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.
3. Complete your registration and payment*.

*Check or money order payable to ATrain Education, Inc (or enter your credit card information on the registration form).

Mail the completed forms with your payment to:

ATrain Education, Inc

5171 Ridgewood Rd

Willits, CA 95490

When we receive your order, we will grade your test, process your payment, and email a copy of your certificate to the email address you provide.

If you would like a fancy copy of your certificate (suitable for framing), please add $8.50 to your payment.

Questions? Call 707 459-1315 (Pacific Time) or email (info@ATrainCeu.com).

[Continue to next page to start course]

Florida Assisted Living: Alzheimer's Disease and Related Dementias, Level One

Author: Lauren Robertson, BA, MPT

Contact hours: 4

Expiration date: September 30, 2024

Florida DOEA Approval: ALF AD 9794

Certified Trainer: The author is certified as an ADRD trainer by the Florida Department of Elder Affairs and is available via e-mail at Lauren@ATrainCeu.com or by phone Monday-Friday from 9 a.m. to 5 p.m. (Pacific Time) at 707 459 1315.

This training is for those of you who have direct contact with residents in assisted living facilities. It is designed to increase your awareness and understanding of Alzheimer's disease and related dementias. Upon completion, you will understand the scope of assisted living in Florida, characteristics of Alzheimer's disease and related dementias, communication challenges, caregiver issues, therapeutic design, and ethical challenges related to working with people with dementia.

Course Objectives

1. Define the term *assisted living facility.*
2. Describe 3 characteristics associated with dementia.
3. Relate a common type of behavior seen in each stage of ADRD.
4. Relate 3 ways in which dementia can affects general conversations.
5. Describe 3 issues family caregivers face as their loved one transitions from mild to moderate to severe dementia.
6. Identify 3 philosophical concepts that are important in the design of a therapeutic environment for those with dementia.
7. Identify common ethical conflicts that may arise when caring for residents with dementia.

1. Assisted Living Communities

Assisted living facilities (ALFs) are non-medical care facilities also referred to as residential care communities, “board and care,” or congregate living (FLAHCA, n.d.). They provide full-time living arrangements in the least restrictive and most home-like setting. These types of facilities can be broadly described as offering **non-institutional residential care** as opposed to the *institutional care* provided by nursing homes (Toth et al., 2020). The assisted living market size in the United States is valued at more than $80 billion (GVR, 2021).

Facilities can range in size from one resident to several hundred (FLAHCA, n.d.). Nationwide, residential care communities range in capacity from 4 to 518 licensed beds, with an average of 35 licensed beds. More than 80% are for-profit facilities, the majority chain-affiliated (Harris-Kojetin et al., 2019). They typically serve people who need help with daily activities and some healthcare services but do not need around-the-clock skilled nursing services.

Residents of assisted living facilities usually live in their own apartments or rooms and share common areas. They have access to services, including up to three meals a day; assistance with personal care; help with medications, housekeeping, and laundry; 24-hour supervision, security, and on-site staff; and social and recreational activities (NIA, 2017, May 1).

An assisted living facility can be an attractive alternative to skilled nursing—especially when people are still largely independent. However, this segment of older adult care has grown so rapidly and with so little oversight that people who need more care than an assisted living facility can provide must either pay for additional services or go without.

A steady decline of the number of people moving into institutional care facilities and instead moving to some sort of assisted living is due to at least three factors: (1) the high costs of residing in a nursing facility, (2) state Medicaid programs enacting policies to shift long-term care services away from the nursing facilities to the community, and (3) people's desire to stay in their own homes (Toth et al., 2020)

A caregiver and older woman in an assisted living facility. Source: NIA/NIH.

Most assisted living facilities are not required to have nurses, nursing assistants, or doctors on staff but are required to be licensed by the state. Typically, a few "levels of care" are offered, with residents paying more for higher levels (NIA, 2017, May 1).

Non-institutional residential care facilities are rapidly becoming a source of care for older adults with Alzheimer’s disease and other dementias. On any given day in 2016 (latest available), more than 800,000 residents lived in nearly 30,000 residential care communities throughout the United States. Nationally, more than 40% of residential care residents were diagnosed with dementia (Sengupta & Caffrey, 2020).

Residential care communities are increasingly serving residents with other complex needs. In 2016 (latest available), approximately 30% of residents had depression, 35% had heart disease, and 18% had diabetes. While all residents in residential care communities may need services and supports, residents with dementia have a greater need for mental health services (Sengupta & Caffrey, 2020). In terms of activities of daily living, more than half of residents in assisted living facilities need help with bathing, walking, and dressing, while nearly half require help with toileting (NCAL, 2016).

Since its inception, assisted living ideally has emphasized consumer dignity, autonomy, and choice as well as privacy and a homelike environment. However, the assisted living landscape is rapidly changing; these settings increasingly house residents who have aged in place in assisted living or who had entered with a higher acuity level. Today, assisted living residents are older, require more care, and may resemble nursing homes residents in acuity (Kelly et al., 2018).

In Florida there are approximately three thousand assisted living facilities and about half of the residents are over the age of 85 (FLAHCA, 2020, December 1). Four types of assisted living licenses are available from the state (standard, extended congregate care, limited nursing services, and limited mental health). A facility must have a **standard** assisted living facility license to operate in Florida. The other three licenses can be added if the facility wishes to provide services designated outside the spectrum of a standard assisted living facility license (FLAHCA, n.d.). Care facilities are grouped as follows:

- **ALFs** (residential facilities that provide direct physical assistance with, or the supervision of, activities of daily living, medications, and other similar services) house ~110,000 Florida residents.
- **ALFs with ECC** (extended congregate care) house ~20,000 Florida residents.
- **ALFs with LMH** (limited mental health) house ~12,000 Florida residents.
- **ALFs with LNS** (limited nursing services) house ~35,000 Florida residents. (FLAHCA 2020, December 1)

In general, for admission to an ALF, a resident must be an adult, be capable of performing day-to-day living activities with supervision or assistance, not require 24-hour nursing supervision, be free of stage II, III, or IV pressure sores, be able to participate in most social and leisure activities, be ambulatory, not display violent behavior, and be able to take their own medication, with assistance of staff if necessary. An ALF can accommodate special dietary needs and provide mobility services. A resident may be discharged if he or she is no longer able to meet these criteria or is bedridden for more than seven days (FLDOEA, 2016).

COVID-19 and Assisted Living

Given their congregate nature and population served, assisted living facilities are at high risk for the spread of COVID-19 and other infectious diseases among their residents. Older adults with underlying medical conditions are at increased risk for severe illness. Experience with outbreaks in nursing homes has demonstrated that residents with COVID-19 **may not report** common symptoms such as fever or respiratory symptoms; some may not report any symptoms (CDC, 2020, May 9).

Additionally, older adults with COVID-19 may not **show** common symptoms such as fever or respiratory symptoms and may instead experience less-common symptoms such as new or worsening malaise, headache, or new dizziness, nausea, vomiting, diarrhea, loss of taste or smell. Identification of symptoms consistent with COVID-19 should prompt isolation and further evaluation for COVID-19. Unrecognized asymptomatic and pre-symptomatic infections can contribute to transmission in these settings (CDC, 2020, May 9).

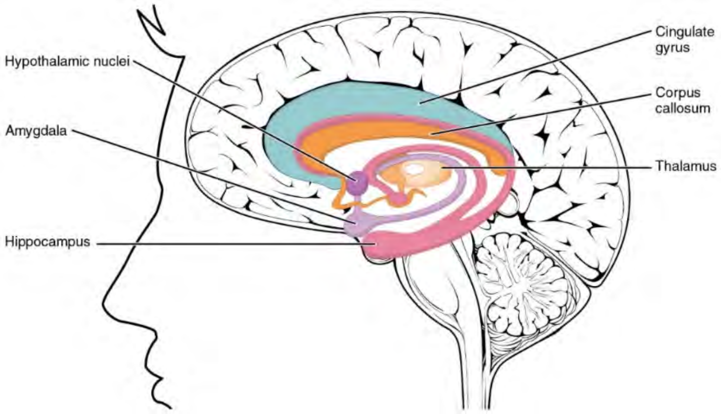
2. Understanding and Defining Alzheimer's Disease and Other Related Disorders

Dementia is a **syndrome**, a collection or grouping of symptoms—the result of progressive deterioration and loss of brain cells and brain mass. Different types of dementia affect different parts of the brain. Some dementias start in a part of the brain that controls a specific function such as short-term memory or emotion. Other dementias affect the entire brain—or more than one part of the brain—causing other symptoms.

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 (AD) is the most common type of dementia, responsible for 60% to 80% of all cases. It 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**.

The Limbic System



Structures arranged around the edge of the cerebrum constitute the limbic lobe, which includes the amygdala, hippocampus, and cingulate gyrus, and connects to the hypothalamus. Source: OpenStax and Rice University. Creative Commons Attribution License v4.0.

Damage to the hippocampus causes 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.

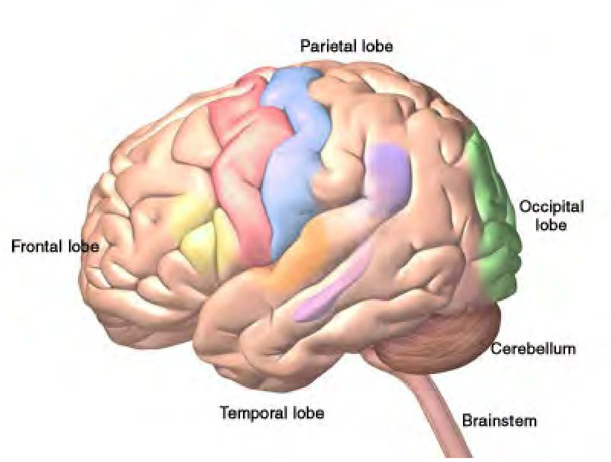
How the Brain Works

The brain is the most complex organ in the body—a sophisticated communications center containing billions of nerve cells (**neurons**). This three-pound mass of gray and white matter is at the center of all human activity. We need it to drive a car, to eat a meal, to breathe, to create an artistic masterpiece, and to enjoy everyday activities. The brain regulates the body's basic functions; it enables us to interpret and respond to everything we experience and shapes our thoughts, emotions, and behavior (NIDA 2020, July).

Within the brain, vast networks of nerve cells pass messages back and forth among different structures within the brain, the spinal cord, and the nerves of the rest of the body (the peripheral nervous system). These nerve networks coordinate and regulate everything we feel, think, and do (NIDA 2020, July). 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 a critically important part of the brain called the **cerebrum**. The cerebrum is divided into 2 hemispheres, each containing four of lobes.

The Human Brain



The four lobes of the cerebrum, plus the cerebellum and the brainstem. Alzheimer's disease starts in hippocampus, located in the temporal lobe. Copyright, 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.

Although the nerve cells of each lobe communicate extensively with nerve calls in other lobes, specific areas of each lobe are responsible for certain functions.

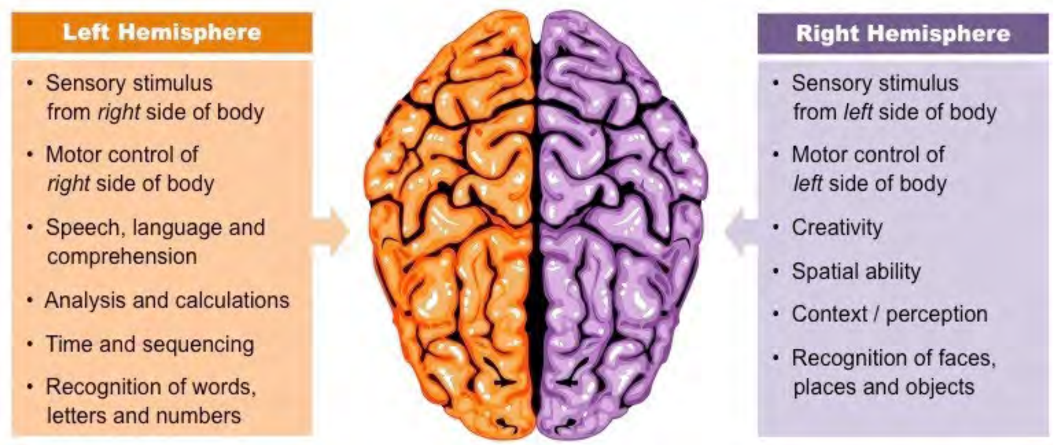
- **Frontal lobes**: reasoning, judgement, motor control, planning, decision-making
- **Temporal lobes**: memory and emotion, hearing, language
- **Parietal lobes**: sensation, touch, temperature, pressure, pain
- **Occipital lobes**: visual processing, depth, distance, location of objects

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 effectively with one another. 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.

The right and left sides or hemispheres of the cerebrum differ in function. For example, in the front part of the brain, damage in the left frontal and left temporal lobes can affect the brain's language centers, causing difficulties with speech and language. Damage to the right side of the brain can cause problems with spatial awareness and the ability to identify objects by touch.

The parietal lobes—behind the frontal and temporal 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.).

The Hemispheres of the Brain

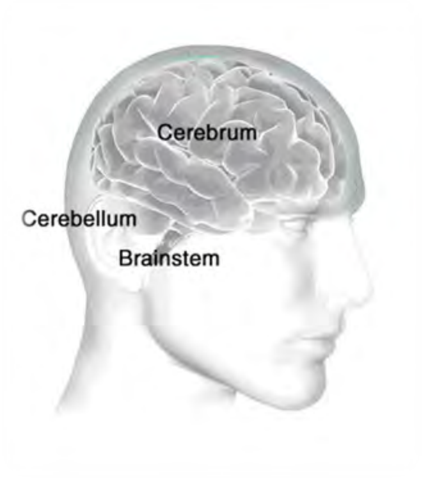


Source: Cornell, B. 2016. BioNinja. Reprinted by permission.

It is important not 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.).

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.

The 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.

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 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 and Memory Loss from Dementia

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.

Normal Aging vs. ADRD

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 nighttime)	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, although a large percentage of people with MCI experience personality changes. They may 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.

Other Neurologic Diseases or Conditions That Can Cause Dementia

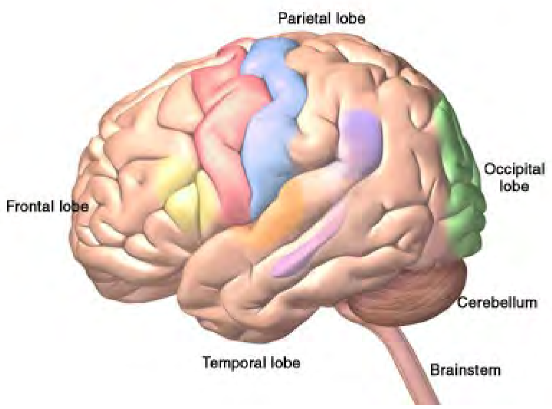
Symptoms are a little different in each type of dementia. It is good to know the difference to help you understand why someone is acting the way they are. Characteristics of the various types of Alzheimer's dementia and accompanying symptoms are described next.

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 5-10% of all cases of dementia. It's not nearly as common as Alzheimer's and usually starts at a much younger age.

Brain Showing Frontotemporal Lobes



Damage to the brain's frontal and temporal lobes causes forms of dementia called frontotemporal disorders. Copyright, 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.

Instead of losing short-term memory like people with Alzheimer's disease, a person with frontal-temporal (or f*rontotemporal*) 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.

Frontotemporal dementia is usually categorized under three subtypes:

1. Behavior variant frontotemporal dementia (bvFTD): changes in personality and behavior that can affect people in their early 50s and 60s. Affects judgement, empathy, foresight, and planning.

2. Primary progressive aphasia (PPA): usually begins before the age of 65. Affects language skills, reading, writing, and comprehension.

3. Disturbances of motor function, muscle weakness or wasting, without behavioral or language problems. (Alzheimer's Association, 2021a)

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% to 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)

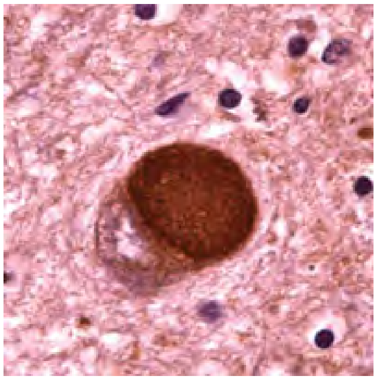
Lewy body dementia is a spectrum of disorders rather than a single diagnosis. **LBD** is less common than Alzheimer's dementia, but more common than frontal-temporal and vascular dementia.

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 build-up 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



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. Public domain.

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 can come and go throughout the day.

Dementia Characteristics and Symptoms

Type of dementia	Characteristics and symptoms
Alzheimer's disease (AD) 60-80% of cases	• Gradual onset • Impaired memory, apathy and depression • Language and visuospatial deficits • Changes in mood, anxiety, and sleep • Later stage: impaired judgment, confusion, major behavioral changes, neuropsychiatric symptoms • Executive functions often impaired
Frontal-temporal dementia 5% to 10% of cases, prevalence thought to be underestimated	• Early onset (45 to 60 years of age) • Behavioral and personality changes • Mood changes • Disinhibition, inappropriate touching, loss of social decorum • Loss of empathy • Language difficulties due to progressive aphasia • Problems with spatial orientation • No single pathology, considered a "family" of neurodegenerative disorders

Vascular dementia 20% to 30% of cases	• Stepwise onset • Similar to AD, but memory less affected, and mood fluctuations more prominent • Physical frailty • Patchy cognitive impairment • Often preventable • Any dementia related to cerebrovascular disease • 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 About 5% to 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

Conditions That May Mimic Alzheimer’s

Conditions other than dementia can affect cognition, causing dementia-like symptoms; some of these conditions are reversible with appropriate treatment (NINDS 2020, March 3):

- Side effects of medications or medication interactions
- Metabolic and endocrine abnormalities
- Vasculitis (inflammation of brain blood vessels)
- Nutritional deficiencies, especially of vitamin B_1 (thiamine)
- Some chronic infections around the brain
- Constipation
- 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
- 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

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

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

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

The most common causes of delirium are related to medication side effects, hypo or hyperglycemia (too much or too little blood sugar), fecal impactions, urinary retention, electrolyte disorders and dehydration, infection, stress, metabolic changes, an unfamiliar environment, injury, or severe pain.

Depression

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

A man depressed about the loss of his spouse. Source: NIA/NIH.

Depression has been suggested as a risk factor for dementia. According to recent studies, late-life depression is associated with increased dementia risk. Some researchers have proposed indirect evidence that the effect of depression on dementia risk is altered by comorbid cerebrovascular disease, which is typically characterized by cerebral ischemia and hemorrhage (Jang et al., 2021).

In a recent study, depression was found to have an exceptionally significant effect on dementia in individuals who have had a stroke. Risk factors for dementia in patients with cerebrovascular disease also includes depressive illness (Jang et al., 2021). Along with apathy, depression is one of the most common mood disorders in Alzheimer’s disease (Nowrangi et al., 2015).

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

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

Although depression can be hard to recognize in people with dementia, there is evidence that it is common and associated with increased disability, poorer quality of life, and shorter life expectancy. Many people with dementia are prescribed antidepressants to treat depression, but it is uncertain how effective they are (Dudas et al., 2018).

Depression in older adults has been linked to dementia, although it is unclear whether it is a risk factor for dementia, or a prodromal symptom.* In some cases, depression and dementia may be caused by common risk factors such as cerebrovascular disease. In others, they may not have a connection at all and simply occur together by chance—as two separate neuropsychiatric diseases. Among depressed older adults, it is difficult to assess who may be at increased risk for developing dementia and, by extension, who would benefit from specific interventions to decrease this risk (Wiels et al., 2020).

Prodromal symptom: a term used to describe a group of symptoms that may precede the onset of a mental illness. It is not a diagnosis.

Although depression is frequently present in those with Alzheimer’s disease, it is much more common in people with Lewy Body dementia. Depressive symptoms in Alzheimer’s disease and dementia with Lewy bodies are associated with a greater cognitive decline and, in Alzheimer’s disease, significantly relate to lower survival rates over a 3-year period (Vermeiren et al., 2015).

Diagnostic Guidelines

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 preclinical dementia is difficult to diagnose accurately in early days 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 biological 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 (cerebrospinal fluid) 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. 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 are settings (University of Gothenburg, 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 with 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 are a little different in each type of dementia. It is good to know the difference to understand why someone is acting the way they are.

Diagnosis of Alzheimer’s disease and other types of dementia is based on symptoms; there is 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. (NIA, 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)

Causes, Cures, and Research Overview

The past decade has been marked by frustrating therapeutic failures that have led some to question the amyloid hypothesis as a central feature of Alzheimer's disease. The emergence of tau-related therapies, developments in biomarkers (including brain imaging and CSF- and blood-based markers) has increased awareness of the importance of neuroinflammation (Galasko & Scheltens, 2020).

A biomarker-based classification of Alzheimer's that enables detection and supports intervention before the development of cognitive decline is receiving extensive investigation. Digital biomarkers including passive sensors, wearables, and device-based testing are increasingly being studied and deployed. Neuropathological and biomarker studies are demonstrating that multiple pathologies contribute to neurodegeneration and cognitive decline (Galasko & Scheltens, 2020).

Extrinsic factors* that may contribute to brain development, resilience, reserve, and vulnerability are being widely studied. Efforts to understand Alzheimer's and related disorders from a genetic and molecular standpoint are rapidly growing. This has led to renewed attention to preclinical models of disease, from cell-based models to animal models (Galasko & Scheltens, 2020).

***Extrinsic factors**: things acting from the outside of a person such as nutrition, environment, smoking/diet, alcohol use, exercise, clutter, assistive devices, footwear, etc.

New methods of protein analysis, including cryo-electron microscopy, are providing insights into the structure of proteins, including aggregated proteins* emblematic of Alzheimer's and related disorders. Drug discovery and translation now include small molecules, immunologic therapies, and biological approaches, as well as efforts to investigate the impacts and biology of lifestyle interventions (Galasko & Scheltens, 2020).

***Aggregated proteins**: a biological phenomenon in which damaged or mis-folded proteins collect either inside or outside a cell. This is associated with many neurodegenerative diseases.

Although there is currently no "cure" for Alzheimer's disease, the Lancet Commission on Dementia Prevention, Intervention and Care Report suggests that, if nine potentially reversible risk factors are considered, up to a third of the dementia cases might be preventable. While prevention is always better than cure, this is particularly important in the field of dementia as it takes years for the Alzheimer's pathology to accumulate and current interventions are not able to modify the disease once pathology is present (Montero-Odassoet et al., 2020).

The Lancet Commission on Dementia noted a reduction of age-related incidence of dementia in several high-income countries, among those with more education or wealth. This suggests that it is possible to delay or prevent dementia. It concluded that up to 35% of dementia could be prevented by modifying nine risk factors:

1. Low education
2. Midlife hearing loss
3. Obesity
4. Hypertension
5. Late-life depression
6. Smoking
7. Physical inactivity
8. Diabetes
9. Social isolation

An important aspect of this life course conceptual framework is that modifications of risk factors can be done by lifestyle interventions, which can influence dementia decades before clinical onset (Montero-Odassoet et al., 2020).

3. Characteristics of Alzheimer's Disease and Related Dementias

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

One of the first characteristics noticeable 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. Usually, long-ago memories are still intact—this is because the areas of the brain that store long-term memories are not as affected in the early stage of 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.

A man in the early stage of memory loss. Source: NIA/NIH, public domain

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.

Promoting Research

In this course, we will describe the stages of dementia as mild, moderate, or severe. For diagnostic and research purposes, 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. Their guidelines describe the stages of Alzheimer's disease as: (1) preclinical Alzheimer's disease, (2) mild cognitive impairment, and (3) Alzheimer's dementia.

- **Preclinical Alzheimer's disease**: the stage in which changes have begun to appear in the brain but no cognitive or emotional symptoms are present.
- **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.
- **Dementia phase**: a period in which symptoms become more obvious and independent living becomes more difficult.

Source: Alzheimer's Association, 2021c.

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

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

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.

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

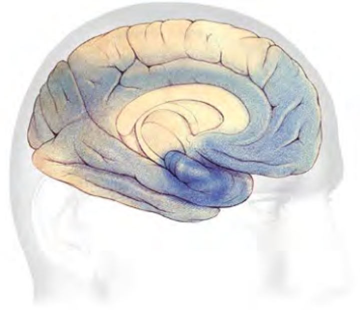
Brain Changes in Moderate Dementia

In mild to moderate stages, plaques and tangles spread from the hippocampus forward to the frontal lobes (shaded in blue). 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



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

With severe dementia, people lose memory of recent events but may still remember events from long ago. They are easily confused, have difficulty making decisions, cannot clearly communicate their needs, and have difficulty thinking logically. Speech, communication, and judgment are severely affected. Sleep disturbances and emotional outbursts are common.

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, it 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.

Did You Know

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 affected impacts 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 rattlesnake 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 might 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, 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 much 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 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 difficult. Speech, communication, and judgment are severely affected. Sleep disturbances are 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 may 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 cause death. One such condition is pneumonia, which is the most common cause of death among older adults who have Alzheimer’s or other dementias.

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 that 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, more than 11 million family members and friends provide over 15 *billion* hours of unpaid care to those with Alzheimer's and other dementias (Alzheimer’s Association, 2021b).

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.

A daughter providing care for her aging mother. Source: NIA/NIH, public domain.

Caregiving for individuals with dementia is more stressful than caregiving for individuals with many other diseases. Caring for aging adults with dementia is associated with increases in burden, distress, and declines in mental health and well-being. 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, 2021).

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 give more support to primary caregivers, they are often able to provide more help to the individual with dementia. Caregivers experience less burden and depression when family cohesion is high, and greater family communication also 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.


Daughter assisting her mother with bills. Source: NIA/NIH.

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 can 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 can 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.

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).

4. Communicating with Residents who have 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

> The 1st person with dementia I ever worked with was an older man who was also hard of hearing. We were doing some exercises that I hoped would improve his balance. I introduced myself, saying, "Hi, my name is Lauren". He responded with a smile, saying "Hi moron." I was shocked at his rudeness and didn't like being called a moron. He also didn't seem to understand that he had insulted me. It happened again with another person and I finally realized that "L" is a difficult letter to hear and my 1st client was trying his best to fill in a gap in his understanding. My sister (an ER nurse) thought it was hilarious.
>
> Physical Therapy Aide, Ft. Lauderdale, Florida

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 in an assisted living facility with 24-hour care and participates in an adult day care program each week on Monday, Wednesday, and Friday. This morning, Randy is up a little early and is waiting for breakfast in his room. Ann, a personal care assistant, 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.

Source: HealthyPeople.gov.

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 further. 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 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 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 say "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 his 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 who has 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 follow-up 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 as verbal conversation. Some residents may understand gestures better than the spoken word.

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.

Develop good communication skills by:

- Listen respectfully, giving your full attention.
- Understand cultural and generational differences.
- Provide comfort using gentle, appropriate touch* and reassurance.
- Redirect to a pleasant activity if the person is feeling anxious or upset.
- Avoid arguments.

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

Source: National Institute on Aging. Public domain.

Practice these habits:

- 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 appropriate touch to communicate your intentions.
- Avoid a condescending tone.

Communicating with Residents Who are Non-Communicative or Non-Responsive

As dementia progresses, verbal communication becomes increasingly challenging. Toward the later stages, verbal language may disappear altogether. People living with dementia may make nonverbal attempts to communicate, but these are often ignored, misinterpreted as “challenging” or judged incomprehensible. Communication difficulties are not only misinterpreted as signifying that people with dementia have nothing to contribute, but that they have lost the desire to participate in the social world (Ellis and Astell, 2017).

A lack of social interaction leads people with dementia to withdraw from social life and has a negative impact on caregivers as well. When faced with someone who has lost the ability to speak, caregivers often withdraw from those they care for. This may be due to discomfort on the part of caregivers who distance themselves as a method of coping with the demands of the situation. Finding alternative methods of communication has the potential to improve not only the quality of life of people with advanced dementia, but also the job satisfaction of care staff (Ellis and Astell, 2017).

Using nonverbal communication, such as soothing music, sounds, movements, appropriate touch, and facial expressions, has the potential to keep people with advanced dementia in the social world. Examples include:

- Encouraging participation in art: drawing, scribbling, painting
- Using scents and smells to evoke memories
- Holding hands
- Using photos and pictures
- Playing favorite music or tunes
- Singing
- Movement and dancing

Validation Therapy

Validation therapy is a type of interactive cognitive therapy developed by Naomi Feil for use in older adults with cognitive disorders and dementia. It arose from Feil’s experience as a young adult watching what she felt was the failure of reality therapy in this patient population. She developed validation therapy as a method of working with patients she described as severely disoriented.

Validation therapy focuses on accepting the reality of the person living with dementia by focusing on the emotional content of a person’s words or expressions. The aim is to reduce negative feelings and enhance positive feelings. Validation therapy is implemented through the use of certain communication techniques, including using nonthreatening words to establish understanding; rephrasing the person’s words; maintaining eye contact and a gentle tone of voice; responding in general terms when meanings are unclear; and using appropriate touch (Scales et al., 2018).

Validation theory explains that many (very) old, disoriented people, who are often diagnosed as having Alzheimer type dementia, are in the final stage of life, trying to resolve unfinished issues in order to die in peace. Their final struggle is important, and caregivers can help them. Validation techniques offer disoriented older adults an opportunity to express what they wish to express, whether it is verbal or non-verbal communication. When disoriented older adults can express the things that may have been suppressed for many years, the intensity of the feelings lessen, people communicate more, and are less likely to withdraw into further stages of disorientation (VTI, 2021).

Validation therapy states that:

1. Very old people struggle to resolve unfinished life issues before death.
2. Caregivers should use a basic, empathetic attitude that respects and values very old people without judgment.
3. Caregivers should use specific techniques for individual as well as group work, based on the needs of the individual and his or her phase of resolution (VTI, 2021).

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

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

Situations in Which Validation Therapy Is Useful

The use of validation in dementia care is a way of demonstrating to the client that their feelings, thoughts, and opinions are acknowledged and respected by the caregiver. A combination of validation and reminiscence helps confused clients experience joy from their earlier life and contributes to their overall quality of life (Zeman, 2015).

Validation therapy is useful in any situation in which a caregiver, family member, or professional must interact with a person who has dementia. Because validation therapy provides techniques for approaching and communicating with a person with dementia, it is particularly helpful in preventing a reaction that might escalate into an unwanted behavior. It is also useful for calming and diffusing challenging behaviors.

Charles Lashes Out at Frances

Frances, a physical therapist working in an assisted living facility, was wheeling her client Charles to the activities room. Charles was quiet and relaxed as they moved down the hall. About fifty feet from the activities room, Frances was stopped by two co-workers who engaged her in a conversation about another client. All three were standing behind Charles, talking animatedly. Frances placed her hand on Charles's shoulder to reassure him and he angrily pushed it away, yelling in a loud voice "Stop that!" When one of Frances's co-workers tried to calm him down, Charles yelled again and tried to hit the woman.

If Frances and her co-workers were familiar with validation therapy or another dementia-specific communication technique, they could have prevented this incident entirely. Instead of ignoring Charles and talking over him, the physical therapist might have stopped, kneeled down beside Charles, offered her upturned hand, and introduced her colleagues. She might have asked Charles if she could talk for a moment with her co-workers or included him in the conversation, while reminding her colleagues that nobody likes having people stand over them. If Charles seemed uncomfortable, she could have asked her colleagues to wait until she and Charles finished what they were doing and continued the conversation after Charles was seated at the activities table.

This is a situation that didn't need to cause Charles discomfort. If Frances and her co-workers had been respectful of Charles and validated his needs and preferences, they could have avoided upsetting him and modeled good practice for their colleagues.

Reality Orientation Therapy

> Mostly, I think the desire to "reorient" a person with dementia is that of the caregiver, not the resident. It can be really irritating when someone doesn't share your reality—it seems obvious what the date is, what town you're in, and who your daughter is. I think sometimes caregivers feel they're doing something positive when they constantly correct and remind a person experiencing memory problems. They don't understand how frustrating it is to be scolded and corrected all the time.
>
> Physical therapist, West Palm Beach, Florida, 2021

Reality therapy or reality orientation is based upon the idea that a person who has lost contact with reality can be guided back to reality and that this process will help a person accept and deal with the reality of their situation. First used with confused, older adults, it is intended to support a client's own insights into the truthfulness of their situation.

For people who are confused or disoriented, reality therapy is designed to improve cognitive and psychomotor function. It is often employed to help clients focus on their immediate surroundings. With this technique, caregivers actively and repetitively present information needed to orient clients to the time and day, as well as their environment and the people around them. This process is most helpful for the person in early stages of dementia (Zeman, 2015).

For most of us, being oriented to reality is essential. But reality orientation isn't helpful if the person is in mid- to late-stage dementia. Short-term memory loss and cognitive deficits make it impossible to remember or even understand much of this information. Trying to get the individual to focus on reality when significant confusion and cognitive loss are present can increase confusion and cause agitation (Zeman, 2015).

Joining Residents in Their Own Reality

When a person with dementia has a delusion or hallucination, or another type of challenging behavior, “getting into their reality” may allay fears, address a problem behavior, or help the caregiver figure out its cause. This often leads to simple, commonsense solutions. It also helps improve the quality of life for the individual by fostering trust in the caregiver and reducing dependence on medications to manage negative behaviors.

Validation Therapy vs. Reality Orientation

Validation therapy and reality therapy differ in a number of ways. Validation therapy deals with a person’s feelings. It is not intended to improve a person’s cognition or to delay cognitive decline. It is intended to draw people out, encourage communication, and validate a client’s personal truth. When used consistently, validation therapy can reduce the number and intensity of challenging behaviors, decrease the use of drugs used to treat these behaviors, and provide comfort to the person with dementia.

Reality orientation, on the other hand, is intended to reduce cognitive decline using repetitive activities that reinforce name, date, place, and time. It is based on the belief that continually and repeatedly telling or showing certain reminders to people with mild to moderate memory loss will result in an increase in interaction with others and improved orientation. This in turn can improve self-esteem and reduce problem behaviors (Takeda et al., 2012).

Getting into Polly’s Reality

Note: In this scenario, caregivers decided to use a “white lie” to encourage Polly’s participation in daycare activities. Lying to a resident is acceptable **only** as a last resort and if the truth leads to a poor outcome.

Introduction*: For older adults, participation in activities provides respite for family caregivers while offering socialization for residents with dementia. Sometimes, success requires a little creativity.*

Client Information*: Polly is 75 years old and lives in an assisted living facility with her husband, Mel, who still works fulltime as a lawyer. She has moderate dementia, is independent in all basic activities of daily living but is no longer able to drive, shop, or manage complex tasks without the help of her husband. Polly had worked as a secretary in a law office for almost twenty years. When she retired, still wanting to keep busy, she took a part-time job at a nursery school and volunteered at the local animal shelter. Polly described herself as a “people person.”*

Timeline*: The activity director did her part to help Mel when he called and asked about his wife participating in the facility’s activities program. Mel believed Polly would do well there. Visiting the next day, he was impressed. Polly could participate in activities for the whole time he was at work, and professionals would make sure she was safe, had a good lunch, a nap if she needed one, and activities she would enjoy. It seemed like the ideal solution, and Mel thought it would allow him to continue working for another year or two.*

Polly, however, had other plans. She did not like the idea of a “daycare center”, and especially the people she imagined were participating. She told Mel she was “not one of them.” She refused to consider it and decided she wanted to go back to work instead. She told Mel she needed to be around people, enjoy her job, and have things “like they used to be.”

Intervention*: Not knowing what else to do, Mel called the activities director for suggestions. That evening, Mel explained to Polly that her previous employer had hired another person. Her old job was gone, but if she was interested, he found another job for her. He told her he thought she would like it because she could be around a lot of other people.*

The following day he and Polly walked over to the activities center. Mel explained that it was a place for people who had problems with their memory, and they were looking for help. The director greeted them and told Polly they wanted to hire her because they needed someone to help the staff keep the people happy and engaged in activities. Her job would include talking to them, helping to set the table for lunch, handing out snacks, accompanying others to activities, and helping with pet therapy. Polly was given a tour of the activities room and was treated as if she were a prospective employee. On the tour she saw the attendees in various activities including group exercise, a reminiscence circle, and flower arranging. She also met the pet therapist, who was bringing in two beautiful dogs that Polly admired.

Discussion*: Mel was pleased that the activities center had recognized Polly’s need to “work” and their willingness to use that to encourage her participation. Of course, they knew that no real demands or expectations would be placed on Polly and that she would be encouraged to make friends and enjoy the activities. They waited to see what Polly’s decision would be.*

Client Perspective*: Polly did decide to take the “job” at the center. For a few weeks, she managed to hang on to the idea that she was there to work with the other people who had dementia. But gradually, Polly just enjoyed going to the center to see her “friends.”*

Source: Adapted with permission from Kisses for Elizabeth: A Common-Sense Approach to Alzheimer’s and Dementia (2012), by Stephanie Zeman, RN, MSN.

An individual's physical and mental condition is only part of what makes them tick. The roles they fill in contemporary life as well as their culture, ethics, spiritual beliefs, education, and the choices they made in earlier life are unique to each person. **Commonsense dementia care addresses the needs of the person with dementia, not just the dementia in the person we care for** (Zeman, 2015).

For healthcare providers working with a client who has dementia, Stephanie Zeman, in her book *Kisses for Elizabeth: A Common-Sense Approach to Alzheimer's and Dementia* (2012), recommends the following guidelines when working with a person with dementia:

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

5. 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, latest available).

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 for frail, older adults creates a tremendous burden on family and society. Currently, about half of people who need help with personal care have dementia (ADI, 2013).

For many caregivers, it takes an average of two years to acknowledge their role as a caregiver. It can be difficult for to see their caring role as separate from the relationship they have with the person for whom they care, whether that relationship is as a parent, a son or daughter, or a friend (NHS, 2014).

The largest proportion of caregivers is spouses, followed by children and children-in-law, mostly female. 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).

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

The motives for becoming a caregiver of a person with dementia are diverse, influenced by, among other things, traditional gender roles, relationships, housing, socioeconomic resources, and cultural influences. A considerable proportion of dementia caregivers indicate that they had no choice but to become an informal caregiver. Common reasons for taking on the role of a caregiver are:

- The wish to protect and enhance the wellbeing of the person in need.
- A sense of obligation to repay the care received as children.
- Care as an extension of the existing caring role within a romantic relationship. (Wiegelmann et al., 2021)

Although 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 have suggested that morbidity and mortality rates for caregivers may be **lower** than for non-caregivers. This may be due to the to the physiologic benefits of prosocial helping behaviors (Roth et al., 2018).

Despite the stress of caring for an older adult with dementia, informal caregiving can create a sense of personal accomplishment and gratification leading to feelings of intimacy and sharing. There can also be an increase in family cohesion and functionality and a sense of personal growth and purpose in life (Wiegelmann et al., 2021).

For family caregivers, moving a family member or spouse into an assisted living facility can create unique challenges. In the United States, residents in assisted living facilities tend to decline in function more rapidly than their peers in nursing homes. Reasons for decline include comorbidities, age, poorly trained caregivers, and lack of physical activity. Assisted living settings typically have barriers to keeping residents physically active, which can contribute to adverse events including falls and hospitalizations (Resnick et al., 2019).

Many assisted living facilities are smaller than nursing homes, have fewer staff, and have less open space for physical activity. Ambulation is discouraged because direct care workers and families fear residents will fall while ambulating. Residents also fear falls and consequently avoid physical activity (Resnick et al., 2019). In fact, there are more falls among residential care residents than adult daycare participants and nursing home residents (Harris-Kojetin et al., 2019).

Because the assisted living industry is primarily based on a pay-per-service model in which residents pay for services provided, payment is higher for residents who are more dependent, placing stress on family members (Resnick et al., 2019). Most residents pay out of pocket for assisted living and similar residential care communities, with a small percentage using Medicaid to help pay for services (Harris-Kojetin et al., 2019).

The expectations of care among residents and families are that direct care workers will complete necessary care tasks—such as assisting with bathing and dressing—and will protect residents from injury. Residents and families often become distressed if direct care workers provide encouragement, cueing, or minimal assistance, thus encouraging residents walk, dress, and bathe at their highest level. Once residents are no longer allowed or encouraged to perform an activity, they often lose the ability, motivation, and confidence to do so (Resnick et al., 2019).

Family Issues by Stages

In the Early Stage

When caring for or assisting a person in the early stage of dementia, family caregivers must begin to adjust to the needs of the person they are caring for. 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 burnout. Depression, along with symptoms of burnout, poor self-rated health, highly perceived stress, and lower levels of life satisfaction are factors that may begin to affect a 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.

In the Late Stages

In the late stages, as people lose the ability to communicate clearly, family caregivers often struggle to find new ways to understand the needs of their loved one. 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.

Grief and Loss

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.

In a Dutch study, researchers interviewed people living with dementia to improve their understanding of the grief and losses associated with the onset of cognitive changes and what it means to be in the world as a person affected by dementia. The people living with dementia explained that it caused profound physical changes, disrupted long-standing relationships, and changed their sense of time and place (van Wijngaarden et al., 2019).

One person described the sense of having a disrupted body, explaining that she felt the need to scrutinize her body. She said she felt a loss of control over her own body.

> *This morning, I stood in front of the mirror and, while looking at my face, closely observing it, I thought: Nothing has really changed yet. You know, I don't have that glazed, staring look you sometimes see in people with dementia. In contrast though, I pondered, within my head, the dementia has definitely changed everything! It's like a kind of grey veil has fallen over your brain and I really want to clean it up. I'll do my best but cleaning up doesn't seem to work. Talking about it, however, does, so I'm trying to be happy about that (van Wijngaarden et al., 2019).*

Another person described the grief and loss associated with disrupted relationships. He reported feeling scrutinized by the suspicious gaze of others, drifting away from significant others, and having difficulties sharing his struggle. He said he longed to be taken seriously and missed engaging in a world of peers.

> *The daily communication with my partner is becoming a problem. To put it like this: If you draw two lines, her line continues on the same level, but mine deflects in a downward curve. Clearly, our communication no longer runs in two parallel lines. As a result, I tend to withdraw. I don't really want to isolate myself, but actually that's what I do. I also feel that, at times, I don't have much to contribute anymore. More than before, I hesitate to ask or discuss things with her. That's a rotten side effect of dementia (van Wijngaarden et al., 2019).*

Yet another described a disrupted sense of space and time. She reported feeling disorientated in an alien place and feeling closed within a shrinking space. Trying to control a dreaded future filled her with grief and dread and she contemplated taking control of her future through euthanasia (van Wijngaarden et al., 2019).

> *Sometimes I'm in one of my moods, and I am worried sick about the future, not being able to organize things, occasionally taking the wrong bus or forgetting to get off, failing to remember street names, searching for words … But most times, I manage to handle myself … I try to stay active and keep doing as much as possible with the help of my iPhone and iPad (van Wijngaarden et al., 2019)*

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

Additional losses for the person living with dementia include:

- Loss of physical strength and abilities
- Cognitive changes and 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

For family caregivers, caring for a person with dementia can lead to:

- Loss of companionship and friendship
- 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, dementia-specific caregiver training, and development of a care plan.

If there is a need to move to a care home, this causes grief and loss both 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—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 2 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).

Strategies for Encouraging Family Involvement

When the person moves to an assisted living facility, family interactions and communication tend to be reduced due to work pressures, a family member living a long distance from the facility, and family members feeling they have a limited role in the provision of care. The loss of communication and social conversations can result in people with dementia feeling isolated and unable to express their needs (Moyle et al., 2014).

Nevertheless, family caregiving responsibilities do not end with the placement of a relative in an assisted living facility. Although direct care workers often assume responsibility for personal care tasks, families remain involved in other aspects of their relative's, including emotional support, social engagement, help with financial management, and advocating for quality care (Gaugler et al., 2020).

Facilitating a family caregiver's involvement is important because their well-being may influence their relative's quality of life. Social engagement, family visits, and other types of activities can improve life satisfaction and health outcomes for assisted living residents. Reducing emotional distress and negative mental health outcomes and enhancing a family's overall perceptions of—and relationships with—staff can have positive effects on resident outcomes (Gaugler et al., 2020).

One way to assist family members is to encourage involvement in a dementia care program—a multidisciplinary program designed to meet a resident's individual needs. The quality and success of a dementia care program depends on a 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.
- Encourages family involvement in the planning of activities.
- Keeps family members informed about changes in their loved one's condition.
- Keeps a log of resident activities to share with the family.
- Encourages residents to call and write to family members and friends.
- Uses technology to keep families in touch with one another.

Family inclusion refers to creating involvement of families within a care facility, by providing family members with opportunities and resources that empower them to participate actively in their relatives' life as well as in the care facility as a community. For family members, being involved may improve satisfaction with the care provided to residents and enriched their own wellbeing (Backhaus et al., 2020).

There are several barriers that hamper family inclusion. In an environment of staff shortages and scarce resources, family members are easily seen as a commodity or as a resource for augmenting staff. Nevertheless, staff often find it difficult to collaborate with family members and may consider them to be difficult or demanding. Instead of fearing that family members may increase their workload, professional caregivers should view them as a valuable resource for providing person-centered care (Backhaus et al., 2020).

While family members of people with dementia spend more time on activities to support resident care, family members of residents without dementia spend more time on their social and community engagement, often outside the facility. Particularly for family members of people with dementia, the tasks often go beyond solely visiting the relative. Instead, family members conduct caregiving tasks that could be considered a staff responsibility, which might be particularly burdensome for family members (Backhaus et al., 2020).

In care conferences (also known as case conferences or multidisciplinary team meetings), family members often occupy a "marginal position relative to staff." Instead of promoting family inclusion, often care conferences are spaces that promote "expert one-way communication." To contribute meaningfully to person-centered care, especially for people with dementia, formal care conferences should promote mutual exchange between staff and family members and should empower family members to participate as equals (Backhaus et al., 2020).

Caregiver Training and Support

> Providers who care for residents with dementia need to be specifically "dementia-trained" because of the unique challenges 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. For family caregivers / informal caregivers, training and support are critical. Training introduces caregivers to resources, support, and equipment to improve health and safety. Support reduces psychological and physical strain while delaying or avoiding transition into residential care (ADI, 2015).

An example of a successful residential caregiver support program in Australia focused on the following components:

1. Provide resources that help caregivers combat social isolation.
2. Educate caregivers about the medical aspects of dementia.
3. Explore issues regarding changes in roles and responsibilities when caring for a person with dementia.
4. Educate caregivers about techniques that encourage reminiscence and orientation to the environment.
5. Provide information about aphasia and how it affects communication, as well as swallowing issues.
6. Provide strategies for dealing with assertive, non-assertive, and aggressive behaviors, and how to cope with criticism.
7. Identify meaningful and enjoyable activities.
8. Educate caregivers about how to give personal care, focusing on washing, assistance with dressing, transfers, and incontinence.
9. Identify the benefits of exercise for both the caregiver and the person with dementia.
10. Educate caregivers about changes in diet, food intake, food preferences, and nutritional needs of people with dementia.
11. Identify and support caregiver needs including stress management and relaxation techniques.
12. Provide information about available community services, including the financial costs of these services. (Birkenhäger-Gillesse et al., 2018)

In recent years, online learning has shown promise as a tool to support and educate caregivers of people with dementia. It has shown promise in improving psychological and emotional distress for caregivers, educating caregivers about dementia and its management, enhancing caregiver's skills, and developing social networks. Programs consist of lessons on caregiver's needs, cognitive decline, daily tasks, behavioral changes, social activities, and "you as a caregiver." For example, the virtual reality intervention *Through the D'mentia Lens* enables caregivers to see what dementia is like and how people with dementia feel (Klimova et al., 2019).

A review of several studies looking at the use of online learning to support people caring for a person with dementia found that participants were satisfied with the online programs and courses because the content reduced their perceived stress and increased their empathy. The flexibility and ease of accessibility from anywhere at any time were other factors that motivated caregivers to participate. Other benefits of e-learning support involved the personalized approach, user-friendliness, avoidance of stigmatized professional (psychiatric) help, development of a social network of informal caregivers, and cost-effectiveness (Klimova et al., 2019).

Keeping a Person's Cultural Background in Mind

Although often overlooked, culture is an important factor that impacts 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 focus groups and for some, 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).

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, caregiving is so culturally ingrained that, when the time comes, care is provided without question. For Asian Americans, caregiving was described as just a normal thing to do (Pharr et al., 2014).

6. Maintaining a Therapeutic Environment

A therapeutic environment is one in which housing and healthcare services are tailored to the individual needs of each resident, utilizing a *social model of care* rather than the medical model found in many eldercare facilities. A therapeutic environment recognizes that people with dementia deserve and need kind and supportive care focused on dignity, respect, and autonomy. This approach to dementia care considers the consequences of the built environment on the well-being of residents with dementia (Rijnaard et al., 2016).

A therapeutic environment should include the following practices:

- Reduce risks, unobtrusively.
- Allow people to see and be seen.
- Reduce unhelpful stimulation.
- Optimize helpful stimulation.
- Support movement and engagement.
- Create familiar places.
- Provide opportunities to be alone and with others.
- Provide links to the community. (Fleming et al., 2020)

In a comparison of “regular” specialized care units and small, homelike specialized care units that utilized a therapeutic approach, clients in homelike care units in The Netherlands needed less support with activities of daily living, 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 their quality of life, showed less negative affect and better social relationships, and were more engaged in activities (Kok et al., 2016).

In 2021, the Joint Commission established an assisted living accreditation program to bring consensus-based standards to facilities nationwide. The standards address the environment, staffing, emergency management, dementia care, medication management, provision of care and services, and process improvement (JC, 2021).

Joint Commission accreditation requires accredited facilities to track and report on five standardized performance measures:

1. Off-Label Antipsychotic Drug Use
2. Resident Falls
3. Resident Preferences and Goals of Care
4. Advanced Care Plan/Surrogate Decision Maker
5. Staff Stability

(JC, 2021)

Dementia Friendly Care

> *Dementia friendly* means more than sticking a green leaf above a hospital bed. It means appreciating that someone with dementia may have a problem with their balance or sight but may have a better memory in some respects than you or me. It means respecting the brilliance with which those same people still sing, identify a little-known shrub, or whittle a piece of wood.
>
> Alzheimer's Disease International, 2019

Dementia friendly care focuses on the *experience* of people with dementia and advocates for positive attitudes and behaviors toward dementia. It treats 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).

Source: Courtesy Alzheimer's Disease International.

The Dementia Friendly Community movement has demonstrated, time and time again, that there is so much we can do to make life for those who have dementia and their caregivers immensely better by making them feel supported, loved, and understood by our society and, wherever possible, by empowering them in every aspect of dementia activity, including advocacy. This makes a marked contrast to feeling shunned, hidden, or ashamed (ADI, 2019).

Person-Centered Care

Person-centered care, an important component of dementia friendly care, relies on the skill, training, and knowledge of an organization and its caregivers. Organizational policies and procedures and caregiver practices are built around the needs and preferences of the resident, the care professional, and family caregivers.

Person-centered care is flexible, creative, and supportive. It promotes inclusion of the people living with dementia and their caregivers in care and treatment decisions, with the aim of increasing positive outcomes (Handley et al., 2015). Person-centered care is the opposite of **task-centered care**. In dementia care, it involves practices aimed at helping residents establish relationships and be treated as individuals 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, where daycare services and 24-hour nursing home care is available for people with dementia. Green care farms offer a selection of activities, including caring for plants and animals, and encourages residents to engage in tasks suited to their level of dementia and physical capabilities (de Boer et al., 2015).

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 are a unique type of small-scale facility that provides nursing home care for people with dementia in a home-like environment on the terrain of a farm. 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).

This preference is seen in residential facilities as well. In a case study conducted for Alzheimer's Disease International, researchers focused on a cost-benefit analysis of outdoor spaces at an assisted living facility in Tennessee. The study assessed environmental features related to outdoor satisfaction. Residents reported satisfaction with outdoor areas, feeling better after being outdoors, and satisfaction with the amount of time spent outdoors. Costs were estimated for improvements to four features most often described as problematic: doorways, unsafe walkways, inadequate seating, and lack of shade. Links were drawn between a resident's satisfaction with the outdoor spaces, their well-being, and their willingness to refer others to the facility. Financial benefits to the facility included increased annual income resulting from increased revenue from new referrals and decreased spending on marketing (Fleming et al., 2020).

Staff as Part of the Environment

Blending staff into the assisted living environment can be challenging. There are no "magic bullets" aimed at changing staff care practices to improve resident outcomes. Although person-centered care is increasingly accepted as a philosophical approach in residential care, it is not clear whether staff and organizational practices are changing, or whether proposed changes are improving quality of care or resident outcomes (Low et al., 2015).

The importance of having sufficient, competent staff to ensure quality of care is a major concern. High turnover, job dissatisfaction, and difficulties recruiting qualified staff are common challenges in all facilities that care for frail older adults. Many factors impact job satisfaction with quality care, which can make it difficult to effectively blend staff into the assisted living environment. These can include:

- Unclear roles and functions
- Heavy workloads
- Demanding work schedules
- Difficult ethical issues
- Job strain, stress of conscience, and burnout (Vassbø et al., 2019)

The Physical Environment

Careful consideration of the physical environment in residential care eases the transition for new residents (ADI, 2020). Unfamiliar, chaotic, or disorganized environments—whether at home or in a residential care facility—are stressful and can cause anxiety, disorientation, and behavioral problems.

A well-designed physical environment can have a positive impact on people with (and without) dementia. The facility layout, sound levels, and access to outdoor areas can improve sleep, orientation, activity, and overall well-being (Nordin, McKee, Wijk, & Elf, 2017). People with dementia rely on environmental cues to support them physically, cognitively, and emotionally.

For people with dementia living in a residential care facility, most of their time is spent inside. They depend on the physical environment to support their activities and social interactions. A high-quality physical environment encourages well-being, safety, and independence and supports person-centered care by creating a sense of home (Nordin, McKee, & Wallinder, 2017).

Thoughtfully designed **indoor** spaces can reduce unwanted behaviors and enhance a sense of well-being. This can include:

- Open plans, automatic doors, and elevators in buildings to facilitate resident movement in communal areas and between floors (Nordin, McKee, & Wallinder, 2017).
- Public spaces and places for semi-private interactions.
- Spaces clean and free of odors.
- Sunlight, ventilation (no dark nooks and crannies).
- Views to the outside.
- Safety devices in apartments and dining rooms (Nordin, McKee, & Wallinder, 2017).
- Spaces that cue specific behaviors (activity kitchen, art and music therapy area, bistro/bar, rummaging room, library, coffee shop/internet café, quiet room, living room).

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

Thoughtfully designed **outdoor** areas are just as important. This can include:

- Arranging outdoor spaces to resemble a natural community.
- Creating continuous circulation routes with looping pathways, rest stops, and areas of interest.
- Including residents 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.

Elements of the physical environment that support residents' cognitive functioning need to be considered in the design process and should also be given special attention in existing facilities. Understanding how the physical environment can support older people's cognitive health allows care staff to improve care practices (Nordin, McKee, Wijk, & Elf, 2017).

Safety and Security

Assisted living facilities must provide an appropriate environment, adequate, trained staff, and plan for adverse events. These are essential components of a safe and secure environment. People with dementia need to feel safe (and be safe) without the use of physical and chemical restraints.

The *National Patient Safety Foundation* (NPSF) defines patient safety as "freedom from accidental or preventable injuries or harm produced by medical care." This includes preventing elder abuse and examining the factors that foster an unsafe environment for both residents and staff. Administrators are legally and morally responsible for ensuring that quality and safety standards are met (Myhre et al., 2020).

The NPSF says a "culture of safety" should include these elements:

- An established and sustained safety culture.
- Centralized and coordinated oversight of patient safety.
- Common safety metrics that reflect meaningful outcomes.
- Adequate support for the healthcare workforce.
- Client and family partnerships focused on the safest care.
- Technology that is safe and optimized for patient safety. (NPSF, 2015)

Although assisted living was originally conceived to provide non-medical, independent living in a home-like environment, nearly half of people currently residing in an assisted living facility in the United States have some sort of dementia. This means that sensory and motor changes such as reduced hearing, loss of visual acuity, and decreased strength and flexibility are common. Judgement and decision-making are also affected by dementia, making safety an important and ongoing concern.

In a well-run facility, simply receiving care can be beneficial for a person with dementia. Having regular contact with a well-trained caregiver can provide a sense of safety and security. A well-designed and well-run facility is secure, comfortable, and predictable; it is a place where residents feel at ease—a place where you can be who you are and feel connected with like-minded people (Rijnaard et al., 2016).

Assisted living facilities, however, vary widely in the number and structure of available services. Some facilities have 24-hour on-call assistance as well as on-call nursing assistance—others do not. Some facilities coordinate care with external home health agencies and allow residents to hire personal care assistants externally (AGS, 2020).

A safe environment also includes features such as proper flooring, handrails, and adequate lighting. The table below illustrates some common safety hazards and measures to help make the environment safe and secure. Interventions should 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.	• Provide short, looping corridors without dead ends. • Create open, common areas of interest. • Create safe, outdoor wandering areas. • 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. • Keep a working fire extinguisher. • Create a work area with an activity kitchen.
Falls	Injury	• Eliminate clutter. • Install handrails in showers and hallways. • Wipe up spills promptly. • Maintain physical activity. • Provide many places to sit.
Poisoning	Sickness or death	• Remove toxic plants. • Lock up chemicals and medications.

An often-overlooked safety issue in eldercare facilities is elder abuse. In a survey of patient safety in 12 nursing homes in Norway, researchers sought to understand elder abuse and neglect as an important aspect of safety and security. They noted three major abuse themes:

1. **Abuse from co-residents**—often described as "a normal part of nursing home life." Resident-to-resident aggression appeared to be so commonplace that care leaders perceived it as normal and had no strategy for handling it.

2. **Abuse from relatives**—often treated as a private affair. A relative engaging in abusive behavior when visiting a resident was described as a "difficult issue" but something that should be kept between the resident and the relative.

3. **Abuse from direct-care staff**—considered "an unthinkable event." Staff-to-resident abuse was difficult to talk about and viewed as not being in accordance with the leaders' trust in their employees. (Myhre et al., 2020)

The COVID-19 pandemic has uncovered huge gaps in the safety and security of residents in nursing homes and assisted living facilities. As of October 15, 2020, an average of 1 death occurred among every 5 assisted living residents with COVID-19, compared with 1 death among every 40 persons in the general population with COVID-19 in states with available data (Yi et al., 2020).

Schedules and Routines

Schedules and routines are an important part of everyone's life. However, when someone enters a facility, 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).

Schedules and routines are often organized around the convenience of the staff, and schedules can change dramatically from day to day. This is difficult for people with dementia because they rely on a predictable routine for orientation and to know what to expect. Routines also give the caregivers a benchmark for evaluating a person's behavior. 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 a resident often precipitates aggressive behaviors that frustrate both parties.

A schedule for someone with dementia should:

- Be carefully planned.
- Consider a person's capabilities and preferences.
- Maintain familiar routines and schedules.
- Maintain regular dental and healthcare appointments.
- Allow plenty of time.
- Note the effects of changes in routines.
- Consider physical issues that disrupt routines such as pain, fatigue, or illness.

Staff Training

> Many people with dementia are advocating for the phasing out all institutional care, the cessation of segregation in locked dementia units, and for all healthcare staff to be fully competent in dementia as well as disability.
>
> Alzheimer's Disease International, 2019

Lack of staff training is a significant problem in the assisted living environment, and in many states, staff qualifications are not mandated. Many states stipulate direct care worker training content, but they may not have enough required training hours (or any specific required training hours) to cover the designated content. Staffing requirements for assisted living facilities also varies by state. If licensed care is needed, some states allow it to be provided remotely (Trinkoff et al., 2020).

No state mandates training related to the role of a personal care assistant, such as their role on the care team, appropriate boundaries, or encouraging client independence in self-care and other activities. There is no standard training for direct care workers in assisted living that allows them to fully grasp their role in nonmedical settings. There is no standard training for these workers on empowering clients to maintain function, health, and well-being (Kelly et al., 2018). Barriers to implementing improvements in training include cost, senior leadership resistance, low-innovation culture, low staff education, and high staff turnover (Low et al., 2015).

Staff Training in Assisted-living Residences (STAR) is a program developed specifically to educate staff about resident behaviors using a structured, individualized approach. First and foremost, staff are taught to understand how dementia affects the brain and how these changes affect memory, mood, and behaviors (Teri et al., 2010).

During training, staff are encouraged to develop the following skills:

- Be a good, caring listener.
- Be calm, consistent, and flexible.
- Be patient and supportive.
- Be honest and respectful.
- Be humorous. (Teri et al., 2010)

The STAR program is structured but flexible. It is designed to teach direct care staff in assisted living strategies and techniques to improve the care of residents with dementia. Staff are taught to use the **ABC approach** to address behavioral problems in residents with dementia (Teri et al., 2010).

The ABC or problem-solving approach encourages caregivers to look for and address the root cause of a behavior—usually with environmental modification, medication management, or caregiver training. This approach encourages caregivers to identify critical points for intervention based on observing the antecedent (activator), behavior, and consequence (A, B, C) of a challenging behavior.

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

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

Proper Staffing

Throughout the United States, about half a million people work in an assisted living facility. Among the nearly 1.5 million nurses and social workers in long-term care, about 300,000 are employed full-time at an assisted living community. Assisted living communities also hire part-time nursing and social work employees, or contract with other organizations to coordinate nursing and social work services in the community. The breakdown of full-time nursing and social work employees in assisted living is as follows (NCAL, 2020):

- 83.3% aide
- 9.9% licensed practical or vocational nurse
- 6.1% registered nurse
- 0.8% social worker

In the United States, aides provide nearly 85% of the nursing care to residents. On a typical day in residential care, the average time spent with a resident each day by nursing staff (overwhelmingly aides) is about two-and-a-half hours. The average staff hours per resident or participant per day in a residential care facility is 19 minutes. The average social work hours per resident is just 2 minutes per day (Harris-Kojetin et al., 2019).

In Florida, every assisted living facility is under the supervision of an administrator who is responsible for its operation and maintenance, including the management of staff and the provision of adequate care to all residents. Facilities must employ direct care staff. A staff member who has completed courses in first aid and cardiopulmonary resuscitation must be always in the facility (ASPE, 2015).

In **nursing homes**, most direct patient care is provided by certified nursing assistants (CNAs), who are subject to federal regulations and are trained and certified through state nurse aide registries or boards of nursing. There is a mandatory federal curriculum for CNA training (Trinkoff et al., 2020).

Assisted living facilities by contrast mostly employ **unlicensed** direct care workers to provide personal care and daily services. Direct care workers are not subject to regulation by most nurse aide registries or boards of nursing. Training hour requirements are diverse across states, with 17 states requiring direct care workers to be trained but without specific training hour requirements, while other states mandate the number of training hours (Trinkoff et al., 2020).

In Florida, training for direct care workers includes first aid, fire and environmental safety, basic nursing and personal care skills, resident rights and dignity, basic restorative services, and population-specific needs (e.g., for residents who are mentally ill, cognitively impaired, frail, or have chronic conditions) (Trinkoff et al., 2020).

Dissatisfaction with work can result in lower loyalty to the workplace and an increased probability of leaving the workplace. 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 (Vassbø et al., 2019).

A person-centered approach has been shown to **decrease** staff turnover, improve 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).

Staff Adjusting to Resident Routines

> Forget dementia, remember the person!
>
> Alzheimer's Disease International, 2019

For those who do not live with dementia, it can be difficult to understand what it might be like for someone experiencing changes in their brain, or to comprehend the way in which communication and the environment around them impacts on their cognitive function (ADI, 2019). This is especially important when considering the difference between staff routine and resident routine.

A diagnosis of dementia often leads to a profound change in a resident's routine activities. Although many people are still capable, they are often forced to give up many familiar routine activities (ADI, 2019).

Resident routines are usually centered on tasks and activities. Ideally, residents are cared for by a small, fixed team of trained caregivers and activities are organized completely, or in large part, by residents and caregivers.

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 residents.
- Limit signage for staff and visitors.
- De-emphasize or camouflage doors to staff and utility areas.
- Keep staff consistent.

7. Ethical Issues with Residents with Dementia

Principles are general categories, rules, or guidelines that form the basis of a discipline. In ethics, there are various kinds of principles that include **basic ethical categories** (e.g., virtues, values, or rights), **ethical commands or rules of conduct** (e.g., not stealing, not harming, or treating others with respect), and **guidelines for weighing outcomes** (e.g., achieving the greatest good for the greatest number, distributing burdens and benefits fairly, or properly proportioning benefit to harm) (Ortmann et al., 2016).

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.

Research conducted with participants living with dementia raises important ethical questions, such as how to protect cognitively impaired persons against exploitation, how to design informed consent procedures with proxies, how to disclose risk-factors for dementia given the lack of evidence for their reliability, and how to apply risk–benefit considerations in such cases (Götzelmann et al., 2021).

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. Residents must be told the truth about their condition and informed about the risks and benefits of treatment. Residents 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.

Avoid Generalizations About Your Residents

A dementia diagnosis does not imply the incapacity to make decisions, nor should it be the basis for assumptions regarding the person’s cognitive ability. In general, dementia is a progressive illness, but symptoms can vary from person to person. The progression is not necessarily linear, so knowing a person’s typical presentation should not lead to a sweeping generalization of their cognitive deficit. There can be high variation day-to-day and even hour-by-hour, with some people experiencing sporadic bouts of confusion or lucidity.

Source: Silva, Cascio, & Racine, 2020.

Empowering a person with dementia in decision-making is an effort to retain their autonomy, and it allows them to act as their own agent as much as possible. Specifically, in dementia research, **empowerment** in decision-making allows participants to make any decision they are cognitively able to and provides participants with assistance in the decision-making processes if needed (Silva, Cascio, & Racine, 2020).

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, 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

> A stark number of 65+ are aging into poverty. At the same time, due to racial inequities, there is unequal access to services and supports in our aging service delivery.
>
> Janet Y. Spears
>
> Advancing Equity in Aging

Justice (equity and fairness) is often defined as a fair distribution of benefits and burdens, particularly in connection with misfortunes for which we cannot be held personally responsible. *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 (Nuffield Council, 2009).

Given the vulnerability of people with dementia, a fair and equitable allocation of resources is important to assure access to good care. Partly, this is 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 promotes and sustains people with dementia throughout the course of their dementia and helps them maintain their independence as much as possible (Nuffield Council, 2009).

When considering justice, equity, and fairness as they relate to the delivery of care, a conflict arises because resources are limited. In the U.S., equal access to healthcare does not exist, creating an ongoing concern about the distribution of resources, particularly as the population ages and the demand for services increases. Because assisted living is primarily private pay, the burden falls upon individuals, no matter their ability to pay.

For groups who have experienced histories of marginalization and discrimination and who continue to experience higher rates of illness and premature deaths than members of the mainstream population, achieving justice and equity is urgent (Ortmann et al., 2016).

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, 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, 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).

Recently, the use of intelligent assistive technology (IAT) has raised ethical issues in their use with people with dementia. Traditionally, assistive technologies involved mostly cognitive aids to support memory, aphasia, and agnosia; physiologic sensors to detect vitals and falls; environmental sensors to detect movement; and advanced security systems. Newer technology includes devices for assistance with activities of daily living, systems for cognitive and emotional assistance, health and behavioral monitoring, social interaction and engagement, remote communication, emergency alarms, and mobility aids (Wangmo et al., 2019).

Intelligent assistive technologies for people with dementia raise many ethical challenges. These technologies are designed for vulnerable older individuals with cognitive disability, who often lack the capacity to consent to their use. The devices collect large amounts of potentially sensitive, personally identifiable data including a person’s medical information and behavioral videos. Wearable IATs operate in close proximity to the patient’s body and may involve varying degrees of artificial intelligence, raising multiple ethical challenges (Wangmo et al., 2019).

A systematic review has observed that 67% of current IATs for dementia are designed in absence of an explicit ethical assessment. This raises concerns about the ethical viability of using these technologies with vulnerable individuals. Among the portion of IATs that did include ethical assessment, primary attention was devoted to respecting the autonomy of patients, preventing harm (**non-maleficence**) and promoting overall good (**beneficence**) (Wangmo et al., 2019).

Ethical concerns such as ensuring fair technology access (**distributive justice**) and preserving by design the privacy of end-users and their data appear underrepresented. The focus on autonomy is unsurprising considering that the need for IATs is often predicated upon the value of empowering older adults with dementia by increasing their independence and prolonging their independent living. Two previous reviews highlighted the importance of issues of informed consent, autonomy, privacy, data security, and affordability as key ethical concerns when using IATs among people with dementia. Other ethical concerns include stigma, social isolation, lacking user-engagement in the design of the technology as well as the ethical dilemma about whether IATs would and should replace human care (Wangmo et al., 2019).

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 the 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.

Justice, Fairness, and Equity

Alycia is a 68-year-old Black woman who has been living independently in an assisted living facility in Florida. She has been able to pay the monthly fee for her room and board but without much left over each month. Over the past year, she experienced increasing difficulty with her balance and fell several times. She was afraid to tell anyone, so she reduced her physical activity, and limited her social participation in facility activities.

Alycia worked her entire life as a waitress and was never able to save much money. Prior to moving into assisted living, she spent more than 10 years caring for her husband. She was unable to hire a caregiver and was forced her to cut back on her hours at work. After her husband died, Alycia sold her modest home in a quiet area of West Palm Beach for $185,000. She moved to an assisted living facility, which costs her $3,850 per month. She has calculated she could afford to live in assisted living for about 4 years before her money runs out.

Alycia did okay at first, then, after breaking her arm in a fall, she realized she was going to need help with some of her daily living tasks. She noticed that one of her neighbors had someone come in to help with shopping, bathing, and exercises. She was interested in hiring the helper but learned that it would cost $15/hour. She knew she couldn't afford that, so she decided to go without.

Alycia managed to get by for another year, not sharing her difficulties with anyone in the facility. During that time, she experienced some cognitive changes—she couldn't figure out how to work the TV and had difficulties with the phone. Normally a fastidious woman who prided herself on her appearance, she stopped bathing and stayed in bed or in her recliner most of the day.

One day she was found on the floor next to her bed, incontinent and confused. She was admitted to the hospital with a broken hip, dehydration, and delirium. After surgery and a 3-week stay in rehab, she was admitted to a local nursing home.

Questions

> *1. Is it fair or equitable that some people can afford private-pay help in an assisted living facility while others cannot?*
>
> *2. Do you think Alycia could have had a better outcome if she had been able to afford a regular caregiver?*
>
> *3. Does Florida pay for private caregivers in assisted living facilities?*

Discussion*: The uneven distribution of care and assistance is an example of* ***distributive justice****. When supply is low or costly, many will be unable to get needed help. In Florida, the average yearly out-of-pocket cost for a person living in an assisted living facility is $44,400 and can be much higher.*

Adverse health conditions are disproportionately associated with race, ethnicity, occupation, and socioeconomic status. A higher burden is experienced by Black Americans and other minority groups, which reflects the impacts of systemic racism and socioeconomic factors. These social groups also experience health inequities, defined as "systematic differences in the health status of different population groups" (NAP, 2020).

Alycia may be eligible for financial assistance from the State of Florida through the Optional State Supplements program. The State may supplement her income to cover room, board, and other services provided by the ALF or other authorized facility. This supplementation will be combined with Alycia's SSI or disability benefits—not exceed an amount set by the State (FLDOEA, 2016).

8. References

Alzheimer's Association (**AA**). (2021a). Frontotemporal Dementia. Retrieved March 31, 2021 from https://www.alz.org/alzheimers-dementia/what-is-dementia/types-of-dementia/frontotemporal-dementiautm_source=google&utm_medium=paidsearch&utm_campaign=google_grants&utm_content=types_of_dementia&gclid=EAIaIQobChMIopfqisa36wIVB7zACh3-ZQKTEAAYASAAEgLwq_D_BwE.

Alzheimer's Association (**AA**). (2021b). 2021 Alzheimer's Disease Facts and Figures. Retrieved March 31, 2021 from https://www.alz.org/alzheimers-dementia/facts-figures.

Alzheimer's Association (**AA**). (2021c). Earlier Diagnosis. Retrieved March 31, 2021 from http://www.alz.org/research/diagnostic_criteria/.

Alzheimer's Disease International (**ADI**). (2020). World Alzheimer Report 2020, Volume 1. Design, dignity, dementia: Dementia-related design and the built environment. Retrieved April 10, 2021 from https://www.alzint.org/u/WorldAlzheimerReport2020Vol1.pdf.

Alzheimer's Disease International (**ADI**). (2019). World Alzheimer Report 2019. Attitudes to Dementia. Retrieved April 2, 2021 from https://www.alzint.org/u/WorldAlzheimerReport2019.pdf.

Alzheimer's Disease International (**ADI**). (2015). The Global Impact of Dementia: An Analysis of Prevalence, Incidence, Cost and Trends. Retrieved April 2, 2021 (latest available) from https://www.alzint.org/resource/world-alzheimer-report-2015/.

Alzheimer's Disease International (**ADI**). (2013, latest available). World Alzheimer Report. A Journey of Caring, an Analysis of Long-term Care for Dementia. Retrieved April 6, 2021 from https://www.alz.co.uk/research/world-report-2013.

American Geriatrics Society (**AGS**). (2020). American Geriatrics Society (AGS) policy brief: COVID-19 and assisted living facilities. *Journal of the American Geriatrics Society* 68(6). Doi:10.1111/jgs.16510. Retrieved March 29, 2021 from https://agsjournals.onlinelibrary.wiley.com/doi/10.1111/jgs.16510.

Assistant Secretary for Planning and Evaluation (**ASPE**). (2015). Compendium of Residential Care and Assisted Living Regulations and Policy: 2015 Edition: Florida. Retrieved May 25, 2021 from https://aspe.hhs.gov/system/files/pdf/110441/15alcom-FL.pdf.

Atri A. (2019, March). The Alzheimer's disease clinical spectrum: Diagnosis and management. medical clinics of North America 103(2): 263–93. Retrieved April 6, 2021 from https://www.sciencedirect.com/science/article/pii/S0025712518301317?via%3Dihub.

Backhaus R, Hoek LJM, de Vries E, et al. (2020). Interventions to foster family inclusion in nursing homes for people with dementia: A systematic review. *BMC Geriatr* 20(434). Doi:10.1186/s12877-020-01836-w. Retrieved April 9, 2021 from https://bmcgeriatr.biomedcentral.com/articles/10.1186/s12877-020-01836-w.

Birkenhäger-Gillesse EG, Kollen BJ, Zuidema SU, et al. (2018). The "more at home with dementia" program: A randomized controlled study protocol to determine how caregiver training affects the well-being of patients and caregivers. *BMC Geriatr* 18(252). Doi:10.1186/s12877-018-0948-3. Retrieved April 20, 2021 from https://bmcgeriatr.biomedcentral.com/articles/10.1186/s12877-018-0948-3#Sec22.

Centers for Disease Control and Prevention (**CDC**). (2020, May 29). Considerations for Preventing Spread of COVID-19 in Assisted Living Facilities. Retrieved March 23, 2021 from https://www.cdc.gov/coronavirus/2019-ncov/hcp/assisted-living.html.

Cloak N, Al Khalili Y. (2020, January). Behavioral and Psychological Symptoms in Dementia. [Updated 2020, Nov 17]. In: *StatPearls*. Treasure Island (FL): StatPearls Publishing. Retrieved April 6, 2021 from https://www.ncbi.nlm.nih.gov/books/NBK551552/.

Cornell B. (2016). Cerebral Hemispheres. *BioNinja*. Retrieved April 8, 2021 from https://ib.bioninja.com.au/options/option-a-neurobiology-and/a2-the-human-brain/cerebral-hemispheres.html.

de Boer B, Verbeek H, Zwakhalen SMG, et al. (2019). Experiences of family caregivers in green care farms and other nursing home environments for people with dementia: A qualitative study. *BMC Geriatr* 19(149). Doi:10.1186/s12877-019-1163-6. Retrieved April 6, 2021 from https://bmcgeriatr.biomedcentral.com/articles/10.1186/s12877-019-1163-6#Sec16.

de Boer B, Hamers JPH, Beerens HC, et al. (2015). Living at the farm, innovative nursing home care for people with dementia—study protocol of an observational longitudinal study. *BMC Geriatrics* 15(144). Doi:10.1186/s12877-015-0141-x. Retrieved July 6, 2021 from http://bmcgeriatr.biomedcentral.com/articles/10.1186/s12877-015-0141-x.

DeMarshall C, Oh E, Kheirkhah R, et al. (2019). Detection of early-stage Alzheimer's pathology using blood-based autoantibody biomarkers in elderly hip fracture repair patients. *PLoS ONE* 14(11): e0225178. Doi:10.1371/journal.pone.0225178. Retrieved April 6, 2021 from https://journals.plos.org/plosone/article?id=10.1371/journal.pone.0225178.

Desrosiers J, Viau-Guay A, Bellemare M, et al. (2014). Relationship-Based Care and Behaviours of Residents in Long-Term Care Facilities. *Current Gerontology and Geriatrics Research* 2014. Article ID 949180. Doi:10.1155/2014/949180. Retrieved March 31, 2021 from http://www.hindawi.com/journals/cggr/2014/949180/.

Diamond J. (2015). Depression: Gender Matters. Retrieved April 8, 2021 from https://www.atrainceu.com/content/082-depression-gender-matters-course-intro.

Dudas R, Malouf R, McCleery J, Dening T. (2018). Antidepressants for treating depression in dementia. *Cochrane Database Syst Rev*. 8(8):CD003944. Doi:10.1002/14651858.CD003944.pub2. Retrieved April 8, 2021 from https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6513376/.

Ellis M, Astell A. (2017) Communicating with people living with dementia who are nonverbal: The creation of Adaptive Interaction. *PLoS ONE* 12(8): e0180395. Doi:10.1371/journal.pone.0180395. Retrieved August 9, 2021 from https://journals.plos.org/plosone/article?id=10.1371/journal.pone.0180395.

Elnasseh AG, Trujillo MA, Peralta SV, et al. (2016). Family dynamics and personal strengths among dementia caregivers in Argentina. *International Journal of Alzheimer's Disease*, Article ID 2386728. Doi:10.1155/2016/2386728. Retrieved April 8, 2021 from https://www.hindawi.com/journals/ijad/2016/2386728/.

Fleming R, Zeisel J, Bennett K. (2020). World Alzheimer Report 2020: Design dignity dementia: Dementia-related design and the built environment. Volume 1, London, England: Alzheimer's Disease International. Retrieved March 29, 2021 from https://www.alzint.org/u/WorldAlzheimerReport2020Vol1.pdf.

Florida Agency for Health Care Administration (**FLAHCA**). (2020, December 1). Assisted Living Facility Directory. Retrieved February 10, 2021 from https://ahca.myflorida.com/mchq/health_facility_regulation/assisted_living/docs/alf/Directory_ALF_12.7.20.pdf.

Florida Agency for Health Care Administration (**FLAHCA**) (n.d.). Consumer guides: Assisted living in Florida. Retrieved February 8, 2021 from https://www.floridahealthfinder.gov/reports-guides/assisted-living.aspx#WhatAre.

Florida Department of Elder Affairs (**FLDOEA**). (2016). Older Floridians Handbook. Laws and Programs Affecting Older Floridians, 6th Edition. Retrieved September 7, 2021 from https://www.floridajusticeinstitute.org/wp-content/uploads/2016/06/OFHandbook-2016_web-07127475xB3B17.pdf.

Galasko D, Scheltens P. (2020). A decade of Alzheimer's research and therapy: Reflections on the past, present, and future. *Alz Res Therapy* 12(67). Doi:10.1186/s13195-020-00629-y. Retrieved March 23, 2021 from https://alzres.biomedcentral.com/articles/10.1186/s13195-020-00629-y#citeas.

Gaugler JE, Statz TL, Birkeland RW, et al. (2020). The Residential Care Transition Module: A single-blinded randomized controlled evaluation of a telehealth support intervention for family caregivers of persons with dementia living in residential long-term care. *BMC Geriatr* 20(133). Doi:10.1186/s12877-020-01542-7. Retrieved April 21, 2021 from https://bmcgeriatr.biomedcentral.com/articles/10.1186/s12877-020-01542-7#Sec1.

Giebel C. (2020). Current dementia care: What are the difficulties and how can we advance care globally? *BMC Health Serv Res* 20(14). Doi:10.1186/s12913-020-05307-1. Retrieved April 8, 2021 from https://bmchealthservres.biomedcentral.com/articles/10.1186/s12913-020-05307-1.

Götzelmann TG, Strech D, Kahrass H. (2021). The full spectrum of ethical issues in dementia research: Findings of a systematic qualitative review. *BMC Med Ethics* 22(32). Doi:10.1186/s12910-020-00572-5. Retrieved April 6, 2021 from https://bmcmedethics.biomedcentral.com/articles/10.1186/s12910-020-00572-5.

Grand View Research (**GVR**). (2021). U.S. Assisted Living Facility Market Size, Share and Trends Analysis Report, and Segment Forecasts, 2021–2027. Retrieved June 29, 2021 from https://www.grandviewresearch.com/industry-analysis/us-assisted-living-facility-market.

Handley M, Bunn F, Goodman C. (2015). Interventions that support the creation of dementia friendly environments in health care: Protocol for a realist review. Systematic Reviews 4(180). Doi:10.1186/s13643-015-0168-2. Retrieved March 31, 2021 from https://systematicreviewsjournal.biomedcentral.com/articles/10.1186/s13643-015-0168-2.

Harris-Kojetin L, Sengupta M, Lendon JP, et al. (2019). Long-term care providers and services users in the United States, 2015–2016. National Center for Health Statistics. *Vital Health Stat* 3(43). Retrieved April 22, 2021 from https://www.cdc.gov/nchs/data/series/sr_03/sr03_43-508.pdf.

Jack CR, Bennett DA, Blennow K, et al. (2018). NIA-AA Research Framework: Toward a biological definition of Alzheimer's disease. *Alzheimer's & Dementia* 14:535–62. Retrieved April 6, 2021 from https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5958625/.

Jang Y, Kang C, Myung W, et al. (2021). Additive interaction of mid- to late-life depression and cerebrovascular disease on the risk of dementia: A nationwide population-based cohort study. *Alz Res Therapy* 13(61). Doi:10.1186/s13195-021-00800-z. Retrieved July 6, 2021 from https://alzres.biomedcentral.com/articles/10.1186/s13195-021-00800-z#Abs1.

Joint Commission, The. (2021). The Joint Commission launches new Assisted Living Community accreditation program. Retrieved September 7, 2021 from https://www.jointcommission.org/resources/news-and-multimedia/news/2021/05/the-joint-commission-launches-new-assisted-living-community-accreditation-program/.

Kelly C, Craft Morgan J, Kemp CL, et al. (2018). A Profile of the Assisted Living Direct Care Workforce in the United States. *Journal of Applied Gerontology* 39(1). Retrieved May 25, 2021 from https://journals.sagepub.com/doi/10.1177/0733464818757000?url_ver=Z39.88-2003&rfr_id=ori%3Arid%3Acrossref.org&rfr_dat=cr_pub++0pubmed&.

Kidder RM. (1996). How Good People Make Tough Choices: Resolving the Dilemmas of Ethical Living. New York: Wm. Morrow.

Klimova, B., Valis, M., Kuca, K. et al. (2019). E-learning as valuable caregivers' support for people with dementia : A systematic review. *BMC Health Serv Res* 19(781). Doi:10.1186/s12913-019-4641-9. Retrieved April 21, 2021 from https://bmchealthservres.biomedcentral.com/articles/10.1186/s12913-019-4641-9.

Kok JS, van Heuvelen MJG, Berg IJ, Scherder EJA. (2016). Small scale homelike special care units and traditional special care units. Effects on cognition in dementia: A longitudinal controlled intervention study. *BMC Geriatrics* 16(47). Doi:10.1186/s12877-016-0222-5. Retrieved April 6, 2021 from http://bmcgeriatr.biomedcentral.com/articles/10.1186/s12877-016-0222-5.

Low LF, Fletcher J, Goodenough B, et al. (2015). A Systematic Review of Interventions to Change Staff Care Practices in Order to Improve Resident Outcomes in Nursing Homes. *PLoS One*. 2015;10(11):e0140711. Doi:10.1371/journal.pone.0140711. Retrieved April 22, 2021 from https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4641718/.

Lumen Learning. (nd). Cerebral Hemispheres and Lobes of the Brain. Retrieved April 8, 2021 from https://courses.lumenlearning.com/teachereducationx92x1/chapter/cerebral-hemispheres-and-lobes-of-the-brain/.

Monk TH, Pfoff MK, Zarotney JR. (2013). Depression in the spousally bereaved elderly: Correlations with subjective sleep measures. *Depression Research and Treatment*. Article ID 409538. Doi:10.1155/2013/409538. Retrieved April 8, 2021 from http://www.hindawi.com/journals/drt/2013/409538/.

Montero-Odasso M, Ismail Z, Livingston G. (2020). One-third of dementia cases can be prevented within the next 25 years by tackling risk factors: The case "for" and "against." *Alz Res Therapy* 12(81). Doi:10.1186/s13195-020-00646-x. Retrieved March 23, 2021 from https://alzres.biomedcentral.com/articles/10.1186/s13195-020-00646-x.

Moyle W, Jones C, Cooke M, et al. (2014). Connecting the person with dementia and family: A feasibility study of a tele-presence robot. *BMC Geriatrics*, 14(7). Doi:10.1186/1471-2318-14-7. Retrieved April 8, 2021 from http://bmcgeriatr.biomedcentral.com/articles/10.1186/1471-2318-14-7.

Myhre, J., Saga, S., Malmedal, W. et al. (2020). Elder abuse and neglect: An overlooked patient safety issue. A focus group study of nursing home leaders' perceptions of elder abuse and neglect. *BMC Health Serv Res* 20(199). Doi:10.1186/s12913-020-5047-4. Retrieved April 6, 2021 from https://bmchealthservres.biomedcentral.com/articles/10.1186/s12913-020-5047-4.

National Academies Press (**NAP)**. (2020). Framework for Equitable Allocation of COVID-19 Vaccine. In: Chapter: 3 A Framework for Equitable Allocation of COVID-19 Vaccine. Retrieved August 23, 2021 from https://www.nap.edu/read/25917/chapter/5.

National Center for Assisted Living (**NCAL**). (2020). Facts and Figures: Workforce. Retrieved May 10, 2021 from https://www.ahcancal.org/Assisted-Living/Facts-and-Figures/Pages/default.aspx.

National Center for Assisted Living (**NCAL**). (2016). Florida assisted living residents fast facts. State profile for assisted living. Retrieved March 23, 2021 from https://www.ahcancal.org/Assisted-Living/Facts-and-Figures/Documents/State%20Facts/Florida-AL.pdf.

National Health Service (**NHS**). (2014). NHS England's Commitment for Carers. Retrieved April 20, 2021 from https://www.england.nhs.uk/wp-content/uploads/2014/05/commitment-to-carers-may14.pdf.

National Institute of Neurological Disorders and Stroke (**NINDS**). (2020, March 23). The dementias: Hope through research. Retrieved April 8, 2021 from https://www.ninds.nih.gov/Disorders/Patient-Caregiver-Education/Hope-Through-Research/Dementia-Hope-Through-Research#risks.

National Institute on Aging (**NIA**). (2020). Alzheimer's Disease Diagnostic Guidelines. Retrieved April 8, 2021 from https://www.nia.nih.gov/health/alzheimers-disease-and-related-dementias/dementia-resources-health-professionals.

National Institute on Aging (**NIA**). (2017, May 1). Residential Facilities, Assisted Living, and Nursing Homes. Retrieved February 10, 2021 from https://www.nia.nih.gov/health/residential-facilities-assisted-living-and-nursing-homes.

National Institute on Drug Abuse (**NIDA**). (2020, July). Drugs, brains, and behavior: The science of addiction. Retrieved May 30,2020 from https://www.drugabuse.gov/publications/drugs-brains-behavior-science-addiction/drugs-brain.

National Institutes of Health (**NIH**). (2019). What Are Frontotemporal Disorders? Retrieved April 8, 2021 from https://www.nia.nih.gov/health/what-are-frontotemporal-disorders.

National Patient Safety Foundation (**NPSF**). (2015). Free from harm: Accelerating patient safety improvement fifteen years after *To Err Is Human.* Retrieved July 6, 2021 from http://www.ihi.org/resources/Pages/Publications/Free-from-Harm-Accelerating-Patient-Safety-Improvement.aspx.

Noel-Weiss J, Cragg B, Woodend AK. (2012). Exploring how IBCLCs manage ethical dilemmas: A qualitative study. *BMC Medical Ethics* 13(18). Doi: 10.1186/1472-6939-13-18. Retrieved April from http://www.biomedcentral.com/1472-6939/13/18.

Nordin S, McKee K, Wallinder, et al. (2017). The physical environment, activity and interaction in residential care facilities for older people: A comparative case study. *Journal of Advanced Nursing*. Doi:10.1111/scs.12391. Retrieved March 29, 2021 from https://onlinelibrary.wiley.com/doi/full/10.1111/scs.12391.

Nordin S, McKee K, Wijk H, Elf M. (2017). The association between the physical environment and the well-being of older people in residential care facilities: A multilevel analysis. *Journal of Advanced Nursing*. Doi:10.1111/jan.13358. Retrieved March 29, 2021 from https://onlinelibrary.wiley.com/doi/full/10.1111/jan.13358.

Nowrangi MA, Lyketsos CG, Rosenberg PB. (2015). Principles and management of neuropsychiatric symptoms in Alzheimer's dementia. *Alzheimer's Research & Therapy*, 7(12). Doi:10.1186/s13195-015-0096-3. Retrieved April 8, 2021 from http://alzres.com/content/7/1/12.

Nuffield Council on Bioethics. (2009, latest available). Dementia: Ethical Issues. Retrieved April 6, 2021 from http://nuffieldbioethics.org/wp-content/uploads/2014/07/Dementia-report-Oct-09.pdf.

Ortmann L.W. et al. (2016). Public Health Ethics: Global Cases, Practice, and Context. In: H. Barrett D., W. Ortmann L., Dawson A., Saenz C., Reis A., Bolan G. (eds) Public Health Ethics: Cases Spanning the Globe. *Public Health Ethics Analysis*, vol 3. Springer, Cham. Doi:10.1007/978-3-319-23847-0_1. Retrieved August 16, 2021 from https://link.springer.com/chapter/10.1007/978-3-319-23847-0_1.

Pharr JR, Francis CD, Terry C, Clark MC. (2014). Culture, caregiving, and health: Exploring the influence of culture on family caregiver experiences. *ISRN Public Health*, Article ID 689826. Doi:10.1155/2014/689826. Retrieved April 8, 2021 from http://www.hindawi.com/journals/isrn/2014/689826/.

Resnick B, Galik E, Boltz M, et al. (2019). Testing of the function focused environment assessment and the function focused policy assessment in assisted living. *J Hous Elderly* 33(2):153–72. Doi:10.1080/02763893.2018.1534180. Retrieved March 29, 2021 from https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7006224/.

Rijnaard MD, van Hoof J, Janssen BM, et al. (2016). the factors influencing the sense of home in nursing homes: A systematic review from the perspective of residents. *Journal of Aging Research*, Article ID 6143645. Doi:10.1155/2016/6143645. Retrieved April 6, 2021 from https://www.hindawi.com/journals/jar/2016/6143645/.

Roth DL, Brown SL, Rhodes JD, Haley WE. (2018). Reduced mortality rates among caregivers: Does family caregiving provide a stress-buffering effect? *Psychol Aging* 33(4):619–29. Doi:10.1037/pag0000224. Retrieved April 8, 2021 from https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6002922/.

Scales K, Zimmerman S, Miller SJ. (2018). Evidence-based nonpharmacological practices to address behavioral and psychological symptoms of dementia. *Gerontologist* ;58(suppl_1):S88–S102. Doi:10.1093/geront/gnx167. Retrieved April 8, 2021 from https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5881760/.

Sengupta M, Caffery C. (2020, December 5). Characteristics of residential care communities by percentage of resident population diagnosed with dementia: United States, 2016. National Health Statistics Reports, number 148. Retrieved February 8, 2021 from https://www.cdc.gov/nchs/data/nhsr/nhsr148-508.pdf.

Silva O, Cascio MA, and Racine E. (2020). Person-oriented research ethics and dementia. The lack of consensus. *Anthropology & Aging* 41(1):31–51.Retrieved April 6, 2021 from http://anthro-age.pitt.edu/ojs/index.php/anthro-age/article/view/211/322.

Takeda M, Tanaka T, Okochi M, Kazui H. (2012). Non-pharmacological intervention for dementia patients. *Psychiatry and Clinical Neurosciences* 66(1). Retrieved September April 8, 2021 from http://onlinelibrary.wiley.com/doi/10.1111/j.1440-1819.2011.02304.x/full.

Teles S, Ferreira A, Seeher K., et al. (2020). Online training and support program (iSupport) for informal dementia caregivers: Protocol for an intervention study in Portugal. *BMC Geriatr* 20(10). Doi:10.1186/s12877-019-1364-z. Retrieved April 20, 2021 from https://bmcgeriatr.biomedcentral.com/articles/10.1186/s12877-019-1364-z.

Teri L, McKenzie GL, Pike KC, et al. (2010). Staff training in assisted living: Evaluating treatment fidelity. *Am J Geriatr Psychiatry* 18(6):502–509. Doi:10.1097/JGP.0b013e3181c37b0e. Retrieved March 23, 2021 from https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3972022/.

Toth M, Martin Palmer LA, Bercaw LE, et al. (2020). Understanding the characteristics of older adults in different residential settings: Data sources and trends. Assistant Secretary for Planning and Evaluation. Retrieved February 8, 2021 from https://aspe.hhs.gov/basic-report/understanding-characteristics-older-adults-different-residential-settings-data-sources-and-trends#where.

Tretteteig S, Vatne S, Mork Rokstad, AM. (2017). The influence of daycare centres designed for people with dementia on family caregivers: A qualitative study. *BMC Geriatrics* 17(5). Doi:10.1186/s12877-016-0403-2. Retrieved April 8, 2021 from https://bmcgeriatr.biomedcentral.com/articles/10.1186/s12877-016-0403-2.

Trinkoff AM, Yoon JM, Storr CL, et al. (2020). Comparing residential long-term care regulations between nursing homes and assisted living facilities. *Nursing Outlook* 68(1). Doi:10.1016/j.outlook.2019.06.015. Retrieved May 10, 2021 from https://www.nursingoutlook.org/article/S0029-6554(18)30441-X/fulltext#%20.

University of Gotherburg. (2020). New blood test for Alzheimer's developed: Sahlgrenska Academy. Retrieved April 8, 2021 from https://sahlgrenska.gu.se/english/research/news-events/news-article/new-blood-test-for-alzheimer-s-developed.cid1684013.

Validation Training Institute (**VTI**). (2021). What is Validation? Retrieved April 8, 2021 from https://vfvalidation.org/get-started/what-is-validation/.

Vassbø TK, Kirkevold M, Edvardsson D, et al. (2019). The meaning of working in a person-centred way in nursing homes: A phenomenological-hermeneutical study. *BMC Nurs* 18(45). Doi:10.1186/s12912-019-0372-9. Retrieved June 4, 2020 from https://bmcnurs.biomedcentral.com/articles/10.1186/s12912-019-0372-9.

Vermeiren Y, Van Dam D, Aerts T, et al. (2015). The monoaminergic footprint of depression and psychosis in dementia with Lewy bodies compared to Alzheimer's disease. *Alzheimer's Research & Therapy* 7(7). Doi:10.1186/s13195-014-0090-1. Retrieved April 6, 2021 from http://alzres.com/content/7/1/7.

van Wijngaarden E, Alma M, The A-M. (2019). 'The eyes of others' are what really matters: The experience of living with dementia from an insider perspective. *PLOS One*. Doi: 10.1371/journal.pone.0214724. Retrieved April 8, 2021 from https://journals.plos.org/plosone/article?id=10.1371/journal.pone.0214724.

Vroomen JM, Bosmans JE, van Hout HPJ, de Rooij SE. (2013). Reviewing the definition of crisis in dementia care. *BMC Geriatrics* 13(10). Doi:10.1186/1471-2318-13-10. Retrieved April 8, 2021 from http://bmcgeriatr.biomedcentral.com/articles/10.1186/1471-2318-13-10.

Wangmo T, Lipps M, Kressig RW, et al. (2019). Ethical concerns with the use of intelligent assistive technology: Findings from a qualitative study with professional stakeholders. *BMC Med Ethics* 20(98). Doi:10.1186/s12910-019-0437-z. Retrieved April 6, 2021 from https://bmcmedethics.biomedcentral.com/articles/10.1186/s12910-019-0437-z#Sec1.

Wiegelmann H, Speller S, Verhaert LM, et al. (2021). Psychosocial interventions to support the mental health of informal caregivers of persons living with dementia: A systematic literature review. *BMC Geriatr* 21(94). Doi:10.1186/s12877-021-02020-4. Retrieved April 10, 2021 from https://bmcgeriatr.biomedcentral.com/articles/10.1186/s12877-021-02020-4.

Wiels W, Baeken C, Engelborghs S. (2020). Depressive symptoms in the elderly: An early symptom of dementia? A systematic review. *Front. Pharmacol* 11(34). Doi:10.3389/fphar.2020.00034. Retrieved April 6, 2021 from https://www.frontiersin.org/articles/10.3389/fphar.2020.00034/full#h1.

Yi SH, See I, Kent AG, et al. (2020, October). Characterization of COVID-19 in assisted living facilities, 39 states. *MMWR Morb Mortal Wkly Rep* 69:1730–35. Doi:10.15585/mmwr.mm6946a3. Retrieved March 29, 2021 from https://www.cdc.gov/mmwr/volumes/69/wr/mm6946a3.htm#suggestedcitation.

Zeman S. (2015). Dementia Care: Common Sense Guidelines. Retrieved April 8, 2021 from https://www.atrainceu.com/content/153-dementia-care-common-sense-guidelines-course-intro.

Zetterberg H, Burnham SC. (2019). Blood-based molecular biomarkers for Alzheimer's disease. *Mol Brain* 12(26). Doi:10.1186/s13041-019-0448-1. Retrieved April 6, 2021 from https://molecularbrain.biomedcentral.com/articles/10.1186/s13041-019-0448-1.

Post Test

1. Assisted living facilities:

a. Are generally small “granny units” attached to a family member’s home.

b. Are non-medical care facilities, also referred to as residential care communities, “board and care,” or congregate living.

c. Are medical facilities that provide assistance to people who no longer wish to live in a home or apartment.

d. Are paid for by Medicare.

2. Older adults with COVID-19 may not show common symptoms such as fever or respiratory symptoms and may instead experience less-common symptoms such as new or worsening malaise, headache, or new dizziness, nausea, vomiting, diarrhea, loss of taste or smell.

a. True

b. False

3. Dementia is:

a. A collection or grouping 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 and strain of aging.

d. Being absent-minded, forgetful, and not remembering names.

4. Neuroplasticity:

a. Is the process by which the brain develops plaques and tangles.

b. Does not help the brain to adapt to experience.

c. Occurs when damage from dementia causes brain cells to change to a plastic-like material.

d. Enables the brain to compensate for damage to one hemisphere by taking on extra functions in the other half.

5. 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.

6. Instead of losing short-term memory like people with Alzheimer's disease, a person with frontal-temporal dementia:

a. Might start doing things that are confusing to their friends and family.

b. They might steal, even though they have never stolen in the past.

c. They might make inappropriate sexual remarks or engage in inappropriate sexual behaviors, even though they have never done these things in the past.

d. All of the above.

7. 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.

8. Depression in people with Alzheimer's disease and Lewy Body dementia:

a. Develops acutely—over hours or days—and is temporary and reversible.

b. Causes a sudden and global impairment in cognition.

c. Is associated with increased mortality, risk of chronic disease, and the need for higher levels of supported care.

d. Is not reversible and is ultimately fatal.

9. 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.

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

a. Don't be afraid to argue or point out something incorrect.

b. Speak as loudly as you can as if you're talking to a small child.

c. Break down your greetings, statements, or questions into short, simple sentences.

d. Keep conversations to a minimum to avoid frustrating your client.

11. 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.

12. A person with severe dementia:

a. May not remember much about their past but usually has good recall of recent events.

b. May exhibit all sorts of challenging behaviors—especially if caregivers are untrained, easily frustrated, or highly stressed.

c. May exhibit fewer challenging behaviors than people with similar levels of dementia living in a nursing home.

d. Usually remain independent in most activities of daily living.

13. Even though the majority of research has focused on burden and other negative aspects of family caregiving, positive aspects include a sense of meaning, a sense of self-efficacy, satisfaction, a feeling of accomplishment, and improved wellbeing and quality of relationships.

a. True

b. False

14. 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.

15. Validation therapy:

a. Trains a person with dementia to understand the reality of their situation.

b. Is not useful when used with people who are disoriented.

c. Relies on verbal communication to increase the intensity of a person's repressed feelings.

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

16. Using validation therapy in an assisted living facility means you:

a. Consider the dementia first, not the whole person.

b. Imagine yourself in the person's place and validate their feelings.

c. Use reality therapy to orient your client to reality.

d. Discourage independence and help as much as possible.

17. Validation therapy is not intended to improve a person's cognition or to delay cognitive decline—is intended to draw people out, encourage communication, and validate a client's personal truth. Reality therapy on the other hand, is intended to reduce cognitive decline using repetitive activities that reinforce name, date, place, and time.

a. True

b. False

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

a. Go on with your life and ignore any changes in their loved one.

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. Receive early, specialized training about dementia.

19. When a loved one dies, family members:

a. Can look forward to a period of improved health.

b. Rarely experience physical symptoms such as headaches and fatigue.

c. Can experience grief that resembles clinical depression.

d. Often feel intense relief along with an increase in energy.

20. In assisted living facilities, practices that can discourage family involvement in the care of a person with dementia include:

a. Family members often occupy a marginal position relative to staff.

b. Staff often view family members as difficult or demanding.

c. Facilities often have staff shortages and scarce resources.

d. All of the above.

21. In recent years, online training and support for caregivers of a person with dementia has shown promise in reducing caregiver distress, increasing empathy, and helping caregivers develop social networks.

a. True

b. False

22. 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 understand environmental cues.

d. Unfamiliar, chaotic, or disorganized environments have very little impact of behavior.

23. Person-centered care:

a. Is the same thing as task-centered care.

b. Should only be used when antipsychotics fail to resolve behavioral problems.

c. Can increase unwanted and aggressive behaviors.

d. Focuses care on residents’ and caregivers’ needs and preferences.

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

a. Make sure staff members don’t get too comfortable with a resident.

b. Hire staff with the emotional skills to interact with people who have memory problems.

c. Increase the number of centralized nursing stations.

d. Clearly mark all doors, including doors to utility areas and staff lunchroom.

25. In an assisted living facility, safety is:

a. Not a concern because people only come in during the day.

b. The responsibility of the department of health.

c. A joint responsibility, shared by the center operators, managers, healthcare workers, and volunteers.

d. Improved if all doors to the outside are kept locked.

26. For people with dementia, safety technologies:

a. Must be completely hidden.

b. Can be cumbersome as long as it does the job.

c. Generally are not accepted and no recommended.

d. Must be easy and satisfying to use.

27. Barriers to implementing improvements in training in assisted living facilities include:

a. Cost and high staff turnover.

b. Senior leadership resistance and low-innovation culture.

c. Low staff education.

d. All of the above.

28. In assisted living facilities, staff turnover is a constant concern. What management practices have been shown to decrease staff turnover?

a. Promoting a person-centered approach to care.

b. Being part of a supportive team.

c. Establishing shared goals with residents and other staff.

d. All of the above.

29. The principle of beneficence or kindness is:

a. Unprofessional and not ethical.

b. The act of being kind.

c. Not that much of an issue when caring for people with dementia.

d. Difficult to keep in mind when caring for someone with dementia.

30. Ethical dilemmas are common when providing care for a person experiencing dementia. This occurs when:

a. There are equally good reasons both for and against a particular course of action and a decision *must* be made.

b. A resident gives consent for the use of assistive technology.

c. A resident with dementia steals a personal item from another resident.

d. A resident without dementia wants to visit a family member outside the facility.

Answer Sheet

Name (Please print) ____

Date ____

Passing score is 80%

1. ______

2. ______

3. ______

4. ______

5. ______

6. ______

7. ______

8. ______

9. ______

10. ______

11. ______

12. ______

13. ______

14. ______

15. ______

16. ______

17. ______

18. ______

19. ______

20. ______

21. ______

22. ______

23. ______

24. ______

25. ______

26. ______

27. ______

28. ______

29. ______

30. ______

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. Define the term assisted living facility. 5 4 3 2 1
2. Describe 3 characteristics associated with dementia. 5 4 3 2 1
3. Relate a common type of behavior seen in each stage of ADRD. 5 4 3 2 1
4. Relate 3 ways in which dementia affects general conversations. 5 4 3 2 1
5. Describe 3 issues family caregivers face as their loved one transitions from mild to moderate to severe dementia. 5 4 3 2 1
6. Identify 3 philosophical concepts that are important in the design of a therapeutic environment for those with dementia. 5 4 3 2 1
7. Identify common ethical conflicts that may arise when caring for residents 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: _____________________