MA: Alzheimer’s Disease and Related Dementias, 3 units (250)

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Contact hours: 3

Course price: $29

Instructions

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This course fulfills the requirement for training related to Alzheimer’s Disease and Related Dementias for Massachusetts healthcare professionals.

Course Summary

This purpose of this course is to provide direct-care staff in nursing homes, hospice, and adult daycare with the skills, techniques, and strategies to care on a daily basis for residents who have Alzheimer’s disease or a related dementia. It includes activities that allow participants to practice the skills and strategies they have learned.

COI Support
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Criteria for Successful Completions
80% or higher on the post test, a completed evaluation form, and payment where required. No partial credit will be awarded.

Course Objectives

When you finish this course you will be able to:

1. Outline types of dementia and the process and diagnosis of Alzheimer's disease.
2. Identify 5 common behavioral and psychological symptoms of dementia.
3. Discuss the use of physical or chemical restraint versus non-pharmacological interventions for persons with dementia.
4. Describe how mild, moderate, and severe dementia affects a person's ability to complete basic activities of daily living (ADLs).
5. Relate the 3 components each that should be part of individual and group activities for residents with dementia.
6. Summarize tasks of , stressors for, and support available to family caregivers.
7. List 3 concepts that are important in the design of a therapeutic environment for those with dementia.
8. Identify 4 concepts that are part of an ethical approach to dementia care.

Causes and Diagnosis of ADRD

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 two or more types of dementia.

Worldwide more than 50 million people live with dementia and because people are living longer this number is expected to more than triple by 2050 (ADI, 2018). In Massachusetts, there are 130,000 residents living with Alzheimer's disease, and by 2025 this number is expected to increase by more than 20,000 (Alzheimer's Association, 2019a).

Defining Dementia

> The ugly reality is that dementia often manifests as a relentless and cruel assault on personhood, comfort, and dignity. It siphons away control over thoughts and actions, control that we take for granted every waking second of every day.
>
> Michael J. Passmore, Geriatric Psychiatrist
> University of British Columbia

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

Researchers believe that in Alzheimer's disease toxic changes in the brain destroy the healthy balance that allows neurons (nerve cells) to communicate with each other and other cells (microglia and astrocytes) to clear away debris and keep neurons healthy (NIA, 2017).

The changes involve the protein fragment beta-amyloid and protein tau in which abnormal tau accumulates and eventually forms tangles inside neurons, and beta-amyloid clumps into plaques. These plaques build up slowly between neurons, and when they reach a tipping point tau spreads rapidly through the brain. This buildup triggers *microglia*, the brain's immune system cells, but they cannot keep up with the buildup of debris and the result is chronic inflammation. Brain atrophy occurs as cells are lost. As the brain's ability to metabolize glucose decreases, normal brain function is further affected (Alzheimer's Association, 2019; NIA, 2017)

This process, which may begin years or decades before the first signs of dementia, can be seen in the following video.

How Alzheimer's Changes the Brain (3:59)

How Alzheimer's Changes the Brain

https://www.nia.nih.gov/health/video-how-alzheimers-changes-brain

Current research identifies three stages of Alzheimer's disease:

- Preclinical Alzheimer's disease (still under investigation) which involves measurable biomarkers but no outward symptoms;

- Mild cognitive impairment (MCI) due to Alzheimer’s disease, which also has biomarkers and some symptoms that do not interfere significantly with everyday activities; and
- Dementia due to Alzheimer’s disease, which divides into 3 stages: mild, moderate, and severe (Alzheimer’s Association, 2019).

In Alzheimer’s disease, damage begins in the temporal lobe, in and around the hippocampus. The hippocampus is part of the brain’s limbic system and is responsible for the formation of new memories, spatial memories, and navigation, and is also involved with emotions.

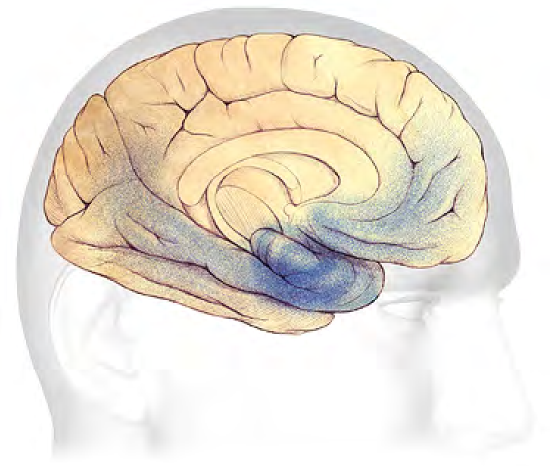
Mild Alzheimer’s Disease (Preclinical)

In the earliest stages of Alzheimer’s disease, before symptoms can be detected, plaques and tangles form in and around the hippocampus (shaded in blue).

Source: Courtesy of The Alzheimer’s Association. Used with permission.

As the disease progresses, plaques and tangles spread to the front part of the brain (the temporal and frontal lobes). These areas of the brain are involved with language, judgment, and learning. Speaking and understanding speech, the sense of where your body is in space, and executive functions such as planning and ethical thinking are affected.

Moderate Alzheimer’s Disease

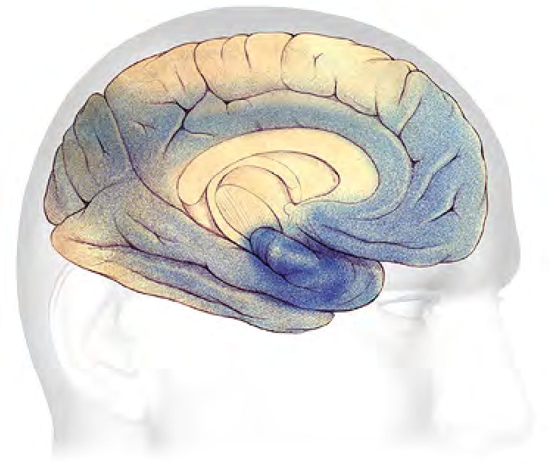


In mild to moderate stages, plaques and tangles (shaded in blue) spread from the hippocampus forward to the frontal lobes.

Source: Courtesy of The Alzheimer’s Association. Used with permission.

In severe Alzheimer’s disease, damage is spread throughout the brain. Notice in the illustration below the damage (dark blue) in the area of the hippocampus, where new, short-term memories are formed. At this stage, because so many areas of the brain are affected, individuals lose their ability to communicate, to recognize family and loved ones, and to care for themselves.

Severe Alzheimer’s Disease



In advanced Alzheimer’s, plaques and tangles (shaded in blue) have spread throughout the cerebral cortex.

Source: Courtesy of The Alzheimer’s Association. Used with permission.

Further research into molecular and cellular mechanisms and their interactions are critical to developing therapies, and progress has been made in identifying underlying factors. Brain imaging advances have allowed observation of the course of plaques and tangles in the living brain, blood and fluid biomarkers can help pinpoint disease beginning and progression, and further understanding of the disease’s genetic underpinnings and their effects are being explored to develop new therapies (NIA, 2017).

Types of Dementia

Although Alzheimer’s disease is the best-known and most common cause of dementia, it is not the only cause, and there are over 100 forms of dementia (ADI, n.d.). Frontal-temporal dementia—which begins in the frontal lobes—is a relatively common type of dementia in those under the age of 60. Vascular dementia and Lewy body dementia are other common types of dementia (see table).

Some Common Types of Dementia			
Dementia subtype	Early, characteristic symptoms	Neuropathology	% of dementia cases
*Alzheimer's disease (AD)	▪ Gradual onset ▪ Impaired memory, apathy and depression ▪ Language and visuospatial deficits	▪ Cortical amyloid plaques ▪ Neurofibrillary tangles	50–75%
Frontal-temporal dementia	▪ Early onset (45 to 60 yrs of age) ▪ Behavioral and personality changes ▪ Mood changes ▪ Disinhibition ▪ Language difficulties	▪ No single pathology: damage limited to frontal and temporal lobes ▪ Damage limited to frontal and temporal lobes	5–10%
*Vascular dementia	▪ Stepwise onset ▪ Similar to AD, but memory less affected, and mood fluctuations more prominent ▪ Physical frailty ▪ Patchy cognitive impairment ▪ Often preventable	▪ Cerebrovascular disease ▪ Single infarcts in critical regions, or more diffuse multi-infarct disease ▪ Group of syndromes	20–30%
Dementia with Lewy-bodies	▪ Marked fluctuation in cognitive ability ▪ Visual hallucinations ▪ Parkinsonism (tremor and rigidity) ▪ Adverse reactions to antipsychotic medications	Cortical Lewy bodies (alpha-synuclein)	<5%

*Post mortem studies suggest that many people with dementia have mixed Alzheimer's disease and vascular dementia pathology and that this "mixed dementia" is underdiagnosed.

Source: Adapted with permission from Alzheimer's Disease International, 2009.

Diagnosing Alzheimer's Disease

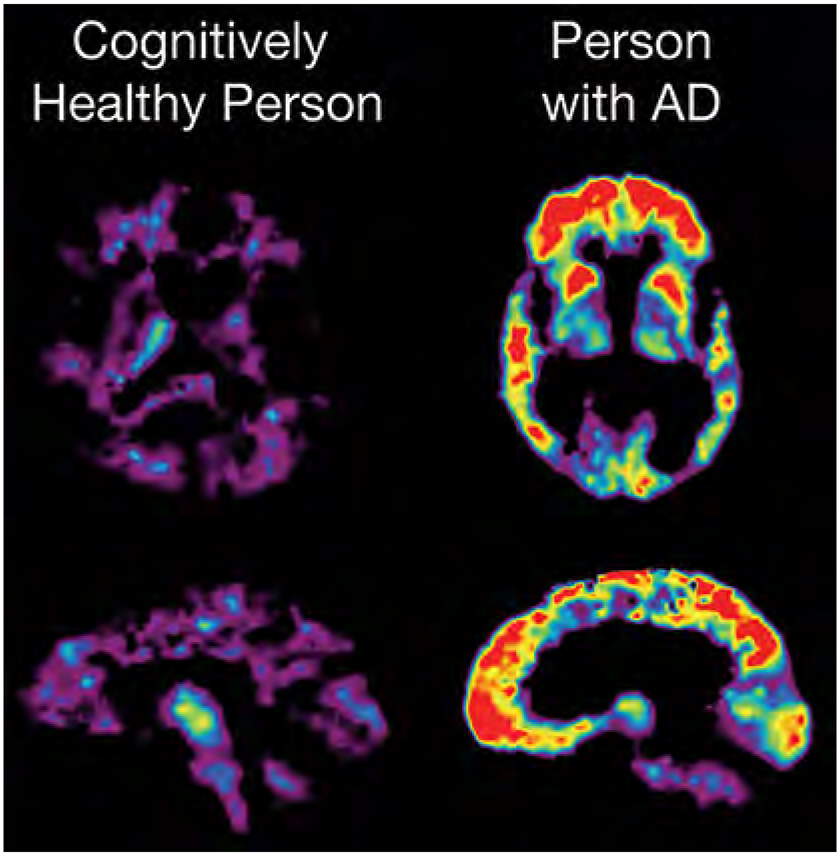
Diagnosis of Alzheimer's disease and other types of dementia is based on symptoms; no test or technique can diagnose dementia. To guide clinicians, the National Institute on Aging and the Alzheimer's Association (NIA-AA) has developed the following diagnostic guidelines indicating the presence of Alzheimer's disease:

1. Gradual, progressive decline in cognition that represents a deterioration from a previous higher level;
2. Cognitive or behavioral impairment in at least two of the following domains:
    a. episodic memory,
    b. executive functioning,
    c. visuospatial abilities,
    d. language functions,
    e. personality and/or behavior;
3. Functional impairment that affects the individual's ability to carry out daily living activities;
4. Symptoms that are not accounted for by delirium or another mental disorder, stroke, another type of dementia or other neurological condition, or the effects of a medication. (DeFina et al., 2013)

First promulgated in 1984, the diagnostic guidelines were significantly updated in 2011. While this remains the current iteration, a working group is currently reassessing them for the Alzheimer's Association (ADI, 2018). The guidelines are available from both the NIA and Alzheimer's Association websites as well as in numerous open-access journal articles.

Neuroimaging shows promise in assisting with early diagnosis of Alzheimer's disease by detecting visible, abnormal structural and functional changes in the brain (Fraga et al., 2013). Magnetic resonance imaging (MRI) can provide information about the shape, position, and volume of the brain tissue. It is being used to detect brain shrinkage, which is likely the result of excessive nerve death. Positron emission tomography (PET) is being used to detect the presence of beta amyloid plaques in the brain.

PET Scans Showing PiB Uptake



PET imaging makes it possible to detect beta amyloid plaques using a radiolabeled compound called Pittsburgh Compound B (PiB). In this PET scan, the red and yellow colors indicate that PiB uptake is higher in the brain of the person with AD than in the cognitively healthy person.
Source: NIA, public domain.

Early diagnosis of cognitive impairment is important for a variety of reasons but it is often overlooked. One study indicated that physicians were unaware of cognitive impairment in more than 40% of their patients who were cognitively impaired. While a second study found that more than half of the patients with dementia had never been given a clinical cognitive evaluation by a physician (NIA, 2014).

Practitioners are sometimes concerned about the time needed and the techniques to use when assessing a patient for cognitive impairment. But the good news is that once trained, and using widely available tools, an initial assessment can be done in 10 minutes or less. While such testing can be done at any time, it is now a required part of the Medicare Annual Wellness Visit. In other situations, determining whether or not cognitive testing is needed can be facilitated by use of the Dementia Screening Indicator.

Among the tools available for practitioners to employ in testing for cognitive impairment are the Mini-Mental State Exam (MMSE), the AD8 and the Mini-Cog. Some doctors may also use one of a number of computerized tests that have been cleared by the FDA (NIA, 2014; Alzheimer's Association, 2019c). If screening is negative, patient and family concerns may be alleviated, at least at that point in time.

If screening is positive and further evaluation is warranted, the patient and physician can work to identify the cause of impairment (for example, medication side effects, metabolic and/or endocrine imbalance, delirium, depression, Alzheimer's disease). This may result in:

- Treating the underlying disease or health condition
- Managing comorbid conditions more effectively
- Averting or addressing potential safety issues
- Allowing the patient to create or update advance directives and plan long-term care
- Ensuring the patient has a caregiver or someone else to help with medical, legal, and financial concerns
- Ensuring the caregiver receives appropriate information and referrals
- Encouraging participation in clinical research (NIA, 2014; NINDS, 2017).

Screening for cognitive impairment will usually be part of a more comprehensive examination but not all elements may be appropriate for every patient or accomplished by the same practitioner, and what is necessary may be dictated by what is already known about the patient's situation.
An assessment generally includes:

- **Medical history and physical exam.** Assessing a person's medical and family history, current symptoms and medication, and vital signs can help the doctor detect conditions that might cause or occur with dementia. Some conditions may be treatable.

- **Neurologic evaluations**. Assessing balance, sensory response, reflexes, and other functions helps the doctor identify signs of conditions that may affect the diagnosis or are treatable with drugs. Doctors also might use an electroencephalogram (EEG), a test that records patterns of electrical activity in the brain, to check for abnormal electrical brain activity.
- **Brain scans**. Computed tomography (CT) and magnetic resonance imaging (MRI) can detect structural abnormalities and rule out other causes of dementia. Positron-emission tomography (PET) can look for patterns of altered brain activity that are

common in dementia. Recent advances in PET can detect amyloid plaques and tau tangles in AD.

- **Cognitive and neuropsychological tests**. These tests are used to assess memory, language skills, math skills, problem-solving, and other abilities related to mental functioning.
- **Laboratory tests**. Testing a person's blood and other fluids, as well as checking levels of various chemicals, hormones, and vitamin levels, can identify or rule out conditions that may contribute to dementia.
- **Presymptomatic tests**. Genetic testing can help some people who have a strong family history of dementia to identify risk for a dementia with a known gene defect.
- **Psychiatric evaluation**. This evaluation will help determine if depression or another mental health condition is causing or contributing to a person's symptoms (NINDS, 2017).
- **Input from family members** as to changes in the person's thinking skills and behavior may also be relevant (Alzheimer's Association, 2019).

While some genetic tests are available and may be appropriate when there is a strong family history of dementia, "health professionals do not currently recommend routine genetic testing for Alzheimer's disease" (Alzheimer's Association, 2019c).

The Future in Research

> We were probably terribly naïve to think a brain disorder like Alzheimer's disease would be more simple than any other human disorder, because there is nobody who thinks that diabetes is simple, or that cardiovascular disease is a simple thing.
>
> Bart de Strooper, Director
> UK Dementia Research Institute

In the *World Alzheimer's Report 2018* published by Alzheimer's Disease International, leading researchers point out that it has become clear that Alzheimer's is not simple. Just as research has shown that AD is not a normal part of ageing as first thought, it is also not something straightforward with a cure right around the corner. There is still debate, and research is still looking at the relative importance of different proteins, and their relationship to each other, why amyloid develops to such high levels, the role of the APOE e4 gene, and the possible role of numerous lifestyle elements (ADI, 2018).

Research is also important in the field of diagnosis where there have been two major breakthroughs in the last 45 years. The first of these was the establishment of diagnostic guidelines for dementia (discussed above) and the second was in the field of biomarkers—measurable indicators of a biologic condition—where structural scanning (CT, PET, and MRI) finally came to be seen as worth the money they cost. Some researchers are also studying blood and spinal fluid biomarkers, but these are still most important in the research setting than the clinical setting (ADI, 2018).

Even though research for dementia lags behind that for some other diseases and conditions, new work is released all the time and it can be challenging to keep up. As one example, a May 2019 PLOS|ONE research article addressed the issue of diagnosis of neurodegenerative diseases causing dementia and the need for methods that can help address the rapid increase in the number of patients presenting for evaluation, the sometimes-prohibitive costs of diagnostic imaging, and the "learning effects which limit the number of possible administrations" of some of the cognitive impairment tests routinely administered in physicians' offices. This research looked at the promising possibilities for "capturing neurodegeneration-associated characteristics in a person's voice" noting that "the incorporation of novel methods based on the automatic analysis of speech signals may give us more information about a person's ability to interact, which could contribute to the diagnostic process" (Al-Hameed et al., 2019).

Conditions That Can Mimic Dementia

A number of medical conditions other than dementia can cause cognitive changes. Gerontology specialists speak of the "3Ds"— delirium, depression, and dementia—because these three conditions are the most common reasons for cognitive changes in older adults. **Delirium and depression may be mistaken for dementia**.

Delirium

Delirium is a sudden, severe confusion with rapid changes in brain function. Delirium develops over hours or days and is **temporary and reversible**. Delirium can affect perception, mood, cognition, and attention. The most common causes of delirium in people with dementia are medication side effects, hypo- or hyper-glycemia, fecal impactions, urinary retention, electrolyte disorders and dehydration, infection, stress, and metabolic changes. An unfamiliar environment, injury, or severe pain can also cause delirium.

Delirium is under-diagnosed in almost two-thirds of cases and can be misdiagnosed as depression or dementia. Since the most common causes of delirium are reversible, recognition enhances early intervention. Early diagnosis can lead to rapid improvement (Hope et al., 2014).

Delirium: A Patient Story at Leicester’s Hospital (6:49)


Delirium: A Patient Story at Leicester's Hospitals

NHS Leicester’s Hospital, England, U.K.

Depression

Depression (**major depressive disorder** or **clinical depression)** is a common but serious mood disorder. It causes severe symptoms that can interfere with how a person thinks and feels and with their ability to work, sleep, study, eat, and enjoy activities. A diagnosis of depression requires that the symptoms be present for at least two weeks. A person may experience a single episode of depression in their life but multiple episodes are more common (NIMH, 2018, 2016).

Persistent depressive disorder, or *dysthymia*, is characterized by long-term (2 years or longer) symptoms that may not be severe enough to disable a person but can prevent normal functioning or feeling well. **Psychotic depression** occurs when a person has severe depression plus some form of psychosis, such as delusions or hallucinations. Psychotic symptoms typically have a depressive “theme,” such as delusions of guilt, poverty, or illness (NIMH, 2018).

Depression is very common in people with Alzheimer's, and experts believe it may be as high as 40%. It is especially common during the early and middle stages, and treatment can have significant benefits. Diagnosis can be difficult because dementia and depression share many symptoms, including apathy, loss of interest in activities and hobbies, social withdrawal, isolation, trouble concentrating, and impaired thinking. However, it can be difficult for patients with Alzheimer's to communicate their feelings effectively. Depression in those with Alzheimer's can be different because it may be less severe, may not last as long and have symptoms that come and go, and a person with Alzheimer's may not talk about or attempt suicide as often as those with Alzheimer's (Alzheimer's Association, 2019b).

Those with co-occurring dementia and depression generally have been found to have a higher mortality rate from all causes. More research is needed, and one question that has been raised is whether there are differences in mortality rates between home-dwelling individuals and those living in nursing homes (Petersen et al., 2017).

Other Conditions

There are other conditions that can cause dementia-like symptoms; many of these conditions can be stopped and may be reversible with appropriate treatment:

- **Normal pressure hydrocephalus** is an abnormal buildup of cerebrospinal fluid in the brain. Elders with the condition usually have trouble with walking and with bladder control before the onset of dementia. Normal pressure hydrocephalus can be treated or even reversed by implanting a shunt system to divert fluid from the brain.
- **Nutritional deficiencies** of vitamin B1 (thiamine), caused by chronic alcoholism, and of vitamin B12 can be reversed with treatment. People who have abused substances such as alcohol and recreational drugs sometimes display signs of dementia even after the substance abuse has stopped.
- **Side effects of medications** or drug combinations may cause cognitive impairment that looks like a degenerative or vascular dementia but which could reverse upon stopping these medications.
- **Vasculitis**, an inflammation of brain blood vessels, can cause dementia after multiple strokes and may be treated with immunosuppressive medications.
- **Subdural hematoma,** or bleeding between the brain's surface and its outer covering (the dura), is common after a fall. Subdural hematomas can cause dementia-like symptoms and changes in mental function. With treatment, some symptoms can be reversed.

- Some **non-malignant brain tumors** can cause symptoms resembling dementia and recovery occurs following their removal by neurosurgery.
- Some **chronic infections** around the brain, so-called chronic meningitis, can cause dementia and may be treatable by drugs that kill the infectious agent. (NINDS, 2017)

Behavior Management

Anyone who has worked with older adults who have dementia is familiar with at least some of the difficult behaviors associated with dementia. Some behaviors are associated with brain changes while others are caused by frustration, loss of control, discomfort, pain, and the inability to communicate needs. Behavioral changes in people with dementia are referred to somewhat generally as **behavioral and psychological symptoms of dementia (BPSD).**

The care for people experiencing behavioral symptoms places stress on caregivers and is costlier no matter what the setting. In nursing homes for example, the cost of care for people with behavioral symptoms is 3 times higher than that of other nursing home residents (Ahn & Horgas, 2013).

Often behavioral symptoms of dementia can be addressed with proper staff training, environmental modifications, and good communication. One common-sense approach—the **problem-solving approach**—addresses challenging behaviors by looking for the root cause of a behavior. This approach encourages caregivers to get in the habit of observing the *antecedent*, *behavior*, and *consequence* (A, B, C) of a challenging behavior:

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

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

Dementia-care mapping (DCM) is another approach, which states that much of the frustration that people with dementia experience is due to negative environmental influences, including staff attitudes and care practices. Dementia-care mapping addresses these frustrations using: (1) systematic observation, (2) feedback to the staff, and (3) action plans (van de Ven et al., 2014).

This method encourages interventions at the individual level and the group level, as well as at the levels of management and organization. Dementia-care mapping is a multi-component intervention aimed at implementing diverse interventions to improve the quality and effectiveness of care (van de Ven et al., 2014).

Common Challenging Behaviors

Among many challenging behaviors associated with dementia, several stand out: agitated and aggressive behaviors, wandering, rummaging and hoarding, delusions and hallucinations, and sleep disturbances.

Agitation and Aggression

Agitation refers to non-specific restless behaviors that are excessive, inappropriate, and repetitive. These behaviors can include verbal, vocal, or motor activity.

Aggression is physically or verbally threatening behaviors directed at people, objects, or self. Aggressive behaviors can be a threat to the safety of those with dementia and to those around them (Burns et al., 2012).

Agitation and aggression occur in more than half of nursing home residents with dementia—often related to loss of control, discomfort, fear, or a response to a perceived threat or violation of personal space. Agitation and aggression often occur during personal care tasks involving close caregiver-resident contact (Burns et al., 2012). Pain is also a cause of agitated and aggressive behaviors, especially in nursing home residents (Ahn & Horgas, 2013).

Psychosocial and environmental interventions can reduce or eliminate agitated or aggressive behaviors. Antipsychotics are also sometimes used to reduce aggression and psychosis, particularly among those most severely agitated. However, in older people, antipsychotics are associated with increased overall mortality, worsening cognitive impairment, hip fracture, diabetes, and stroke (Jordan et al., 2014).

Wandering

Wandering is aimless, repetitive locomotion, hyperactivity, or excessive walking. Wandering patterns can include moving to a specific location, lapping or circling along a path, pacing back and forth, or wandering at random. Up to 60% of persons with dementia will wander at some point during the course of their disease (Rowe et al., 2011). Wandering is a particular concern in nursing homes, where about half of residents with dementia wander (Ahn & Horgas, 2013).

People with Alzheimer’s are more likely to wander than those diagnosed with other types of dementias. People with frontal-temporal dementia tend to pace and lap whereas people with Alzheimer’s disease tend to wander randomly. Psychotropic medications, particularly antipsychotics, are associated with restlessness and a compelling need for movement or pacing (Burns et al., 2012).

Wandering is likely related to boredom, pain and discomfort, disorientation, and memory problems. People may wander out of habit or because they think something from their past needs to be done. Wandering can be addressed or even encouraged by providing safe, looping wandering paths with interesting rest areas and by providing regular exercise and activities.

Interestingly, a person’s pre-dementia lifestyle may be a factor in their desire to wander. People with certain characteristics are more likely than others to wander:

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

Mrs. Winkler is a resident in a five-story nursing home in San Francisco. She has moderate dementia and is non-ambulatory. After breakfast in her room, an aide wheels her to the activities room and parks her at a table with a jigsaw puzzle. After about 20 minutes Mrs. Winkler gets bored with the puzzle, exits the activities room, and heads down the hall. She is stopped twice by staff members, who turn her back toward the activities room with a reprimand.

When the staff member is out of sight, Mrs. Winkler turns around and continues in the direction she was headed. She stops near the elevator, where she sits for a while watching people come and go. Several staff members pass her and tell her not to get on the elevator. Each time she is left in exactly the same place next to the elevator. Finally, when no one is looking, Mrs. Winkler wheels into the elevator.

Antecedent

Mrs. Winkler is curious and used to like walking around the city, exploring the different neighborhoods. She was never one to sit around doing nothing. The room she is in is kind of boring so she heads down the hall and stops near the elevator.

Behavior

The door to the elevator is an interesting visual cue and Mrs. Winkler enjoys seeing people coming and going. People talk to her—and she likes the interaction—but she doesn ’t understand what they are saying. When a door opens, Mrs. Winkler wheels into the elevator. When the door opens on the ground floor, she wheels out of the elevator, heads to the front door, and out onto the street. Her behavior is consistent with her personality and her previous habits.

Consequence

Once she gets into the elevator, Mrs. Winkler ’s inability to think logically puts her at risk. She exits the elevator next to a door that leads out of the building and wanders into the street. Fortunately, someone sees her wandering down the middle of the street and is able to convince her to return to the nursing home.

Discussion

One solution is move Mrs. Winkler to a place where she cannot see or hear the elevator. Caregivers should try to understand the reason for her wandering and make sure her wandering is not the result of medication side effects, overmedicating, or drug interactions. To keep Mrs. Winkler out of the elevator, try the following:

- Redirect her to a purposeful activity.
- Provide a place where she can wander safely.
- Schedule regular exercise.
- Offer simple, meaningful chores.
- Attach an electronic device that alerts caregivers when she has wandered out of a designated area.
- Place a plastic PVC pole on the back of her wheelchair and a horizontal pole across the entrance to the elevator so that she is physically stopped from entering the elevator.
- Encourage a family member to take her for a stroll outside the building or for a ride in a car.

Rummaging and Hoarding

Rummaging and hoarding occurs when a person obsessively gathers, hides, or puts away items in a secretive and guarded manner. These behaviors are not necessarily dangerous or unsafe but they can be frustrating for caregivers and other residents.

A person with dementia may hoard due to fear of losing money or possessions, a lack of control, a need to "save for a rainy day," or simply out of confusion. Hoarding is associated with insecurity and anger and an attempt to hold onto possessions and memories from the past. These actions are a type of obsessive-compulsive behavior.

Memory loss, poor judgment, and confusion can contribute to the impulse to rummage and hoard. People may rummage out of boredom or to find something they think has been misplaced. They may fear being robbed and feel a need to protect their possessions. Rummaging through familiar items can create a sense of safety and security.

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 the home, important items such as credit cards or keys should be placed out of reach or in a locked cabinet. Other recommendations:

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

Psychosis

[Material in this section is from Burns et al., 2012.]

Psychosis is a disturbance in the perception or appreciation of objective reality. Psychotic symptoms can manifest delusions, hallucinations, and paranoia. Sensory deficits can contribute to psychosis because of distortions of sound or sight.

A delusion is a false idea or belief or a misinterpretation of a situation. Hallucinations are sensory events in which a person hears, tastes, smells, sees, or feels something that is not there. **Paranoia** is a type of delusion in which person believes, without evidence, that others are mean, threatening, lying, or unfair.

Paranoia can cause feelings of persecution, fear, anxiety, and exaggerated self-importance. A person experiencing paranoia may be suspicious of caregivers and friends; they may feel people are stealing from them or planning them harm.

Psychotic symptoms can be caused by health factors such as urinary tract infections (UTIs) or environmental factors such as poor lighting or sensory overload. Changes in the brain can also contribute to these behaviors, especially changes related to sensory awareness, memory, and decreased ability to communicate or be understood.

Visual hallucinations can occur in the moderate to severe stages of dementia and are particularly common in those with Lewy body dementia. While atypical antipsychotics are sometimes used off-label to manage hallucinations, in a person with Lewy body dementia, antipsychotic medications can make hallucinations worse.

The first step in the management of psychosis is to rule out delirium as a cause. Another important factor is to determine if the claims by the person with dementia actually did occur.

In a person with new onset of visual hallucinations, the number one cause is medication side effects. For this reason, all medications the person is receiving should be carefully reviewed. This includes prescription and over-the-counter (OTC) medications, as well as herbal supplements.

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

Delusions and hallucinations can be addressed using behavioral interventions or, in some cases, antipsychotic medication. Atypical antipsychotics have largely replaced typical or traditional antipsychotics as the main treatment for psychosis, hallucinations, and delusions in those with dementia.

To manage hallucinations, decrease auditory and visual stimuli and evaluate for visual or hearing impairment. Other suggestions include:

- Minimize violent or noisy TV, remove wall hangings
- Reduce noise, play relaxing music
- Cover mirrors
- Reduce glare from windows
- Ensure adequate lighting

Sleep Disturbances

Sleep disturbances, including sleep problems or changes to sleep schedule, are common in people with dementia. Approximately one-quarter to one-third of those with Alzheimer's disease have problems with sleep, although scientists are not certain why. As with behavior and memory changes, they are a result of Alzheimer's impact on the brain (Alzheimer's Association 2019d; Deschenes & McCurry, 2009). Importantly, sleep disturbances can contribute to the onset and severity of some behavioral problems, particularly anxiety, increased confusion, wandering, and sundowning.*

*__Sundowning__: increased confusion and restlessness in the late afternoon and early evening, possibly due to damage to the part of the brain that regulates sleep patterns.

In a recent review of research Petrovsky and others noted that "sleep disruption was negatively associated with all four quality-of-life domains [physical, social/behavioral, emotional well-being, and cognitive] in persons with dementia." (Petrovsky et al., 2018). Sleep research is ongoing, and more is needed, especially for non-pharmacologic interventions.

Sleep disruption may have the following features:

- Increased sleep latency
- Fragmented sleep and increased early-morning awakenings
- Decreased total sleep time, decreased sleep efficiency
- Decreased slow-wave and rapid-eye-movement (REM) sleep
- Nocturnal confusion
- Increased daytime napping and daytime sleepiness
- Agitation, verbally disruptive behaviors, hallucinations, and nighttime wandering (Burns et al., 2012; Savaskan, 2015; Alzheimer's Association 2019d)

Medications used to treat behavioral symptoms of dementia, as well as those used to slow the progression of dementia, can cause daytime sleepiness and lead to sleep disturbances. Short-term sleep disturbances in people with dementia are often treated with antidepressants, benzodiazepines, or non-benzodiazepines, although there is limited evidence to support their long-term safety in cognitively impaired older adults (Deschenes & McCurry, 2009; Savaskan, 2015).

Commonly used sleep medications generally do not improve overall sleep quality in older adults. In the cognitively impaired, these also come with greater risk of falls and fractures, confusion, and decline in the ability to exercise self-care. Antipsychotics, which are sometimes used because of behaviors that accompany the sleep disturbance, have a higher risk of stroke and death among older dementia patients. “Most experts and the National Institutes of Health (NIH) strongly encourage the use of non-drug measures” in patients with Alzheimer’s disease. When medications are needed, the recommendation is “begin low and go slow” (Alzheimer’s Association 2019d)

Before treating sleep disturbances, look for potentially treatable causes such as pain, hunger and thirst, the need to urinate, infections, adverse drug reactions, and even noise. In addition, depression, restless legs syndrome, and sleep apnea need to be ruled out (Alzheimer’s Association 2019d).

Nonpharmacologic treatments (many currently being researched) include:

- Light therapy
- Good sleep hygiene practices
- Exercise during the day and individualized social activities
- Restriction or elimination of caffeine, nicotine, and alcohol
- Calm atmosphere
- Biofeedback (Deschenes & McCurry, 2009; Savaskan, 2015)

The Alzheimer’s Association (2019d) suggests these practices, which can be implemented by anyone:

- Maintain regular times for meals and for going to bed and getting up
- Seek morning sunlight exposure
- Encourage regular daily exercise, but no later than four hours before bedtime
- Avoid alcohol, caffeine and nicotine
- Treat any pain
- If the person is taking a cholinesterase inhibitor (tacrine, donepezil, rivastigmine or galantamine), avoid giving the medicine before bed
- Make sure the bedroom temperature is comfortable
- Provide nightlights and security objects
- If the person awakens, discourage staying in bed while awake; use the bed only for sleep

- Discourage watching television during periods of wakefulness (Alzheimer's Association, 2019d)

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 (Agens, 2010). This right to be free from physical or chemical restraints is reinforced by the Massachusetts Executive Office of Elder Affairs (Mass.gov, 2019a).

Use of restraints should be:

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

In the most recent update of final regulations by the Centers for Medicare and Medicaid Services (CMS), effective 2019, for nursing homes participating in its programs this wording remains:

> § 483.12 Freedom from abuse, neglect, and exploitation.
>
> … (a) The facility must — … (2) Ensure that the resident is free from physical or chemical restraints imposed for purposes of discipline or convenience and that are not required to treat the resident's medical symptoms. When the use of restraints is indicated, the facility must use the least restrictive alternative for the least amount of time and document ongoing re-evaluation of the need for restraints.

There is concern about the strength of enforcement of these regulations, and these rights are not always observed. Those who care for and about elders with dementia need to remain vigilant, ask questions, and advocate for their patients and loved ones. Many families, for instance, do not realize they have the right to ask about and say no to inappropriate medications (CANHR, 2018, 2016, 2012; Seegert, 2018; Arlotta, 2015).

Physical Restraints

A **physical restraint** is any device, material, or equipment attached to or near a person's body that can neither be controlled nor easily removed by the person, and that deliberately prevents or is deliberately intended to prevent a person's free body movement to a position of choice or a person's normal access to the body. The prevalence of physical restraint varies from 5% to 56% as reported in existing literature (Lai et al., 2011).

Physical restraints include vests, straps, wrist ties, splints, mitts, belts, recliners, geri-chairs, and bedside rails, among others. Restraint also includes using (or threatening) force to make a person do something that they are resisting, and restricting their movements, whether or not they resist.

The use of physical restraints (including belts), can increase the risk of death or serious injury as well as increase the length of a hospital stay. Both prolonged and short periods of physical restraint use are associated with pressure sores, loss of muscle strength and endurance, joint contractures, incontinence, demoralization, humiliation, feelings of low self-worth, depression, aggression, and impaired social functioning (Gulpers et al., 2010). The use of physical restraints can also create an ethical dilemma by restricting a person's autonomy and independence (Lai et al., 2011).

Chemical Restraints

> Tens of thousands of nursing home residents with dementia receive powerful antipsychotic drugs that are not intended or approved for their medical conditions. Rather, the drugs are often used to sedate and control them, a terrible substitute for the individualized care they need and deserve. The U.S. Food and Drug Administration (FDA) has issued its most dire warning—known as a black box warning—that antipsychotic drugs cause elders with dementia to die.
>
> California Advocates for Nursing Home Reform, 2012

We do not usually think of a medication as having the potential to restrain a person's free movement. However, in older adults with dementia there is a long history of antipsychotic and sedative use—chemical restraints—to subdue or otherwise alter a person's behavior.

A **chemical restraint** is the *intentional* use of any medications to subdue, sedate, or restrain an individual. Chemical restraints have been used to restrict the freedom of movement of a patient—usually in acute, emergency, or psychiatric settings. Chemical restraints are often prescribed for what healthcare workers describe as dangerous, uncontrolled, aggressive, or violent behavior.

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

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

In 2019 the American Geriatrics Society (AGS) Updated Beers criteria for safe medication use in older adults and recommended that if not treating for psychosis, use antipsychotics **with caution**. Drugs such as haloperidol (Haldol), risperidone (Risperdal), or quetiapine (Seroquel) are commonly used to treat behavioral problems in older adults with dementia. However, they can increase the risk of stroke and even death in those patients. They can also cause tremors and other side effects, and increase the risk of falls. In addition, dextromethorphan/quinidine should be avoided for the treatment of behavioral symptoms of dementia (Medscape, 2019).

Alternatives to Restraints

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

In a small Dutch study involving 30 residents, education, institutional changes, and alternative interventions resulted in a significant reduction in the use of belt restraints. Belts were replaced with resident-centered interventions such as movement and balance training, lower beds, hip protectors, extra supervision, and monitoring devices (video camera, sensor mat, and infrared alarm systems) (Gulpers et al., 2010).

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

- Redesign the location of nursing stations so they are part of a home-like design.
- Provide pressure-relief wheelchair and chair cushions to improve comfort.

- Lower wheelchairs to allow self-propelling with feet.
- Provide comfortable, easy-to-access alternative seating.
- Install carpeting to reduce injury from falls.

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

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

For a nonpharmacologic toolkit for reducing antipsychotic use in older adults by promoting positive behavioral health, click here.

Activities of Daily Living (ADLs)

> The humanity with which assistance for everyday living is offered, especially help with eating and intimate care, is crucial in helping the person retain their self-esteem and dignity, as are the manner and tone in which a person is addressed; the care taken to ensure that they participate as much as they can or wish in any decision about their day-to-day life; the trouble taken about appropriate and attractive food and environments; and access to meaningful activity.
>
> Nuffield Council on Bioethics

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

Basic ADLs are the skills needed to take care of personal needs:

- Eating and drinking
- Toileting and bathing

- Walking
- Grooming, dressing, and undressing
- Transfers

Instrumental ADLs (IADLs) are the skills needed to function within society and within the community. As with basic ADLs, these skills decrease as dementia progresses. IADLs include:

- Housework
- Financial management
- Shopping
- Preparing meals
- Communicating with the outside world
- Medical management

Symptoms, Stages, and Behavioral Symptoms

As independence with ADLs decrease, caregiver responsibilities naturally increase. For example, when a person is no longer able to perform basic math calculations, a caregiver must begin to oversee finances. When insight becomes limited and memory is significantly compromised, medical decision-making and medication management will also shift to the hands of a caregiver (DeFina et al., 2013).

How Mild Dementia Affects ADLs

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

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

How Moderate Dementia Affects ADLs

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

In the moderate phase:

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

How Severe Dementia Affects ADLs

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

Those with severe dementia who try to wander will require constant monitoring. If the person lives at home, tired and overworked caregivers must provide even more support with ADLs and to maintain a safe environment. If in a skilled nursing or assisted living situation, the facility must provide enough staffing and equipment to ensure a safe environment.

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

Strategies for Assisting with ADLs

When assisting someone with basic or instrumental 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.

When assisting someone with basic ADLs such as dressing, grooming, eating, bathing, and toileting, certain strategies will help you to complete these tasks successfully. Use common sense, be aware of your body language, and use a quiet, confident tone of voice. Whatever the activity, move slowly, give clear, simple commands, limit choices, and allow plenty of time to complete the task.

There are times when the caregiver and the person with dementia have different goals. A caregiver in a residential care facility may want to bathe a resident and get her dressed quickly because the caregiver has two more people to get dressed before breakfast. The resident may want just to watch TV for 30 minutes before going to breakfast. The resident’s wishes should be respected.

ADL Strategies: Mild Dementia

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

- Dressing
    - Encourage choice.
    - Allow resident to direct the activity.
- Grooming
    - Allow residents to groom themselves, provide tools if needed.
    - Provide assistance as needed.
- Eating
    - Ask for food preferences.
    - Encourage the person to help with meal preparation and meal set-up.
    - Provide adaptive utensils if needed.
    - Provide assistance as needed.
- Bathing
    - Encourage choice.
    - 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.

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

ADL Strategies: Moderate Dementia

A person in the moderate stage of dementia will need more help with ADLs, especially instrumental ADLs. There is variability at this stage depending on a person’s physical capabilities and the type of dementia, but for some, walking, transferring, bed mobility, and basic ADLs remain relatively independent. For others, especially those with physical limitations, more help will be required. In the moderate stage of dementia:

- Dressing
    - Provide comfortable clothes with elastic waistbands and Velcro closures.
    - Limit choices but encourage participation in the choice of clothing.
    - Encourage independence, provide assistance as needed.
- Grooming
    - Limit choices (“Would you like lipstick today?” “Would you like to brush your hair?”)
    - Encourage as much independence as possible.
- Eating
    - Ask for food preferences.
    - Set up the meal before serving: open packages, uncover trays.
    - Provide adaptive equipment as needed.
    - Monitor closely, encourage independence.
- Bathing
    - Ask about bathing preferences.
    - Initiate and monitor the activity.
    - Provide direct assistance as needed, particularly in showers.
- Toileting
    - Ask regularly if the resident needs to use the bathroom.
    - Provide close assist, particularly with transfers.
    - Label bathroom door for easy identification.
    - Provide toileting on a regular schedule.

ADL Strategies: Severe Dementia

Once a person reaches the severe stage of dementia, the more complex instrumental ADLs have likely been completely taken over by a family member or caregiver. Basic ADLs will require a great deal of assistance to complete, depending on the person’s physical capabilities. A person with severe dementia may still be able to walk independently and may be independent or nearly so with bed mobility and transfers.

With severe dementia, anything that requires planning, sequencing, or judgment will be severely impaired, so close assistance is needed for dressing, bathing, meal preparation, grooming, and toileting. If mobility is compromised, close assistance will be needed for all ADLs. In the severe stage of dementia:

- Dressing
    - Limit choices, select clothes and set them out.
    - Choose comfortable clothing that is easy to wash.
    - Use simple, one-step commands and gestures.
    - Encourage independence wherever 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 assistance.
    - Offer liquids on a regular schedule.
    - Allow plenty of time to finish eating.
- Bathing*
    - Provide complete bathing care.
    - Retain earlier bathing rituals as reasonable.
    - Use resident behavior as a guide.
- Toileting**
    - Expect both bowel and bladder incontinence requiring total care.
    - Set up timed toileting schedule.

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

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

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

Antecedent

In her room, the aide undresses Mrs. Cavelia and wraps her in a bath blanket. Unable to find a shower chair, she helps Mrs. Cavelia into a toilet chair. Mrs. Cavelia’s bottom is hanging out 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.

Behavior

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

Consequence

The resident, staff, and the patient’s daughter are all upset. The situation created an unpleasant environment for everyone, and showering has become a dreaded experience for Mrs. Cavelia.

Discussion

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

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

Activities for Residents with Alzheimer’s

Carefully designed activities have a positive effect on depression, confusion, and challenging behaviors. An activities program should include physical activity, intellectual stimulation, and social interaction (Ruthirakuhan et al., 2012).

Research continues to support the efficacy of a variety of activities and therapies for alleviating neuropsychiatric symptoms in dementia patients, and some are also being evaluated for reduction of caregiver burden and use with outpatients (de Oliveira, 2018, 2015). However, much remains to be investigated and the more interventions can be integrated to account for the complexity of dementia the more long-term success seems possible (Caspar et al, 2017).

A recent project evaluated a **TAP-O (tailored activity program-outpatient version)** intervention designed for outpatients with dementia and their caregivers. During eight sessions, an occupational therapist assessed the patient’s abilities and interests; prescribed tailored activities; and educated caregivers about dementia, NPS, and how to implement meaningful activities in the daily routine. As a result, patients experienced significant decreases in hallucinations, agitation, anxiety, aggression, sleep disorder, aberrant motor behavior, and there was a reduction in caregiver burden, suggesting TAP-O may be an effective non-pharmacologic intervention (de Oliveira, 2018).

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

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

For people with dementia, Montessori-type programs include detailed interviews with family caregivers about the resident’s former interests and skills coupled with assessments of cognitive, language, and motor skills. A range of activities are presented, tested, and refined. When dementia is advanced, the activities are simplified. Facilitators present tasks deliberately, demonstrating them first, and using language as appropriate (van der Ploeg et al., 2012).

Everyone—even people with dementia—yearn for meaning in their lives. We like helping one another, teaching someone a new skill, and contributing to the success of an activity. In institutional settings we have stripped people of meaningful ways to contribute, to help, to learn, and to grow as a person. A good activity program can help accomplish that goal.

Individual Activities

Individual activities that stimulate the senses are encouraged at all stages of dementia. Successful programs for individuals with dementia are based on a person's likes and interests. Adults often have a fear of failure (especially those aware of their cognitive decline), and may refuse to participate in activities because of this fear. Be consistent, have fun, and by all means introduce new activities. Look for signs of frustration and agitation and address these behaviors immediately.

Individual Activities for People Who Have ADRD

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

Individual Activities for People Who Have ADRD			
Type of activity	Mild	Moderate	Severe
Gardening	▪ Garden in raised beds ▪ Help plan the garden and harvest	▪ Perform specific tasks with supervision ▪ Eat food grown in garden	▪ Sit in garden ▪ Participate in projects as able ▪ Eat food grown in garden
Crafts	Knitting or crochet using large needles and bulky yarn	Choose colors, roll balls of yarn	Choose colors, use the items that are created
At home activities	Help with laundry with supervision, put clothes away, assist with housekeeping	Sort and fold laundry	Fold laundry—may want to fold the same items repeatedly
Shopping	▪ Go along to store ▪ Help with purchasing decisions ▪ Help put groceries away	▪ Go along to store ▪ Help as able with shopping decisions ▪ Help put food away	▪ Go along to store ▪ Sit in car with supervision or shop with wheelchair or electric cart

Group Activities

Many people with dementia sense that their cognitive impairment isolates them from other people. This leads to anxiety, depression, societal withdrawal, and decreased self-confidence. Encouraging social interaction helps a person regain a sense of self-worth. This may improve eating, exercise habits, and social interactions (Ruthirakuhan et al., 2012).

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

Group Activities for People Who Have ADRD			
Activity	Mild	Moderate	Severe
Singing	▪ Sing while reading words	▪ Sing songs that are familiar	▪ Listen and sing along as able
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
Outdoor Activities	▪ 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 ▪ Theater and music events ▪ Museum visits ▪ Library visits ▪ Eat out ▪ 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

Caregivers

More than 18.5 billion hours of informal care were provided by Alzheimer’s and other dementia caregivers in 2018, a contribution to the nation valued at nearly $234 billion.

> In Massachusetts in 2018, 340,000 caregivers provided 387 million hours of care worth $4.89 billion.
>
> Alzheimer's Association, 2019

A **caregiver** (care provider, care partner, or carer) is someone who provides assistance to a person in need. Care can be physical, financial, or emotional. Caregivers can help with basic activities of daily living such as bathing, dressing, walking, and cooking, or with more complex tasks such as medication and home management. A caregiver may provide direct care or manage care from a distance and can be a family member, a neighbor, a friend, or a professional; professionals are normally paid and the others are not—and thus are often referred to as "informal."

Caregiving for those with Alzheimer's and other related dementias is most beneficial when it is a cooperative venture between primary care and specialist medical providers, community groups, patients, family members, and caregivers—both family and other informal caregivers and those who are paid to provide care to home-dwelling patients or are on the staff of long-term care facilities.

Who Are Caregivers?

In the United States, family members, friends, and other unpaid caregivers supply 83% of the help provided to older adults. Nearly half of all caregivers to older adults provide care for someone with Alzheimer's or another dementia. About one-third of dementia caregivers are themselves 65 or older. More than 60% are married or in long-term relationships and about 40% have a college degree or more education. About two-thirds live with the person they care for (Alzheimer's Association, 2019).

Much of the responsibility for caring for someone who has dementia falls to women; about two-thirds of dementia caregivers are women and over one-third are daughters. It is also more common for wives to care for husbands than husbands for wives. Women generally spend more time providing care when they are the caregiver and report somewhat higher levels of burden and psychological effects (Alzheimer's Association, 2019).

Among paid direct-care workers it is nurse aides, home health aides, and personal and home care aides who provide most of the care to older adults in homes and in residential settings. In nursing homes, the majority of the staff working with cognitively impaired residents are nursing assistants. Most of them are women and they come from a diversity of ethnic, racial, and geographic backgrounds (Alzheimer's Association, 2019).

Caregiving Tasks

[Material in this section is from Alzheimer’s Association, 2019.]

Caregivers of people with dementia may provide some or all of a wide range of assistance that includes:

- Helping with IADLs
- Medication management
- Aiding adherence to treatment plans
- Helping with ADLs
- Managing behavioral symptoms
- Locating and using support or adult day services
- Arranging for paid assistance, in and outside the home
- Hiring and supervising those providing care
- Additional tasks such as managing the person’s day, intra-family communication, managing other health conditions, or providing companionship, emotional support, and security

While these tasks may look similar to ones provided by caregivers to people without dementia, dementia caregivers tend to provide more executive assistance, more help with health monitoring, self-care, mobility, and health or medical care. More than half of dementia patients receive help with ADLs from informal caregivers while only 11% of older adults without dementia receive the same help (Alzheimer’s Association, 2019).

Caring for a person with dementia also means managing symptoms that caregivers of people with other diseases may not face, such as neuropsychiatric symptoms and severe behavioral problems. Family caregivers of those with dementia also deal more often with emotional or mental health problems and behavioral issues than do those caring for people without dementia (Alzheimer’s Association, 2019).

If a person with Alzheimer’s or another dementia moves to an assisted living or nursing home family caregiver tasks may segue into an emphasis on emotional support, and working with staff or advocating for care. However, sometimes these caregivers continue to help with ADLs (Alzheimer’s Association, 2019).

Caregiver Training and Support

Education, training, and support are critical for caregivers, family members, and healthcare providers. The responsibilities of caregiving can be overwhelming, especially for spouses, family members, and friends. A caregiver may be in poor health and have difficulty taking on the burdens of fulltime caregiving. Even trained healthcare providers can find it difficult to deal with demented patients day in and day out.

Caregivers must learn to differentiate dementia from other illnesses and be able to manage difficult behaviors when they arise. They must be able to take a deep breath, slow down, listen, and find effective ways to communicate. It is possible to get better at caring for someone with dementia. Training introduces caregivers to resources, support, and equipment that improve health and safety.

A dementia care program at the University of California at Los Angeles provides caregiver training and social and medical services to families caring for a person with dementia. The UCLA Alzheimer's and Dementia Care program partners with community-based organizations to provide comprehensive, coordinated, patient-centered care for patients with Alzheimer's disease and other dementias.

The program has five key components: (1) patient recruitment and a dementia registry, (2) structured needs assessments of patients and their caregivers, (3) individualized dementia care plans based on needs assessments and input from the primary care physician, (4) monitoring and revising care plans, and (5) access 24/7, 365 days a year for assistance and advice (Reuben et al., 2013).

The overall goal of the program is to address lack of support and training for caregivers, improve care transitions, and provide access to community-based services. Physicians report that the program has provided valuable behavioral and social recommendations and nearly all said they would recommend the program for other patients (Tan, Jennings, and Reuben, 2014).

Results of a further study of the UCLA program that examined healthcare utilization and cost outcomes for the program for Medicare fee-for-service beneficiaries will be fully released in December 2019, but preliminary information indicates: "Comprehensive dementia care may reduce the number of admissions to long-term care facilities, and depending on program costs, may be cost neutral or cost saving. Wider implementation of such programs may help people with dementia stay in their communities" (Jennings et al., 2019).

Dementia care consultant discussing resources with family members. Source: AHRQ, 2015.

A program in North Dakota called the Dementia Care Services Program uses trained consultants to support individuals who care for people with dementia, offering emotional support, education, and referrals to local agencies. The consultants work with the caregivers to develop a care plan with action steps that address key problems and subsequently check on their progress in following the plan. The consultants speak with the caregivers three times during the first 6 months and remain available for as long as is needed. Participating caregivers report the program has helped them feel more empowered, which in turn has reduced the need for costly medical services and placements in long-term care facilities. The program has generated an estimated $40 million in savings in North Dakota, primarily due to the reductions in the use of long-term care (AHRQ, 2015a).

Mastery over Dementia is a program that uses Internet-based training to reduce anxiety and depression among family members caring for a person with dementia. Caregivers' symptoms of depression and anxiety were significantly reduced after participating in the program, compared to a minimal intervention in which caregivers received digital newsletters by e-mail (Blom et al., 2015).

These are just a few examples of programs that have demonstrated benefits. Research continues on a wide variety of programs and interventions that emphasize a holistic management approach and patient-centered or family-centered care that seem to have the most success. However, most researchers note that not everything works equally well in every situation and continued investigation is important.

Causes of Stress for the Caregiver

Caring for a relative or friend who has Alzheimer's or another dementia can be rewarding but can be very stressful in a variety of ways. While some care tasks are similar to those one might perform for any older person, dementia care carries additional challenges. As dementia progresses the person loses judgment, orientation, and communication skills and their personality and behavior are affected. These losses can be some of the most difficult for family members to deal with. As the disease progresses the person requires more supervision and help, which can increase emotional/social, physical, and employment/financial stress on caregivers.

Caregivers may experience additional stress, depression or other mental health challenges, strain, and stress from care transitions. In a survey done by the National Alliance for Caregiving/American Association of Retired Persons (NAC/AARP) a Burden of Care Index figure combines the number of hours of care and the number of ADL tasks performed into a numerical score that represents burden. Forty-six percent of dementia caregivers were classified as having a high level of burden compared with 38% of those not providing dementia care. Twice as many dementia caregivers indicate substantial emotional, financial, and physical difficulties.

The prevalence of depression is higher among dementia caregivers and the risk increases as the patient's dementia worsens. Caregivers of spouses had two-and-a-half times higher odds of developing depression than those who care for someone other than a spouse. The more behavioral and psychological symptoms (eg, wandering, agitation, aggression) the patient has, the higher the likelihood of depression in the caregiver, with four symptoms appearing to be the "tipping point."

The category of strain includes factors such as difficulty accomplishing medical/nursing tasks, lack of experience or training for medical tasks, having felt they had no choice about accepting caregiver responsibilities, and having no help with those responsibilities. Additional stress often surrounds the time at which a decision must be made about putting the person with dementia in residential care and at the end of life. Studies have shown both less stress and more stress in both of these situations.

Caregivers also face challenges to their own physical health as evidence suggests the stress of care can make them more susceptible to disease and health complications and can affect their sleep. Many caregivers report concern about their own health and 35% report that it has worsened due to their care responsibilities. In one poll, 27% reported that they delayed or skipped actions they should have taken to protect their own health. Caregivers may experience physiologic changes indicating increased risk for cardiovascular disease or kidney problems. Caregivers of a spouse appear to have higher risk for a number of other conditions. However, the results of studies have not been consistent and more research is needed.

Dementia caregivers have higher healthcare costs for themselves. Depression is one culprit, plus increasing doctor visits, test and procedures, and costs for medication. The risk of death for caregivers may also be increased—but studies have returned inconsistent findings.

Finally, employment and financial effects are a component of the stress a dementia caregiver may face. Caregivers with outside employment may find themselves needing to take time off or reduce their hours in order to provide care. This in turn can affect their financial situation at a time when many report increasing out-of-pocket expenses (Alzheimer's Association, 2019).

Managing Caregiver Stress

The Alzheimer's Association notes that for more than 30 years strategies to help and support family caregivers of those with Alzheimer's have been developed and evaluated. These interventions (strategies) fall into seven types, each with a particular focus. The types are:

- Case management
- Psychoeducational approaches
- Counseling
- Support groups
- Respite
- Psychotherapeutic approaches
- Multicomponent approaches

The general goal of interventions is to address the negative aspects of caregiving in order to improve the health and well-being of caregivers. Some interventions also work to delay the need to place the person with dementia into a nursing home by giving caregivers additional skills they may need to continue helping their friend or family member as the disease progresses.

Approaches include:

- Providing education to caregivers
- Helping caregivers manage dementia-related symptoms
- Improving social support for caregivers
- Providing caregivers with respite from caregiving responsibilities

A wide-ranging review of interventions has identified characteristics of those that are effective. The three critical elements in these are that family caregivers are actively involved and not just passive receivers of information, the interventions are tailored and flexible to evolve with the changing reality of the situation, and they meet the needs not just of caregivers but of the people they are caring for.

When studies have found interventions to be efficacious they have been implemented in the community and are usually successful, but they still are not reaching a wide area and are not available to all family caregivers. Various methods are being explored for expanding availability, including online training and video-phone delivery options. More research is clearly indicated to understand what interventions are most successful and in what specific situations, how they can be more widely disseminated, and how they can be tailored to serve caregivers in many different situations (Alzheimer's Association 2019).

Specific Issues for Caregivers

In the Early Stage

In the early stage of dementia, family members are confronted with many issues, worries, and concerns and must adjust their own behavior and manage their own frustrations as they learn about dementia. They are often unaware of available dementia-care services and may find their family member's primary care physician is of little help.

Spouses who care for a person with dementia may not be in good health themselves and may worry about not being able to provide good care as the dementia progresses. An adult child caregiver will be concerned about having to take over the care of the parent and assume a new role in the family.

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

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

In the Middle Stages

In the middle stages, behavioral and psychological problems will likely arise, requiring complicated decisions about behavioral interventions and, perhaps, medications. Family caregivers often have to cut back on employment as the demands of caregiving increase.

As the dementia progresses from the mild to moderate stage, caregivers begin to invest more time, energy, and money, which involve exhausting tasks leading to high levels of burnout. Depression, along with symptoms of burnout, poor self-rated health, highly perceived stress, and lower levels of life satisfaction are factors that begin to affect the caregiver's health.

Family caregivers are also less likely to engage in preventive health behaviors. As a consequence, they are at risk for serious illness, increased emergency department use and hospitalization, and increased risk of mortality (Lykens et al., 2014).

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

In the Late Stages

In the late stages, as people lose the ability to speak clearly, family caregivers will struggle to find new ways to communicate using fewer and fewer words. 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.

The demands of caregiving intensify as people with dementia approach the end of life. In the year before the person's death, 59% of caregivers felt they were "on duty" 24 hours a day, and many felt that caregiving during this time was extremely stressful. One study of end-of-life care found that 72% of family caregivers experienced relief when the person with Alzheimer's disease or another dementia died (Alzheimer's Association, 2019).

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

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

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

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

The Grief Process

The diagnosis of dementia affects the person with dementia as well as family and friends. Grief is related to uncertainty about the course of the disease and anticipated loss of independence. Grief can manifest itself in physical symptoms such as shortness of breath, headaches, fatigue, a feeling of heaviness, and a lack of energy. Psychological symptoms will almost certainly develop, including depression, anxiety, insomnia, and loss of interest in normal hobbies and activities. These issues can lead to self-destructive behaviors, such as alcohol or drug abuse.

Losses for the person experiencing dementia include:

- Loss of physical strength and abilities
- Increased confusion and changes in mental abilities
- Loss of income and savings
- Changes in housing and personal possessions, including loss of pets
- Loss of self-sufficiency and privacy
- Changes in social roles, loss of friends and social networks

Losses for family members and caregivers include:

- Loss of companionship
- Loss of income
- Loss of privacy and free time
- Changes in routines and social roles
- Little time for hobbies and social activities

In the early stage, supportive interventions to address grief should include counseling, assessment of co-morbid conditions, education and training, and development of a care plan.

There may come a time when person with severe dementia needs to be moved to a care home. This can cause tremendous stress and grief for the person with dementia and for family caregivers. People with dementia newly admitted to an institution are often disoriented and disorganized in their new environment and feel a loss of control over their lives (Vroomen et al., 2013).

When a loved one dies, family members (especially spouses) experience a period of acute grief that can include 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, a third of surviving spouses will experience major depression. This risk of depression peaks during the first 6 months of bereavement but can last up to 2 years. Even bereaved persons with minor depression may suffer; they have a greater likelihood of functional impairment, poorer health, more physician visits and mental health counseling, and increased use of antidepressants than do non-bereaved individuals (Monk et al., 2013).

Family, Residents, and Dementia Care

When a person enters a long-term care facility, family interactions and communication are reduced. The loss of in-depth communication, as well as social conversations, can result in the person with dementia feeling socially isolated and without the opportunity to express needs (Moyle et al., 2014).

To address this, family members should be encouraged to participate in a dementia care program, multidisciplinary programs designed to meet the individual needs of residents. The quality and success of a dementia care program is influenced by the environment of a care facility and by the facility’s philosophy of care, services available, and staff experience and training. They usually include support groups for family members, friends, and caregivers.

A dementia care program:

- Allows and encourages families to visit at any time
- Plans activities that include family members
- Encourages family involvement in the planning of activities
- Informs family members about changes in their loved one’s condition
- Shares information about resident activities with the family
- Encourages residents to call and write to family members and friends
- Uses technology to keep families in touch with one another

Maintaining a Therapeutic Environment

A therapeutic environment is an environment that is **supportive** of individuals with dementia and their families. It recognizes that people with dementia are influenced by their surroundings and do better with environments that are individualized, flexible, and designed to support differing functional levels and approaches to care (Campernel & Brummett, 2010).

Maintaining a positive and healthy physical environment is important because people with dementia rely on environmental cues to support them physically, cognitively, and emotionally. Unfamiliar, chaotic, or disorganized environments are stressful and can cause anxiety, disorientation, and contribute to behavioral problems.

Assessing an Organization's Philosophy of Care

When assessing a care home, family members should feel free to question the facility's philosophy of care. They should consider the following issues before choosing a long-term care facility:

- Is the facility's philosophy for caring consistent with your beliefs?
- Does the facility provide services to persons at all stages of dementia?
- What conditions or behaviors determine whether a facility will admit or retain someone with dementia?
- Is dementia care provided in a separate unit or as an integrated part of facility services?
- Is the facility's philosophy and practice of handling "difficult behaviors" compatible with your views?
- What is the facility's philosophy about using physical restraints to deal with certain behaviors?
- Does the facility recommend the use of psychoactive drugs to treat behaviors? (CANHR, 2018)

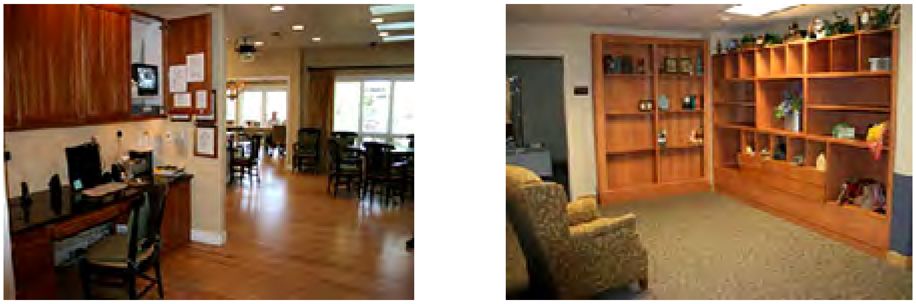
At a minimum, an organization caring for people with dementia should share a philosophical approach that understands that people with dementia deserve and need kind and supportive treatment focused on dignity, respect, and autonomy. This approach, called **person-centered care,** depends not only on the caregivers' skills and knowledge but also on tailoring care to both residents' and caregivers' needs and preferences. This means that there must be flexibility in an organization (Desrosiers et al., 2014). Person-centered care is also referred to as **dementia-friendly care**, which promotes inclusion of the person living with dementia and their caregivers in care and treatment decisions, with the aim of increasing positive outcomes for both (Handley et al., 2015).

The Physical Environment

There is a connection between the environment and how people feel and behave. Homes or buildings thoughtfully designed for the care of people with dementia encourage community, maximize safety, support caregivers, cue specific behaviors and abilities, and redirect unwanted behaviors (Campernel & Brummett, 2010). This holistic vision of dementia care considers the consequences of the built environment on the well-being of residents with dementia (Rijnaard, et al. 2016).

Indoor design changes that have been shown to reduce unwanted behaviors and enhance a sense of well-being in people with dementia include:

- Provide private space in the resident's room with a private bathroom and a separate bedroom or recess for sleeping.
- Provide public spaces with easy accessibility and places for semi-private interactions.
- Personalize rooms with furniture, memorabilia, pictures, and personal possessions.
- Provide televisions and computers within a person's room.
- Ensure cleanliness in private rooms and public spaces and get rid of odors.
- Provide sunlight, ventilation, and remove dark nooks and crannies.
- 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, family visiting area).



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

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

- Arrange spaces to resemble a natural community.
- Create continuous circulation routes with looping pathways and areas of interest.
- Include residents in the design of new features such as walking paths and gardens.

- Create safe, purposeful, and accessible outdoor areas.
- Offer attractive landscaping, gardens, and a view to the outside. (Rijnaard et al. 2016)


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

In a comparison of “regular” specialized care units and small, homelike specialized care units in the Netherlands, residents 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, better social relationships, and were more engaged in activities (Kok et al., 2016).

Although there is a trend towards the development of smaller, home-like nursing homes, large nursing homes are still the norm. In the U.S., the number of beds per nursing home has remained largely unchanged in recent years at an average 108.7 beds per facility. Between 2009 and 2014, Massachusetts rose slightly from 114 beds per facility to 116, while occupancy declined slightly from 88.13% to 86.8% during the same period (Harrington & Carrillo, 2015). In 2017, the average number of beds remained at 116 and while occupancy had declined steadily to 84% (KFF, 2017).

Safety and Security

People with dementia need 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 or unplanned events.

The table below illustrates some common safety hazards along with suggestions 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	▪ Paint the inner surfaces of doors so that they are not readily recognizable as an exit. ▪ Place locks where they are not visible. ▪ 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.
Cooking without supervision	Fire, injury	▪ Install a shut-off valve on the stove. ▪ Remove burner on-off handles. ▪ Keep a working fire extinguisher. ▪ Create a work area with an activity kitchen
Falls	Injury	▪ Rule out medical conditions. ▪ Create an uncluttered environment. ▪ Install handrails in showers and hallways. ▪ Install carpeting to reduce injuries. ▪ Wipe up spills promptly. ▪ Maintain physical activity. ▪ Supervise walking and use assistive devices. ▪ Remove throw rugs. ▪ Maintain good vision and hearing. ▪ Provide many places to sit.
Poisoning	Sickness or death	▪ Remove toxic plants from the environment. ▪ Lock up chemicals and medications.

*The Alzheimer's Association has a product called MedicAlert + Alzheimer's Association Safe Return is a 24-hour nationwide emergency response service for individuals with Alzheimer's or a related dementia who wander or have a medical emergency. Information is available here. There are many proprietary companies now offering location services.

Simply living in a longterm care facility or receiving care at an adult day care center can be a source of safety and security for a person with dementia. Having regular contact with a caregiver provides a sense of privacy, safety, and security. A well-designed and well-run facility is secure, comfortable, and predictable; 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).

Schedules and Routines

Schedules and routines are an important part of any person’s life and well-being. However, when someone enters a long-term care facility they are unable to continue with their usual routines; their lives are undeniably altered. There is a continual tension between the necessary institutional routines and the residents’ personal habits and needs (Rijnaard et al., 2016).

In traditional nursing homes, daily life is primarily organized around the routines of the nursing home and the convenience of the staff; 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 also gives caregivers a benchmark for evaluating a person’s behavior.

The degree to which residents can maintain personal routines is related to the degree to which they are able to exert control over their day-to-day life. Institutional routines, rules, and lack of control as well as continual intrusions to privacy often negatively impact residents’ well-being (Rijnaard et al., 2016).

Although caregivers are responsible for maintaining a routine schedule, they must be flexible and know when to make an adjustment. For example, when someone does not want to take a shower on a usual bathing day, it is best to simply help the person wash up and schedule the shower for another day. People with dementia tend to be slow, so caregivers need to allow ample time when preparing for an outing or an appointment. Attempting to rush can precipitate aggressive behaviors and frustrate both parties.

Staff as Part of the Environment

In 2017 there were 15,483 certified nursing homes in the United States (399 in Massachusetts) with about 1.6 million certified beds (KFF, 2017; Harrington & Carrillo, 2018). All are required to meet minimum staffing standards to attain or maintain the highest possible physical, mental, and psychosocial well-being of residents. Most facilities struggle to hire, train, and retain staff in the face of low wages, poor benefits, and risk of injury.

In facilities that serve patients with dementia, the overall work environment is challenging and training/education is not always adequate. Training programs have been shown to have modest benefits (Alzheimer's Association, 2019). Staff turnover is one of the most vexing problems for nursing homes and other organizations that provide care for people with dementia. The turnover rate for registered nurses, licensed vocational nurses, and certified nursing assistants is significantly higher in nursing homes than in other healthcare settings.

Proper Staffing

Proper staffing is critical in nursing homes and is consistently associated with higher quality of care. Nursing homes with more RN hours per patient have been associated with positive outcomes. The benefits of higher staffing levels, especially RNs, include lower mortality rates; improved physical functioning; less antibiotic use; fewer pressure ulcers, catheterized residents, and urinary tract infections; lower hospitalization rates; and less weight loss and dehydration (Harrington & Carrillo, 2018).

States that have instituted higher minimum staffing levels have seen improvement in nurse staffing levels and in quality outcomes. A number of recommendations for minimum staffing levels have been put forth but there is no consensus or national requirement. One expert panel recommends 4.55 hours per resident day, including RNs, LVNs, and nursing assistants. In 2016 the average in Massachusetts fell in the 3.76 to 4.02 range, placing it in the lower 50% of states (Harrington & Carrillo, 2018).

Staff Adjusting to Resident Routines

When a medical-based facility is reorganized into a home-like care facility staff must adjust their routines to the routines of the residents. This requires a fundamental shift in how medical professionals have been educated and trained.

In a home-like setting, staff, residents, and family caregivers form a household together. Residents are cared for by a small fixed team of professional caregivers who are part of the household. Daily life is organized completely, or in large part, by residents and caregivers. Staff members, residents, and family members prepare meals together and staff members are involved in multiple tasks such as medical and personal care, domestic chores, and activities (Verbeek et al., 2009).

To encourage integration of the staff into a home-like environment:

- Hire staff with the emotional skills to interact with people with memory problems.
- Eliminate institutional, centralized nursing stations.
- Locate nursing and work areas throughout the building for staff convenience.

- Allow staff to control lighting and environmental levels.
- Emphasize signage for residents, limit signage for staff and visitors.
- De-emphasize or camouflage doors to staff and utility areas.
- Keep staff consistent.

Ethical Issues with Dementia Patients

Those who work in dementia care settings face difficult ethical decisions each day. Caregivers must balance the needs of multiple residents or clients while considering patient 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 step in and make difficult decisions. 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 Approaches to Care

Healthcare providers are routinely called upon to make ethical decisions and must incorporate ethical principles into daily care. This is particularly true in the complex and ethically difficult area of dementia care. 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).

In biomedical ethics, several basic ethical principles are commonly accepted. These are (1) autonomy and well-being, (2) beneficence, (3) justice. Veracity or truthfulness must also be considered.

Autonomy and Well-Being

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

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

Beneficence: Kindness

Beneficence is the act of being kind. This means providing care that is in the best interest of the patient or 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 “right” as long as they are in the interest of the patient and avoid negative consequences.

Justice: Equity and Fairness

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

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

Veracity (Truthfulness)

When interacting with a person who has dementia, the ethical reasoning behind most interactions is based on concern for the well-being of the person with dementia, with conflicts experienced between the desires to maintain trust while at the same time avoiding distress. Consideration for the person with dementia must coexist with beliefs about the moral importance of telling the truth 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 remaining grip the person with dementia has on the everyday world. Others point out that telling the truth in circumstances where the person with dementia will not believe it may equally undermine trust because the person will think that they are being lied to. For care 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).

Ethical Conflicts and Dilemmas

Ethical dilemmas arise when there are equally compelling 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. Usually 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). This is 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 a *moral temptation* (Kidder, 1996).

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

Examples of Ethical Decision-Making

Case 1

Mr. Corona is 82 years old and lives in a cottage on his daughter's property. He was a fighter pilot during World War II and has been fiercely independent his entire life. He is in the moderate-to-severe stage of ADRD and is unable to perform instrumental ADLs.

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

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

Discussion: In making decisions on Mr. Corona's behalf, his daughters are using the principles of autonomy and beneficence. Mr. Corona's lifelong desire to be independent guided their decision to allow him to continue to live alone. They are balancing his need for autonomy with his need for safety and protection. The three sisters decide 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.

Case 2

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

Discussion: Mrs. Gould's son is acting from what he believes is the best course of action for her; however, he is expressing his opinion and neglecting to consider what his mother would say if she were able. He is not adhering to the principle of autonomy and is not demonstrating loyalty or support of his mother's wishes. While her son might think that he is acting in concert with the principle of beneficence by feeding her, studies show that feeding tubes do not prolong life or improve quality of life in people in the later stages of ADRD (Sampson et al., 2009). At the very latest stages of ADRD, the natural course of the disease is that people stop eating and drinking.

Concluding Remarks

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

Although people with dementia often exhibit behaviors that are challenging for family and professional caregivers to manage, the behaviors are caused by damage to the brain and are not intentional. Challenging behaviors can be caused by unmet needs and are often a means of communication. By carefully observing what occurs before and after a behavior, a caregiver should be able to identify the underlying need and determine 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 should be used only as a last resort and for the shortest possible time. There are many proven alternatives to physical and chemical restraints that are the mainstays of individualized care.

Activities of daily living are disrupted in people with dementia. As the dementia progresses, caregivers must step in and assist with personal care and household management. They must also design individual and group activities that provide a sense of accomplishment and well-being.

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

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

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

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Post Test: MA ADRD (250)

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

1. Most people with dementia have:

    a. "Pure" Alzheimer's disease.
    b. "Pure" vascular dementia.
    c. A mixture of two or more types of dementia.
    d. Alzheimer's disease and Lewy bodies.

2. In Alzheimer's disease, damage is thought to be caused by:

    a. Destruction of the healthy balance in the brain of beta-amyloid and tau proteins along with neuron destruction and no other factors.
    b. Female gender, old age, and loss of the sense of smell.
    c. Male gender, old age, and toxin exposures.
    d. Destruction of the healthy balance in the brain of beta-amyloid and tau proteins along with neuron destruction and potentially several other factors.

3. Alzheimer's disease is typically diagnosed by:

    a. Symptoms, including a gradual decline in mental capacity and changes in behavior.
    b. A test that shows the amount of beta-amyloid plaques in the lymph.
    c. Biomarkers, which show abnormal substances in urine.
    d. Magnetic resonance imaging.

4. Delirium:

    a. Generally lasts several months.
    b. Has a sudden onset, a fluctuating course, and can be associated with infections.
    c. Is usually permanent and leads to eventual death.
    d. Is characterized by a normal level of consciousness.

5. Diagnosis of depression in those with dementia:

    a. Is easy because the symptoms of each are distinctly different.
    b. Can be difficult because of shared symptoms of gregariousness, short-term memory loss, and impaired thinking.

c. Can be difficult because of shared symptoms of apathy, social withdrawal, trouble concentrating, and impaired thinking.

d. Is easy because a person cannot have both at the same time.

6. The ABC approach to challenging behaviors in dementia encourages caregivers to:

a. Approach a misbehaving person cautiously, identify the behavior, and help the person compensate for bad behaviors.

b. Determine the antecedent of a behavior, decide the best option for stopping the behavior, and acknowledge that a person with dementia doesn't understand consequences.

c. Approach demented patients with caution, be aware of any danger posed by the behavior, and determine the consequences of the behavior.

d. Understand what caused the behavior, identify the behavior, and identify the consequences of the behavior.

7. Wandering, a common activity in people with dementia can be addressed by:

a. Providing a safe area to walk with looping pathways and places to rest.

b. Telling a person that wandering is unsafe and telling them to stop.

c. Prescribing an antipsychotic to calm the person and prevent wandering.

d. Using a physical restraint to keep the person safely in a wheelchair, recliner, or bed.

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

a. Loss of control, discomfort, or the inability to communicate discomfort.

b. Health factors such as urinary tract infections or environmental factors such as poor lighting or sensory overload.

c. Boredom, pain and discomfort, disorientation, and memory problems.

d. Degeneration of neurons in the part of the brain that controls circadian rhythms.

9. Chemical restraints are used:

a. To make dementia patients obey the caretaker's orders.

b. With great care due to issues of side effects and personal freedom.

c. To smooth out the daily routine when multiple patients are involved.

d. To prevent interruptions like searching for a wandering patient.

10. Basic activities of daily living (ADL) include:

a. Using the telephone, toileting, and gardening

b. Dressing, climbing stairs, and cooking

c. Using the computer, maintaining financial records

d. Eating, bathing, and dressing

11. Instrumental activities of daily living (IADLs) include:

a. Cooking, shopping, and medical management

b. Eating, bathing, and dressing

c. Housework, bathing, and grooming

d. Transferring from bed to chair, toileting

12. In terms of ADLs, signs of severe dementia can include:

a. Losing car keys several times a day.

b. The need for increased assistance with ADLs.

c. Compete or nearly complete dependence on caregivers.

d. Trying to cover up deficits by making up stories.

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

a. Give the resident something else to do as a distraction.

b. Do not allow the resident to assist because it will prolong the task.

c. Make the tools available, encourage participation, and allow simple choices.

d. Do it quickly so that the person does not have time to fight back.

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

a. Proceeding with bathing as scheduled regardless of the resident's wishes.

b. Changing from a shower to a bed bath.

c. Enlisting the assistance of a co-worker to prevent injury.

d. Engaging the resident, allowing choices, and keeping the person comfortable.

15. A person who is in the moderate to severe stages of dementia might enjoy :

a. Listening to music that was popular when he was young.

b. Reading books and discussing them with other residents.

c. Learning how to knit.

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

16. Your patient, who has mild to moderate dementia, sits in his room all day, and is reluctant to participate in group activities. The best way to get him involved is:

a. Let him be—he probably doesn't like to participate in groups.
b. Interview him about his experiences, hobbies, and interests.
c. Take him to group activities even if he protests.
d. Tell him he must come to activities.

17. The majority of caregivers for those with dementia are:

a. Unpaid, female, unmarried, living alone.
b. Paid, female, in a relationship, living with the care receiver.
c. Unpaid, female, in a relationship, living with the care receiver.
d. Paid professionals.

18. Caregivers of people with dementia:

a. Only assist with activities of daily living (ADLs).
b. Handle everything for anyone they are helping.
c. Don't provide any different care than those helping people without dementia.
d. Provide some or all of a wide range of assistance that may include ADLs.

19. The prevalence of depression is higher among dementia caregivers and is even higher among those caring for a:

a. Friend.
b. Spouse.
c. In-law.
d. Sibling.

20. Interventions developed to help manage caregiver stress include:

a. Counseling, support groups, and drug testing.
b. Respite services, support groups, and help with shopping.
c. Counseling, respite services, and case management.
d. Only single component approaches.

21. Person-centered care:

a. Tailors care to residents’ and caregivers’ needs and preferences.

b. Is only used when a course of antipsychotics fails to resolve behavioral problems.

c. Can increase unwanted and aggressive behaviors.

d. Is the same thing as task-centered care and commonly used in nursing homes.

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

a. The environment has little impact on those with dementia.

b. There is a connection between the environment and how we behave.

c. People with dementia do not rely on environmental cues to support them cognitively and emotionally.

d. People with dementia do fairly well in unfamiliar, chaotic, or disorganized environments.

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

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

b. Increase the number of centralized nursing stations.

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

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

24. The principle of beneficence or kindness is:

a. Should not be used when making ethical decisions.

b. Not really applicable to people with dementia.

c. Difficult to apply in ethical situations involving people with dementia.

d. The act of being kind.

25. An ethical dilemma arises when:

a. A resident refuses to go to the dining room for breakfast.

b. A person with dementia steals food from another resident.

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

d. A person with dementia is no longer able to independently perform their ADLs.

Answer Sheet

MA: Alzheimer’s Disease and Related Dementias, 3 units (250)

Name (Please print your name): ______________________________

Date: ______________

Passing score is 80%

1. _______
2. _______
3. _______
4. _______
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23.________

24.________

25.________

Course Evaluation: MA ADRD (250)

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:

a. Outline types of dementia and the process and diagnosis of Alzheimer's disease.

○1 ○2 ○ 3 ○4 ○5

b. Identify 5 common behavioral and psychological symptoms of dementia.

○1 ○2 ○ 3 ○4 ○5

c. Discuss the use of physical or chemical restraint versus non-pharmacological interventions for persons with dementia.

○1 ○2 ○ 3 ○4 ○5

d. Describe how mild, moderate, and severe dementia affects a person's ability to complete basic activities of daily living (ADLs).

○1 ○2 ○ 3 ○4 ○5

e. Relate the 3 components each that should be part of individual and group activities for residents with dementia.

○1 ○2 ○ 3 ○4 ○5

f. Summarize tasks of , stressors for, and support available to family caregivers.

○1 ○2 ○ 3 ○4 ○5

g. List 3 concepts that are important in the design of a therapeutic environment for those with dementia.

○1 ○2 ○ 3 ○4 ○5

h. Identify 4 concepts that are part of an ethical approach to dementia care.

○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

* This course contained no discriminatory or prejudicial language.

○ Yes ○ No

* The course was free of commercial bias and product promotion.

○ Yes ○ No

* As a result of what you have learned, do you intend to make any changes in your practice?

○ Yes ○ No

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

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

○ Yes, within the next 30 days.

○ Yes, during my next renewal cycle.

○ Maybe, not sure.

○ No, I only needed this one course.

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

○ Yes, definitely.

○ Possibly.

○ No, not at this time.

* What is your overall satisfaction with this learning activity?

○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?

○ 60 minutes (or more) per contact hour

○ 50-59 minutes per contact hour

○ 40-49 minutes per contact hour

○ 30-39 minutes per contact hour

○ Less than 30 minutes per contact hour

I heard about ATrain Education from:

○ Government or Department of Health website.

○ State board or professional association.

○ Searching the Internet.

○ A friend.

○ An advertisement.

○ I am a returning customer.

○ My employer.

○ Other

○ Social Media (FB, Twitter, LinkedIn, etc)

Please let us know your age group to help us meet your professional needs.

○ 18 to 30

○ 31 to 45

○ 46+

I completed this course on:

○ My own or a friend's computer.

○ A computer at work.

○ A library computer.

○ A tablet.

○ A cellphone.

○ A paper copy of the course.

Please enter your comments or suggestions here: ____________________________________

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Registration Form: MA ADRD (250)

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

* Name: ______________________________

* Email: ______________________________

* Address: ______________________________

* City: ______________________________ * State: ________ * Zip: ________

* Country: ______________________________

* Phone: ______________________________

* Professional Credentials/Designations:

____

* License Number and State: ______________________________

* Please email my certificate:

○ Yes ○ No

(If you request an email certificate we will not send a copy of the certificate by US Mail.)

Payment Options

You may pay by credit card or by check.
Fill out this section only if you are **paying by credit card.**
3 contact hours: $29

Credit card information

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Address (if different from above): ______________________________

* City: ______________________________ * State: ________ * Zip: ________

* Card type:

○ Visa ○ Master Card ○ American Express ○ Discover

* Card number: ______________________________

* CVS#: ________________

* Expiration date: ________________