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Florida: Specialized Alzheimer's Adult Daycare, Level One (347)

Author: Lauren Robertson, BA, MPT

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

Course Summary

This course is for those of you who have direct contact with clients in a specialized adult daycare center. It discusses Alzheimer's disease and other common types of dementia from the perspective of both healthcare workers, clients, and family members. It describes management of behaviors you will see in people with mild, moderate, and severe dementia and how activities of daily living are affected at different stages of dementia.

We discuss physical and chemical restraints and alternatives to their use. The course includes activities you can do with your daycare clients. We also include information about family issues, caregiver stress, and share some innovative ideas about "therapeutic environments." We conclude with a discussion of ethical issues you may encounter.

Course Objectives

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

1. List the 3 types of services provided at adult daycare centers.
2. Identify 3 common behavioral and psychological symptoms of dementia.
3. Describe 4 alternatives to the use of restraints in older adults with dementia.
4. Identify the 3 key components of the problem-solving approach for managing challenging behaviors.
5. List 5 general measures to keep in mind when assisting someone with their ADLs.
6. Relate 3 components that should be part of individual and group activities for clients with dementia.
7. Describe 3 ways in which stress can affect a caregiver's quality of life.
8. Describe 3 issues family caregivers face as their loved one transitions from mild to moderate to severe dementia.

9. Identify 3 philosophical concepts that are important in the design of a therapeutic environment for those with dementia.
10. Identify common ethical conflicts that may arise when caring for clients with dementia.

Pre-Test

1. Specialized Adult Day Care services are for people who **do not** have dementia.
2. Geriatrics specialists refer to behavioral changes in people with dementia as behavioral and psychological symptoms of dementia (BPSD) or neuropsychiatric symptoms of dementia (NSP).
3. Challenging behaviors arising in people with dementia are best managed when interventions are tailored to each person.
4. In a specialized adult daycare facility, a physical restraint should always be used when a person is acting out.
5. The humanity with which assistance is offered, especially help with eating and intimate care, is crucial in helping the person retain their self-esteem and dignity.
6. Carefully designed activities can have a positive effect on depression, confusion, and challenging behaviors for people with dementia.
7. Providing care for a person with dementia places practical, psychological, and emotional stress on caregivers, which can lead to denial, anger, and depression.
8. 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.
9. A therapeutic environment recognizes that people with dementia are influenced by their surroundings and do better with environments that are individualized, flexible, and designed to support differing functional levels and approaches to care.
10. For people working in facilities catering to people with dementia, staffing is often negatively affected by unclear roles and functions, heavy workloads, demanding work schedules, difficult ethical issues, job strain, and burnout.
11. A key ethical principle in dementia care 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.

Questions 1 and 4 are false, the remainder are true.

1. Alzheimer's Disease and Related Disorders

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

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

For those of you working in adult daycare, it is very likely you will have contact with clients with dementia. Many of your clients will also have chronic conditions and recent hospitalizations. A major goal of adult daycare is to reduce the risk of hospitalizations and readmissions and help families and caregivers learn about dementia, and successfully manage their loved one's chronic conditions (Caffrey and Lendon, 2019).

1.1 Adult Day Care in Florida

In Florida, as of 2021, there are approximately 349 non-specialized adult daycare centers providing therapeutic programs, social services, health services, and activities for adults in a non-institutional setting. Nearly half of non-specialized adult daycare clients have Alzheimer's disease or a related disorder (FADSA, 2021).

Adult day service centers provide non-residential coordinated services in a community setting for less than a day. There are three types:

1. Social,
2. Medical/health, and
3. Specialized (providing programs for people with dementia) (FADSA, 2021)

1.2 Specialized Adult Day Care

Specialized adult daycare centers are specifically designated to treat clients with Alzheimer's disease and other types of dementia. Specialized centers enroll a higher percentage of clients with dementia than do regular adult day centers and require specialized dementia training for their staff. A specialty license is required to provide services as a Specialized Alzheimer's Services Adult Daycare Center. (O'Keeffe, 2014, latest available).

Most adult daycare participants attend at least 3 days each week and most clients use transport services provided by the centers. In 2022, the median cost of adult daycare services in the U.S. was \$81 per day (Alzheimer's Association, 2023).

In Florida, specialized Alzheimer's adult day centers must have, at a minimum, 1 staff member providing direct services for every 5 participants with Alzheimer's disease or other dementia. All adult day centers must have, at a minimum, 2 staff members present in the center at all times (1 of whom has a certification in first aid and CPR) (O'Keeffe, 2014).

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

2. Common Symptoms and Behavior Changes by Stages

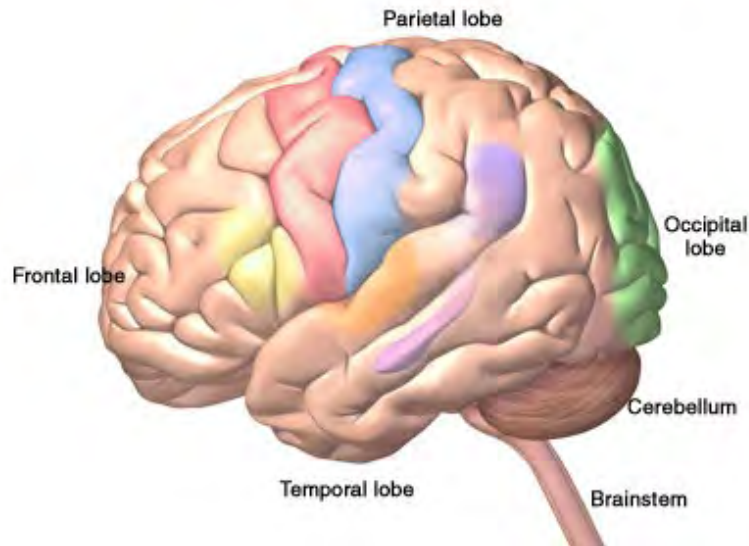
The onset of dementia and its gradual progression often leads to changes in personality and behavior. Geriatrics specialists refer to these changes as behavioral and psychological symptoms of dementia (BPSD) or neuropsychiatric symptoms of dementia (NSP).

A symptom is a change in the body or the mind while 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.

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 health, family support, and co-morbid conditions* can affect how fast and how far the dementia progresses from one stage to another.

***Co-morbid conditions:** when someone has more than one disorder or illness at the same time.

The Human Brain



The lobes of the human brain. ©Zygote Media Group, Inc. Used with permission.

2.1 Symptoms and Behavior Changes: Mild Dementia

The early or mild stage of dementia begins with mild forgetfulness, which might be the most obvious symptom at this stage, especially in Alzheimer's disease. Logical thinking and judgment can be mildly affected, especially in certain types of dementia. These changes are thought to be related to the formation of plaques and tangles, beginning in the temporal lobes in and around the hippocampus.

Brain Changes in Mild Dementia



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

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

Even when symptoms are mild, a person's behavior may begin to change, especially in Alzheimer's disease. People with mild dementia often know something is wrong, which can cause depression, stress, anxiety, mood changes, and episodes of anger or aggressiveness. They still might be able to work, drive, and live independently, but they will begin to need some help from family or coworkers.

2.2 Symptoms and Behavior Changes: 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. Spatial awareness*, and executive functions such as planning, judgment, and ethical thinking can be affected. Work and social life become more difficult and episodes of confusion increase. Many people are first diagnosed with Alzheimer's disease in this stage.

***Spatial awareness:** an awareness of where we are in relation to the things around us including distance, direction, and location.

Brain Changes in Moderate Dementia



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

In the moderate stage, behavior changes become more obvious to family members. Episodes of inappropriate behaviors such as cursing, kicking, hitting, and biting can occur. Some people may start 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 often 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 using a wheelchair, they might begin to wander. More direct monitoring is needed than during the early stage of dementia. People may no longer be safe on their own and caregiver responsibilities increase. This often increases stress, anxiety, and worry for family members and caregivers.

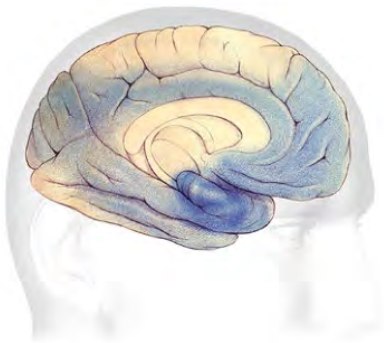
2.3 Symptoms and Behavior Changes: Severe Dementia

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

Family Caregiver, Ft. Lauderdale, Florida

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

Brain Changes in Severe Dementia



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

All sorts of challenging behaviors can occur in people with severe dementia—especially if caregivers and family members 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.

2.4 Symptoms and Behavior Changes: End of Life

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

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

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

At the end of life, people with dementia are often completely dependent on caregivers. They may refuse to eat, have difficulty swallowing fluids and medications, and will likely need close supervision for all activities of daily living. Weight loss, which may have been gradual over time, can rapidly increase.

A person with severe dementia may have medical complications that significantly increase the risk of acute conditions. One such condition is pneumonia, which is the most commonly identified cause of death among older adults who have Alzheimer's or other dementias.

3. Physical and Chemical Restraints

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

Use of restraints should be (GovTrack, 2020):

- Reserved for documented indications.
- Time limited.
- Frequently re-evaluated for their indications, effectiveness, and side effects in each patient.

Although OBRA is intended for nursing homes, these regulations should be followed in all other settings, including in the home.

Florida Nursing Home Bill of Rights

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

. . . the right to be free from mental and physical abuse, corporal punishment, extended involuntary seclusion, and from physical and chemical restraints, except those restraints authorized in writing by a physician for a specified and limited period of time or as are necessitated by an emergency. In case of an emergency, a restraint may be applied only by a qualified licensed nurse who shall set forth in writing the circumstances requiring the use of restraint, and, in the case of use of a chemical restraint, a physician shall be consulted immediately thereafter. Restraints may not be used in lieu of staff supervision or merely for staff convenience, for punishment, or for reasons other than resident protection or safety (Florida Statutes, 2023).

3.1 Physical Restraints

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

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

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

Restraints are not limited only to physical devices. Restraint can include using (or threatening) force or restricting a person’s movements—even if they do not resist (Nuffield Council on Bioethics, 2009 latest available). Forced isolation (such as locking a person in their bedroom) is also a type of restraint.

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

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

3.2 Chemical Restraints

Antipsychotics and psychotropic medications are often used intentionally to chemically subdue, sedate, or restrain an individual. Traditionally they have been used to restrict the freedom of movement of a patient—usually in acute, emergency, or psychiatric settings. Chemical restraints should be prescribed for the shortest time possible for dangerous, uncontrolled, aggressive, or violent behaviors.

A 2022 report from the *Office of the Inspector General (OIS)* found that psychotropic drugs were prescribed to about 80% of nursing home residents between 2011 and 2019. Higher use of psychotropic drugs, including antipsychotics, anticonvulsants, mood stabilizers, and central nervous system agents was associated with nursing homes that have certain characteristics. Those with lower ratios of registered nurse staff to residents used more psychotropic drugs. Nursing homes with a higher percentage of low-income residents were also associated with higher use of these drugs (OIS, 2022).

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

Clinical trials have consistently demonstrated an increased risk of mortality with the use of atypical antipsychotics in older adults with dementia. All atypical antipsychotics now carry a black box warning from the FDA about this risk, and a similar warning applies to conventional antipsychotics.

In 2023, the *American Geriatrics Society Beers Criteria® for Potentially Inappropriate Medication Use in Older Adults* modified and clarified the criteria for delirium, dementia, and Parkinson disease, including adding opioids to the list of drugs that can exacerbate delirium. The update stresses the need to avoid antipsychotics and other medications for behavioral problems of dementia and delirium because their use is frequently associated with harm (AGS, 2023).

Behavioral interventions are the preferred management strategy for treatment of challenging behaviors associated with dementia. The use of antipsychotics and other potentially inappropriate medications should be a last resort. The decision to use or not use a chemical restraint should always be made in collaboration with the patient and their care partner (AGS, 2023).

For a person with dementia (Reus et al., 2016):

- Nonemergency antipsychotic medication should only be used for the treatment of agitation or psychosis when symptoms are severe, dangerous, and/or cause significant distress to the patient.
- Nonpharmacological interventions should be assessed prior to non-emergency use of an antipsychotic medication to treat agitation or psychosis.
- Potential risks and benefits should be assessed by the clinician and discussed with the patient as well as with family or others involved with the patient.

A prescriber may choose to prescribe antipsychotic medications for behavioral and psychological symptoms associated with dementia and they may be effective in some cases. The prescriber must, however, disclose to the patient and family that the medication is being used off-label* meaning a drug has not been approved by the FDA for treatment of behavioral symptoms of dementia. The prescriber must obtain permission from the patient or family member to use it for behavioral symptoms of dementia.

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

3.3 Alternatives to Restraints

The preferred choice is to use no restraints. Physical, chemical, or environmental restraints should not be used as a substitute for safe and well-designed environments or for the care and management of a person with dementia. One of the most successful strategies for dealing with difficult behaviors without using restraints is to use a problem-solving approach (Alzheimer Society, 2023), which will be discussed in the next section.

Certain policies and activities can reduce or eliminate the use of restraints. Establishing a routine, including a toileting schedule, will improve comfort and reduce anxiety. Regular exercise and comfortable places to rest and nap are important. Other suggestions:

- Assess and treat hunger, thirst, and discomfort.
- Change or taper medications with adverse effects.
- Treat all underlying causes, including pain.
- Assess hearing and vision.
- Establish a nap schedule.
- Relieve impaction.

A friendly, uncluttered, home-like environment provides a safe and effective alternative to physical restraints. Keep hallways free of equipment and obstacles, make liberal use of rails, grab bars, and transfer poles in rooms, bathrooms, hallways, and common areas. Additional suggestions:

- Provide pressure-relief wheelchair and chair cushions to improve comfort.
- Lower wheelchairs to allow self-propelling with feet.
- Provide comfortable, easy-to-access alternative seating.
- Install carpeting, where practical, to reduce injury from falls.

4. Managing Challenging Behaviors

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

Challenging behaviors are best managed when interventions are tailored to each person. This can include psychosocial interventions and short-term pharmacologic treatment (only when necessary). Before deciding on a course of action, a comprehensive assessment, and a determination of reversible causes of a challenging behavior should be completed.

4.1 The Problem-Solving Approach

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

Family Caregiver, West Palm Beach, Florida

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

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

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

Conditions other than dementia can be the cause of a challenging behavior and some of these conditions are reversible with appropriate treatment. Acute conditions such as constipation, dehydration, urinary tract infections, skin breakdown, head injuries, epileptic seizures, and the side effects of medications or medication interactions can cause temporary changes in a person's cognition and affect their behavior (NINDS, 2023, December 19).

4.2 Managing Common Behaviors

The management of challenging behaviors in people with dementia requires a thoughtful and consistent approach. Among the many challenging behaviors associated with Alzheimer's disease and related dementias, three stand out: aggressive behaviors, agitated behaviors, and wandering.

Other challenging behaviors will arise, especially in the later stages. In addition to aggression, agitation, and wandering, delirium and depression, rummaging, hoarding, delusions, hallucinations (psychoses), and sleep disturbances will be discussed here. This is by no means an exhaustive list and other challenging behaviors are sure to occur.

4.2.1 Delirium and Depression

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

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

When a person with dementia is admitted to the hospital or finds themselves in an unfamiliar environment, precipitating factors for delirium include multiple medications started during the admission, use of centrally active medications*, use of physical restraints, bladder catheterization, elevated serum urea or elevated blood urea nitrogen to creatinine ratio**, and adverse events during the hospitalization (Faeder et al., 2023).

***Centrally active medications:** medicines that lower heart rate and reduce blood pressure.

****Elevated serum urea or elevated blood urea nitrogen to creatinine ratio:** an indication that the kidneys are not functioning properly.

Management of delirium starts with prevention. Identifying risk factors, especially in older adults with dementia can significantly decrease its incidence. Following hospitalization or surgery, reorientation, early mobilization, hydration, nutrition, sleep, and hearing and/or vision adaptation has been shown to reduce episodes of delirium in older adults (Faeder et al., 2023).

About 16% of people with dementia have a diagnosis of a **major depressive disorder** and many experience symptoms of depression without a formal diagnosis (Watt et al., 2021). Low energy, irritability, sadness, socially isolation, anxiety, "empty" mood, feelings of hopelessness, guilt, worthlessness, or helplessness can be signs of depression. Depression can lead to difficulty concentrating, remembering, or making decisions, difficulty sleeping, poor appetite, early-morning awakening, or oversleeping (NIA, 2021, July 7).

Drugs such as antidepressants and antipsychotics and non-drug treatments such as reminiscence therapy and exercise can be used to treat depression in people with dementia. There is increasing evidence of harm associated with antidepressant use in people with dementia, particularly from falls and fractures. Non-drug interventions such as *social prescribing*—linking patients with non-drug interventions in their community—can combat symptoms of depression, loneliness, and isolation (Watt et al., 2021).

4.2.2 Agitation and Aggression

Agitation is a general term that includes physically **aggressive** behaviors, including hitting, grabbing, kicking, and pushing. Agitation also includes **physically non-aggressive** behaviors (pacing, restlessness), **verbally aggressive** behaviors (swearing, threats) and **verbally non-aggressive** behaviors (requests for attention, complaining, negativism, ceaseless talking, groaning) (James et al., 2023).

Aggression is often seen as a threat to the safety of the person with dementia and to those around them, including family caregivers, staff, and other residents. Aggressive behaviors occur in both men and women, but overt aggression is more common in men.

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

To understand and prevent agitation and aggression, use the problem-solving approach to consider the antecedent (cause) of the behavior:

- Observe the person and try to identify the behavior.
- Look for patterns and consequences.

Psychosocial and environmental interventions can reduce or eliminate agitated or aggressive behaviors. Touch*, music therapy, massage, craniosacral therapy**, therapeutic touch, acupressure, and tactile massage have been used to treat aggression. Individual behavioral therapy and individualized, person-centered care based on psychosocial management is recommended (Burns et al., 2012, latest available).

***Touch:** When using touch as a strategy, it is important to consider religious, ethnic, and personal preferences as well as professional and ethical standards.

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

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

4.2.3 Wandering

Wandering is when someone walks aimlessly around a facility or home or away from a particular location. Individuals who wander often become lost, putting them at risk of injury and death. More than half of people with dementia may wander at some point during the course of their disease. For caregivers and family members, wandering is extremely stressful because of safety concerns and the seeming inability to stop the behavior short of using a restraint.

Wandering is often related to boredom, pain, discomfort, disorientation, and memory problems. Someone with Alzheimer's disease is more likely to wander than a person diagnosed with another type of dementia, and it is more prevalent in men and in younger people with dementia. Of particular interest, a person with AD will often wanders in the direction of their dominant hand.

People may wander out of habit or because they think something needs to be done, such as going home after work, walking the dog, getting exercise, or searching for something they think they have lost. Restlessness, with a compelling need for movement or pacing, has been linked to side effects of psychotropic medications, particularly antipsychotics.

A person's pre-dementia lifestyle may be a factor in wandering. Studies have indicated that people with certain characteristics are more likely than others to wander. This includes people who respond to stress by engaging in motor activities and people who have been physically active throughout their lives. Additionally, a person with an active interest in music, an extroverted personality showing warmth, positive emotion, altruism, and those who were very involved with social activities and social-seeking behaviors may be more likely to wander (Adekoya and Guse, 2019).

An assessment of the reasons for wandering should include regular review of medications to make sure wandering is not the result of medication side effects, overmedicating, or drug interactions. Redirecting a person to a purposeful activity, offering safe, looping wandering paths with interesting rest areas, and providing regular exercise allows caregivers to address wandering in a positive way. Using a physical barrier (such as yellow tape) can prevent wandering into unsupervised areas. Putting up visual barriers on exit doors, such as "Stop" signs, and installing alarms on entryways into unsafe areas or to the outside can also be helpful.

Engaging a person in simple chores such as folding laundry or assisting with dinner can give them a sense of purpose and fulfillment. Electronic devices attached to the person's ankle or wrist alert staff or family members when someone has wandered out of a designated area. Subjective barriers such as grid patterns on the floor in front of exit doors, camouflage, and concealment of doors and doorknobs have been shown to discourage a wanderer from exiting a building.

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

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

4.2.4 Rummaging and Hoarding

Rummaging and hoarding refer to behaviors in which a person gathers, hides, or puts away items in a secretive and guarded manner. These actions are considered to be a type of obsessive-compulsive behavior. Rummaging and hoarding are not necessarily dangerous or unsafe, but they can be frustrating for caregivers and family members. Hoarding is associated with insecurity and anger and may be an attempt to hold onto possessions and memories from the past.

Cognitive changes such as memory loss, poor judgment, and confusion can contribute to the impulse to rummage and hoard. People may rummage out of boredom or to find something they think they have misplaced. They may have a fear of being robbed or feel a need to protect their possessions. Confusion can lead to rummaging through another person's belongings, which can be particularly frustrating for other clients.

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

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

In a home setting (and even in a healthcare setting), place important items such as credit cards or keys out of reach or in a locked cabinet. Consider having mail delivered to a post office box and check wastepaper baskets before disposing of trash.

Other recommendations:

- Get rid of poisonous items such as caustic liquids and poisonous plants.
- Label cabinets, doors, and closets.
- Use labels or pictures to help the person find what they are looking for.
- Reduce clutter.
- Check garbage for missing items.

4.2.5 Psychosis

Psychosis is a disturbance in the perception or appreciation of objective reality. Symptoms can include delusions, visual and auditory hallucinations, and paranoia, among others.

Psychosis is relatively common in people with Alzheimer's disease and other types of dementia. Its prevalence varies depending on the underlying disease, with an overall prevalence of approximately 30% in Alzheimer's disease, 75% in dementia with Lewy bodies, 50% in Parkinson's disease, 15% in vascular dementia, and 10% in frontotemporal dementia (Cummings et al., 2020).

Psychosis can be triggered by medical conditions, pain, physical discomfort, urinary tract infection, constipation, delirium, and polypharmacy. Overstimulation, poor lighting, sensory overload, social isolation, premorbid personality, and poor coping mechanisms are also factors (Cummings et al., 2020). Changes in the brain contribute to these behaviors, especially changes related to sensory awareness, memory, and decreased ability to communicate or be understood.

Visual hallucinations can occur in the moderate to severe stages of dementia and are particularly common in people with Lewy body dementia. For a person with new onset of visual hallucinations, the number one cause is medication side effects. For this reason, all medications should be carefully reviewed. This includes prescription and over-the-counter medications, as well as herbal supplements.

Management of delusions and hallucinations starts with ruling out delirium or other physical or medical reasons for a person's behavior. During the process of attempting to identify the cause of a behavior—especially paranoia and delusions, determine if the claims by the person with dementia actually did occur.

Observe the behavior and listen to what the person experiencing the paranoia or delusion has to say. Is the feeling pleasant or frightening? If the hallucination elicits a fearful or negative response, address the person's need to regain control. For example, you may ask "What will make you feel safe?" "What will make you feel comfortable?"

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

Here are some suggestions for addressing hallucinations:

- Reduce stimulation in the environment.
- Minimize violent or noisy TV, remove wall hangings, reduce noise, play relaxing music.
- Cover mirrors.
- Reduce glare from windows.
- Ensure adequate lighting.

4.2.6 Sleep Disturbances

For people with dementia, sleep disturbances can lead to worsening of cognitive symptoms, challenging behaviors, restlessness, wandering, and accidental falls. Sleep disturbances also cause significant caregiver distress and have been reported as a factor contributing to institutionalization of people with dementia (Wilfling et al., 2023).

There is an inaccurate belief that reduced hours of sleep and decreased ability to sleep well in old age are “normal” aspects of aging. This mistaken belief, coupled with the reluctance of people with dementia and their families to seek help for sleep issues, contributes to the under-diagnosis and under-treatment of disordered sleep in this population (Brown et al., 2014).

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

Sleep disturbances and accompanying symptoms often lead providers to prescribe psychoactive medications, including hypnotics. Because little research has been done on sleep disorders in people with dementia, it is not known if these medications improve sleep. Non-medicine interventions are frequently recommended such as light therapy, social and physical activities, changes of the environment—such as reducing noise and light at night—and avoiding daytime sleep (Wilfling et al., 2023).

A Cochrane Review of interventions for disordered sleep affecting people with dementia did not draw firm conclusions, mostly due to differences between interventions and lack of methodological quality. Physical activity and social activities, caregiver interventions, and multimodal interventions may slightly or modestly improve night-time sleep in people with dementia. The review found no evidence that light therapy, slow-stroke back massage, or transcranial electrostimulation reduced sleep problems in people with dementia (Wilfling et al., 2023).

4.2.7 Sundown Syndrome

Sundown syndrome is the emergence or worsening of neuropsychiatric symptoms in the late afternoon or early evening. It has long been recognized as an aspect of dementia and is well known among most of healthcare providers involved in the care of persons with dementia. Nevertheless, sundown syndrome has so far drawn limited clinical and scientific interest compared to other neuropsychiatric symptoms and behavioral disturbances occurring in dementias such as apathy, depression, and psychotic symptoms (Canevelli et al., 2016).

The term "sundowning" was first used in the early 1940s to describe an increase in disorientation and agitation in a dementia patient placed in a darkened room (Madden and Feldman, 2019). It was believed then that low light levels were the major cause of this phenomenon, and that changes in behavior were caused by the reduced levels of light at sunset (Guu et al., 2022).

Although the concept of a sundowning syndrome remains in common use, it is poorly defined. Recent research has focused on dysregulation of circadian biology and changes in circadian rhythm* related to reduced light and that mood, sleep, and aggressive behaviors might be regulated by the circadian system (Guu et al., 2022).

***Circadian rhythms:** the physical, mental, and behavioral changes experienced over a 24-hour cycle. Light and dark have the biggest influence on circadian rhythms, but food intake, stress, physical activity, social environment, and temperature also affect them.

Caregiver fatigue and stress may contribute to sundowning in people with dementia. Researchers have noted that sundown syndrome behaviors are higher at the end of weekends, in less sunny states, in states at higher latitudes, and during winter months. These results provide support for both the caregiver stress and disrupted circadian rhythm hypotheses for sundown syndrome behaviors (Madden and Feldman, 2019).

The diagnosis of sundowning is essentially clinical in nature. In most of cases, it is easily identified by direct observation or interviews with caregivers. History taking should be followed by a general physical examination to determine the presence of potentially contributing or precipitating factors such as pain or sensory deprivation. An evaluation of potential environmental factors such as lighting, noise levels, and changes in daily routine important. Illness, injury, or disease caused by medical or surgical treatments, diagnostic procedures, or side-effects of a drug should also be considered (Canevelli et al., 2016).

5. Assistance with Activities of Daily Living (ADLs)

The “small things” of care are particularly important in ensuring that care is genuinely supportive of the individual and enhances that person’s autonomy and well-being. The humanity with which assistance is offered, especially help with eating and intimate care, is crucial in helping the person retain their self-esteem and dignity.

Nuffield Council on Bioethics

Activities of daily living (ADLs) are the personal tasks we do during our daily lives. Because ADL skills tend to decline as dementia progresses, caregiver involvement naturally increases over time.

ADLs are generally divided into two categories: **basic** ADLs and **instrumental** ADLs. Basic ADLs are those skills needed to take care of personal needs. Instrumental or functional ADLs are the skills needed to function within society and within the community.

Clients participating in adult day programs tend to need less assistance with ADLs than people in long-term care settings. In general, nearly half of daycare clients need some assistance with walking, about one-third need help with toileting, transfers, or medication management, and about one-quarter need help with eating (Singh et al., 2022).

Basic and Instrumental ADLs

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

No matter what a person’s level of dementia, when assisting someone with activities of daily living, encourage them to express their wishes. “No, I don’t want to!” means just that, even when spoken by someone with dementia. However, it is necessary to understand why a person might be refusing help. Are they scared? Do they misunderstand what you are asking them to do? Are they embarrassed? Are they cold or in pain?

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

If the person seems confused, repeat your request in the same words rather than rephrasing. Offer simple choices, such as "Do you want orange juice or apple juice?" Engage the client. Be empathetic. Examples of empathetic responses include "You must be cold" or "Are you uncomfortable in that chair?" "What would help now?"

Keep these general measures in mind when assisting someone with their ADLs:

- Make eye contact (where culturally appropriate).
- Be calm.
- Give your client physical space—do not crowd.
- Be aware of your body language and vocal tone.
- Slow the speed of your movements and speech.

5.1 ADL Strategies: Mild Dementia

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

At this stage, there may be some loss of interest in hobbies and activities. Mood changes, such as depression and anxiety, can occur. Learning new tasks, especially complex tasks, may be difficult. Faulty judgment and mild changes in personality become obvious to caregivers.

Dressing

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

Grooming

- Allow clients to groom themselves, provide tools if needed.
- Monitor progress and provide help as needed.

Eating

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

Bathing

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

Toileting*

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

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

5.2 ADL Strategies: Moderate Dementia

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

In the moderate stage, family caregiver responsibilities increase, along with stress, anxiety, and worry. Cooking, housework, and shopping may require direct assistance. Basic ADLs may require assistance for set-up and safety and may be disrupted by behavioral and psychological symptoms such as anger, frustration, and denial. Driving is no longer safe.

Dressing

- Provide comfortable clothes with elastic waistbands and Velcro closures.
- Limit choices but encourage participation in the choice of clothing.
- Assist closely but encourage independence.
- Lay out clothes in order.
- Provide multiple pairs of favorite outfits.

Grooming

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

Eating

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

Bathing

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

Toileting

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

5.3 ADL Strategies: Severe Dementia

Dealing with Delaying Tactics

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

Family Caregiver, Cottondale, Florida

In the severe stage, a great deal of independence is 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.

Difficulty swallowing (dysphagia) can develop in the later stage of dementia, leading to aspiration* of food, fluids, or saliva into the lungs. To prevent this from happening, food choices will need to be modified by softening the texture of food and thickening liquids.

***Aspiration:** the misdirection of secretions or gastric contents into the larynx and lower respiratory tract.

Positional swallowing maneuvers can also help such as tucking the chin, massaging the throat, or rotating the head. Prevention can include (Metheny, nd):

- Providing a 30-minute rest period prior to meals.
- Sitting in an upright position.
- Adopting a chin-down posture.
- Adjusting the rate of feeding and the size of bites.
- Avoiding the use of sedatives and narcotics, which impair swallowing and the cough reflex.
- Providing good oral care.

During this stage, complex instrumental ADLs have likely been completely taken over by a family member or caregiver. Basic ADLs will require a great deal of set-up and assistance, depending on the person's physical capabilities.

A person with severe dementia may still be able to walk somewhat independently and may be independent or nearly so with bed mobility and transfers. But anything that requires planning, sequencing, or judgment is severely impaired at this stage. Close assistance will be needed for dressing, bathing, meal preparation, grooming, and toileting. If mobility is compromised, close assistance will be needed for all ADLs.

Control of bodily functions can be inconsistent, requiring direct help with bathing and toileting. Family members may find it impossible to continue to provide care and if they can afford it, may need to hire a caregiver, or move their loved one to assisted living or skilled nursing.

Safety awareness often declines in a person with severe dementia, requiring significant direct help with transfers, gait, and mobility. To prevent injuries from falls, it may be necessary to use bed and chair alarms or provide a one-on-one caregiver, which increases the cost of care. Caregivers and healthcare providers must make difficult decisions to prevent injury and to provide a safe environment.

For caregivers, healthcare providers, direct care workers, and family members, this is the stage of dementia that requires all your skills and expertise. People are creatures of habit and older adults with severe dementia still want to participate in social activities, use the bathroom without assistance, get out of bed whenever they want, and live in the way they have lived for their entire lives. These needs, desires, and habits are deeply embedded in our psyche, and it requires a great deal of patience and wisdom on the part of caregivers to understand these changes and provide support in a dignified and respectful manner.

In the severe stage of dementia:

Dressing

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

Grooming

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

Eating

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

Bathing*

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

Toileting**

- Expect both bowel and bladder incontinence requiring total care.
- Set up timed toileting schedule.

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

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

Bathing

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

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

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

Consequence: The client, staff, and the client's daughter are all upset. The situation was unpleasant for everyone and now showering is a dreaded experience for Mrs. Washington.

Discussion: Mrs. Washington's daughter has told the nursing staff that her mother prefers to undress in the shower room and hates being wheeled half-naked down the hall. The nursing assistant bathing her today is new and hasn't been told about Mrs. Washington's preferences.

To address Mrs. Washington's concerns, staff must find a way to communicate preferences such as these. Consider whether she needs to have a shower or if there are other ways of bathing that might be more acceptable to her.

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

6. Activities for Clients with Alzheimer's

Carefully designed activities can have a positive effect on depression, confusion, and challenging behaviors. Activities should provide a positive experience, be meaningful, and be challenging.

Telenius et al., 2022

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

Activity programs start with a detailed interview about the person's interests and skills. The nursing and therapy staff complete a thorough cognitive, language, and motor skills assessment. As a person's dementia advances, activities are reassessed and simplified.

Activities programs can positively influence a person's quality of life. Adult daycare facilities typically provide include strength and balance training, flexibility exercises, and cardiovascular activities. Other common activities are recreation and games, arts and crafts, musical activity, and rest.

The *Montessori-based Activities for Person with Dementia* has had some notable successes in the design of activity programs for people with dementia. This approach emphasizes matching a person's abilities with the activity. It uses personalized interventions to maximize the abilities of each individual (Chan et al., 2021).

Montessori programming highlights task breakdown, guided repetition, progression in task difficulty from simple to complex or concrete to abstract, the careful matching of individual past interests and occupations, and self-correcting. The activities are designed with an individual's past experiences and interests in mind. This approach is consistent with the person-centered care approach recommended for dementia care (Chan et al., 2021).

This program engages participants in meaningful activities that promote learning through procedural* or implicit** memory with the support of a prepared environment and external cues. The acronym "CREATE" represents the principles of type of activity design.

Program designers **create** a prepared environment and **remove** unnecessary distractions. They design an **error** free process in which **all** materials are familiar to the participants. **Templates** are provided according to individual needs and ability, and the **environment** is home-like. (Chan et al., 2021).

***Procedural memory**: a form of long-term memory associated with motor skills, habits, and tasks.

****Implicit memory**: unconscious or automatic memory.

6.1 Individual Activities

Successful individual activities for individuals with dementia are based on a person's likes, dislikes, and interests. This means a caregiver must learn a person's history and understand their capabilities and preferences. Understanding a person's lifestyle, whether they can still read, write, or use a computer and determining what a person is physically capable of doing is the basis for the design of individual activities. Individual activities that stimulate the senses, such as cooking, singing, exercise, going for a drive, gardening, and aromatherapy, are encouraged at all stages of dementia.

Some organizations that serve older adults, such as the *Eden Alternative*, encourage pets in their facilities. Pets provide companionship, promote relationships, and provide meaningful activity and exercise. Taking care of an animal gives a sense of purpose and companionship and is a key component of person-centered care.

Adults often have a fear of failure (especially those aware of their cognitive decline) and may refuse to participate in activities because of this fear. Be on the lookout for signs of frustration and agitation and address these behaviors immediately.

Individual Activities at Different Stages of Dementia

Activity	Mild	Moderate	Severe
Word games	Word searches, crossword puzzles Card/computer games	Simple word searches, simple crossword puzzles Simple computer games	Discuss a simple topic Listen to others
Letter writing	Write a letter Send email, use Facebook, social media	Dictate a letter or email Use Facebook with help	Listen to a letter or email being read
Art/Music	Take photos Create a photo album Draw, play an instrument	Take photos Maintain a photo album Draw, sing along with others	View photos Listen to music Sing along to familiar songs
Woodworking	Use tools Plan and complete projects with assistance	Use simple tools with supervision Assist with projects	Use activity board with bolts, screws Watch projects
Sewing	Use sewing machine with help Plan and complete projects with help	Use simple tools with supervision Assist with projects	Use sewing cards, activity blankets or aprons with buttons, snaps, ties, Velcro, and zippers, watch projects
Gardening	Garden in raised beds Help plan the garden and harvest	Perform specific tasks with supervision Eat food grown in garden	Sit in garden, eat food grown in garden Participate as able
Crafts	Knitting or crochet using large needles	Choose colors, roll balls of yarn	Choose colors, use the items that are created
At home activities	Help with laundry, put clothes away, assist with housekeeping	Sort and fold laundry	Fold laundry—may want to fold the same items repeatedly
Shopping	Go along to store, help with purchasing decisions Help put groceries away	Go along to store, help as able with shopping decisions Help put food away	Go along to store, sit in car with supervision or shop with wheelchair or electric cart

6.2 Group Activities

Cognitive impairment isolates us from other people, and can lead to anxiety, depression, societal withdrawal, and decreased self-confidence. Meaningful social interactions help a person with dementia regain a sense of self-worth.

As dementia progresses, group activities may become more challenging and individual activities may be preferred. Small groups of 5 to 6 people allow more activity and personal attention, although well-planned large-group activities can also be successful.

Group Activities at different Stages of Dementia

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

6.3 Virtual Reality

Recently, a great deal of research has been done on the use of virtual reality programs for older adults with and without dementia. The programs are designed to reduce loneliness, improve physical activity, and engage older adults in activities such as virtual travel.

Mynd Immersive, in collaboration with several large companies, has created the "Great American Elderverse", which allows older adult to socialize with friend and family, learn about the world, and engage in pursuits and passions. Elderverse programs focus on exercise and rehabilitation, recreation, reminiscence, and distraction. For older adults with dementia, the programs have been shown to reduce challenging behaviors, improve mood, and stimulate cognition.

7. Caregiver Stress Management

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

Richard Schulz and Lynn Martire

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

Much has been written about the negative effects that caregiving can have on the physical and mental health of caregivers, especially when they lack the necessary education, information, resources, and support (ADI, 2022). This is a critically important societal issue because each year more than 11 million family members and friends provide over 18 *billion* hours of unpaid care to those with Alzheimer's and other dementias, a contribution valued at nearly \$340 billion (Alzheimer's Association, 2023).

7.1 Causes of Stress for the Caregiver

Oh, what to say about caring for a family member with dementia? The stress is real and kind of creeps up on you. It's not too hard at first—you know—when my mom still had a good appetite, could walk around the house, take care of her garden, answer the phone, and listen to books on tape. Near the end, things got really difficult—lack of sleep, family squabbles, having to directly help with everything—and she wouldn't eat! There were more medical appointments and a very disinterested and unhelpful doctor made things much worse. I'm convinced I had a mild heart attack during this time, but I didn't go to the doctor because there was no one to watch her while I was gone.

Family Caregiver, West Palm Beach, FL

The responsibilities of caregiving for a person with dementia can be overwhelming. Nearly 60% 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, 2023).

Caring for individuals with dementia is more stressful than caregiving for individuals with many other diseases. This is because dementia caregiving is characterized by specific problems such as the lack of free time, isolation from others, behavioral problems and personality changes, and fewer positive experiences resulting from the lack of expressed gratitude by the care recipient (Elnasseh et al., 2016).

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

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

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

Family dynamics are an important part of the caregiving experience. Communication, adaptability, flexibility, and marital cohesion are connected to the well-being 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 can 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 and good family support are associated with lower levels of caregiver strain. When families increase their support to primary caregivers, it often results in helping the individual with dementia. Caregivers experience less burden and depression when family cohesion is high; also, greater family communication plays an important role in reducing caregiver burden (Elnasseh et al., 2016).

Whether paid or unpaid, most caregivers across most cultures are women. Unfortunately, many women may be relatively disadvantaged with respect to education, career opportunities, income, assets and (in older age) pension entitlements. Taking on caring responsibilities for a person with dementia can lead to social isolation, cutting back or stopping work, and risks to physical and mental health (ADI, 2015, latest available).

Factors and Characteristics Associated with Caregiver Strain

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

Source: Adapted with permission from ADI, 2022.

7.2 Challenges for Caregivers at Each Stage

I've been hired to help care for a woman with mild dementia. She has five kids who come to their mother to discuss their personal problems. When they talk about their problems, I notice the mom always agrees with them but when they leave, she turns around and says, "I can't stand to hear all their complaints."

She gets really agitated after they visit. Sometimes she sits and cries for the rest of the day and I can't snap her out of it. She didn't used to be like this. I get so tired it almost isn't worth it—I never get any sleep when I'm there. I finally had to cut back from 7 to 4 days. It was really difficult caring for this woman.

Professional Caregiver, Miami, Florida

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

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.

A person with mild dementia may only need help with complex activities such as banking, bill paying, medical appointments, and medications. They may still live alone, drive, and even have a job. They can usually handle activities of daily living such as bathing, eating, and cooking.

In the moderate stage, the increased time needed to care for a previously independent person often increases caregiver anxiety and stress. 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?

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, 2024

Challenging behaviors that can arise in a person in the later stage of dementia, such as agitation, irritability, obscene language, tantrums, and yelling can be embarrassing, tiring, and frustrating for caregivers. Caregivers may be injured if a person throws things, strikes out, or bites. Caregivers may react out of fear and strike back or yell to stop these behaviors, creating guilt and more frustration.

In this stage, safety is a challenge for caregivers. 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.

Family members may find it impossible to continue to provide care at home and may decide to move their loved one to an assisted living or skilled nursing facility. Although this can reduce 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.

7.3 Strategies for Managing Caregiver Stress

Reducing caregiver strain is possible when the caregiver receives education, training, support, and respite. These four components have been shown to decrease caregiver stress and reduce or delay the transition from home to a care facility (ADI, 2022).

Caregivers can also reduce their stress by paying attention to their own health. This means getting enough sleep, eating properly, seeing their own doctors, and sharing their feelings about their caregiving duties with co-workers, family, and friends.

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

Adult daycare centers (Tretteteig et al., 2017):

- Provide separation time, giving family caregivers time that can be used for undisturbed work, rest, or other pursuits.
- Reduce behavioral problems and the need for assistance with ADLs.
- Reduce care demands, stress, and depression as well as increase wellbeing.
- Increase motivation for care and postponement of residential placement.

Addressing Caregiver Stress

Reducing caregiver stress	Things to avoid
<ul style="list-style-type: none"> • Join a support group or see a counselor to discuss your feelings. • Set limits on caregiving time and responsibility. • Become an educated caregiver. • Discuss your situation with your employer. • Accept changes as they occur. • Make legal and financial plans. • Take regular breaks (respite). • Seek out daycare services. 	<ul style="list-style-type: none"> • Don't isolate yourself. • Don't try to be all things to all people. • Don't expect to have all the answers. • Don't deny your own fears about dementia and aging.

7.4 Caregiver Bill of Rights

A caregiver bill of rights was first crafted by Jo Horne in her 1985 book *CareGiving: Helping an Aging Loved One*. Her widely adopted principles, although not legally binding, have provided a framework for additional research on the critically important role that informal, unpaid caregivers play in the care of dependent older adults.

The original caregiver bill of rights contains nine items that encourage caregivers to consider their own health and well-being and to set boundaries. Among other things, the Caregiver Bill of Rights states, "I have the right to":

1. Take care of myself.
2. Seek help from others.
3. Maintain facets of my life that do not include the person I care for.
4. Get angry or depressed.
5. Resist attempts by the person I am caring for to manipulate me.
6. Receive consideration, affection, forgiveness, and acceptance from the person I am caring for.
7. Take pride in what I am doing.
8. Protect my individuality.
9. Demand resources to support and aid caregivers.

For a comprehensive list of these rights, [please click here](#).

8. Working with Families and Caregivers

Throughout the world, family is the cornerstone of care for older people who have lost the ability to live independently. 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 among this population creates a tremendous burden on family and society (ADI, 2013).

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

The system of informal, unpaid care provided by family members is under pressure due to declining fertility rates and fewer young people willing to care for older adults. Changing attitudes and expectations among the young as well as increased workforce mobility mean that family members are not always living 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).

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. A large, population-based study however suggested that morbidity and mortality rates for caregivers may be lower than for non-caregivers. This may be due to the physiological benefits of prosocial helping behaviors (Roth, et al., 2018).

Positive aspects of caregiving include feelings of meaning and self-efficacy, satisfaction, feelings of accomplishment, and improved wellbeing and quality of relationships. These positive experiences can help sustain family members in their work as caregivers (Tretteig et al., 2017).

8.1 Family Issues by Stages

Most people with dementia, no matter what the stage, live in the community, and for approximately 75% of these individuals, care is provided by family and friends. The largest proportion of caregivers is spouses, followed by children and children-in-law, mostly female. Most caregivers of a person with dementia are middle-aged or older, female, and the child or spouse of the person with dementia. 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).

8.1.1 In the Early Stage

In the early stage of dementia, family members must adjust their own behaviors and manage their own frustrations as they learn (of often don't learn) about the early effects of dementia. They may be 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 their spouse's 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 short periods of time.

Early, specialized training is strongly recommended. This is an often-neglected component of dementia care. Training prepares family caregivers for what lies ahead and allows them to partner more easily with healthcare providers to provide competent and compassionate care.

Enrolling a person with mild dementia in an adult day program provides an opportunity for caregivers to learn about dementia and gain techniques for managing any challenging behaviors that might arise. It is also a place to learn about assistive equipment and things a caregiver can do to "harden" the home against falls and accidents. This area of dementia care can, among other things, encourage caregivers to install grab bars, raise couches and chairs, lock up poisons and caustic materials, remove or lock up guns, and install remote sensors for climate control.

8.1.2 In the Middle Stages

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

The increased need to handle practical tasks can be a physical burden for family caregivers, especially those in poor health. Many caregivers must take over cooking and cleaning and other household chores. As the need for help increases, family members must decide whether to hire a private caregiver, which is costly. At this stage, family caregivers' cumulative stress is associated with increased nursing home placement, institutionalization, or hospitalization of the patient with dementia.

If a family member is enrolled in an adult day program, education and support are critical. Daycare programs provide needed respite for the caregiver while providing ongoing information about managing challenging behaviors, home safety measures, medication management, and techniques for managing caregiver stress.

8.1.3 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 ones. Caregivers must learn to interpret facial expressions for sadness, anger, or frustration, and physical gestures such as grasping at undergarments, which may communicate the need to use the bathroom.

One of the most difficult issues—usually in the middle to late stages of dementia—is whether or not to place a family member in residential care or skilled nursing. There are a number of reasons cited by caregivers for placement:

- The need for skilled care and assistance.
- The family caregivers' health.
- The loved one's dementia-related behaviors.

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.

Moving a family member to a care facility requires family caregivers to learn to navigate a complicated healthcare system. Healthcare personnel can provide support by determining the preferences, abilities, and resources of each family member. Regular face-to-face meetings with family members and facility staff can help families work through these difficult issues.

For caregivers and family members of a person in the late stage of dementia, respite and emotional support are critical. This is when stress, fatigue, and worry are at their highest point. Carefully designed activities, medication (and medical) management are crucial aspects of a person's care. The go-to resource for most caregivers is the family doctor, who often does not have the time, interest, or knowledge to help family caregivers. Healthcare providers in a specialized adult daycare facility can have a profound impact at this stage when help and support are most needed.

8.2 The Grief Process

Physical symptoms such as shortness of breath, headaches, fatigue, a feeling of heaviness, a lack of energy, and loss of physical strength and abilities are often related to feelings of grief. Psychological symptoms associated with grief include clinical depression, hypochondria, anxiety, insomnia, increased confusion, and the inability to get pleasure from normal daily activities. These issues can lead to self-destructive behaviors, such as alcohol or drug abuse.

A person who receives a diagnosis of dementia can experience grief related to the actual (or anticipated) losses associated with the diagnosis. Physical and psychological changes and losses for the person with dementia can include:

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

Caregivers of people with dementia often experience intense feelings of grief and loss prior to the physical death of their loved one. The losses experienced by caregivers can build up as the disease progresses. The grieving encompasses feelings of ambiguity, loss of companionship, freedom, and control, as well as anger and guilt, but can also include psychosocial reorganization and coping (Rupp et al., 2023).

Some interventions may help manage or reduce grief reactions. Cognitive-Behavioral Therapy (CBT) programs, group formats, family therapy, mindfulness-based interventions, and new technology formats can have a positive impact on burden and caregiver grief and distress (Rupp et al., 2023).

Grief and guilt are often intensified when a loved one moves to a care home, contributing to a sense of loss for the person with dementia and for caregivers. For the person with dementia, moving to an institutional setting can be profoundly disorienting. Depression and grief are common reactions that can be addressed through education, support groups, meaningful activities, and social support.

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

8.3 Family, Clients, and Dementia Care Programs

Dementia care programs are multidisciplinary and multi-departmental programs designed to meet the daily, individual needs of clients. The quality and success of a dementia care program is strongly influenced by facility's environment, philosophy of care, available services, and staff experience and training.

A well-designed dementia care program offers activities that include family members and allows and encourages families to visit at any time. Care programs:

- Encourage family involvement in the planning of activities.
- Inform family members about changes in their loved one's condition.
- Keep a log of resident activities to share with the family.
- Use technology to keep families keep in touch with one another.

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

Belonging to an ethnic minority group can lead to inequalities in diagnosis and access to care. 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 medications (Giebel, 2020).

8.4 Caregiver Training and Support

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

Support for caregivers of people with dementia includes education, cognitive-behavioral therapy, case management, general support, and respite. For the person with dementia, interventions that focus on improving cognitive and functional impairments can reduce caregiver stress (Walter and Pinquart, 2020).

Training introduces caregivers to resources, support, and equipment to improve health and safety. Education can reduce a caregiver's psychological and physical strain while delaying or avoiding their loved one's transition to a care home (ADI, 2015).

Caregivers are likely to need education and training in the medical aspects of dementia care. They are responsible for managing a confusing array of medications that can change each time their loved one visits the doctor or hospital. They must be able to differentiate dementia from other illnesses and understand how to manage difficult behaviors when they arise.

9. Maintaining a Therapeutic Environment

All of us rely on environmental cues to support us physically, cognitively, and emotionally. This is even more important for a person experiencing the many cognitive, sensory, and physical changes associated with dementia. Unfamiliar, chaotic, or disorganized environments—whether at home, in adult daycare, or in a care facility—create stress and anxiety and contribute to behavioral problems.

A therapeutic environment recognizes that people with dementia are influenced by their surroundings and do better with environments that are individualized, flexible, and designed to support differing functional levels and approaches to care (Campenel & Brummett, Nd). At a minimum, an organization caring for people with dementia should understand that people with dementia do better in a setting that is designed to support their dignity and autonomy.

There is a trend toward designing facilities for people with dementia to be as homelike as possible. This idea was pioneered in Sweden in the 1980s. Today, similar concepts can be found all over the world, from Green Houses in the U.S. to group homes in Japan, small-scale living arrangements in the Netherlands, and German shared-housing arrangements (Gräske et al., 2015).

9.1 Philosophy of Care

An organization's philosophy of care is a framework that identifies its goals and values. The family, and the person receiving services, has the right to know—and should feel free to question—a center's philosophy of care. Key questions can include:

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

California Advocates for Nursing Home Reform, 2024

9.1.1 Dementia Friendly Care

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 family and caregivers with dignity and respect and calls for an end to stigma. It seeks community support for people affected by dementia so they can "live well with dementia" (ADI, 2015).

Dementia Friends



Courtesy Alzheimer's Disease International.

Dementia Friends is an international public awareness initiative delivered through volunteers and an online tool. Dementia Friends began in the United Kingdom and is run by Alzheimer's Society (Dementia Friends USA).

The Dementia Friends program, now available in the U.S., focuses on five key messages (Dementia Friends USA):

1. Dementia is not a natural part of aging.
2. Dementia is caused by diseases of the brain.
3. It is not just about losing your memory.
4. It's possible to live well with dementia.
5. There is more to the person than the dementia.

9.1.2 Person-Centered Care

Person-centered care relies on caregivers' organization's skills, training, and knowledge. It means that care is built around the needs and preferences of the client, the care professional, caregivers, and family members. It is the opposite of task-centered care. The goal is to create a high-quality, joyful, shared environment.

Person-centered care is flexible, creative, and supportive. It includes the person living with dementia and their family members and caregivers in care and treatment decisions, with the aim of increasing positive outcomes.

An innovative person-centered approach called "green care farms", developed in the Netherlands, provides daycare services and 24-hour nursing home care to people with dementia. Green care farms offer a broad selection of activities—including caring for plants and animals. It encourages clients to engage in tasks suited to their level of dementia and physical capabilities (de Boer et al., 2019).

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

9.2 The Physical Environment

There is a profound and direct connection between the environment and the way people feel and behave. Buildings thoughtfully designed for the care of people with dementia encourage community, maximize safety, support caregivers, cue specific behaviors and abilities, and redirect unwanted behaviors (Campernel & Brummett, Nd).

Certain design principles have been shown to reduce unwanted behaviors and enhance a sense of well-being in people with dementia. For example, getting rid of dark nooks and crannies, providing views to the outside, including private spaces and a separate room or recess for sleeping or resting, and having easily accessed public spaces and places for semi-private interactions support person-centered care and can reduce unwanted behaviors.

Additional design recommendations:

- Keep public spaces clean and get rid of odors.
- Replace institutional, centralized nursing stations with smaller, residential-looking stations.
- Create spaces to cue specific behaviors (activity kitchen, art and music therapy area, bistro/bar, rummaging room, library, coffee shop/internet café, quiet room, living room).

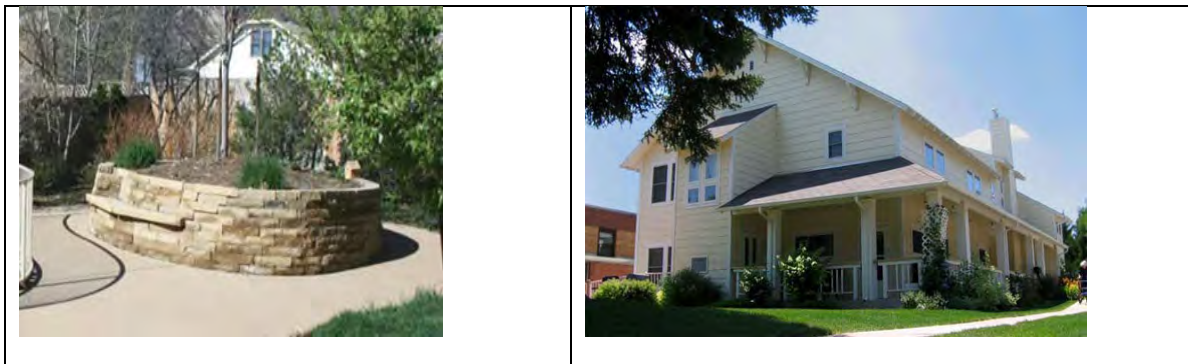
Living Spaces Designed for Dementia Patients



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

For outdoor design (Rijnaard et al. 2016):

- Arrange outdoor spaces to resemble a natural community or yard.
- Create looping pathways with generous seating and areas of interest.
- Include clients in the design of new features.
- Create safe, purposeful, heated, and accessible outdoor areas.
- Offer attractive landscaping, gardens, and pleasing views.



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: Campnerl & Brummett, Nd. Used with permission.

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

9.3 Safety and Security

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

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

Measures to Promote Safety and Security

Safety issue	Possible consequence	Intervention
Wandering	Getting lost, exposure to environmental hazards.	Use technology such as the Alzheimer Association's Comfort Zone.* Provide short, looping corridors without dead ends. Create open, common areas of interest. Create safe, outdoor wandering areas that are accessible from indoor wandering paths. Paint the inner surfaces of doors so that they are not readily recognizable as an exit. Place locks where they are not visible.
Cooking without supervision	Fire, injury	Install a shut-off valve on the stove. Remove burner on-off handles. Keep a working fire extinguisher. Create a work area with an activity kitchen.
Falls	Injury	Rule out medical conditions. Create an uncluttered environment. Install handrails in showers and hallways.

		<p>Install carpeting to reduce injuries.</p> <p>Wipe up spills promptly.</p> <p>Maintain physical activity.</p> <p>Supervise walking and use assistive devices.</p> <p>Remove throw rugs or tape edges down.</p> <p>Maintain good vision and hearing.</p> <p>Provide many places to sit.</p>
Poisoning	Sickness or death	<p>Remove toxic plants from the environment.</p> <p>Lock up chemicals and medications.</p>

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

Simply receiving care at an adult daycare center can be a source of safety and security for a person with dementia. A well-designed and well-run facility is secure, comfortable, and predictable; it is a place where one can feel at ease—a place where you can be who you are and feel connected with like-minded people (Rijnaard et al., 2016). Adult daycare centers can also offer a sense of safety and security for caregivers, providing a feeling of shared responsibility and respite (Tretteteig et al., 2017).

9.4 Schedules and Routines

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

In traditional facilities providing services for older adults, schedules and routines are primarily organized around the convenience of the staff. As a result, schedules can change dramatically from day to day. This is difficult for people with dementia because they rely on a predictable routine for orientation. A regular routine allows a person with dementia to know what to expect and gives caregivers and family members a benchmark for evaluating any changes in a person's behavior.

A schedule for someone with dementia should be planned carefully, allowing plenty of time for activities of daily living. Always keep in mind a person's capabilities and preferences. Additionally:

- Maintain regular mealtime routines.
- Maintain regular dental and healthcare appointments.
- Note the effects of changes in routines.
- Address issues that disrupt routines such as pain, fatigue, or illness.

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

9.5 Staff as Part of the Environment

In Florida, adult daycare centers must employ qualified staff to provide the services, personal assistance, and safety measures required by participants. Nearly 60% of workers in adult daycare centers are aides, 18% are registered nurses, 11% are licensed practical nurses, and about 12% are social workers (Singh, 2022).

In centers providing adult daycare services, the following staff are required (O'Keeffe, 2014):

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

9.5.1 Proper Staffing

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

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

A person-centered approach can decrease staff turnover, improve worker satisfaction, and reduce clients' unwanted behaviors. This is important for people who work in care facilities as well as the clients they are serving. A person-centered approach includes establishing shared goals, sharing professional values, and being part of a supportive team (Vassbø et al., 2019).

9.5.2 Staff Adjusting to Resident Routines

In adult daycare settings, clients are ideally cared for by a small, fixed team of trained caregivers. Activities, rest periods, and meals should be organized completely, or in large part around each client's needs and routines. To encourage this practice, a facility must hire and train staff with the emotional skills to interact with people with memory problems.

Experienced staff understand that a client may have a favorite chair, a preferred location during mealtimes, and food and rest preferences. A client may have differing needs with regards to heating and cooling, blankets or no blankets, styles and type of music, preferred activities, and preferred friends. Consistency and communication keep staff members aware of client preferences and allow them to adjust to a client's needs and routines.

10. Ethical Issues with Dementia Patients

Healthcare providers, caregivers, and family members are often faced with difficult ethical decisions, 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.

Ethical issues can range from questions about how to engage with a person with dementia who is unwilling to accept that they have the disease to how to decide whether manipulating a person with dementia is ethically permissible if it promotes their best interest (Lauridsen et al., 2023).

10.1 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. 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).

10.1.1 Autonomy and Well-Being

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

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

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

10.1.2 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.

10.1.3 Justice: Equity and Fairness

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

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

10.1.4 Veracity (Truthfulness)

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

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

10.2 Incorporating Ethical Principles into Care

Ethical dilemmas or ethical challenges 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).

Ethical issues in dementia care can be a conflict between respecting the self-determination of a person with dementia, in terms of what they want, and acting in their best interest. Other ethical issues concern how caregivers prioritize the needs of the people they are caring care for. This includes avoiding causing harm to people with dementia while allowing them to make their own decisions (Lauridsen et al., 2023).

10.3 Examples of Ethical Conflicts and Dilemmas

Maintaining Independence: Mr. Corona

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

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

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, albeit with close oversight. They are balancing his need for autonomy with his need for safety and protection. The three sisters decide to 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

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 needed help with her meals for two years, but over the last month has intermittently refused food. As a result, in the past 6 weeks, she has lost 15% of her body weight. 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 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.

Principles of Justice and Injustice: James Coppola

Jimmy Coppola is a 90-year-old, increasingly non-verbal resident living in a small nursing home in Gainesville, Florida. As his verbal skills have declined, he has had less and less meaningful interaction with other residents, staff, and family members. Recently, he was moved to a new, somewhat-isolated room a relatively long distance from the nursing station and activities room. His new room has no pictures or décor that might help others get to know him as a person. Other rooms in the facility, with people in earlier stages of dementia, are warm, cozy, and welcoming. In general, it was noted that residents in the facility in the later stage of dementia, especially non-verbal residents were in the same situation as Jimmy.

Discussion: Recall that justice is related to a fair distribution of benefits and burdens. Although most caregivers and healthcare providers may not see Mr. Coppola's situation as unjust, it is in fact a common example of a lack of comparative justice: the way in which healthcare benefits are delivered at an individual level. Mr. Coppola is experiencing a type of injustice described as "a distinctive class of wrongs, in which someone is disingenuously downgraded and/or disadvantaged in respect of their status". This form of injustice is rooted in unfair prejudice, stigma, ignorance, and isolation.

Caregivers, and even family members, may view people with dementia as stupid, child-like, crazy, or not themselves anymore. They may believe that people with dementia are incapable of purposeful and meaningful communication and unable to participate in relationships and activities. Non-verbal people with dementia are frequently ignored because it is more challenging to see and recognize them as relational human beings when they are no longer able to respond verbally. This can be viewed as a form of non-verbal injustice.

Recent studies have shown that benefits offered to verbal residents are denied to non-verbal residents and other options are often not offered. If a person is excluded from social activities and, therefore, social interactions in advance, they are essentially silenced.

Most people with language inhibiting dementia not only struggle to communicate verbally but also struggle to understand verbal communication. For this reason, it is vitally important to pay close attention be particularly attuned to your own facial expressions, eye contact, bodily contact, posture, hand gestures, and proximity to the other person.

Learning to use gestures to communicate can open caregivers and healthcare workers a shared openness with the non-verbal person. This enables family members and caregivers to participate in interactions using alternative forms of expression and communication, transforming interactions for both parties.

Modified from Spencer (2023), *Epistemic Injustice in Late-Stage Dementia: A Case for Non-Verbal Testimonial Injustice*.

11. Concluding Remarks

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

People with dementia often exhibit symptoms and behaviors that are challenging for family members and professional caregivers to manage. These symptoms and behaviors are caused by damage to the brain and are not intentional.

Challenging behaviors are a form of communication, often related to unmet needs. By carefully observing what comes directly before and after a behavior and determining the underlying cause family members and caregivers can learn how to address the challenging behavior.

People with dementia need to be treated with kindness and with the knowledge that they can still enjoy life. Physical and chemical restraints are not recommended for managing challenging behaviors except for the shortest possible amount of time and only as a last resort. There are many proven alternatives to physical and chemical restraints that are the mainstays of person-centered care.

A person's ability to independently complete activities of daily living is disrupted with the onset of dementia. As dementia progresses, family members and caregivers must step in to assist with personal care and household management. Caregiver training is an essential component for anyone caring for a person with dementia. Family caregivers play a critical and often-overlooked role in the care of people with dementia—especially in the early to moderate stages. Caregivers often experience stress, which can be lessened by accessing respite care and adult daycare services.

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

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

Working with a person experiencing the effects of dementia can be satisfying and rewarding. However, it takes consistency, patience, practice, and training to learn to understand the world from the person's point of view.

People with dementia can still enjoy life. They are not children. They can enjoy memories, interactions with the people around them, and activities that are matched to their preferences and abilities. Your efforts to make the person comfortable and happy can make a big difference in their final years of life.

Resources

2-1-1 Information and Referral Search

For help with food, housing, employment, healthcare, counseling, and crisis intervention, and more in many counties in Florida. www.211.org, or call 211

Alzheimer's Association

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

Alzheimer's Disease Education and Referral (ADEAR) Center

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

AlzOnline: Caregiver Support Online

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

Alzheimer's Project

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

Area Agency on Aging for North Florida

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

CJE Senior Life

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

Eldercare Locator

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

Family Caregiver Alliance National Center on Caregiving

A community-based nonprofit organization that addresses the needs of families and friends providing long-term care for loved ones at home. Provide assistance, education, research, and advocacy. [www.caregiver.org /](http://www.caregiver.org/) 800 445 8106

Florida Adult Day Services Association (FADSA)

Provides leadership, education, planning, and development of adult day services across Florida. Promotes quality day services, respite programs, adult day health centers, and education, training, and advocacy within the long-term care industry. <https://www.fadsafl.org/>

Florida Council on Aging

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

Florida Department of Elder Affairs

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

Florida Elder Helpline: Florida Department of Elder Affairs

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

Florida Hospice and Palliative Care Association (FHPC)

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

Florida Telecommunications Relay (FTRI)

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

Positive Approach to Care

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

Share the Caregiving

Dedicated to educating the caregiving communities about the effectiveness of the Share the Care model. Share the Care encourages ordinary people to pool their efforts to help ease the burden on family caregivers and help those without family nearby. www.sharethecare.org/

Today's Caregiver

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

[Continue to next page for references]

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[Continue to next page to start quiz]

13. Quiz: FL Specialized Alzheimer's Adult Day Care, Level 1

1. Adult daycare centers provide non-residential coordinated services in a community setting for less than a day.

- a. True
- b. False

2. For a person experiencing the effects of dementia:

- a. Symptoms change as dementia progresses, often affecting behavior.
- b. Disease progression differs from person to person.
- c. Co-morbid conditions can affect how fast and how far the dementia progresses from one stage to another.
- d. All of the above.

3. 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.

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

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

5. Use of restraints should be:

- a. Reserved for documented indications.
- b. Time limited.
- c. Frequently re-evaluated for their indications, effectiveness, and side effects in each patient.
- d. All of the above.

6. The ABC or problem-solving approach to behaviors in dementia includes:

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

7. Agitated and aggressive behaviors are almost always related to loss of control, physical discomfort, need for attention, feelings of humiliation, misunderstanding, or fear.

- a. True
- b. False

8. Wandering in a person with dementia can be addressed by:

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

9. Mrs. Cortez has moderate to severe dementia. When her caregivers attempt to bathe her, she pinches and bites. A good way to address and minimize this behavior is:

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

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

- a. Learn about experiences and hobbies that might be of interest to him.
- b. Let him be—he is probably happy in his room.
- c. Make him participate in activities even if he protests.
- d. Take away his T.V. until he agrees to participate in another activity.

11. Many women face challenges associated with caring for a person with dementia. This can include:

- a. Be relatively disadvantaged compared to men with respect to career opportunities.
- b. Having lower income, assets and (in older age) pension entitlements.
- c. Needing to cut back on or stop working.
- d. All of the above.

12. Ann's husband has severe dementia, and she has been his sole caregiver for more than 6 years. She has refused help, rarely leaves the house, and when a friend visited, she noticed the house was filthy. The bed was covered with dirt from the dogs and the bathroom hadn't been cleaned in months. Ann and her husband are well-off, own their own home, and rent another home to a friend. What might be happening with Ann? C

- a. She is certain that she cannot afford to hire a caregiver.
- b. She doesn't want a stranger in the house.
- c. She is highly stressed and is unable to cope with her husband's worsening dementia.
- d. She wants to care for her husband rather than clean the house.

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

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

14. For a person with dementia, grief:

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

15. A therapeutic environment:

- a. Is one in which psychologists are available 24/7.
- b. Provides easy access to antipsychotics and restraints for addressing behavioral problems.
- c. Recognizes that people with dementia do better with environments that are individualized and flexible.
- d. Are designed to support people on hospice.

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

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

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

- a. Eliminate institutional, centralized nursing stations.
- b. Make sure doors and windows are locked at all times.
- c. Rotate staff so clients get to know everyone.
- d. Don't allow people with dementia to take naps.

18. A key principle of bioethics is:

- a. People with dementia are no longer able to participate in decisions about their care.
- b. People with dementia are the same, equally valued, people throughout the course of their illness, regardless of the changes in their mental abilities.
- c. Bioethics cannot be applicable to people with dementia.
- d. People with dementia have less value than people without dementia.

19. The principle of beneficence is:

- a. Not usually used when making ethical decisions.
- b. Not applicable to people with ADRD.
- c. Difficult to apply to ethical situations.
- d. The intention to do good.

20. Ethical dilemmas or ethical challenges arise when there are equally good reasons both for and against a particular course of action and a decision must be made.

- a. True
- b. False

[Continue to next page for answer sheet]

Answer Sheet: FL Specialized AD Adult Day Care, Level 1

Name (Please print) _____

Date _____

Passing score is 80%

1. _____	11. _____
2. _____	12. _____
3. _____	13. _____
4. _____	14. _____
5. _____	15. _____
6. _____	16. _____
7. _____	17. _____
8. _____	18. _____
9. _____	19. _____
10. _____	20. _____

[Continue to next page for course evaluation]

14. Course Evaluation: FL Specialized Adult Day Care, Level 1

Please use this scale for your course evaluation. Items with asterisks * are required.

1 = Strongly agree 2 = Agree 3 = Neutral 4 = Disagree 5 = Strongly disagree

*Upon completion of the course, I was able to:

1. List the 3 types of services provided at adult daycare centers. 1 2 3 4 5
2. Identify 3 common behavioral and psychological symptoms of dementia. 1 2 3 4 5
3. Describe 4 alternatives to the use of restraints in older adults with dementia. 1 2 3 4 5
4. Identify the 3 key components of the problem-solving approach for managing challenging behaviors. 1 2 3 4 5
5. List 5 general measures to keep in mind when assisting someone with their ADLs. 1 2 3 4 5
6. Relate the 3 components that should be part of individual and group activities for clients with dementia. 1 2 3 4 5
7. Describe 3 ways that stress can affect a caregiver's quality of life. 1 4 3 4 5
8. Describe 3 issues family caregivers face as their loved one transitions from mild to moderate to severe dementia. 1 2 3 4 5
9. Identify 3 philosophical concepts that are important in the design of a therapeutic environment for those with dementia. 1 2 3 4 5
10. Relate common ethical conflicts that may arise when caring for clients with dementia. 1 2 3 4 5

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

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

*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? 1 2 3 4 5

*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?

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_____ 40-49 minutes per contact hour _____ 30-39 minutes per contact hour
_____ Less than 30 minutes per contact hour

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_____ 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: FL Specialized Adult Day Care, Level 1

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

*Name: _____

*Email: _____

*Address: _____

*City and State: _____

*Zip: _____

*Country: _____

*Phone: _____

*Professional Credentials/Designations:

*License Number and State: _____

Payment Options

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

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

3 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: _____