures a specific variant of tau protein in an ordinary blood plasma sample. The test measures the presence of the P-tau181 variant, using a method called **Single Molecule Array** (Simoa). P-tau181 has long been measured in CSF and is seen in advanced positron emission tomography (PET) scans. But both of these methods are expensive and not universally available and therefore not practical in primary care settings (Gustafsson Kubista, 2020).

There is potential to use this blood test to identify Alzheimer's in its early stage when cognitive impairment is mild. This may provide primary care practitioners the ability to evaluate and treat people early in the disease rather than when symptoms are so obvious that they show up during cognitive testing.

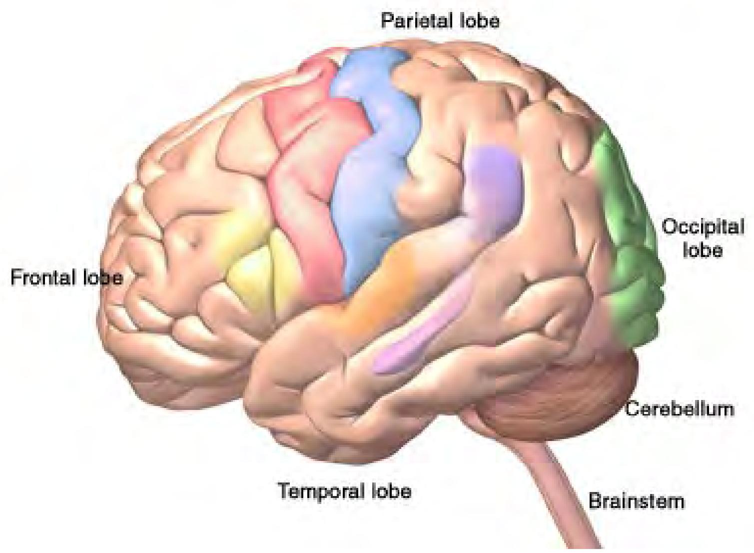
Symptoms differ little among the types of dementia. It is good to know the difference to help you understand why someone is acting the way they are. Characteristics of Alzheimer's dementia will be described in module 2.

Frontal-Temporal Dementia

Look at the picture of the brain below. Put your hand on your forehead. The part of your brain just behind your forehead is called the **frontal lobe**. Now slide your fingers from the front to the side of your head (your temple). This part of the brain is called the **temporal lobe**.

There is a type of dementia that affects this part of the brain. It is called **frontal-temporal dementia**. It is thought to be the most common type of dementia in people under the age of 60 and is responsible for 5% to 10% of all cases of dementia. It's not nearly as common as Alzheimer's and usually starts at a much younger age.

Lobes of the Brain



Damage to the brain's frontal and temporal lobes causes forms of dementia called frontotemporal disorders. ©Zygote Media Group, Inc. Used with permission.

We use the front part of our brain to make decisions, to tell right from wrong, to control our emotions, and to plan for the future. Someone with dementia in this part of the brain will have poor judgment and lose the ability to tell right from wrong. They also have less control over their behavior.

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

Frontal-temporal dementia is usually categorized under three subtypes:

- Behavior variant frontotemporal dementia (bvFTD)—changes in personality and behavior that can affect people in their early 50s and 60s. Affects judgement, empathy, foresight, and planning.
- Primary progressive aphasia (PPA)—usually begins before the age of 65. Affects language skills, reading, writing, and comprehension.
- Disturbances of motor function, muscle weakness or wasting, without behavioral or language problems. (Alzheimer's Association, 2020c)

Vascular Dementia

Vascular dementia is a general term used to describe changes in cognition resulting from impaired blood flow to the brain. It can be caused by a stroke or a series of small strokes or any condition that causes brain damage or reduces blood flow to the brain. Factors that increase the risk of heart disease such as diabetes, high blood pressure, high cholesterol, and smoking also increase the risk of developing vascular dementia. You might have cared for more than one client with vascular dementia because many older adults have high blood pressure that isn't under good control.

Vascular dementia is responsible for 20-30% of all cases of dementia. Generally, vascular dementia doesn't affect memory as much (or in the same way) as Alzheimer's, at least in its early stage. Symptoms are related to the part of the brain experiencing reduced blood flow.

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

Lewy Body Dementia (LBD)

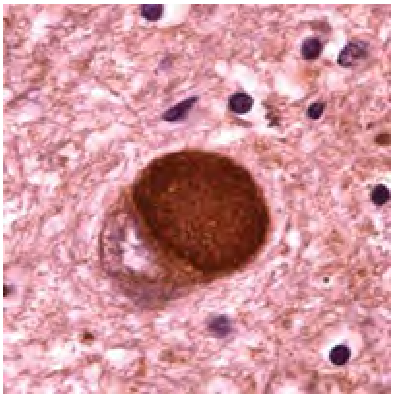
Lewy body dementia is a spectrum of disorders rather than a single diagnosis. LBD is less common than Alzheimer's dementia, but more common than frontal-temporal and vascular dementia.

There are two types of LBD: dementia with Lewy bodies and Parkinson's disease dementia, which share a common etiology. Symptoms are caused by the buildup of Lewy bodies—accumulated bits of alpha-synuclein protein—inside the nuclei of neurons in areas of the brain that control certain aspects of memory and motor control. These unwanted molecules (Lewy bodies) can become scattered throughout the brain. Symptoms can include:

- **Disturbances of movement** (slowness of movement, rigidity, shuffling gait, tremors, difficulties with balance)
- **Cognition decline** (fluctuations in concentration, alertness, and attention)
- **Behavioral changes** (mood fluctuation, depression, anxiety, apathy, hallucinations, delusions)
- **Sleep disturbances** (daytime sleepiness, restless leg syndrome, difficulties awakening, acting out dreams, falling out of bed)
- **Autonomic dysfunction** (constipation, urinary incontinence, sexual dysfunction, difficulty regulating blood pressure and temperature, low blood pressure)

In Parkinson's disease dementia, movement deficits are the first symptoms to appear. This can include festinating gait (shuffling), balance problems, muscle rigidity, resting tremors, bradykinesia (slow movement), and loss of facial expressiveness.

Lewy Body



In general, memory is less affected than in Alzheimer's disease, at least at first. But hallucinations, visuospatial changes, fluctuation in cognitive abilities, and sudden confusion can be present. These symptoms may come and go throughout the day.

Microscopic image of a Lewy body. Courtesy of Carol F. Lippa, MD, Drexel University College of Medicine. Source: Alzheimer's Disease Information and Referral Center

Dementias and Their Characteristics

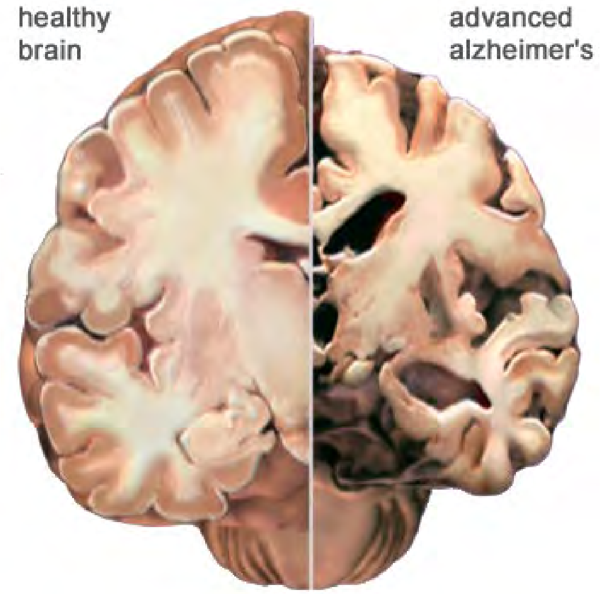
Type of dementia	**Characteristics and symptoms**
Alzheimer's disease (AD) 60%–80% of cases	Gradual onset, changes in mood, anxiety, and sleep Impaired memory, apathy and depression Language and visuospatial deficits Later stage: impaired judgment, confusion, major behavioral changes, neuropsychiatric symptoms Executive functions often impaired
Frontal-temporal dementia 5%–10% of cases, prevalence thought to be underestimated	Early onset (45 to 60 yrs of age) Behavioral and personality changes, loss of empathy Mood changes, disinhibition, inappropriate touching, loss of social decorum Language difficulties due to progressive aphasia Problems with spatial orientation No single pathology, considered a "family" of neurodegenerative disorders
Vascular dementia 20%–30% of cases	Stepwise onset, often preventable Similar to AD, but memory less affected, and mood fluctuations more prominent Physical frailty, patchy cognitive impairment Most common cause is related to cerebral small vessel disease Single infarcts in critical regions, or more diffuse multi-infarct disease Considered a "group" of syndromes

Dementia with Lewy bodies ~5%–10% of cases	Marked fluctuation in cognitive ability, executive and attentional deficits Rapid eye movement sleep behavioral disorder Visual hallucinations, significant visuospatial deficits Parkinsonism (tremor and rigidity) Adverse reactions to antipsychotic medications

How Dementia Affects the Brain

Dementia changes the entire brain. In Alzheimer's disease, nerve cells in the brain die and are replaced by abnormal proteins called plaques and tangles. As the nerve cells die, the brain gets smaller. Over time, the brain shrinks, affecting nearly all its functions.

Normal Brain Contrasted with AD Brain



A view of how Alzheimer's disease changes the whole brain. Left side: normal brain; right side, a brain damaged by advanced AD. Source: Courtesy of The Alzheimer's Association. Used with permission.

Alzheimer's disease usually affects memory and emotional control before other symptoms are obvious. Other types of dementia, because the damage is to another part of the brain, will have different symptoms. Although dementia can start in one part of the brain, eventually it will affect the entire brain.

Normal Age-Related Changes

We all experience physical and mental changes as we age. Some people become forgetful when they get older. They may forget where they left their keys. They may also take longer to do certain mental tasks. They may not think as quickly as they did when they were younger. These are called age-related changes. These changes are normal—they are not dementia.

Age-related changes don't affect a person's life very much. Someone with age-related changes can easily do everything in their daily lives—they can prepare their own meals, drive safely, go shopping, and use a computer. They understand when they are in danger and continue to have good judgment. They know how to take care of themselves. Even though they might not think or move as fast as when they were young, their thinking is normal—they do not have dementia.

The table below describes some of the differences between someone who is aging normally and someone who has dementia.

Differences between Normal Aging and Dementia

Normal aging	AD or other dementia
Occasionally loses keys	Cannot remember what a key does
May not remember names of people they meet	Cannot remember names of spouse and children—don't remember meeting new people
May get lost driving in a new city	Get lost in own home, forget where they live
Can use logic (for example, if it is dark outside it is night time)	Is not logical (if it is dark outside it could be morning or evening)
Dresses, bathes, feeds self	Cannot remember how to fasten a button, operate appliances, or cook meals
Participates in community activities such as driving, shopping, exercising, and traveling	Cannot independently participate in community activities, shop, or drive

In some older adults, memory problems are a little bit worse than normal age-related changes. When this happens, the person has **mild cognitive impairment**, also called **MCI**.

Mild cognitive impairment isn't dementia. A large percentage of people with MCI experience personality changes. They also have a little more difficulty than is normal with thinking and memory. For some people, mild cognitive impairment gets worse and develops into dementia, but this doesn't happen with everyone.

Video: Dementia 101 (5:49) Teepa Snow

https://www.youtube.com/watch?v=EpV83BVhXr4&feature=emb_logo

Diagnostic Guidelines

Diagnosis of Alzheimer's disease and other types of dementia is based on symptoms; no test or technique that can diagnose dementia. To guide clinicians, in 2011 the National Institute on Aging and the Alzheimer's Association (NIA-AA) published updated diagnostic guidelines, which are intended to provide a deeper understanding Alzheimer's disease than earlier guidelines. The 2011 guidelines:

- Recognize that Alzheimer's disease progresses on a spectrum with three stages: (1) an early, preclinical stage with no symptoms; (2) a middle stage of mild cognitive impairment; and (3) a final stage marked by symptoms of dementia. Cognitive decline is gradual and progressive.
- Expand the criteria for Alzheimer's dementia beyond memory loss as the first or only major symptom and recognize that other aspects of cognition, such as word-finding ability or judgment, may become impaired first. Other cognitive changes can include changes in:
  - Episodic memory
  - Executive functioning
  - Visuospatial abilities
  - Language functions
  - Personality and/or behavior
- Reflect a better understanding of the distinctions and associations between Alzheimer's and non-Alzheimer's dementias, as well as between Alzheimer's and disorders that may influence its development, such as vascular disease, delirium, or stroke.
- Recognize the potential use of biomarkers—indicators of underlying brain disease—to diagnose Alzheimer's disease. However, the guidelines state that biomarkers are almost exclusively to be used in research rather than in a clinical setting. (National Institute on Aging, 2020)

Since the publication of the 2011 guidelines, researchers have increasingly come to

- Understand that cognitive decline in AD occurs continuously over a long period, and that
- Progression of biomarker measures* is also a continuous process that begins before
- Symptoms are evident. The disease is now regarded as a continuum rather than three distinct clinically defined stages. (Jack et al., 2018)

*β amyloid deposition, pathologic tau, and neurodegeneration neuronal injury.

A 2018 update of the 2011 NIA–AA diagnostic guidelines added a "numerical clinical staging scheme." This staging scheme reflects the sequential evolution of AD from an initial stage characterized by the appearance of abnormal biomarkers in asymptomatic individuals. As biomarker abnormalities progress, the earliest subtle symptoms become detectable. Further progression of biomarker abnormalities is accompanied by progressive worsening of cognitive symptoms, culminating in dementia (Jack et al., 2018).

The numerical clinical staging scheme is as follows:

1. Performance within expected range on objective cognitive tests
2. Normal performance within expected range on objective cognitive tests. (Transitional cognitive decline: Decline in previous level of cognitive function, which may involve any cognitive domains
3. Performance in the impaired/abnormal range on objective cognitive tests
4. Mild dementia
5. Moderate dementia
6. Severe dementia (Jack et al., 2018)

In 2018 an Alzheimer's Association workgroup lead by Alireza Atri published a report describing the need for clinical practice guidelines for use in primary and specialty care settings. The guidelines build on the NIA_AA guidelines but add a clinical component for the evaluation of cognitive impairment thought to be related to Alzheimer's disease or a related type of dementia. Key components include:

- All middle-aged or older individuals who self-report or whose care partner or clinician report cognitive, behavioral or functional changes should undergo a timely evaluation.
- Concerns should not be dismissed as "normal aging" without a proper assessment.
- Evaluation should involve not only the patient and clinician but, almost always, also involve a care partner (e.g., family member or confidant). (Atri, 2018)

3. Characteristics of Alzheimer's Disease and Related Dementias

Each type of dementia has its own set of characteristics. A **characteristic** is a feature or quality you would typically expect to see in a disease. One characteristic of frontal-temporal dementia is that it starts at an earlier age than Alzheimer's.

One of the first things you will notice in someone with Alzheimer's disease is that they have trouble making new memories. This is called **short-term memory loss**. This happens because the part of the brain that forms new memories (the hippocampus) is damaged by dementia. You may also notice that long-ago memories are still intact—this is because the areas of the brain that store long-term memories are not as affected by Alzheimer's dementia. Especially at first, people can remember and talk about events from earlier times in their lives. As the dementia progresses and more parts of the brain are affected, long-term memories may also start to fade.

Stages of Alzheimer's Disease and Other Types of Dementia

One way to describe the progression of Alzheimer's disease, as well as other types of dementia, is in stages. **Stages** are usually described as mild, moderate, and severe or early, middle, and late. Even though disease progression differs from person to person, we nevertheless associate certain symptoms and behaviors with these stages. The type of dementia, along with a person's underlying medical condition, general health, family support, and co-morbid conditions can affect how fast and how far the dementia progresses from one stage to another.

Although this course will discuss the stages of dementia as mild, moderate, or severe, the National Institute on Aging and the Alzheimer's Association have published guidelines aimed at improving current diagnosis, strengthening autopsy reporting of Alzheimer's brain changes, and promoting research into the earlier detection of Alzheimer's disease. The guidelines describe three stages of Alzheimer's disease: (1) preclinical Alzheimer's disease, (2) mild cognitive impairment, and (3) Alzheimer's dementia.

1. **Preclinical Alzheimer's disease**: the stage in which changes have begun to appear in the brain but no cognitive or emotional symptoms are present.
2. **Mild cognitive impairment (MCI):** characterized by a decline in cognitive function that falls between the changes associated with typical aging and changes associated with dementia.
3. **Dementia phase**: a period in which symptoms become more obvious and independent living becomes more difficult (Alzheimer's Association, 2020a)

Mild Dementia

In the early, mild stage of Alzheimer's disease, plaques and tangles begin to damage the temporal lobes in and around the hippocampus. The hippocampus is part of the brain's limbic system and is responsible for the formation of new memories, spatial memories, and navigation—and is also involved with emotions.

Brain Changes in Mild Dementia

At this stage, changes that have been developing over many years begin to affect memory, decision-making, and complex planning. A person with mild dementia can still perform all or most activities of daily living such as shopping, cooking, yard work, dressing, bathing, and reading but will likely begin to need help with complex tasks such as balancing a checkbook and planning for the future.

In the early stages of AD, before symptoms can be detected, plaques and tangles form in and around the hippocampus, an area of the brain responsible for the formation of new memories (shaded in blue). Source: The Alzheimer's Association. Used with permission.

Neuroimaging tests, which show changes in brain volume and amyloid levels, indicate that the areas or the brain associated with events that occurred in the last few minutes are the first to show signs of deterioration. Brain regions associated with memories of the distant past decline at a later stage of the disease, but more rapidly.

Moderate Dementia

As Alzheimer's disease progresses from the mild to moderate stage, plaques and tangles spread forward to the areas of the brain involved with language, judgment, and learning. Speaking and understanding speech, spatial awareness, and executive functions such as planning, judgment, and ethical thinking are affected. Many people are first diagnosed with Alzheimer's disease in this stage.

In the moderate or middle stage, work and social life become more difficult and confusion increases. Damage spreads to the areas of the brain involved with:

- Speaking and understanding speech
- Logical thinking
- Safety awareness

Brain Changes in Moderate Dementia

In mild to moderate stages, plaques and tangles (shaded in blue) spread from the hippocampus forward to the frontal lobes. Source: The Alzheimer's Association. Used with permission.

Severe Dementia

In the advanced or severe stage of Alzheimer's disease, damage is spread throughout the brain. At this stage, because so many areas of the brain are affected, people's ability to communicate, to recognize family and loved ones, and to care for themselves is severely affected.

Brain Changes in Severe Dementia

People with severe dementia lose memory of recent events although they may still remember events from long ago. They are easily confused, are unable to make decisions, cannot clearly communicate their needs, and can no longer think logically. Speech, communication, and judgment are severely affected. Sleep disturbances and emotional outbursts are very common.

In advanced Alzheimer's, plaques and tangles (shaded in blue) have spread throughout the cerebral cortex. Source: The Alzheimer's Association. Used with permission.

Stages of Other Types of Dementia

Although generally dementia gets worse over time, other types of dementia can progress differently from Alzheimer's disease. Because **vascular dementia** is caused by a stroke or series of small strokes, dementia may worsen suddenly and then stay steady for a long period of time. If the underlying cardiovascular causes are successfully addressed, dementia may stabilize.

In **Lewy body dementia**, which is often associated with Parkinson's disease, symptoms—including cognitive abilities—can fluctuate drastically, even throughout the course of a day. Nevertheless, the dementia is progressive and worsens over time. In the later stages, progression is similar to that of Alzheimer's disease.

In **frontal-temporal dementia**, which often starts at an earlier age than Alzheimer's disease, symptoms nevertheless progress over time. In the early stages, people may have difficulty with just one type of symptom, such as planning, prioritizing, or multitasking. Other symptoms appear (inappropriate behaviors and comments, difficulty recognizing and responding to emotions) as more parts of the brain are affected.

Recall that there are three subtypes of frontal-temporal dementia: (1) behavior and personality changes, (2) speech and language impairment, (3) movement disorders.

Behavioral and personality changes can be mild at first, then become more extreme, leading to a progressive loss of judgement, loss of interest in normal activities, inappropriate social behaviors, and a decline in personal hygiene.

Speech and language impairment can involve increasing difficulty understanding and using written and spoken language.

Movement disorders, although rarer than the other subtypes, can include tremors, rigidity, muscle spasms, lack of coordination, and muscle weakness and wasting. These changes are progressive, becoming more pronounced as the dementia worsens.

In frontal-temporal dementia, the lobe of the brain that is affected determines which symptoms first appear. If the disease starts in the part of the frontal lobe responsible for decision-making, then the first symptom might involve difficulty managing finances. If it begins in the part of the temporal lobe that connects emotions to objects, then the first symptom might be an inability to recognize potentially dangerous objects; for example, a person may not fear reaching for a rattle snake or plunging a hand into boiling water (NIH, 2019).

Symptoms and Behavior Changes by Stages

A symptom is a change in the body or the mind. A behavior is how we act, move, and react to our environment. Symptoms change as dementia progresses often affecting behavior. For some people, symptoms can worsen quickly. For others, symptoms progress more gradually—over 10 to 20 years. A good way to understand this is to look at how symptoms and behaviors change in the early, middle, and late stages of dementia.

Symptoms and Behaviors in Mild Dementia

The early or mild stage of dementia begins with mild forgetfulness, especially memories of recent events. Forgetfulness might be the most obvious symptom at this stage, especially in Alzheimer's disease. Logical thinking and judgment are mildly affected, especially in frontal-temporal dementia.

In the early stage of Alzheimer's disease, as well as in other types of dementia, there might be a little confusion with complex, multi-step tasks. People naturally try to cover up mild confusion so friends, coworkers, and family may not notice that something is wrong. This behavior can be tiring, frustrating, and concerning for the person experiencing the first signs of cognitive change.

Even when symptoms are mild, people's behavior can begin to change, especially in Alzheimer's disease. People with mild dementia often know something is wrong, which can cause depression, stress, and anxiety. Mood changes are common, particularly in someone with vascular dementia.

People struggling with the effects of mild dementia may become angry or aggressive. They might have difficulty making decisions. They will ask for help more often. They still might be able to work, drive, and live independently, but they will begin to need more help from family or coworkers.

Symptoms and Behaviors in Moderate Dementia

In the moderate stage of dementia, people become more forgetful and confusion worsens. Speech and communication are obviously affected. Judgment and logical thinking are much worse than in the early or mild stage.

Because of memory problems and confusion, caregivers must take over tasks that the person with dementia was able to do in the past. In this stage, travel, work, and keeping track of personal finances are much more difficult.

In the moderate stage, behavior changes are more obvious. Inappropriate behaviors such as cursing, kicking, hitting, and biting are not uncommon. Some people may begin to repeat questions over and over, call out, or demand your attention. Sleep problems, anxiety, agitation, and suspicion can develop.

A person with moderate dementia is usually still able to walk. This is because the part of the brain that controls movement is not affected. If a person can still walk or if they can get around easily in a wheelchair, they **might begin to wander**. More direct monitoring is needed than during the early stage of dementia. During this stage, people are no longer safe on their own. Caregiver responsibilities increase. This causes stress, anxiety, and worry among family members and caregivers.

Symptoms and Behavior in Severe Dementia

> My mom is 96 years old and has pretty severe dementia. She lives at home with 24/7 care. If we put her in a nursing home, she would not survive. Loud noises, people that don't know her needs and habits, boredom, loneliness—those things would drive her crazy. I'm sure she'd wander, yell, swear, shout, hit, and cry. At home she almost never does any of these things, but we work pretty hard to keep things quiet, warm, and steady for her.
>
> Family Caregiver, Ft. Lauderdale, Florida

People with severe dementia lose most or all memory of recent events although they may still remember events from long ago. They are easily confused, lose much of their ability to think logically and sequentially, and find decision-making very difficult. Speech, communication, and judgment are severely affected. Sleep disturbances are very common.

All sorts of challenging behaviors can occur in people with severe dementia—especially if caregivers are untrained, easily frustrated, or highly stressed. Wandering, rummaging, or hoarding can occur. A person may become paranoid or have delusions or hallucinations. Screaming, swearing, crying, shouting, loud demands for attention, negative remarks to others, and self-talk are common. These outbursts are often triggered by frustration, boredom, loneliness, depression, cold or heat, loud noises, and pain.

In the severe stage, a great deal of independence has been lost and around-the-clock care may be needed. Caregivers will likely need to oversee and directly assist with eating, bathing, walking, dressing, and other daily living activities.

Symptoms and Behavior at the End of Life

As people with dementia approach the end of life, they may lose all memory—not just memory of recent events. They are startled by loud noises and quick movements. They can no longer communicate their needs and desires using speech. At this stage, people can develop other illnesses and infections. They may experience agitation, psychosis,* delirium,** restlessness, and depression.

***Psychosis**: loss of contact with reality.

****Delirium**: a sudden, severe confusion that can be caused by infections, a reaction to medications, surgery, or illness.

At the end of life, people are completely dependent on caregivers. They may be unable to eat, swallow fluids, or move without help. Dementia becomes so severe that people may be bedridden. Severe dementia frequently causes complications such as immobility, swallowing disorders, and malnutrition that significantly increase the risk of acute conditions that can lead to death. One such condition is pneumonia, which is the most commonly identified cause of death among older adults who have Alzheimer's or other dementias (Alzheimer's Association, 2017).

Challenges for Caregivers at Each Stage

> I've been hired to help care for a woman with mild dementia. She has five kids who come to their mother to discuss their personal problems. When they talk about their problems, I notice the mom always agrees with them but when they leave, she turns around and says, "I can't stand to hear all their complaints."
>
> She gets really agitated after they visit. Sometimes she sits and cries for the rest of the day and I can't snap her out of it. She didn't used to be like this. I get so tired it almost isn't worth it—I never get any sleep when I'm there. I finally had to cut back from 7 to 4 days. It was really difficult caring for this woman.
>
> Professional Caregiver, Miami, Florida

A caregiver is someone who provides assistance to a person in need. Care can be physical, financial, or emotional. Each year nearly 16 million family members and friends provide over 18 *billion* hours of unpaid care to those with Alzheimer's and other dementias (Alzheimer's Association, 2020b).

Caregivers help with basic activities such as bathing, dressing, walking, and cooking. They also help with more complex tasks such as managing medications and taking care of the home. Caregiver's can provide direct care or manage care from a distance. Dementia caregiving is usually the responsibility of the spouse or an adult child.

Caring for aging adults with dementia is associated with increases in burden, distress, and declines in mental health and well-being. Caregiving for individuals with dementia is more stressful than caregiving for individuals with many other diseases. This is because dementia caregiving is characterized by specific problems such as the lack of free time, isolation from others, behavioral problems and personality changes, and fewer positive experiences resulting from the lack of expressed gratitude by the care recipient (Elnasseh et al., 2016).

The responsibilities of caregiving can be overwhelming. More than half of Alzheimer's and dementia caregivers rate the emotional stress of caregiving as high or very high. About 40% of caregivers report symptoms of depression. One in five cut back on their own doctor visits because of their care responsibilities. And, among caregivers, 3 out of 4 report they are "somewhat" to "very" concerned about maintaining their own health since becoming a caregiver (Alzheimer's Association, 2020b).

Family dynamics are an important part of the caregiving experience. Family communication, adaptability/flexibility, and marital cohesion have all been connected to the emotional functioning of caregivers. Depression and anxiety are more likely to occur among caregivers in families with poor functioning, and conflicted family dynamics can intensify caregiver depression and caregiver strain. The poor functioning of families is likely to result in a decrease in the time spent on patient care, potentially impacting the quality of care the individual with dementia receives (Elnasseh et al., 2016).

Conversely, healthier family dynamics, such as family support, are associated with lower levels of caregiver strain. When families increase their support to primary caregivers, it often results in helping the individual with dementia. Caregivers experience less burden and depression when family cohesion is high; also, greater family communication plays an important role in reducing caregiver burden (Elnasseh et al., 2016).

Even though the majority of research has focused on burden and other negative aspects of family caregiving, positive aspects have been presented, including a sense of meaning, a sense of self-efficacy, satisfaction, a feeling of accomplishment, and improved wellbeing and quality of relationships. These positive experiences can help sustain family members in their work as caregivers (Tretteteig et al., 2017).

In the early stage of dementia, family caregivers may not know much about dementia and may not seek help. They may be confused and frustrated when their family member "acts funny."

During this time, caregiving responsibilities and duties can usually be handled by family members. The person with dementia may only need help with complex activities such as banking, bill paying, medical appointments, and medications. People with mild dementia may still live alone, drive, and even have a job. They can usually handle activities of daily living such as bathing, eating, and cooking.

In the moderate stage, the time needed to care for a previously independent person increases. It can cause anxiety, stress, sleep disruption, anger, and depression. Loss of free time, work conflicts, and family issues may seem impossible to resolve. Often the responsibility of caregiving falls mostly on one person—generally a woman—leading to anger and frustration with other family members.

In the later stages of dementia, when fulltime care is needed, family members face difficult decisions and primary caregivers often become overburdened. Should the person with dementia move in with a family member? Should a full-time caregiver be hired? Should their loved one be admitted to a long-term care facility?

Behaviors such as agitation, irritability, obscene language, tantrums, and yelling are embarrassing, tiring, and frustrating for caregivers. Caregivers may be injured if a person throws things, strikes out, or bites. Caregivers may react out of fear and strike back or yell to stop these behaviors, creating guilt and more frustration.

> I'm exhausted. I can't sleep because I have to watch out for my wife. She wanders around the house, takes out all kinds of stuff from the kitchen. I never know what she's going to do.
>
> Family Caregiver, West Palm Beach, Florida, 2020

In this stage, safety is a challenge for caregivers. A one-on-one caregiver may be needed during the day. Spouses and family members become exhausted tending to a person who needs constant supervision. Jobs, hobbies, friendships, travel, and exercise fall to the side. Caregivers often neglect their own health, causing more stress.

If the person with dementia is still living at home, caregivers try to provide more support. Family members may find it impossible to continue to provide care and may decide to move their loved one to an assisted living or skilled nursing facility. Although this reduces caregiver burden, it does not relieve spouses and family members of the stress of continuing to worry about and manage care for their loved one.

4. Communicating with Clients with Alzheimer's Disease

> My mom struggles for words—she tries to explain something by saying "you know—that thing" and then gets frustrated when I don't understand. When I read the newspaper to her, the articles get jumbled up in her head and she doesn't know when one article ends and another starts. So, I just read short articles, Miss Manners, that sort of thing. I tell her "that's the end of the article about former President Obama—this is a new article about the weather on the east coast."
>
> Caregiver, Pensacola, Florida, 2020

How Dementia Affects Communication

Think about the last conversation you had with a friend or family member. You said what you wanted to say. You understood the conversation and remember what was said. You probably had the conversation while doing something else—fixing breakfast or getting ready for work. You had no trouble understanding the conversation even if there was a lot of noise in the background.

When communicating with a person who has dementia, there are several things to keep in mind. What is the level of the person's dementia? Is there a hearing loss? What is the setting? Are you having a general, social conversation or do you have a specific goal or task in mind?

A person with dementia has to work harder than you do to say what they want to say. They might not remember what was said a few moments ago and they have trouble talking and doing something else at the same time. Background noise can be confusing and irritating.

General Conversations

General conversations are friendly and informal. They are not usually related to a specific task or goal. General conversations are social, a way to greet people and find out how they are doing. You can begin a general conversation by offering a greeting and asking for an opinion or giving an opinion. You can make a suggestion or ask for an explanation.

A general conversation can be about yourself, about your workday, your hobbies, or your family. It can include positive comments about people you work with or other family members or caregivers. If there is another person nearby you can include that person in the conversation.

You can connect with people by learning about what they liked when they were younger. What music was popular? Who was president? What major events happened in their younger years? Did they serve in the military? Where did they work? Where did they travel? What were their interests and hobbies?

People with dementia—especially moderate or severe dementia—may have difficulty with general conversations. They have difficulty understanding complex questions or statements. For example, instead of stringing together several thoughts or statements it is better to break down your greetings, statements, or questions into short, simple sentences. Listen carefully and use your judgment to determine if the person understood you. Although they may not remember what you talked about yesterday they still want to hear what you have to say, even if you are repeating something said earlier.

Conversations Related to a Task or Goal

Dementia affects goal-directed conversations just as much as it affects general conversations. When you want to complete a specific task, use what is called a "closed question." This shows interest and invites a person to respond. Ask, for example, "Are you hungry?" or "Are you ready to get dressed?" Closed questions limit the conversation and keep the conversation focused on the task at hand.

Talk slowly and don't argue. Use gentle persuasion and be positive when giving directions. Share your goals with the resident. Be respectful and relaxed. Keep in mind that the person you are caring for may not share your goal or agree with what you are asking. Or they may not understand what you want. It is very common for caregivers to mistake a response for understanding. At times, we all fake our understanding of a conversation—even those of us without dementia. The following story featuring Randy and Ann illustrates this point. Think about what you would do in this situation.

Randy in the Morning

Randy has moderate dementia. He lives at home with 24-hour care and participates in an adult daycare program each week on Monday, Wednesday, and Friday. This morning, Randy arrived a little early and is waiting for breakfast in the activities room.

Source: HealthyPeople.gov. Public domain.

Ann, a homecare aide, enters his room and calls out to him, "Come on Randy. Are you hungry? Did you sleep well? Time for breakfast! Stand up. Let's go." Randy doesn't move, so Ann tries again, "Come on, Randy, get up! You don't want your breakfast to get cold, do you? I don't think so. Come on Randy, I'm really busy!" Ann takes his arm and helps him stand up. Randy pulls away and sits back in his chair.

What Is Randy Thinking?

Randy is comfortable and a little sleepy. He's not sure what time of day it is. He isn't hungry. A young woman he doesn't know is saying something to him in a loud voice. He is trying to figure out what she is saying—when she says something else. Her voice is loud and he grimaces a little. He is not sure what she wants. She grabs his arm and he supposes he should go with her but she is being too pushy and this makes him mad. So he pulls away from the young woman and turns away. He tries to ignore her, hoping she will go away.

What Is Ann Thinking?

Ann is really busy. Her co-worker called in sick so she was asked to cover at the last minute despite having just completed a night shift at the local nursing home. She is tired and wants to get Randy to the dining room for breakfast. After breakfast she wants Randy to go back to the activities room. She tells him it's time for breakfast, takes his arm, and tries to help him stand up. Randy seems confused and he pulls away. Ann repeats what she had just said, only more loudly. She reaches for him again but he turns away, crosses his arms, and refuses to budge.

What Could Ann Have Done?

Ann should approach Randy quietly and respectfully. She should ask "Good morning Randy", and wait for Randy's reply. Approaching Randy more slowly, squatting next to him, introducing herself, and offering her upturned hand gives Randy a chance to understand who she is. A pause at the end of each sentence gives Randy time to respond. "Hi, Randy." Pause. "I'm Ann—I'll be helping you today." Pause. "How are you?" Pause. "It's 9 a.m." Pause. "Time for breakfast." Pause. If Randy doesn't respond, Ann can repeat what she just said in a calm voice or ask another short, closed question: "Randy, would you like to join me for breakfast?" Pause. Now Randy only has one simple statement to think about and he is more likely to understand and respond. Ann must remember that Randy doesn't have to do what she asks. It's okay for Randy to have his breakfast in the activities room or even skip breakfast and eat when he is hungry.

Strategies and Guidelines for Verbal Communication

Verbal communication is communication with words. It is an important part of daily life. Verbal communication creates positive relationships and lets us know that someone cares. It allows us to express our feelings and gives us the opportunity to assess the well-being of the person we are caring for.

A conversation with a person with dementia begins with eye contact and an introduction. Starting with something light and conversational such as the weather or what's happening in the news puts people at ease. Nonverbal gestures such as head nods, a light touch on the arm, and a warm expression create trust.

No matter how severe the dementia, practice these habits:

- Approach from the front, then kneel down to the side.
- Take a deep breath, relax, and offer your hand.
- Take a moment to really look at the person.
- Greet the person using their name, then introduce yourself.
- Avoid standing over the person, which may appear threatening.
- Ask a short, 1- or 2-step question and wait for a reply.
- Be attentive and sympathetic.
- Continue the conversation by asking a followup question.

Improving Nonverbal Communication

Nonverbal communication is communication without words. Facial expressions, eye movements, hand gestures, body language, and movements of the arms and legs are examples of nonverbal communication. Tone of voice and how well you listen and pay attention are nonverbal skills that matter just as much verbal conversation.

How you dress, your posture, how you approach a person with dementia and how close you stand to a person are also examples of nonverbal communication. Even silence is a form of nonverbal communication.

Touch is a powerful form of nonverbal communication. Touch can be friendly, frightening, soothing, dominant, or supportive. Touch has different meanings depending upon your culture, gender, age, and situation.

The way you speak carries nonverbal information. Your tone can reveal calmness or impatience, affection or disapproval, confidence or fear. When you are talking, the loudness of your voice and its tone and rhythm are communicating additional information. If you are hurried, frustrated, or angry, a person will pick up on your mood and body language more quickly than your verbal communication.

How the environment looks is a form of nonverbal communication. A clean, nicely decorated room with good lighting is supportive. It encourages people to interact. A drab room with harsh lighting and little decoration has the opposite effect—it shows a lack of support and respect. Some studies have shown that people say they don't like other people when they see them in unattractive rooms.

Nonverbal communication using hand gestures and unhurried movement reinforces your words. If the person does not answer right away, be patient and wait a bit. It's okay to be silent, which is calming and reassuring—especially in social conversations.

Communicating When a Person Is Unresponsive

People in the late stage of dementia may become unresponsive. This means they do not respond to what is happening around them. It does not mean they have no response—only that they can no longer communicate their wishes clearly using speech.

Communicating with a person who is unresponsive can be a challenge for family and caregivers. It's difficult to know what the person is thinking or feeling. Fortunately, many of the techniques that work in the earlier stages of dementia are useful in this stage as well.

Assume that the person can hear and possibly understand even if they don't respond. Use gestures and facial expressions to support what you're trying to say. Give the person time to understand why you are there. Practice a calm, slow, and respectful attitude. You can communicate concern and caring by using pillows for neck, arm, and leg support, a warm blanket, and gentle repositioning. Mild range-of-motion exercises, gentle touching, and massage are reassuring.

Therapeutic touch can be a form of therapy and can include massage, therapeutic touch, reflexology, shiatsu, acupressure, and other hands-on techniques. Therapeutic touch can be used to decrease behavioral symptoms of dementia, specifically restlessness and vocalization (Oliveira et al., 2015).

Touch must always be applied appropriately* and ethically, providing support and reassurance with the goal of decreasing pain or discomfort, calming anxiety, or relieving depression. As with other interventions, clients have the right to refuse care, including massage and touch.

***Appropriate touch** refers to professional and ethical behavior while considering the individual's religious, cultural, and personal preferences.

Massage and appropriate touch are nonverbal types of communication that can reduce depression, anxiety, and aggression. Expressive, emotional touch as opposed to instrumental/task–associated touch such as patting or holding a client's hand can be used to calm a client or to show concern (O'Neil et al., 2011).

A systematic review that examined therapeutic touch interventions among other treatments for dementia identified a small study that found that an expressive touch intervention that involved 5.5 minutes a day of touching, including 2.5 minutes a day of gentle massage and 3 minutes a day of intermittent touching with someone talking, over a 10-day period decreased disturbed behavior from baseline immediately and for 5 days after the intervention (O'Neil et al., 2011).

Therapeutic Touch

Source: National Institute on Aging. Public domain.

Even though a person is unresponsive, culture and language must be respected. Organizations that encourage a person-centered approach to care encourages you to learn as much as possible about a client's beliefs and values. Additional suggestions for improving communication with a person who is unresponsive:

- Link staff and clients from the same background
- Avoid assumptions and judgements
- Offer support for non-English speakers
- Recognize when a person's preferences change (SCIE, 2015)

A person who is unresponsive has no direct way to tell you when a sound is annoying or if the environment is not peaceful. Sounds that you can ignore or tolerate may be unbearable to a person with dementia. Because of this, it is important to reduce discomfort and confusion by reducing noise.

Practice these habits for unresponsive and responsive clients:

- Approach in a calm and relaxed manner.
- Slow your own movements.
- Re-introduce yourself at each encounter.
- Address the person by a preferred name or title.
- Use short, simple sentences.
- Use hand gestures and light touch to communicate your intentions.
- Avoid a condescending tone.

5. Activities for Clients with Alzheimer's

Everyone finds enjoyment engaging in activities they have enjoyed all their lives. An artist or musician may want to continue to paint or play an instrument. A carpenter or contractor might enjoy an activity board with nuts, bolts, screws. Enjoyment depends on the level of dementia, personal interests, and the person's physical abilities.

A number of studies have suggested that carefully designed activities can have a positive effect on depression, confusion, and challenging behaviors (Ruthirakuhan et al., 2012). Structuring a program to include activities in the following three categories can positively influence cognition, general functioning, and overall quality of life:

- **Physical activity**—aerobic exercises (walking, swimming, and cycling) and non-aerobic exercises (strength and resistance training, flexibility and balance exercises)
- **Intellectual stimulation**—cognitive hobbies (reading, word puzzles, and card games) and cognitive training (computer training games, memory and attention games)
- **Social interaction**—participation in group-related activities, such as mealtime conversations, support groups, or other forms of social engagement (Ruthirakuhan et al., 2012)

The Montessori-based Activities for Person with Dementia has had some notable successes in the design of activity programs for people with dementia. This approach emphasizes matching a person's abilities with the activity. It borrows from the concept of having older children teach younger children by setting up programs in which people with mild dementia serve as group activity leaders for those with advanced dementia. This provides an older adult with the opportunity to give as well as receive care.

Montessori-based activities promote engagement in learning by sequencing tasks from simple to complex, providing cues to successful completion, encouraging repetition, and carefully matching demands to individuals' interests and levels of competence (van der Ploeg et al., 2012).

Montessori-type programs include detailed interviews with family caregivers about the person's former interests and skills coupled with assessments of cognitive, language, and motor skills. A range of activities are then presented, tested, and refined. As dementia advances, the activities are simplified. Facilitators present tasks deliberately, demonstrating them first, and using language as appropriate. The main objective is to engage participants' interest and involvement (van der Ploeg et al., 2012).

Individual Activities

Individual activities involve a caregiver or family member and the person with dementia. Activities that stimulate the senses, such as cooking, singing, exercise, going for a drive, gardening, and aromatherapy, are encouraged at all stages of dementia. Taking care of an animal gives a sense of purpose and companionship and is a key component of person-centered care.

Some eldercare organizations, such as the Eden Alternative, encourage pets in their facilities. Pets provide companionship, promotes relationships, and provides meaningful activity and exercise.

Successful activity programs for individuals with dementia are based on a person's likes and interests. This means a caregiver must learn a person's history and understand their capabilities and preferences. Determine whether a person can still read, write, or use a computer. Learn about the person's lifestyle and determine what a person is physically capable of doing.

Adults often have a fear of failure (especially those aware of their cognitive decline) and may refuse to participate in activities because of this fear. Be consistent, have fun, and by all means introduce new activities. Look for signs of frustration and agitation and address these behaviors immediately.

Individual Activities for People Who Have Dementia

Activity	**Mild**	**Moderate**	**Severe**
Word games	Word searches, crossword puzzles Card/computer games	Simple word searches, simple crossword puzzles Simple computer games	Discuss a simple topic Listen to others
Letter writing	Write a letter Send email, use Facebook	Dictate a letter or email Use Facebook with help	Listen to a letter or email being read
Art/Music	Take photos Create a photo album Draw, play an instrument	Take photos Maintain a photo album Draw, sing along with others	View photos Listen to music Sing along to familiar songs
Woodworking	Use tools Plan and complete projects with assistance	Use simple tools with supervision Assist with projects	Use activity board with bolts, screws Watch projects

Activity	**Mild**	**Moderate**	**Severe**
Sewing	Use sewing machine with help Plan and complete projects with help	Use simple tools with supervision Assist with projects	Use sewing cards, activity blankets or aprons with buttons, snaps, ties, Velcro, and zippers, watch projects
Gardening	Garden in raised beds Help plan the garden and harvest	Perform specific tasks with supervision Eat food grown in garden	Sit in garden, eat food grown in garden Participate as able
Crafts	Knitting or crochet using large needles	Choose colors, roll balls of yarn	Choose colors, use the items that are created
At home activities	Help with laundry, put clothes away, assist with housekeeping	Sort and fold laundry	Fold laundry—may want to fold the same items repeatedly
Shopping	Go along to store, help with purchasing decisions Help put groceries away	Go along to store, help as able with shopping decisions Help put food away	Go along to store, sit in car with supervision or shop with wheelchair or electric cart

Group Activities

Many people with Alzheimer's disease sense that their cognitive impairment isolates them from other people. This leads to anxiety, depression, societal withdrawal, and decreased self-confidence. Encouraging social interaction helps those with dementia regain a sense of self-worth and have a better attitude toward life. This may improve eating and exercise habits and social interactions, which in turn may result in improved AD prognosis (Ruthirakuhan et al., 2012).

People in the early stages of dementia may especially enjoy working with others. As dementia progresses, the person may be more likely to enjoy solitary activities. Small groups of 5 to 6 people are generally preferred because they allow more activity and personal attention, although well-planned large-group activities can also be successful.

Group Activities for People Who Have Dementia

Activity	**Mild**	**Moderate**	**Severe**
Karaoke	Sing while reading words	Sing familiar songs	Listen and sing along
Cooking	Bake cookies, prepare a snack plate for others, clean up after cooking	Participate in making cookies, assist with cleaning up	Help decorate cookies that are already baked, eat the cookies
Nature	Nature walks, outings to nature areas, fruit picking	Shorter walks Picnicking outdoors	Escorted walk or wheelchair outside the facility, attend picnic
Crafts	Make ornaments Decorate room or facility for holidays	Participate in making ornaments Assist with decorating for the holidays	Participate in crafts Participate in decorating parties
Outings	Shopping, eat out Theater and music events, museum visits, library visits, attend sporting events	Same as mild with some adaptation and more supervision.	Set up a store where the resident can purchase items Watch movies, outings with direct supervision

Whatever the stage of the dementia, everyone appreciates meaningful activities. We like helping one another, teaching someone a new skill, and contributing to the success of an activity. Caregivers often make the mistake of doing everything for the person they are caring for, stripping them of any meaningful way to contribute, to help, to learn, and to grow as a person. Remember that everyone yearns for meaning in their lives. A good activity program can help accomplish that goal.

6. Stress Management for the Caregiver

> Caregiving is the provision of extraordinary care, exceeding the bounds of what is normative or usual in family relationships. It typically involves a significant expenditure of time, energy, and money over potentially long periods of time; it involves tasks that may be unpleasant and uncomfortable and are psychologically stressful and physically exhausting.
>
> Richard Schulz and Lynn Martire

A **caregiver** is someone who provides assistance to a person in need, which can be physical, financial, or emotional in nature. Caregivers help with basic activities of daily living such as bathing, dressing, walking, and cooking, and with more complex tasks such as medication and home management. A caregiver may provide direct care or manage care from a distance and can be a family member, a neighbor, a friend, or a medical professional.

Caregiving is an evolving process with key transition phases. The onset of caring tends to emerge naturally from the customary family transactions that existed before the onset of dementia. Needs for care tend to increase over time, from increased support for household, financial, and social activities, to personal care, to what for some is almost constant supervision and surveillance. Important transitions include the involvement of professional caregivers, institutionalization, and bereavement (ADI, 2013).

Whether paid or unpaid, most caregivers across most (if not all) cultures are women. Women are already likely to be relatively disadvantaged with respect to education, career opportunities, income, assets and (in older age) pension entitlements. Taking on caring responsibilities for a person with dementia can lead to social isolation, cutting back or stopping work, and risks to physical and mental health (ADI, 2015).

Causes of Stress for the Caregiver

Providing care for a person with dementia places practical, psychological, and emotional stress on caregivers, which can lead to denial, anger, and depression. Caregivers overwhelmed by the demands of caring for someone with dementia can experience irritability, anxiety, and sleep disturbances. Many studies have documented a higher prevalence of depressive symptoms among caregivers, with the highest prevalence among those caring for someone with dementia (ADI, 2013).

The economic impact of caregiving is an additional stressor for caregivers. In an analysis of survey data conducted by the Organization for Economic Co-operation and Development (OECD) of caregivers of older people (not dementia caregivers specifically) a 1% increase in hours of care was associated with a reduction in the employment rate of caregivers by around 10% (ADI, 2013).

In a survey of American caregivers conducted by the Alzheimer's Association, 13% had to go from working full- to part-time, 11% had to take a less demanding job, and 11% had to give up work entirely. Cutting back or giving up on work is associated with higher caregiver strain, while strain was reduced by hiring a paid caregiver, or having additional informal support (ADI, 2013).

The amount of stress experienced by caregivers is associated with caregiver demographics, personality, and their perception of their role as a caregiver, their coping strategies, and relationships they have outside of their caregiving role.

Factors and Characteristics Associated with Caregiver Strain

Factors	Characteristics associated with caregiver strain
Demography	Female caregiver Spousal caregivers, particularly those of younger people with dementia Living with the care recipient, low incomes or financial strain
Caregiver personality	High level of neuroticism, high expressed emotion
Perception and experience of caregiving role	A low sense of confidence by the caregiver in their role High "role captivity"—caregivers feeling trapped in their role
Coping strategies	Emotion-based or confrontive coping strategies Type and severity of dementia Behavioral issues such as apathy, irritability, anxiety, depression, delusions
Relationship factors	Intimacy—poor relationship quality, ow levels of past and current intimacy

Source: Adapted with permission from ADI, 2016.

Strategies for Managing Caregiver Stress

Reducing caregiver strain is possible when the caregiver receives education, training, support, and respite. These four components have been shown to decrease caregiver stress and reduce or delay the transition from home to a care facility (ADI, 2013). Caregivers can also reduce their stress by paying attention to their own health. This means getting enough sleep, eating properly, seeing their own doctors, and sharing their feelings about their caregiving duties with co-workers, family, and friends.

Adult daycare centers offer respite and support services and can provide relief for family caregivers, reduce caregiver burden, and increase caregiver motivation. A primary goal is to develop knowledge and skills in dementia care and prevent early institutional placement (Tretteteig et al., 2017). Adult daycare centers:

- Provide separation time, giving family caregivers time that can be used for undisturbed work, rest, or other pursuits.
- Reduce behavioral problems and the need for assistance with ADLs, although research on these effects is largely anecdotal.
- Reduce care demands, stress, and depression as well as increase wellbeing.
- Increase motivation for care and postponement of residential placement by offering information and support about dementia-related topics (Tretteteig et al., 2017).

Addressing Caregiver Stress

Reducing caregiver stress	Things to avoid
• Join a support group or see a counselor to discuss your feelings. • Set limits on caregiving time and responsibility. • Become an educated caregiver. • Discuss your situation with your employer. • Accept changes as they occur. • Make legal and financial plans. • Take regular breaks (respite). • Seek out daycare services.	• Don't isolate yourself. • Don't try to be all things to all people. • Don't expect to have all the answers. • Don't deny your own fears about dementia and aging.

7. Family Issues

Throughout the world, the family is the cornerstone of care for older people who have lost the capacity for independent living. In many developed countries, the vital caring role of families and their need for support is often overlooked. In developing countries, the reliability and universality of the family care system is often overestimated (ADI, 2013).

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. The need for personal care assistance among this population creates a tremendous burden on family and society. Currently, about half of people who need help with personal care have dementia (ADI, 2013).

The system of informal unpaid care provided by family members is under 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).

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

Family Issues by Stages

The majority of people with dementia live in the community, and for approximately 75% of these individuals, care is provided by family and friends. The largest proportion of caregivers is 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). Caring for a person with dementia is time-consuming and, on average, caregivers spend 14 hours per week assisting with basic ADLs and up to 43 hours per week when more complex assistance and supervision are needed (ADI, 2013).

In the Early Stage

In the early stage of dementia, family members must begin to adjust their own behaviors and manage their own frustrations as they learn about the early effects of dementia. They are often unaware of available dementia-care services and may find their family member's primary care physician of little help. Spouses who care for a person with dementia may not be in good health themselves and may worry about not being able to provide good care as the dementia progresses. An adult child may have to take over care of the parent and assume a new role in the family.

Nevertheless, caregiver burden is usually manageable in the early stages of dementia. Direct care is generally not needed, and caregivers can often leave their family member alone for periods of time.

Early, specialized training is recommended. This is an essential but often neglected component of dementia care. Training can prepare family caregivers for what lies ahead and allow them to partner more easily with healthcare providers to provide competent and compassionate care.

In the Middle Stages

As the dementia progresses from the mild to moderate stage, caregivers begin to invest more time, energy, and money, often involving tiring tasks leading to high levels of burnout. Depression, along with symptoms of burnout, poor self-rated health, highly perceived stress, and lower levels of life satisfaction are factors that begin to affect the caregiver's health. At this stage, perhaps due to a lack of time, family caregivers are also less likely to engage in preventive health behaviors.

The increased need to handle practical tasks can be a physical burden for family caregivers, especially those in poor health. Many of these caregivers do all the cooking and cleaning and take care of the laundry (Tretteteig et al., 2017). As the need for help increases, family members must decide whether to hire a private caregiver, which can be costly.

At this stage, family caregivers' cumulative stress is associated with increased nursing home placement, institutionalization, or hospitalization of the patient with dementia. Thus, caring for a patient with dementia can undermine the health and well-being of both the patient and the caregiver (Lykens et al., 2014).

In the Late Stages

In the late stages, as people lose the ability to communicate clearly, family caregivers will struggle to find new ways to understand the needs of their loved ones. Caregivers must learn to interpret facial expressions for sadness, anger, or frustration, and physical gestures such as grasping at undergarments, which may communicate the need to use the bathroom.

One of the most difficult issues—usually in the middle to late stages of dementia—is the decision to place a family member in residential care or skilled nursing. There are a number of reasons cited by caregivers for placement:

- Need for skilled care
- Family caregivers' health
- Patient's dementia-related behaviors
- Need for assistance

Relinquishing full-time care can cause feelings of loss, sadness, resignation, and depression for family caregivers. Paradoxically, placement of a loved one in a care facility may do little to alleviate the stress that caregivers experience.

Once a family member has moved to a care facility, family caregivers must learn to navigate a complicated healthcare system. Healthcare workers can support family members by determining the preferences, abilities, and resources of each family member. Regular face-to-face meetings with family members and facility staff will help families work through difficult conflicts.

The Grief Process

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

Grief can manifest itself in 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.

Losses for the person with dementia include:

- 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

Losses for family members and caregivers include:

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

Supportive interventions to address grief should include counseling, assessment of co-morbid conditions, information about dementia, caregiver training, and development of a care plan. If there is a need to move to a care home, this causes grief and loss for the person with dementia and for caregivers. People with dementia newly admitted to an institution are often disoriented and feel 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. 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.

When a spouse dies, about 28% of surviving spouses experience major depression. 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).

Family, Clients, and Dementia Care

When the person enters long-term care, family interactions and communication tend to be reduced. This is particularly the case 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 people with dementia feeling socially isolated and unable to express their needs (Moyle et al., 2104).,

One way to improve this situation 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, individual needs of clients. The quality and success of a dementia care program is strongly influenced by facility's environment, philosophy of care, available services, and staff experience and training.

A 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 clients 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 clients remain oriented to their environment, electronic door security for safety, comfortable and familiar furniture, specialized foods and beverages, and regular personalized group and individual activities.

The effectiveness or even the existence of a good dementia care program is affected by a number of issues. Inequalities in care exist in rural communities, where access to memory care specialists and caregiver support group is limited.

Belonging to an ethnic minority group can lead to inequalities in diagnosis and care access in dementia. People from black and minority ethnic groups often experience delays in receiving a diagnosis, which leads to inequalities in accessing post-diagnostic care, including anti-dementia medication (Giebel, 2020).

Caregiver Training and Support

> Providers who care for residents with dementia need to be specifically "dementia-trained" because of the unique challenge this group presents. Training should include knowledge of disease trajectory, symptoms, approaches to care, goals of care, palliative care measures, end of life issues, signs of impending death for persons with dementia, and how to interact with residents and families.
>
> Tilly and Fok, 2007

The responsibilities of caregiving can be overwhelming, especially for spouses, family members, and friends. If spouses (and even adult children) are in poor health, they may be unable to take on the burdens of fulltime caregiving. Even trained healthcare providers can find it difficult to deal with a demented patient day in and day out.

To be successful, caregivers must be able to differentiate dementia from other illnesses and understand how to manage difficult behaviors should they arise. Healthcare providers must be able to take a deep breath, slow down, listen, and find effective ways to communicate.

For both professional and family caregivers, training and education are critical. Training introduces caregivers to resources, support, and equipment to improve health and safety. Education reduces psychological and physical strain while delaying or avoiding transition into care homes (ADI, 2015).

Culture has an impact on the family caregiving experience. In research involving feedback from 35 caregivers representing four groups (African American, Asian American, Hispanic American, and European American) there were significant differences in the cultural values that shaped the caregiver experience. Caregiving was seen as “right and correct” by all of the focus groups. However, for some of the groups, caregiving was an expected part of life that was passed down from generation to generation. In fact, caregiving was so embedded in the life experience for some of the groups that the decision to care or not to care was irrelevant; caregiving was just something that was done without question (Pharr et al., 2014).

To provide care for one’s family or community was deeply rooted in the culture, arising “naturally” without conscious thought. This perspective was shared by Asian American, Hispanic American, and African American focus group participants who reported seeing many examples of caregiving, not just within their own families but throughout their communities. In fact, it was so culturally ingrained to care for family that, when the time came, care was provided without question. For Asian Americans, caregiving was described as just a normal thing to do (Pharr et al., 2014).

Local resources for these and other services can be found in Module 13.

8. Behavior Management

The onset of dementia and its gradual progression inevitably leads to changes in personality and behavior. Geriatrics specialists refer to these changes as behavioral and psychological symptoms of dementia (BPSD) or neuropsychiatric symptoms of dementia (NSP). It is estimated that up to 90% of dementia patients will eventually experience challenging behaviors associated with their dementia (Passmore, 2013).

The exact cause of Alzheimer’s disease and other types of dementia is still unknown. In Alzheimer’s disease, and likely in other forms of dementia, damage within the brain is related to a so-called pathologic triad: (1) formation of beta-amyloid plaques; (2) disruption of a protein called tau, leading to the formation of neurofibrillary tangles; and (3) degeneration of cerebral neurons (Lobello et al., 2012).

But these pathologies explain only a part of the cognitive decline in older adults and a large part of the cognitive impairment in late life remains unexplained (White et al., 2017). Approximately a third of Alzheimer’s dementia cases may be attributed to seven potentially modifiable risk factors: diabetes, midlife hypertension and obesity, smoking, depression, cognitive inactivity, and low educational attainment (Killin et al., 2016).

Genetics likely plays a role in the development of some types of dementia, especially early-onset Alzheimer's disease. Early-onset Alzheimer's disease occurs between a person's thirties and mid-sixties and represents less than 10 percent of all people with Alzheimer's. Some cases are caused by an inherited change in 1 of 3 genes, resulting in a type known as early-onset familial Alzheimer's disease, or FAD. For other cases of early-onset Alzheimer's, research suggests there may be a genetic component related to factors other than these three genes (ADEAR, 2019).

In all, more than twenty types of dementia have been identified and symptoms are a little different in each type. Knowing the differences will help you understand why someone with dementia is acting the way they are.

Challenging Behaviors and Dementia

Challenging behaviors increase demands on staff and can increase job-related stress, burnout, and staff turnover. For clients with dementia who are experiencing behavioral and psychological symptoms of dementia, the cost of care is three times higher than that of other nursing home clients. About 30% of these costs are related to the management of disruptive behaviors (Ahn & Horgas, 2013).

Changes in personality and behavior can range from disinterest and apathy to agitation, disinhibition,* and restlessness. Behavioral interventions can be used along with medications to create a structured, safe, low-stress environment that promotes regular sleep and good eating habits, minimizes unexpected changes, and employs redirection and distraction (DeFina et al., 2013).

***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.

Conditions other than dementia can affect cognition, causing dementia-like symptoms; some of these conditions are reversible with appropriate treatment (NINDS, 2017):

- Side effects of medications or medication interactions
- Metabolic and endocrine abnormalities
- Nutritional deficiencies, especially of vitamin B1 (thiamine)
- Some chronic infections around the brain
- Constipation
- Head injuries and subdural hematomas
- Poisoning from exposure to lead, heavy metals, or other poisonous substances
- Alcohol, prescription medications, and recreational drugs
- Brain tumors, space-occupying lesions, and hydrocephalus
- Hypoxia or anoxia (not enough oxygen)
- Autoimmune cognitive syndromes
- Epilepsy
- Sleep apnea

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

Delirium is a syndrome with an acute onset and a fluctuating course. It develops over hours or days and is temporary and reversible. The most common causes of delirium are related to medication side effects, hypo or hyperglycemia (too much or too little blood sugar), fecal impactions, urinary retention, urinary tract infections, electrolyte disorders and dehydration, infection, stress, metabolic changes, an unfamiliar environment, injury, or severe pain.

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

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

Symptoms of depression can include:

- Persistent sad, anxious, or "empty" mood
- Feelings of hopelessness, guilt, worthlessness, or helplessness
- Irritability, restlessness, or having trouble sitting still
- Loss of interest in once pleasurable activities, including sex
- Decreased energy or fatigue
- Moving or talking more slowly
- Difficulty concentrating, remembering, making decisions
- Difficulty sleeping, early-morning awakening, or oversleeping
- Eating more or less than usual, usually with unplanned weight gain or loss
- Thoughts of death or suicide, or suicide attempts
- Aches or pains, headaches, cramps, or digestive problems without a clear physical cause and/or that do not ease with treatment
- Frequent crying (NIA, 2017)

Agitation and Aggression and Its Causes

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 is characterized by 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 and includes:

- Verbal insults
- Shouting, screaming, obscene language
- Hitting, punching, kicking, pushing, throwing objects
- Sexual aggression (DCRC, 2014)

Agitation and aggression occur in about 50% to 80% of nursing home residents with cognitive impairments (Ahn & Horgas, 2013). Aggressive behaviors occur in both men and women, but overt aggression is more common in men. A person with physical or functional impairment may express their frustration with agitation, vocal outbursts, or loud complaints.

Agitated and aggressive behaviors are almost always related to loss of control, physical discomfort, need for attention, feelings of humiliation, misunderstanding, or fear. People may become agitated or aggressive if they feel threatened or feel their personal space is being invaded. This is a common reaction with personal care tasks that require close contact, such as bathing or toileting.

Aggression may have a physiologic basis; it may be related to a decrease in the activity of serotonin* or to 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 positively 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).

*__Serotonin:__ a neurotransmitter found throughout the body, helps to regulate mood, appetite, digestion, sleep, memory, and sexual desire. There is thought to be a link between serotonin and depression.

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

Wandering and Its Causes

At some point during the course of their disease, people with dementia may wander or try to leave their home or facility without a companion—a behavior often called exit-seeking. Although there are no reliable estimates of the percentage of people who do this, more than half of people with dementia may wander at some point during the course of their disease. Wandering is a safety concern and one of the more challenging dementia-related behaviors for family and paid caregivers (Tilly, 2015).

Wandering can include aimless locomotion with a repetitive pattern, hyperactivity, and excessive walking, as well as leaving a safe environment and becoming lost alone in the community. Wandering can be goal-directed, in which a person tries to reach an unobtainable goal, or non-goal-directed, in which a person wanders aimlessly.

Wandering patterns can include moving to a specific location, lapping or circling along a path or track, pacing back and forth, or wandering at random. 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).

Those 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 persons with dementia. Those with frontal-temporal dementia have a greater tendency to pacing and lapping behaviors whereas those with AD are more inclined to wander at random. 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 likely related to boredom, pain, discomfort, disorientation, and memory problems. People may wander out of habit or because they think something 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 wandering. Studies have indicated that people with certain characteristics are more likely than others to wander:

- People with an active physical and mental interest in music
- People with an extroverted personality showing warmth, positive emotion, altruism
- People who were very involved with social activities and 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)

Rummaging and Hoarding and Its Causes

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 and clients.

Hoarding can be due to fear of losing money or possessions, lack of control, the need to "save for a rainy day," or simply out of confusion. Hoarding is associated with insecurity and anger and may be an attempt to hold onto possessions and memories from the past.

Cognitive changes such as memory loss, poor judgment, and confusion can contribute to the impulse to rummage and hoard. People may rummage out of boredom or to find 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. Confusion can lead to rummaging through another person's belongings, which can be particularly frustrating for other clients.

Psychosis and Its Causes

Psychosis is a disturbance in the perception or appreciation of objective reality (Burns et al., 2012). Symptoms can include delusions, hallucinations, and paranoia, among others. 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 be triggered by health factors such as urinary tract infections or environmental factors such as poor lighting or sensory overload. 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.

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 the person is receiving should be carefully reviewed. This includes prescription and over-the-counter medications, as well as herbal supplements.

Delirium vs. Psychosis

It may be difficult to distinguish delirium from psychosis, but it is important to understand the difference. Delirium (also called acute confusion) is a sudden, severe confusion with rapid changes in brain function and a fluctuating course. Delirium develops over hours or days and is temporary and reversible. Delirium can be caused by urinary tract infections or other simple infections, low sodium, constipation, dehydration, and a number of other underlying medical causes. It is important to review vital signs and check for these causes before concluding that a behavioral change is caused by psychosis.

Causes of Sleep Disturbances

Many older adults with dementia have sleep and circadian rhythm disturbances due to advanced age, the effects of certain chronic illnesses and medications, declining brain health, diminished mobility, and other causes. The American Geriatrics Society and the National Institute on Aging recognize a geriatric syndrome in which physical and mental risk factors overlap to increase risk for sleep and circadian disturbances. Numerous negative consequences are associated with sleep disturbances, including increases in cognitive decline, metabolic disease, high blood pressure, cardiovascular disease mortality, frailty, impaired quality of life, and hypersensitivity to pain (Capezuti et al., 2018).

Sleep disturbances can 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.

Sleep disruption can have the following features:

- Increased sleep latency
- Fragmented sleep and increased early-morning awakenings
- Decreased total sleep time, decreased sleep efficiency
- Decreased slow-wave and rapid-eye-movement (REM) sleep
- Nocturnal confusion
- Increased daytime napping and daytime sleepiness
- Agitation, verbally disruptive behaviors, hallucinations, and nighttime wandering (Burns et al., 2012)

In AD, and likely in other neurodegenerative diseases, sleep disorders appear early and worsen as the disease progresses. Their progression in the late stage of the disease is a strong predictive factor for mortality (Brzecka et al., 2018).

Sleep disturbances and accompanying symptoms often lead providers to prescribe psychoactive medications, including hypnotics. About half of nursing home residents with dementia are prescribed sedative-hypnotics, especially when displaying anxiety and agitation. However, many of these medications have been associated with an increased risk of falls and fractures in older adults (Capezuti et al., 2018).

Disordered sleep is also an issue for family caregivers. Providing home-based care to people with dementia can significantly affect the sleep of family members, and therefore their health and ability to cope with the emotional and physical demands of caregiving, all to the detriment of their continued ability to maintain the person with dementia at home. Support for caregivers is now understood as key for preventing institutionalization (Brown et al., 2014).

Healthcare providers, service organizations, and care providers lack awareness regarding disordered sleep and sleep interventions for both people with dementia and for their sleep-deprived caregivers. Although nonpharmacological sleep interventions are effective for improving restorative sleep among older persons, the inaccurate belief is pervasive that reduced hours of sleep and decreased ability to sleep well in old age are "normal" aspects of aging. This mistaken belief, coupled with the reluctance of people with dementia and their families to seek help for sleep issues, contributes to the under-diagnosis and under-treatment of disordered sleep in this growing population (Brown et al., 2014).

Adult daycare services can have a positive effect on sleep patterns. In a Norwegian study, caregivers reported that attending adult daycare helped readjust the sleep patterns of the person with dementia: more activity during the day led to better sleep at night, which also meant better sleep for the caregiver (Tretteteig et al., 2017).

The Problem-Solving Approach

> My mom has dementia and my sister and I take turns staying with her at her home. She used to get really agitated and angry in the evening—we blamed this on her dementia. We finally figured out that she gets cold—even when it's warm outside. She doesn't tell us, but if we ask, she'll say "I'm freezing." Once we realized this, we ordered special heated slippers and also got her an electric blanket. It sounds simple but it took us a long time to figure it out because she doesn't complain. Now she's rarely agitated or angry in the evening!
>
> Family Caregiver, West Palm Beach, Florida

The **problem-solving approach** encourages caregivers to look for the root cause of a behavior and treat it—usually with environmental modification, medication management, and caregiver training. The problem-solving approach allows caregivers and healthcare workers to identify critical points for intervention based on observing the antecedent, behavior, and consequence (A, B, C) of a challenging behavior.

- **A**ntecedent—what precipitated or caused the behavior?
- **B**ehavior—what is the behavior?
- **C**onsequence—what are the consequences of the behavior?

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

Dementia-care mapping (DCM) is a problem-solving approach based on the idea that many of the ills that people with dementia experience are due to negative environmental influences, including staff attitudes and care practices (van de Ven et al., 2014).

Dementia-care mapping consists of three components: (1) systematic observation, (2) feedback to the staff, and (3) action plans. The action plans are developed by the nursing staff and are based on the observation of the actual needs of the clients. This method allows for initiation of interventions at the individual level and the group level, as well as at the levels of management and organization. In short, dementia-care mapping is an approach aimed at implementing diverse interventions to improve the quality and effectiveness of care (van de Ven et al., 2014).

Dealing with Challenging Behaviors

Among many challenging behaviors associated with Alzheimer's disease and related dementias, three stand out: aggressive behaviors, agitated behaviors, and wandering. Other challenging behaviors will arise, especially in the later stages. Rummaging and hoarding, delusions and hallucinations (psychoses), and sleep disturbances will be discussed here. This is by no means an exhaustive list and other challenging behaviors are sure to arise.

In general, challenging behaviors are best managed through the use of multidisciplinary, individualized, and multifaceted care, including psychosocial interventions and short-term pharmacologic treatment only when necessary (Burns et al., 2012). Before deciding on a course of action, a risk assessment, comprehensive assessment, and a determination of reversible cause or factors should be completed.

Management of Agitation and Aggression

To understand and prevent agitation and aggression, consider the antecedent: What precipitated the behavior? Carefully observe the person and try to determine the cause of the agitation. Look for patterns. You can use one of the following scales to assess aggressive behaviors:

- Rating scale for Aggressive behavior in the Elderly (RAGE)
- Overt Aggression Scale (OAS)
- The physically aggressive subscale of the Cohen-Mansfield Agitation Inventory (CMAI)
- Agitation/aggression subscale of the Neuropsychiatric Inventory (NPI)
- Aggression subscale of the NPI-Clinician (Burns et al., 2012)

For agitated behaviors, a number of instruments can be used to assess the different aspects of agitation:

- Cohen-Mansfield Agitation Inventory
- Pittsburgh Agitation Scale
- Agitation/aggression and aberrant motor behavior subscales of the Neuropsychiatric Inventory
- NPI-Clinician
- Brief Agitation Rating Scale (Burns et al., 2012)

Psychosocial and environmental interventions can be of help in reducing or eliminating agitated or aggressive behaviors. Touch, 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, and Montessori activities, and individualized, person-centered care based on psychosocial management are 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).

Management of Wandering

Wandering can be a beneficial activity if there are safe places to wander, in and around a facility. An assessment of the reasons for wandering should include 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 residents' rooms, or eloping from the facility. Wandering can be addressed by:

- Redirecting to a purposeful activity
- Providing safe, looping wandering paths with interesting rest areas
- Providing regular exercise
- Engaging the 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 have been shown to discourage a wanderer from exiting a building.

For people who wander away from their home or care facility, Florida maintains a Silver Alert program for cognitively impaired older adults who become lost while driving or walking. The Silver Alert program broadcasts information to the public so they can assist in the rescue of the endangered person and notify law enforcement with helpful information. For more information, contact the Silver Alert information line, local law enforcement, or the Florida Department of Law Enforcement either online or by phone at 888 356 4774.

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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).

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 the person can pick through. Restricting all rummaging and hoarding can be frustrating for a person who enjoys these activities.

In a home setting (and even in a healthcare setting), 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

Management of Psychosis

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

Observe the behavior and listen 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?" "What will make you feel comfortable?"

When communicating with someone who is expressing paranoia or delusions, realize that even if their complaint is not true, it is very 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.

To manage hallucinations, the first step is to decrease auditory and visual stimuli. The second step is 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. Atypical antipsychotics have largely replaced typical or traditional antipsychotics as the main treatment for psychosis, hallucinations, and delusions in those with dementia (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

Management of Sleep Disturbances

Before treating sleep disturbances, look for potentially treatable causes, which can include 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
- Exercise during the day
- Individualized social activities
- Restriction or elimination of caffeine, nicotine, and alcohol
- Calm atmosphere
- Biofeedback (Deschenes & McCurry, 2009)

Alternatives to Physical and Chemical Restraints

The Omnibus Budget Reconciliation Act of 1987 (OBRA 87) established a resident's right to be free of physical or chemical restraints in nursing homes when used for the purpose of discipline or convenience and when not required to treat the resident's medical symptoms. Uncooperativeness, restlessness, wandering, or unsociability are not sufficient reasons to justify the use of a restraint (GovTrack, 2020).

Use of restraints should be:

- Reserved for documented indications
- Time limited
- Frequently re-evaluated for their indications, effectiveness, and side effects in each patient (GovTrack, 2020)

Florida Nursing Home Bill of Rights

In most states the use of physical and chemical restraints on nursing home patients is illegal. In Florida, the Nursing Home Bill of Rights states that a nursing home resident has

> . . . the right to be free from mental and physical abuse, corporal punishment, extended involuntary seclusion, and from physical and chemical restraints, except those restraints authorized in writing by a physician for a specified and limited period of time or as are necessitated by an emergency. In case of an emergency, restraint may be applied only by a qualified licensed nurse who shall set forth in writing the circumstances requiring the use of restraint, and, in the case of use of a chemical restraint, a physician shall be consulted immediately thereafter. Restraints may not be used in lieu of staff supervision or merely for staff convenience, for punishment, or for reasons other than resident protection or safety (Florida Statutes, 2020).

Physical Restraints

A **physical restraint** is defined by the Centers for Medicare and Medicaid Services (CMS) as "any manual method, physical or mechanical device, material, or equipment attached to or adjacent to the resident's body that the individual cannot remove easily which restricts freedom of movement or normal access to one's body." Physical restraints can include belts, mittens, vests, bedrails, geriatric chairs, and other devices (Staggs et al., 2016).

Use of physical restraints has come under intense scrutiny because they can cause agitation, confusion, deconditioning, pressure ulcers, strangulation, adverse psychological effects, and even death. They affect a person's sense of well-being, causing feelings of low self-worth, depression, humiliation, and anger.

Because of these potentially serious consequences, physical restraint use is part of public reporting for nursing homes through the CMS Nursing Home Compare website (Staggs et al., 2016). Several studies have demonstrated that carefully orchestrated restraint-reduction programming can greatly reduce the use of physical restraining devices (Lai et al., 2011).

Restraints are not limited just to physical devices. Restraint can include using (or threatening) force or restricting their movements—even if they do not resist (Nuffield Council on Bioethics, 2009 latest available).

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

Regular interaction with caregivers in an adult daycare setting provides the opportunity to educate family members about the use of restraints in the home. Current evidence indicates that restraints are regularly used in home care; that they are mainly applied to vulnerable older persons; and that informal caregivers, who have less knowledge of the negative consequences of restraint use, play an important role in the application of restraints, by granting permission for the use of restraints and deciding to use restraints (Scheepmans et al., 2020).

Nurses also play a pivotal role in the use of restraints. Recent studies suggest they have insufficient knowledge of the concept of restraints, the frequency of their use in clinical practice, and the negative impact on the client (Scheepmans et al., 2020).

Chemical Restraints

A chemical restraint is the intentional use of any medications to subdue, sedate, or restrain an individual. Traditionally they 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 the shortest time possible for dangerous, uncontrolled, aggressive, or violent behaviors.

In older adults with dementia, psychotropic agents such as anti-anxiety, antidepressant, and antipsychotic medications are often 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 are often overused as a means of behavioral control in older adults with dementia (Peisah & Skladzien, 2014).

Atypical antipsychotics were approved by Food and Drug Administration (FDA) in the 1990s exclusively for the treatment of schizophrenia. Soon after, these medications became the new standard of care for behavioral and psychological symptoms of dementia.

In the older adult population, the largest number of prescriptions for atypical antipsychotics is written for delusions, depression, and agitation. Although neuropsychiatric symptoms affect up to 97% of people with dementia at some point during the course of their disease, it is important to note that no atypical antipsychotic is FDA-approved for the treatment of any neuropsychiatric symptoms in dementia (Steinberg & Lyketsos, 2012).

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

The 2012 American Geriatric Society (AGS) Beers consensus criteria for safe medication use in elders recommend avoiding antipsychotics for treatment of neuropsychiatric symptoms of dementia due to the increased mortality and cerebrovascular events risk "unless nonpharmacologic options have failed and the patient is a threat to self or others" (Steinberg & Lyketsos, 2012).

In 2015, the American Psychiatric Association published practice guidelines on the use of antipsychotics to treat agitation or psychosis in people with dementia. Expert consensus suggests that use of an antipsychotic medication in individuals with dementia can be appropriate, particularly in individuals with dangerous agitation or psychosis, and can minimize the risk of violence, reduce patient distress, improve patient's quality of life, and reduce caregiver burden (Reus, Fochtmann, Eyler et al., 2016).

In clinical trials, however, the benefits of antipsychotic medications are at best small whether assessed through placebo-controlled trials, head-to-head comparison trials, or discontinuation trials. There is also consistent evidence that antipsychotics are associated with clinically significant adverse effects, including mortality (Reus, Fochtmann, Eyler et al., 2016).

Key points about the benefits and risks of antipsychotic use include:

- Nonemergency antipsychotic medication should only be used for the treatment of agitation or psychosis in patients with dementia when symptoms are severe, dangerous, and/or cause significant distress to the patient.
- Clinical response to nonpharmacological interventions should be assessed prior to non-emergency use of an antipsychotic medication to treat agitation or psychosis.
- Potential risks and benefits should be assessed by the clinician and discussed with the patient as well as with family or others involved with the patient. (Reus, Fochtmann, Eyler et al., 2016)

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.

***Off-label** use is the practice of prescribing pharmaceuticals for an unapproved indication, age group, dose, or form of administration.

Alternatives to Restraints

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 30 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.

9. Assistance with Activities of Daily Living (ADLs)

> 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 is offered, especially help with eating and intimate care, is crucial in helping the person retain their self-esteem and dignity.
>
> Nuffield Council on Bioethics

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

In adult day services programs, clients tend to need less assistance with ADLs than people in other long-term care settings, particularly with bathing, dressing, and toileting (Harris-Kojetin et al., 2016). In general, about one-third of daycare clients need help with toileting, about one-quarter need help with eating, and about one-third need help with medication management. Nearly half need some assistance with walking and about one-third need help with transfers (Dwyer et al., 2014).

Instrumental or functional ADLs are the skills needed to function within society and within the community. These skills decline as dementia progresses. When a person is no longer able to perform basic math calculations, when insight becomes limited and memory is significantly compromised, financial and medical decision-making and medication management will 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).

Basic and Instrumental ADLs

Basics ADLs (skills needed to take care of personal needs)	Eating, bathing or showering, grooming Walking Dressing and undressing Transfers, toileting
Instrumental ADLs (skills needed to function within the community and society)	Housework Financial management Shopping, preparing meals Communicating with the outside world Medical management

Although there is often no clear demarcation between mild, moderate, and severe dementia, caregiver responsibilities will increase as ADL skills decline. In the early stage of dementia most people remain independent with basic ADLs. Most will begin to need help with instrumental ADLs—especially complex tasks requiring multiple steps or extensive planning. Basic activities of daily living such as eating, dressing, and bathing are likely still independent.

At this stage, a person will naturally 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.

As dementia progresses to the moderate stage, instrumental ADLs such as work, medication management, and management 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.
- Basic ADLs may be disrupted by behavioral and psychological symptoms such as anger, frustration, and denial.

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 hire a caregiver or move their loved one to assisted living or skilled nursing.

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. In skilled nursing or assisted living, the facility must provide enough staffing and equipment to create a safe environment.

As severe dementia progresses, balance and safety awareness can decline, 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, which increases the cost of care. Caregivers and healthcare providers must make difficult decisions to prevent injury and to provide a safe environment.

Strategies for Assisting with ADLs

No matter what the level of dementia, when assisting someone with activities of daily living, encourage them to express their wishes. "No, I don't want to!" means just that, even when spoken by someone with dementia. Keep these general measures in mind when assisting someone with their ADLs:

- 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.

Examples

When assisting with basic ADLs, use common sense, non-challenging body language, and a quiet, confident tone of voice. Whatever the activity, move slowly, give clear, simple commands, limit choices, and allow plenty of time to complete the task.

There are times when the caregiver and the client have different goals. A caregiver in an adult daycare facility may want to assist a client with a transfer from a recliner to a wheelchair as quickly as possible because the caregiver has two more people to help before an activity starts. The client may want just to watch TV and not participate in an activity.

Delaying

My mom needs help with everything, including transfers and walking. When she has a doctor's appointment, I try to start preparations at least an hour to an hour-and-a-half ahead of time. I get everything ready and think I've got things handled but just before we are ready to go, she insists on brushing her teeth. This takes about 15 or 20 minutes and requires me to stand next to her at the sink the entire time. If I try to get her to go without brushing her teeth, she grabs the door, or even sits down on the step and refuses to go. It drives me crazy. Once in the car she yells at me to hurry up.

ADL Strategies: Mild Dementia

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

Dressing

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

Grooming

- Allow clients 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.

ADL Strategies: Moderate Dementia

Although there is no clear delineation between mild and moderate dementia, it will become clear to caregivers that as dementia progresses, clients 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 and 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 client needs to use the bathroom.
- Provide close assist, particularly with transfers.
- Label bathroom door for easy identification.
- Provide toileting on a regular schedule.

ADL Strategies: Severe Dementia

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, depending on the person's physical capabilities.

A person with severe dementia may still be able to walk independently and 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 client's earlier bathing rituals as is reasonable.
- Use client 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 client to be clean and comfortable. Shower or tub bath is not necessary—a sponge bath may suffice.

Bathing

Mrs. Cavelia has moderate dementia due to Alzheimer's disease and lives in a nursing home. Tuesday is her shower day—a nursing assistant helps her undress in her room, covers her with a blanket, and wheels her to the shower room using a rolling commode chair. When they leave the room and enter the hallway, Mrs. Cavelia starts to fidget. As they approach the shower room she begins to yell and protest. When she is placed in the shower she screams, grabs the door, and tries to push her caregiver away.

***Antecedent**: In her room, the care assistant undresses Mrs. Cavelia and wraps her in a bath blanket. Unable to find a shower chair, she helps Mrs. Cavelia into a toilet chair. Mrs. Cavelia's bottom is hanging out of the hole in the chair, which embarrasses her. She tries to stop the caregiver from wheeling her out into the hallway by grabbing at the doorway as they exit. She says "No! No!" but the caregiver tells her she is dirty and needs a shower, which embarrasses Mrs. Cavelia even more.*

***Behavior**: By the time Mrs. Cavelia reaches the shower room she is very upset. She slaps the nursing assistant and repeatedly grabs the shower room door. The nursing assistant manages to get Mrs. Cavelia into the shower room, but when she turns on the water, Mrs. Cavelia screams, grabs the shower hose, and pushes the nursing assistant away. She sprays water all over the caregiver and into the hallway.*

***Consequence**: The client, staff, and the client's daughter are all upset. The situation created an unpleasant environment for everyone and showering has become a dreaded experience for Mrs. Cavelia.*

***Discussion**: Find out how Mrs. Cavelia bathed earlier in life. Allow her to participate in her bathing even if it takes longer. Ask her if she wants a shower. Allow her to undress in the shower room rather than in her room. Talk with her during the procedure and get continual feedback from her. Ask her questions such as "Is this too hot?" "Do you want to wash your face?" "Are you cold?"*

Mrs. Cavelia's daughter has told the nursing staff that her mother prefers to undress in the shower room and hates being wheeled half-naked down the hall. The nursing assistant bathing her today is new and hasn't been told about Mrs. Cavelia's preferences. Find a way to communicate preferences such as these. Consider whether she needs to have a shower or if there are other ways of bathing that might be more acceptable to her.

10. Maintaining a Therapeutic Environment

People with dementia rely on environmental cues to support them physically, cognitively, and emotionally. Unfamiliar, chaotic, or disorganized environments—whether at home, in adult daycare, or in a care facility—are stressful and can cause anxiety, disorientation, and contribute to behavioral problems.

A therapeutic environment provides support for someone with dementia and their family. It recognizes that people with dementia are influenced by their surroundings and do better with environments that are individualized, flexible, and designed to support differing functional levels and approaches to care (Campernel & Brummett, 2010). At a minimum, an organization caring for people with dementia should understand that people with dementia deserve and need kind and supportive care focused on dignity, respect, and autonomy.

Philosophy of Care

Environment is dictated by an organization's philosophy of care—a framework that identifies care goals and values. A healthcare organization's philosophy of care may differ from that of the family. Family members have the right to know and should feel free to question a center's philosophy of care:

- Is the center's philosophy for caring consistent with your beliefs?
- Does the center provide services to persons at all stages of dementia?
- What conditions or behaviors determine whether a center will admit or retain someone with dementia?
- Is dementia care provided in a separate unit or as an integrated part of center's services?
- Is the center's philosophy and practice of handling "difficult behaviors" compatible with your views?
- What is the center's philosophy in using physical restraints to deal with certain behaviors?
- Does the center recommend the use of psychoactive drugs to treat behaviors? (California Advocates for Nursing Home Reform, 2020)

Dementia Friendly Care

In long-term care *dementia friendly* is a commonly used term. It focuses on the experience of people with dementia and advocates for positive attitudes and behaviors toward dementia. It seeks to treat people with dementia and their caregivers with dignity and respect and calls for an end to stigma. It seeks community support for people affected by dementia so they can "live well with dementia" (ADI, 2015).

Dementia Friends

Courtesy Alzheimer's Disease International.

The Japanese Dementia Friends model is an example of a program that provides services throughout the country. Japan's nationwide campaign, a 10-Year Plan to Understand Dementia and Build Community Networks, has provided training for 1 million "cognitive disorder" supporters. The program has been copied in the United Kingdom.

Person-Centered Care

Person-centered care, also called dementia-friendly care, depends on a caregiver's and organization's skills, training, and knowledge. It means that care is built around the needs and preferences of the client, the care professional, and the caregiver. The goal is to create a high-quality, joyful, shared environment.

Person-centered care is flexible, creative, and supportive. Person-centered care promotes inclusion of the person living with dementia and their caregivers in care and treatment decisions, with the aim of increasing positive outcomes for both (Handley et al., 2015).

Person-centered care is the opposite of task-centered care. In dementia care, it involves practices aimed at helping your client establish relationships and be treated as an individual with their own life history and interests (Desrosiers et al., 2014).

An innovative person-centered approach called "green care farms" has been developed in the Netherlands, which provides daycare services and 24-hour nursing home care to people with dementia. Green care farms offer a broad selection of activities, including caring for plants and animals, and encourage clients to engage in tasks suited to their level of dementia and physical capabilities (de Boer et al., 2015).

Some green care farms provide day-care services. In a study on daycare services at green care farms it was suggested people deliberately chose green care farms because of their dislike of the institutional environment of regular daycare facilities. Green care farms were perceived as more useful for clients, more meaningful, and providing more opportunities to be physically active and to go outdoors (de Boer et al., 2019).

The Physical Environment

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

For long-term care facilities, there is a trend toward designing facilities to be 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, small-scale living arrangements in the Netherlands, and German shared-housing arrangements (Gräske et al., 2015).

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).

Specific design principles have been shown to reduce unwanted behaviors and enhance a sense of well-being in people with dementia. These include:

- Providing private spaces and a separate room or recess for sleeping or napping
- Providing easily accessed public spaces and places for semi-private interactions
- Keeping public spaces clean and getting rid of odors
- Providing sunlight, ventilation, and getting rid of dark nooks and crannies
- Providing views to the outside.
- Replacing institutional, centralized nursing stations with smaller, residential-looking stations
- Creating spaces to cue specific behaviors (activity kitchen, art and music therapy area, bistro/bar, rummaging room, library, coffee shop/internet café, quiet room, living room)

Living Spaces Designed for Dementia Patients

Left: Residential-looking, smaller-scaled nurses' station. Right: a room for rummaging. Source: Campernel & Brummett, 2010. Used with permission.

Outdoor design ideas for people with dementia and memory disorders include:

- Arranging outdoor spaces to resemble a natural community
- Creating continuous circulation routes with looping pathways and areas of interest
- Including clients in the design of new features such as walking paths and gardens
- Creating safe, purposeful, heated, and accessible outdoor areas
- Offering attractive landscaping, gardens, and pleasing views (Rijnaard et al. 2016)

Left: Safe, looping wandering paths with areas of interest along the way. Right: A memory-care facility with home-like outdoor porch area for seating and reflection. Source: Campernel & Brummett, 2010. Used with permission.

In a comparison of "regular" specialized care units and small, homelike specialized care units in the Netherlands, clients in the homelike care units needed less support with activities of daily life, were more socially engaged, showed less agitation over time, and needed less psychotropic medication and physical restraints. Residents of the small, homelike units awarded higher scores to aspects of quality of life, showed less negative affect and better social relationships, and were more engaged in activities (Kok et al., 2016).

Safety and Security

People with dementia need to feel safe (and be safe) without the use of physical and chemical restraints. Safety includes creating an appropriate environment as well as planning for adverse events, such as wandering away from the home or facility.

The table below illustrates some common safety hazards and measures to help make the environment more safe and secure. Since every situation is different, interventions must be tailored to match the specific circumstances.

Measures to Promote Safety and Security

Safety issue	Possible consequence	Intervention
Wandering	Getting lost, exposure to environmental hazards.	Use technology such as the Alzheimer Association's Comfort Zone.* Provide short, looping corridors without dead ends. Create open, common areas of interest. Create safe, outdoor wandering areas that are accessible from indoor wandering paths. Paint the inner surfaces of doors so that they are not readily recognizable as an exit. Place locks where they are not visible.
Cooking without supervision	Fire, injury	Install a shut-off valve on the stove. Remove burner on-off handles. Keep a working fire extinguisher. Create a work area with an activity kitchen.
Falls	Injury	Rule out medical conditions. Create an uncluttered environment. Install handrails in showers and hallways. Install carpeting to reduce injuries. Wipe up spills promptly. Maintain physical activity. Supervise walking and use assistive devices. Remove throw rugs or tape edges down. Maintain good vision and hearing. Provide many places to sit.
Poisoning	Sickness or death	Remove toxic plants from the environment. Lock up chemicals and medications.

*The Alzheimer's Association has a product called Comfort Zone that uses GPS technology to locate a person who has wandered and become lost. There are many proprietary companies now offering similar location services.

Simply receiving care at an adult daycare center can be a source of safety and security for a person with dementia. Having regular contact with a caregiver provides a sense of privacy, safety, and security. A well-designed and well-run facility is secure, comfortable, and predictable; it is a place where one can feel at ease—a place where you can be who you are and feel connected with like-minded people (Rijnaard et al., 2016).

Adult daycare services can also offer a sense of safety and security for caregivers, providing a feeling of shared responsibility and respite (Tretteteig et al., 2017).

Schedules and Routines

Schedules and routines are an important part of any person's life and well-being. However, when someone enters a facility or participates in a daycare program, their usual routines are interrupted and altered. This creates a tension between the necessary institutional routines and the clients' personal habits and needs (Rijnaard et al., 2016).

In traditional elder care facilities, schedules and routines are primarily organized around the convenience of the staff. As a result, schedules can change dramatically from day to day. This is difficult for people with dementia because they rely on a predictable routine for orientation. A regular routine allows a person with dementia to know what to expect. Routines also give the caregivers a benchmark for evaluating a person's behavior. A schedule for someone with dementia should:

- Be planned carefully.
- Consider each person's capabilities and preferences.
- Continue familiar routines and schedules.
- Maintain mealtime routines.
- Maintain regular dental and healthcare appointments.
- Allow plenty of time.
- Note the effects of changes in routines.
- Consider issues that disrupt routines (ie, pain, fatigue, illness).

Caregivers responsible for maintaining a routine schedule must be flexible. People with dementia tend to be slow, so caregivers must allow ample time for meals and activities. Attempting to rush can precipitate aggressive behaviors and frustrate both parties.

Staff as Part of the Environment

In Florida, adult daycare centers must employ qualified staff to provide the services, personal assistance, and safety measures required by participants. Nearly 60% of workers in adult daycare centers are aides, 18% are registered nurses, 11% are licensed practice nurses, and about 12% are social workers (Harris-Kojetin et al., 2016).

If centers provide adult day health care, the following staff members are required:

- A registered nurse or licensed practical nurse on site during the primary hours of program operation and on call during all hours the center is open; all LPNs must be supervised by an RN;
- A social worker or case manager to provide and supervise the provision of social services, including counseling for participants' families and caregivers and compilation of a social history and psychosocial assessment of formal and informal support systems, and mental and emotional status; and
- An activity director or recreation therapist, who may be retained as a consultant. All services provided by program aides must be directly supervised by the activity director or recreation therapist (O’Keefe, 2014).

Proper Staffing

The importance of having sufficient, competent staff to ensure quality of care is a major concern in many countries. High turnover and difficulties recruiting qualified staff are common challenges. Several significant factors that may impact job satisfaction and the ability to provide quality care have been identified. These include unclear roles and functions, heavy workloads, demanding work schedules, difficult ethical issues, and job strain, such as stress of conscience and burnout (Vassbø et al., 2019).

Dissatisfaction with work can result in lower loyalty to the workplace and an increased probability of leaving the workplace. Research indicates that those who are dissatisfied with their working conditions have an increased tendency to avoid work responsibilities through absence, purposely avoiding activities, taking shortcuts, or making themselves unavailable when actions are required. Therefore, there is a great need to identify ways to improve job satisfaction (Vassbø et al., 2019).

A person-centered approach has been shown to decrease staff turnover, improved worker satisfaction, and reduce participants’ unwanted behaviors. This is accomplished by (1) meeting an individual's needs and preferences in close relationships, (2) establishing shared goals, (3) understanding clients’ rhythms and preferences, (4) doing the “little extra” for clients, (5) being a part of a supportive team, and (6) sharing professional values (Vassbø et al., 2019).

In adult daycare centers in Florida, staffing must be maintained to meet participants' needs, including centers that serve persons with Alzheimer's disease and other types of dementia (O’Keefe, 2014):

- All adult day centers: at a minimum, 1 staff member providing direct services for every 6 participants.
- Specialized Alzheimer's adult day center: at a minimum, 1 staff member providing direct services for every 5 participants with Alzheimer's disease or other dementia.
- All adult day centers: at a minimum, 2 staff (1 of whom has a certification in first-aid and CPR) must be present in the center at all times. (O’Keefe, 2014)

The owner or operator may be counted as one of the required staff members if that person provides direct services and is included in the center's work schedule. However, the owner or operator must not be counted more than once in the staff-to-participant ratio, calculated on the basis of daily census (O'Keefe, 2014).

Staff Adjusting to Resident Routines

In adult daycare settings, as in other elder-care settings, activities are usually centered on tasks and activities. Ideally, clients are cared for by a small, fixed team of trained caregivers and activities are organized completely, or in large part, by clients and caregivers. Staff members, clients, and family members can prepare meals together, assist with personal care, and participate in activities.

To encourage integration of the staff into a home-like environment, the following practices are recommended:

- Hire staff with the emotional skills to interact with people who have memory problems.
- Eliminate institutional, centralized nursing stations.
- Locate nursing and work areas throughout the building for staff convenience.
- Allow staff to control lighting and environmental levels.
- Emphasize signage for clients.
- Limit signage for staff and visitors.
- De-emphasize or camouflage doors to staff and utility areas.
- Keep staff consistent.

11. Ethical Issues with Dementia Patients

Healthcare providers and caregivers are often faced with difficult ethical decisions. This is particularly true in the complex and ethically difficult area of dementia care. Caregivers must balance their own needs while considering issues related to confidentiality, the potential for abuse, and the benefits and risks of medications and procedures. If patients are no longer able to express their own will, designated decision-makers must put aside their own needs and desires and carry out what they believe the person with dementia would do if able.

A key principle is to understand and remember that people with dementia remain the same equally valued people throughout the course of their illness, regardless of the extent of the changes in their mental abilities (Nuffield Council on Bioethics, 2009, latest available).

Key Ethical Principles

In biomedical ethics, several basic ethical principles are commonly accepted. These are (1) autonomy and well-being, (2) beneficence, (3) justice. In addition, veracity (truthfulness) is an ethical principle that must be observed in all situations.

Autonomy and Well-Being

Autonomy is the right of individuals to make decisions about their own healthcare and their own life. Clients must be told the truth about their condition and informed about the risks and benefits of treatment. Clients can refuse treatment even if the best and most reliable information indicates that treatment would be beneficial, unless this decision has a negative impact on the well-being of another individual. This sort of conflict can create an ethical dilemma.

For someone with dementia, autonomy means fostering important relationships, maintaining a sense of self, and having a way to express values. Autonomy is not simply the ability to make rational decisions. A person's well-being includes both their moment-to-moment experiences of contentment or pleasure and more objective factors such as their level of cognitive functioning (Nuffield Council on Bioethics, 2009).

Beneficence: Doing Good

Beneficence is the act of doing good. This means providing care that is in the best interest of the client. A decision is beneficent or kind when the same decision would be made regardless of who was making it. Beneficence is closely related to the concept of "do no harm." Actions or practices of a healthcare provider are beneficent as long as they are in the best interest of the client and avoid negative consequences.

Justice: Equity and Fairness

Justice is often defined as a fair distribution of benefits and burdens, particularly in connection with misfortunes for which we cannot be held personally responsible (Nuffield Council on Bioethics, 2009). Distributive justice is the degree to which healthcare services are distributed equitably throughout society. Comparative justice refers to the way healthcare is delivered at the individual level.

Given the vulnerability of people with dementia, it is particularly important that the allocation of resources supports dementia care. This is in part an issue of appropriate resources and practical support, but also requires both caregivers and care workers to be recognized and valued as people who have an important expertise and role in society. A fair distribution of benefits and burdens should promote and sustain people with dementia throughout the course of their dementia and help them maintain their autonomy as much as possible (Nuffield Council on Bioethics, 2009).

Veracity (Truthfulness)

Truthfulness is taught us from childhood and it is particularly important when interacting with those who have dementia; ethical reasoning behind most interactions must be driven by concern for the well-being of the person with dementia. Conflicts inevitably arise between the desire to maintain trust and practical concerns about how to get through the day (Nuffield Council on Bioethics, 2009).

Some argue that failing to tell the truth is a breach of trust and undermines the grip the person has on the everyday world. Others point out that telling the truth when the person with dementia will not believe it may equally undermine trust because the person will think that they are being lied to. For healthcare providers, there is the added issue of whether telling a lie undermines the integrity of professional care, and for those involved in providing care there is the concern that failing to tell the truth is detrimental to their own moral well-being (Nuffield Council on Bioethics, 2009).

Incorporating Ethical Principles into Care

Ethical dilemmas arise when there are equally good reasons both for and against a particular course of action and a decision must be made. It is a dilemma because there is a conflict between available choices. One action, though morally right, violates another ethical standard. A classic example is stealing to feed your family. Stealing is legally and ethically wrong—but, if your family is starving, stealing food might be morally justified (Noel-Weiss et al., 2012).

Kidder calls this a "right vs. right" dilemma. When evaluating the alternatives, both courses of action have positive and negative elements. Right vs. right is an ethical dilemma, whereas right vs. wrong is identified as a moral temptation (Kidder, 1996).

Working through an ethical dilemma until a satisfactory conclusion is reached, making decisions that lead to good actions, and avoiding regrets and negative consequences are the foundational principles of ethical practice (Noel-Weiss et al., 2012).

Examples of Ethical Conflicts and Dilemmas

Maintaining Independence

Mr. Corona is 90 years old and lives in a cottage on his daughter's property. He was a pilot during Korean War and has been fiercely independent his entire life. He is in the moderate-to-severe stage of dementia and is unable to independently perform many of his ADLs.

Mr. Corona is in the clinic for his annual evaluation. He does not know his address, the current date, the president's name, the season, day, or time. His Mini Mental State Exam score is 11/30. When asked what he would do if the house caught on fire, he replied, "I would get some water and put it out."

His three daughters discussed the situation with a social worker and a nurse practitioner in the neurology clinic. Although Mr. Corona's safety is questionable, his daughters state that he has always been independent and does not like people taking care of him. They decide that for now they will support his living in the cottage.

***Discussion**: In making decisions on Mr. Corona's behalf, his daughters are using the principles of autonomy and beneficence. Mr. Corona's lifelong desire to be independent guided their decision to allow him to continue to live alone. They are balancing his need for autonomy with his need for safety and protection. The three sisters decide take turns sleeping at his house overnight and have agreed to stop in during the day. They accept that he is at some risk living alone but believe that his quality of life will be better in his own home and that living alone is consistent with their father's life philosophy.*

Ceasing to Eat

Mrs. Gould is 92 years old and has had Alzheimer's disease for fifteen years. She has lived in a nursing home for the past seven years. She has had help with her meals for two years, but over the last month has intermittently refused food. As a result, she has lost 15% of her body weight in the past 6 weeks. The Physician Orders for Life-Sustaining Treatment (POLST) form that she completed when she was able to make her own decisions indicated that she did not want a feeding tube if she was unable to eat on her own. Her son has durable power of attorney to make decisions for her when she is no longer able to do so. He wants her kept alive as long as possible and wants a feeding tube inserted.

***Discussion:** Mrs. Gould's son is acting from what he believes is the best course of action for her; however, he is expressing his opinion and neglecting to consider what his mother would say if she were able. He is not adhering to the principle of autonomy and is not demonstrating loyalty or support of his mother's wishes. While one might think that he is acting in concert with the principle of beneficence by feeding her, studies show that feeding tubes do not prolong life or improve quality of life in people in the later stages of Alzheimer's disease. At the very latest stages of Alzheimer's, the natural course of the disease is that people stop eating and drinking.*

12. Concluding Remarks

Dementia is a disease of the brain that interferes with a person's ability to perceive and think in a normal manner. Alzheimer's disease is the most common cause of dementia, but there is more than one kind of dementia.

Although people with dementia often exhibit behaviors that are challenging for family and professional caregivers to manage, 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, caregivers 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 to 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 people with dementia—especially in the early to moderate stages. Caregivers often experience stress, which can be lessened by accessing respite care and adult daycare services.

Adult daycare centers 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 clients and staff work together has been shown to improve outcomes in those with dementia.

Communication issues affect people with dementia. As the dementia progresses, it becomes more difficult for people with dementia to communicate their needs. Good verbal and nonverbal communication skills are needed for caregivers to provide a high level of care as the dementia progresses.

Caregivers—both family and professional—experience many ethical conflicts when caring for a person with dementia. Education and training in ethical decision making and conflict resolution are invaluable tools to improve the experience of those with dementia.

Working with people who have dementia can be satisfying and rewarding. It takes patience, practice, and training to learn to understand the world from that person's point of view. People with dementia can still enjoy life. They can enjoy memories, interactions with the people around them, and activities that are matched to their preferences and abilities. Your efforts to make the person comfortable and happy can make a big difference in their final years of life.

14. Resources

2-1-1 Information and Referral Search
For help with food, housing, employment, healthcare, counseling, and crisis intervention, and more in many counties in Florida. www.211.org, or call 211

Alzheimer's Association
Provides support, education, and research throughout Florida. They have excellent educational material, a newsletter, fundraising and volunteer opportunities, and a 24/7 helpline. www.alz.org.

Alzheimer's Disease Education and Referral (ADEAR) Center
Established by an act of Congress in 1990—part of the National Institutes of Health. Compiles, archives, and disseminates information about AD for health professionals, people with AD and their families, and the public. The website provides excellent educational material about Alzheimer's disease, current research initiatives, support services, and much more. www.nia.nih.gov/alzheimers.

AlzOnline: Caregiver Support Online
Part of the Center for Telehealth and Healthcare Communications at the University of Florida. It provides caregiver education, information, and support for those caring for a family member or friend with Alzheimer's disease or related dementias. alzonline.phhp.ufl.edu/

Alzheimer's Project
A nonprofit organization located in Tallahassee. Provides comfort, support, and assistance to persons with memory disorders and their caregivers. Serves the Big Bend community of Florida with education and training, in-home respite, support groups, counseling, referral to community resources, and recovery of wanderers through the Project Lifesaver program. Services are free of charge. www.alzheimersproject.org/ 850 386 2778

Area Agency on Aging for North Florida
Serves as the designated Aging Resource Center for the Panhandle and Big Bend areas. Consumers, families and caregivers can access the Aging Resource Center in their community by calling the Elder Helpline. www.aaanf.org/ 800 963 5337

CJE Senior Life
Provides caregivers with educational materials and resources applicable to many different caregiving situations. Addresses risk of caregiver burnout by sharing expertise in dealing with the older adult population. www.cje.net/

Eldercare Locator
A public service of the Administration on Aging, U.S. Department of Health and Human Services; a nationwide service that connects older Americans and their caregivers with information on senior services. https://eldercare.acl.gov/Public/Index.aspx, or call 800 677 1116

Family Caregiver Alliance National Center on Caregiving
A community-based nonprofit organization that addresses the needs of families and friends providing long-term care for loved ones at home. Provide assistance, education, research, and advocacy. www.caregiver.org / 800 445 8106

Florida Adult Day Services Association (FADSA)
Provides leadership, education, planning, and development of adult day services across Florida.

Promotes quality day services, respite programs, adult day health centers, and education, training, and advocacy within the long-term care industry. https://www.fadsafl.org/

Florida Council on Aging
A statewide association that represents aging interests through education, information-sharing, and advocacy. www.fcoa.org / 850 222 8877

Florida Department of Elder Affairs
Coordinates and develops policy for the Alzheimer's Disease Initiative, provides services for individuals with Alzheimer's disease, and similar memory disorders, and their families. Provides supportive services including counseling, consumable medical supplies and respite for caregiver relief; memory disorder clinics to provide diagnosis, research, treatment, and referral; model daycare programs to test new care alternatives; research database and brain bank to support research. elderaffairs.state.fl.us/index.php, or call 850 414 2000

Florida Elder Helpline: Florida Department of Elder Affairs
Provides information about elder services and activities. Information is available through the Elder Helpline Information and Assistance service within each Florida County. elderaffairs.state.fl.us/doea/elder_helpline.php, or call 800 955 8770

Florida Hospice and Palliative Care Association (FHPC)
A not-for-profit organization representing Florida's hospice programs. Ensure excellence and access to hospice care; advocates for the needs of those in the final phases of life. floridahospices.org/ 800 282 6560

Florida Telecommunications Relay (FTRI)
A statewide nonprofit organization that administers the Specialized Telecommunications Equipment Distribution Program for citizens of Florida who are deaf, hard of hearing, deaf/blind, and speech impaired. FTRI is also responsible for the education and promotion of the Florida Relay Service. ftri.org

Positive Approach to Care
Positive Approach® enhances life and relationships of those living with brain change by fostering an inclusive global community. Until There's A Cure, There's Care. https://teepasnow.com/

Share the Caregiving
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. www. sharethecare.org/

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. www.Caregiver.com

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Post Test

1. Dementia is:

a. A constellation of symptoms that can be caused by many factors and leads to deterioration.
b. A change in thinking that happens to everyone as they age.
c. An older person's reaction to a life of stress.
d. Being absent-minded or extremely forgetful.

2. You are working with a person who looks very worried, even scared, and says he sees hundreds of bugs crawling on the wall. What type of dementia do you think this person might have?

a. Alzheimer's disease.
b. Lewy body dementia.
c. Frontal-temporal dementia.
d. Parkinson's dementia.

3. How is dementia different from normal aging?

a. Age-related changes and dementia are the same thing.
b. A person with dementia does not get lost when driving in a new city.
c. In dementia, a person gradually loses the ability to think logically.
d. A person with normal age-related changes cannot live independently.

4. Alzheimer's disease is:

a. The immediate loss of long-term memory.
b. Diagnosed by a special blood test.
c. The most common type of dementia.
d. The formal name for all types of dementia.

5. Describing Alzheimer's disease in stages places the focus on:

a. Has been replaced by precise blood tests, which test cognitive decline.
b. What a person is still able to do as well as abilities that have been lost.
c. Alzheimer's disease rather than other types of dementia.
d. The amount of reimbursement available from Medicare.

6. A common reaction of people in the mild stage of dementia is to:

a. Shrug off others' concerns and go on with their life.
b. Immediately give up driving because it could be dangerous.
c. Enlist the help of family and friends.
d. Begin to plan for a life with diminished abilities.

7. My mom has dementia. She answers the phone and talks to whomever is on the other end of the line. Last month she bought $300 worth of financial books and audiotapes even though she can't see the print and doesn't handle her own finances anymore. Why does she do these things?

a. She just likes getting new things and has the right to spend her money in any way she wants.
b. She has moderate dementia that has affected her usually good judgment.
c. Even though she has dementia, she loves to talk on the phone.
d. Even though she has moderate dementia, she wants to learn more about her finances.

8. Typically, when multiple family members are involved with the care a person with dementia:

a. They should not follow advice given by a medical professional.
b. Healthy family dynamics play almost no role in the quality of caregiving.
c. Most families have high cohesion and easily come together to provide care.
d. Caregiver burden and depression are reduced when family cohesion is high.

9. A sudden change in behavior in a person with dementia:

a. Is probably because the dementia is getting worse.
b. May be due to a medical problem and should be addressed immediately.
c. Is a normal part of aging but more serious because of the dementia.
d. Is not something to worry about but should be carefully monitored.

10. When having a general conversation with a person with dementia:

a. Don't be afraid to argue or point out something incorrect.
b. Keep in mind that people with dementia can understand what you're asking but are unable to respond.
c. Break down your greetings, statements, or questions into short, simple sentences.
d. Keep conversations to a minimum to avoid frustrating your client.

11. Nonverbal communication is:

a. Using a very quiet tone of voice and repeating what you just said.
b. Communicating through facial expressions, hand gestures, and body language.
c. Speaking calmly, or speaking with affection, disapproval, confidence, or fear.
d. Doing your job without speaking so you don't bother the resident.

12. When communicating with someone who is unresponsive, it is best to:

a. Approach from behind, hug the person around the shoulders, and speak loudly.
b. Talk normally, using complex sentences.
c. Slow your movements, kneel down to the side, and introduce yourself.
d. Stand over the person, gently shake their shoulders, and speak loudly.

13. 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 clients.
d. Doing crossword puzzles if she enjoyed them earlier in life.

14. Your client, who has mild to moderate dementia, sits in his bedroom all day, and is reluctant to participate in any activities. The best way to get him involved is:

a. Ask him about his experiences, hobbies, and interests.
b. Let him be—he is probably happy in his room.
c. Make him participate in activities even if he protests.
d. Take away his T.V. until he agrees to participate in another activity.

15. Ann has been her husband's sole caregiver for six years. Ann's husband has severe dementia and Ann has been reluctant to reach out for help. She rarely leaves the house and when a friend visited, she noticed the house was filthy, the bed was covered with dirt from the dog, and the bathroom hadn't been cleaned in months. Ann has recently been diagnosed with mild frontal-temporal dementia. Ann and her husband are well-off, own their own home, and rent another home to a friend. What might be happening with Ann?

a. She is certain that she cannot afford to hire a caregiver.
b. She feels it is her duty as a spouse to provide care for her husband until he dies.
c. She may have cognitive changes related to her frontal-temporal dementia and may be unable to cope with her husband's worsening dementia.
d. She has a high degree of confidence in her role as a caregiver and wants to care for her husband rather than clean the house.

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

a. Receive specialized training about dementia.
b. Quit their jobs and provide 24/7 care.
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.

17. For a person with dementia, grief:

a. Is very rare.
b. Can be related to loss of physical strength and abilities.
c. Can cause feelings of euphoria.
d. Can be treated effectively with antipsychotics.

18. Wandering, a common activity in people with dementia may be more common in people who:

a. Were physically inactive as young adults.
b. Were involved with social activities and social-seeking behaviors.
c. Have been prescribed an antipsychotic.
d. Respond to stress by becoming depressed.

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

a. Loss of control, discomfort, or the inability to communicate discomfort.
b. Boredom, pain and discomfort, disorientation, 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 or environmental factors such as poor lighting or sensory overload.

20. The ABC approach to behaviors in dementia includes:

a. Approach, behavior, compensate.
b. Antecedent, best option, consequence.
c. Approach, beware, consequence.
d. Antecedent, behavior, consequence.

21. Wandering can be addressed by:

a. Redirecting to a purposeful activity.
b. Verbally admonishing a person to stop or else.
c. Discussing the behavior with the doctor.
d. Restraining the person in a wheelchair.

22. Mrs. Cortez pinches and bites her caregivers when they attempt to bathe her. A good way to address and minimize this behavior is:

a. Ask her family to come in and bathe her.
b. Restrain her in a shower chair and bathe her anyway.
c. Stop trying to shower her and give her a bed bath instead.
d. Observe her behavior, determine the cause of her agitation, and adjust accordingly.

23. A facility can restrain a client:

a. For the purpose of discipline or convenience.
b. To prevent a client from wandering.
c. When the client is being uncooperative.
d. In the case of an emergency only by a qualified, licensed nurse.

24. Antipsychotic medications are sometimes used to manage the behavioral symptoms of dementia. This is an off-label use, meaning:

a. The FDA has not been approved them for treatment of behavioral symptoms of dementia.
b. They are prescription medications approved by the FDA.
c. A prescriber can lose his or her license if these medications are prescribed to treat behavioral symptoms of dementia.
d. It is against the law to prescribe them for treating behavioral symptoms of dementia.

25. 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. Compete dependence on caregivers.
d. Trying to cover up deficits by making up stories.

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

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

27. Your client 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 client, allowing choices, and keeping the person comfortable.

29. Person-centered care:

a. Is the same thing as task-centered care.
b. Is only used when pharmacotherapy fails.
c. Usually increases unwanted behaviors.
d. Tailors care to clients' and caregivers' needs and preferences.

30. The use of design as a therapeutic tool recognizes:

a. There is a connection between the environment and how we behave.
b. The environment has little impact on those with dementia.
c. People with dementia do not rely on environmental cues to support them cognitively and emotionally.
d. People with dementia do fairly well in unfamiliar, chaotic, or disorganized environments.

31. To encourage integration of the staff into a homelike environment:

a. Increase signage for staff and visitors.
b. Rotate staff so clients get to know everyone.
c. Eliminate institutional, centralized nursing stations.
d. Clearly mark all doors, including doors to utility areas and staff lunch room.

32. The principle of beneficence is:

a. The intention to do good.
b. Never used to make ethical decisions.
c. Not really applicable to people with ADRD.
d. Difficult to apply to ethical situations.

33. A key principle of bioethics is:

a. People with dementia are the same, equally valued, people throughout the course of their illness, regardless of the changes in their mental abilities.
b. People with dementia are no longer able to participate in decisions about their care.
c. Bioethics is applicable only to people without dementia.
d. People with dementia have less value than people without dementia.

Answer Sheet

Print 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:

1. Give 3 examples of normal changes in thinking that occur as we age. 5 4 3 2 1
2. Describe 3 characteristics associated with dementia. 5 4 3 2 1
3. Relate 3 ways in which dementia can affects general conversations. 5 4 3 2 1
4. Relate the 3 components that should be part of individual and group activities for clients with dementia. 5 4 3 2 1
5. Describe 3 ways in which stress can affect a caregiver's quality of life. 5 4 3 2 1
6. Describe 3 issues family caregivers face as their loved one transitions from mild to moderate to severe dementia. 5 4 3 2 1
7. Identify 3 common behavioral and psychological symptoms of dementia. 5 4 3 2 1
8. Describe how mild, moderate, and severe dementia affects a person's ability to complete basic activities of daily living. 5 4 3 2 1
9. Identify 3 philosophical concepts that are important in the design of a therapeutic environment for those with dementia. 5 4 3 2 1
10. Identify common ethical conflicts that may arise when caring for clients with dementia. 5 4 3 2 1

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

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

*Did this course contain discriminatory or prejudicial language? Yes No

*Was this course free of commercial bias and product promotion? Yes No

*As a result of what you have learned, will make any changes in your practice? Yes No

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

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

______Yes, within the next 30 days. ______Yes, during my next renewal cycle.

______Maybe, not sure. ______No, I only needed this one course.

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

______Yes, definitely. ______Possibly. ______No, not at this time.

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

*Navigating the ATrain Education website was:

______Easy. ______Somewhat easy. ______Not at all easy.

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

______60 minutes (or more) per contact hour ______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. ______Social Media

______Other ________________________________

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 and Payment Form

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

*Name: ____

*Email: ____

*Address: ____

*City and State: ____

*Zip: ____

*Country: ____

*Phone: ____

*Professional Credentials/Designations:

____

*License Number and State: ______________________________

*Name and credentials as you want them to appear on your certificate.

____

Payment Options

You may pay by credit card, check or money order.

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

4 contact hours: $29

Credit card information

*Name: ____

Address (if different from above):

*City and State: ____

*Zip: _______________

*Card type: Visa Master Card American Express Discover

*Card number: ____

*CVS#: ______________ *Expiration date: _____________________