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Contact Hours: 1

Dementia: Alzheimer's Disease Diagnosis, Treatment, and Care

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LEARNING OUTCOME AND OBJECTIVES: Upon completion of this continuing education course, you will have increased your knowledge of diagnosis, treatment, and care for persons with Alzheimer's disease (AD). Specific learning objectives to address potential knowledge gaps include:

- Describe the diagnosis of Alzheimer's disease.
- Discuss pharmacologic and medical treatments.
- Outline management and care for individual's with AD.
- Identify effective communication strategies for patients with AD.

INTRODUCTION

Alzheimer's disease (AD) is an irreversible, progressive, degenerative disease of the brain that damages and eventually destroys brain cells, leading to loss of memory and impaired judgment, language, orientation, and executive functioning. Over time, it causes behavior and personality changes and eventually loss of physical function. When the individual becomes incapacitated, death is usually caused by complications such as pneumonia, hip fracture, pulmonary embolism, cachexia, or dehydration (Rosenzweig, 2020).

The course of Alzheimer's and the rate of decline vary from person to person. AD can be present for many years before there are clinical signs and symptoms of the disease. On average, a person

with Alzheimer's lives for four to eight years after diagnosis. However, some may live for as many as 20 years (Alzheimer's Association, 2020).

DIAGNOSING ALZHEIMER'S DISEASE

The cause of Alzheimer's disease is poorly understood and includes many environmental and genetic risk factors that are associated with its development. There are several hypotheses, but the exact cause of AD is still unknown.

Alzheimer's is largely associated with amyloid plaques, neurofibrillary tangles, and loss of neuronal connections in the brain. The role plaques and tangles play in Alzheimer's disease is unknown, but it is believed they disable or block communication among nerve cells and disrupt processes the cells need to survive. The destruction and death of nerve cells causes memory failure, personality changes, problems in carrying out daily activities, and other symptoms of Alzheimer's.

Clinical diagnosis of Alzheimer's disease is usually made during the early stage. The affected person and the family may mistake early signs of Alzheimer's for normal age-related changes. Deciding to seek diagnostic testing can be a major hurdle for the person and the family. Various approaches and tools are used to assist in making a diagnosis. Dementia can almost always be determined, but it may be difficult to identify the exact cause. Diagnosis is made based on:

- Medical history
- Physical examination
- Neurological examination
- Mental cognitive status tests (e.g., Mini-Mental State Exam, Montreal Cognitive Assessment)
- Diagnostic laboratory tests (primarily to rule out other health issues that can cause similar symptoms to dementia)
- Brain imaging (Alzheimer's Association, 2021a)

Mental Cognitive Status Testing

The most widely used tools for cognitive assessment are the Mini-Mental State Exam and the Montreal Cognitive Assessment.

• The **Mini-Mental State Exam** (MMSE) assesses multiple cognitive domains, particularly memory and language, which may be most relevant to dementia due to Alzheimer's disease. The MMSE can be performed in a short time period (5–10 minutes)

and is most sensitive to patients at the mild to moderate stage of Alzheimer's dementia (Alzheimer's Association, 2021a; Slavych, 2019).

The Montreal Cognitive Assessment is a 30-point test that assesses short-term memory recall, visuospatial ability, and different aspects of executive function. It takes about 10 minutes to complete (Mendez, 2021; Slavych, 2019).

Informant- or caregiver-completed questionnaires can also be employed. These include asking an informant who knows the patient well to answer a series of questions about the patient's memory and other cognitive functions. Three such questionnaires are:

- Informant Questionnaire on Cognitive Decline in the Elderly (IQCODE)
- Alzheimer's Disease Caregiver Questionnaire
- AD8 Dementia Screening Interview

Blood Test for Alzheimer's Disease

An international research team has developed a 19-protein biomarker panel blood test for early detection and screening of Alzheimer's disease, with an accuracy level of over 96%. This test can also differentiate among the early, intermediate, and late stages of the disease and can be used to monitor the progression of the disease over time (Jiang et al., 2021).

Imaging Studies

Structural neuroimaging is performed to rule out potentially treatable causes of progressive cognitive decline, such as stroke, small vessel disease, tumors, or hydrocephalus, and to assess specific causes (i.e., neurodegenerative or otherwise) of dementia (Alzheimer's Association, 2021a; Lakhan, 2021).

Molecular imaging modalities include positron emission tomography (PET) and single photon emission computed tomography (SPECT). PET and SPECT can help narrow down a diagnosis by revealing deficits common in Alzheimer's disease that are distinct from findings for other dementias.



PET scans of the brain. (Source: National Institute on Aging/National Institutes of Health.)

Functional Assessment

Functional status can be assessed using one of a number of valid and reliable instruments. Examples include:

- Lawton Instrumental Activities of Daily Living Scale
- Barthel ADL Index
- Katz Index of Independence in Activities of Daily Living
- Functional Activities Questionnaire (FAQ)

PHARMACOLOGIC AND MEDICAL MANAGEMENT

Management of patients with Alzheimer's dementia primarily addresses symptoms, including treatment of behavioral disturbances, environmental manipulations to support function, and counseling regarding issues of safety (discussed later in this course). However, some FDA-approved medications can help improve or maintain the patient's cognitive and functional status and help lessen symptoms such as memory loss and confusion. Some medicines also improve behavioral and psychological symptoms and can be used in addition to nonpharmacologic strategies (Alzheimer's Association, 2021b).

FDA-approved medications for treating the cause of Alzheimer's disease include:

- Aducanumab (Aduhelm), an anti-amyloid antibody intravenous infusion therapy given once a month
- Lecanemab (Leqembi), an anti-amyloid antibody intravenous infusion therapy given every two weeks (Alzheimer's Association, 2023)

Treating Cognitive and Memory-Related Symptoms

As Alzheimer's progresses, the following medications may help temporarily lessen or stabilize symptoms related to memory and thinking by affecting chemicals involved in carrying messages among and between the brain's nerve cells (Alzheimer's Association, 2021b). These include:

- **Cholinesterase inhibitors** donepezil, rivastigmine, and galantamine, for treating symptoms related to memory, thinking, language, judgment, and other thought processes
- **Glutamate antagonist** memantine, for moderate to severe Alzheimer's disease, to improve cognition and global assessment of dementia, but with only small effects that are not of clear clinical significance
- Antioxidant vitamin E (alpha-tocopherol), for modest benefit in delaying progression of functional decline in patients with mild to moderate Alzheimer's, but with no measurable effect on cognitive performance (Press & Buss, 2021)

Treating Behavioral and Psychological Symptoms

Behavioral and neuropsychiatric symptoms are common in dementia patients and are often more problematic than memory impairment.

Suvorexant (Belsomra) is approved by the FDA to address insomnia in those with dementia. Other medications are used "off label" and include the following:

- Selective serotonin reuptake inhibitors (SSRIs), for the management of agitation and paranoia
- Benzodiazepine anti-anxiety medications, for anxiety, restlessness, verbally disruptive behaviors, and resistance
- Antipsychotic agents in low doses, for short-term use to manage symptoms, including hallucinations, delusions, aggression, agitation, hostility, and uncooperativeness
- Analgesics, for pain control in order to improve behavior and function (Alzheimer's Association, 2021a; Press & Alexander, 2021)

MANAGEMENT AND CARE FOR THE PERSON WITH ALZHEIMER'S DISEASE

Supportive care focuses on preventing and relieving suffering and on providing the best quality of life for patients and their families facing serious illness.

Providing a Safe Home Environment

As dementia progresses, physical and social environments prove ever more difficult for the person. A safe environment should include:

- Simple and consistent furniture arrangement, lack of clutter
- Removing loose rugs and taping down carpet edges to avoid falls
- Extra lights and night lights in entryways, doorways, stairwells, hallways, and bathrooms
- Seating near the bed to help with dressing
- Closet shelves at an accessible height to prevent shelf climbing and objects falling from overhead
- Securing book shelves, cabinets, and large TVs to prevent tipping
- Safely storing old and current medications
- Hiding stove gas valve or circuit breaker and removing knobs from the stove
- Disconnecting the garbage disposal
- Removing any toxic plants and decorative fruits to avoid being mistaken for food
- Removing small appliances near water sources
- Installing locks out of sight and deadbolts high or low on exterior doors to prevent wandering
- Removing locks in bathrooms or bedrooms
- Disabling or removing guns or other weapons
- Regulating water temperature with an automatic thermometer on plumbing
- Providing a walk-in shower and/or grab bars in the shower or tub and vanity
- Applying textured, nonslip stickers to slippery surfaces
- Securely locking up cleaning products, chemicals, and other potentially hazardous items
- Locking the laundry room door
- Fitting appliances with automatic cut-off mechanisms
- Replacing long electrical cords on appliances with coiled or retractable cords (Alzheimer's Association, 2021a)

Supporting Basic Activities of Daily Living (ADLs)

To persons with Alzheimer's disease, the tasks of daily living can be frustrating and overwhelming, as they are often quite complicated when broken down into steps. Supporting these tasks involves:

- Activity analysis to determine the manual and cognitive activities involved in the completion of a task, and organizing the task into manageable sections
- Verbal coaxing to allow the person to perform the activity and retain the ability longer
- **Providing cues** such as labeling, placing equipment and clothes out in view, and offering demonstrations
- Establishing and maintaining a routine so that the person no longer needs to stop and think what to do next (e.g., a fixed routine for eating and toileting to reduce the incidence of incontinence)
- **Offering choices** for those who refuse to attend to daily activities, such as asking them "when" instead of "if" they want to bathe

BATHING AND ORAL CARE

Bathing and oral care can be challenging. The following are ways of managing resistance:

- Avoid a discussion as to whether a bath is needed or not; if the person adamantly refuses to bathe, wait and try again later.
- Partial baths may be sufficient.
- Follow the person's previous routines.
- Prepare the bathroom in advance.
- Complete one step at a time, talking through each step. Be calm; don't rush.
- Use a seat and hand-held shower attachment, which can be less frightening.
- Check the temperature of the water.
- Introduce warm shower water gradually, starting at the feet and moving up the body.
- Use dry shampoo products for those who resist hair washing.
- Use electric razors to reduce risk of cuts.
- Use toothettes with diluted hydrogen peroxide solution for oral care.
- Provide apples to help clean the teeth. (Piedmont Healthcare, 2021; Alzheimer's Association, 2021a)

DRESSING

Self-esteem is important, and past grooming habits should be considered, as well as the person's style and cultural clothing preferences.

- Maintain the person's preferred hairstyle, beard, and makeup.
- Remove clothes that are seldom worn from the closet.
- Provide simple garments with large zipper pulls, hook-and-loop fasteners, few buttons, and pull-on pants and shirts.
- Use cardigan sweaters instead of pullovers.
- Lay out clothes in the order in which they will be put on.
- If needed, provide constant repetition of each step.
- Provide nonskid shoes, such as washable rubber-sole shoes and shoes with hook-and-loop fasteners or slip-ons.
- If the person wants to wear the same clothes every day, provide duplicates. (Piedmont Healthcare, 2021; Alzheimer's Association, 2021a)

TOILETING

A matter-of-fact, calm, and reassuring manner with the person with dementia is the best approach to toileting. Ways to assist may include:

- Check mirror location in the bathroom to avoid confusion that there is someone else occupying the room.
- Know that the person may not recognize the toilet as the appropriate place to urinate; remove objects in the environment that can be mistaken for a toilet.
- Provide a bedside commode or urinal if getting to the bathroom is difficult, especially at night.
- Post a colorful sign on the bathroom door to identify the room.
- Set a regular bathroom schedule.
- Monitor mealtimes so as to predict when to use the bathroom.
- Respect the person's privacy.
- Assist with removing or adjusting clothing.
- Help the person get in the right position.
- Give cues and talk through each step.
- Learn to recognize signs that the person may need to use the toilet.

• Use a urinary alarm system for reminders.

When assisting the person to a **public restroom**, go together. If a caregiver is assisting a dementia patient of the opposite sex, use the caregiver gender's room and, if necessary, hand out a card to others stating the person has dementia.

When the person loses bowel or bladder control, a medical evaluation should be obtained. When the person becomes **incontinent**, the following suggestions are helpful:

- Restrict fluid and caffeine intake 2 hours before bedtime.
- Use incontinence aids (disposable briefs and pads for beds and chairs or condom catheters for men at night).
- Dress the person in manageable clothing and consider eliminating underwear.

Constipation and fecal impaction can cause a great deal of discomfort and lead to unwanted behavioral problems. Avoid using laxatives, but encourage a high-fiber diet (Piedmont Healthcare, 2021; Alzheimer's Association, 2021a).

EATING

Proper nutrition reduces the risk of constipation, dehydration, and vitamin deficiency, all of which can increase confusion and decrease physical functioning.

In early-stage Alzheimer's, depression may result in anorexia and weight loss. Persons may forget to eat or refuse to eat. Confusion and agitation may lead to extreme eating behaviors such as gorging. It is important to monitor what the person eats and drinks to avoid inappropriate items being eaten.

In the later stage of the illness, profound memory loss interferes with the recognition of food, need to eat, and mechanics of eating. The person may become resistant to being fed. A nutritionist can make suggestions. Evaluation by a speech pathologist is indicated when the person has trouble swallowing.

Physiologic factors affecting eating behaviors may include dental problems such as uncomfortable dentures, missing teeth, and/or periodontal (gum) disease. Neurofibrillary tangles and plaques can affect the function of the hypothalamus, which regulates appetite, hunger, and thirst signals. Many persons with Alzheimer's lose their sense of smell, affecting taste and appetite. Medications can also affect appetite.

In addition to depression, other psychological factors that affect eating behaviors include new and unfamiliar environments, distractions such as loud noises, unappealing food, and unusual odors.

Supporting the Eating Process

Helpful ways to assist the person with dementia to eat and to enjoy the process of eating include:

- Provide a quiet, relaxing, homelike, and well-lit atmosphere.
- Reduce distracting stimuli; keep the table free of clutter.
- Play soothing music.
- Facilitate social eating in the earlier stages of AD; limit social stimulation in later stages.
- Maintain familiar dining routines; allow the person to choose mealtimes.
- Adjust mealtimes based on agitation or disorientation.
- Offer food choices, but limit the number; offer culturally appropriate foods.
- Put one utensil and one food in front of the person at a time.
- Use plain white dishes (to help distinguish food from the plate) and placemats of contrasting color (to help distinguish the plate from the table).
- Provide bendable straws or lidded cups for liquids.
- Limit access to food between meals, maintain a schedule, and monitor intake.
- Provide ample, unrushed time to eat.
- Ignore messy eating.
- Sit level to the person, make eye contact, and speak with the person while assisting with eating.
- Remind the person to eat slowly, chew thoroughly, and swallow the food.
- Provide verbal prompts or physical cues if required to encourage eating.
- Encourage independence.
- Adapt foods and provide assistance when utensils can no longer be used.
- Provide appropriate foods and beverages to match swallowing capability.
- Use adaptive devices/utensils as needed. (Piedmont Healthcare, 2021; Alzheimer's Association, 2021a)

Maintaining Nutritional Well-Being

The following steps can support nutritional well-being:

- Provide a balanced diet with a variety of foods, including vegetables, fruits, whole grains, low-fat dairy products, and lean protein foods.
- Limit foods with high saturated fat and cholesterol.
- Offer nutrient-dense foods.

- Reduce sugars, but in the later stages of Alzheimer's, if loss of appetite is a problem, add sugar to foods to encourage eating.
- Limit high-sodium foods and use less salt.
- Provide supplements between meals for loss of appetite and weight loss.
- Encourage fluids throughout the day and foods with high water content (e.g., fruit, soups, milkshakes, smoothies).
- Encouraging simple exercises such as walking to increase appetite.

Monitoring the person's nutritional status for weight loss and possible nutritional deficiencies also includes:

- Review medications for drugs that may affect appetite.
- Assess for vision problems that may cause confusion at mealtime.
- Assess for depression.

Ensuring Proper Swallowing

Those who are unable to swallow properly can become dehydrated and aspirate food, leading to aspiration pneumonia.

- Assess the person's ability to swallow food. Remind them to swallow with each bite and show them how. Gently stroke the throat to promote swallowing, and at the end of the meal, check the person's mouth to make sure all food has been swallowed.
- Grind foods, cut food into bite-size pieces, or serve soft foods (e.g., cottage cheese, scrambled eggs, mashed potatoes, applesauce). Avoid foods like popcorn or raw vegetables.
- Provide thicker liquids, which are easier to swallow and less likely to cause choking. If needed, use thickening agents in liquids.

A speech-language pathologist can also assess the person's needs and make recommendations (Alzheimer's Association, 2021a; Piedmont Healthcare, 2021).

AMBULATING

Because Alzheimer's and other types of dementia can affect areas of the brain that are responsible for movement and balance, ambulation problems will slowly begin to occur. Loss of balance is one reason why people with dementia are eight times more likely to fall than older adults without dementia.

Almost any physical activity that safely gets a person moving is good for Alzheimer's symptoms, and low-impact workouts that include light resistance activities may be particularly helpful in improving balance. A twice-weekly, home-based physical therapy program of music-cued gait training may help some with mild to moderate AD increase ambulation speed.

Other ways to help the person move around more easily and avoid falls include:

- Remove any obstacles on the floor that the person could trip over or otherwise need to steer around.
- Keep useful items within reach to avoid straining to reach or using a stepping stool.
- Keep the house well-lit, especially at night.
- Provide nonskid slippers and shoes.

Canes and walkers may actually increase the likelihood of falls, especially if used incorrectly. Provide appropriate training in the use of any new assistive devices (preferably by a physical or occupational therapist). Consistently monitor usage for any difficulty or decline in the patient's ability to use such devices, with or without assistance.

Novel surfaces may affect gait speed, such as walking on shiny surfaces that appear icy or slick. Waiting in a line, taking a few steps forward, and stopping can become confusing. Getting in and out of cars can take longer.

In later stages, the person may require physical support in order to walk, and they may eventually lose the ability to ambulate, even with assistance. At this point, they may require a wheelchair. In the later stages of severe dementia, the person may also lose the ability to sit up without assistance, requiring some form of external physical support, such an arm rest, belt, or other device to keep from sliding down in the chair (Dementia Care Central, 2020; Wittwer et al., 2020; Cohen & Verghese, 2019).

Supporting Instrumental Activities of Daily Living (IADLs)

Performing IADLs is the first ability to decline in persons with Alzheimer's disease, even while their ability to perform basic activities remains unimpaired.

SHOPPING AND MEAL PREPARATION

The person may begin to lose skills needed to shop for and prepare proper meals. For those living alone or who need extra support with meals:

- Assist the person to complete a menu and a shopping list.
- Accompany the person to the store if necessary or shop online.
- Buy frozen or refrigerated ready-to-eat meals or have meals delivered.

- Use simple notes about where certain foods are stored or place pictures on cupboards or the refrigerator.
- Provide simple written instructions for cooking or reheating food.
- Plan meals that do not require any cooking. (Alzheimer's Society, 2021)

DRIVING AND TRANSPORTION NEEDS

Once the diagnosis of Alzheimer's disease is established, healthcare professionals encourage the family to discuss the issue of driving with the person. Each state has its own laws and policies regarding physician reporting of driving with dementia to the Department of Motor Vehicles. Healthcare professionals should be aware of the regulations in their own state and local jurisdiction.

When driving is no longer an option, rides can be provided by family, friends, neighbors, public transportation, taxis, or senior and special needs transportation services (Piedmont Healthcare, 2021; FCA, 2021a).

MANAGING MEDICATIONS

Healthcare professionals can review all medications, provide guidance on ways to simplify medication regimens, and make recommendations for managing resistance. Consulting a pharmacist can also be helpful.

The following information can be taught to family caregivers regarding managing patient medications:

- Make taking medications part of the daily routine by pairing it with specific events.
- Use a pill box organizer and a daily log of what medications are to be taken and when.
- Use simple language and clear instructions.
- Keep medications stored in a locked location.
- Know that herbal therapies and over-the-counter medications can interact with prescribed medications.
- Understand how to determine if medications are effective.
- Know which medications are priorities as well as which medications can safely be skipped when the patient is resistant to taking them.
- Give medications with meals, if allowed, and administer the most important medications first.
- With prescriber's approval, give medications in the morning, when agitation is less likely to occur.

- Make certain the patient is wearing their glasses and hearing aids.
- If a person refuses to take the medication, stop and try again later.
- To cope with resistance, give medications covertly in food or drink.
- Create a list of distraction activities to employ so that taking medication is more pleasant.
- Avoid arguing or trying to convince the patient to take medications.
- Should resistance become routine, talk about medication options with the prescriber to see if some medications can be discontinued or given in an alternate form.
- Request healthcare assistance if the patient has difficulty swallowing pills.
- Know the types of medication mistakes that can happen, such as giving the wrong dose, and when and how to notify the healthcare provider if this occurs.
- Have emergency numbers easily accessible. If a medication overdose is suspected, call poison control or 911 before taking any action. (Alzheimer's Association, 2021a)

Healthcare providers should provide caregivers with a copy of the written care plan and reinforce the teaching points described above.

PROVIDING PHYSICAL AND SOCIAL ACTIVITIES

Persons with Alzheimer's disease and other dementias may withdraw from activities, family, and friends. Social and cognitive stimulation may help maintain general well-being and prevent boredom and agitation in people with Alzheimer's disease. Stimulation can also encourage self-expression, lessen anxiety and irritability, make the person feel more engaged, and stir memories.

Walking provides good exercise and may relieve tension and stress. Gardening, painting with water colors or finger paints, drawing, or coloring are good ways for confused people to express themselves.

Activities common from their past can resonate with the older person with advancing dementia. For example, a retired business executive may enjoy sitting at a desk with files filled with papers. Keep activities on an adult level, although children's toys can be usefully adapted in the later stages of dementia. The person may enjoy playing games such as cards, bingo, board games, or simple jigsaw puzzles.

Music can help stir pleasurable memories. Dance music from their youth might encourage dancing.

Plan social visits for times when the person feels best and in environments that are calm and quiet.

Books, newspapers, magazine articles, and family photo albums can serve as cues for reminiscence and provide an opportunity for family conversation in which the person may still participate.

Certain television programs can be of interest, but avoid violent, suspenseful, or horror shows.

Many people with dementia regularly attend adult day programs specifically for those with dementia (Piedmont Healthcare, 2021).

MANAGING CHALLENGING BEHAVIORS

As Alzheimer's disease progresses, dementia can cause mood swings and changes in the person's personality and behaviors, including agitation and restlessness, vocal outbursts, wandering, sleep disturbances, "sundowning," and inappropriate sexual activities.

Agitation and Aggression

Agitation is a state of extreme irritability often characterized by hitting, pacing, yelling, cursing, arguing, threatening, and verbal or physical aggression. Agitation can be triggered by environmental factors, fear, fatigue, and feelings of abandonment. Often it is triggered when the person perceives that control is being taken away from them.

An agitated person requires an assessment for any physical cause of discomfort or pain. The following strategies may also be helpful when dealing with agitation and aggression:

- Give the person space and time to calm down.
- Avoid confrontational body language.
- Avoid criticizing or correcting the person.
- Speak slowly, using a low and soothing pitch.
- Remember that anger or fear responses naturally subside within seconds in the absence of continued triggers.
- Reduce noise, clutter, or number of persons in the room.
- Keep routines and maintain a consistent environment with familiar objects and photographs.
- Reduce intake of caffeine, sugar, and other energy-spiking foods.
- Use gentle touch, soothing music, reading, or taking a walk.
- Avoid restraining the person.
- Support independence.
- Acknowledge anger over loss of control, and verbalize understanding.

- Validate feelings and then attempt distraction or redirection.
- Keep dangerous objects out of reach.
- Use the **three Rs**: Repeat, reassure, and redirect. (FCA, 2021b)

Vocal Outbursts

Disruptive vocal outbursts become increasingly common as Alzheimer's progresses and the ability to communicate is lost. Verbal outbursts are often triggered by fear, anger, depression, grief, confusion, helplessness, loneliness, sadness, impatience, and frustration. Environmental factors may include poor lighting, seasonal changes, overstimulation or lack of stimulation, loud noises, or excessive heat.

Outbursts may also signal physical illness or discomfort, including pain, hunger, thirst, incontinence, constipation, infection, or fatigue. React by staying calm and reassuring. Validate feelings and try to distract or redirect the person's attention to something else. Do not try to reason with the person.

Interventions to prevent vocal outbursts related to environmental or physical factors may include:

- Assess for pain, hunger, thirst, constipation, full bladder, fatigue, infections, and skin irritation.
- Avoid being confrontational or arguing about facts.
- Redirect the person's attention.
- Respond to the emotion not the behavior.
- Create a calm environment.
- Allow adequate rest between stimulating events.
- Provide the person with a security object.
- Acknowledge requests and respond to them.
- Look for reasons behind each behavior.
- Explore various solutions.
- Don't take the behavior personally. (Alzheimer's Association, 2021a)

Wandering

At least 6 out of 10 people with dementia will wander at least once. If not found within 24 hours, up to half suffer serious injury or death (ASAC, 2021). The following approaches may be helpful in addressing wandering:

- Make time for regular exercise to minimize restlessness.
- Use large-print signs to mark destinations, with a drawing of the activity.
- Place a photo of the person as a younger adult on the room door to help the person find "home."
- Ensure that doors have locks requiring a key. Recognize that a danger of this approach is fire safety; the lock(s) must be accessible to others and not take more than a few seconds to open.
- Do not try to restrain the person unless there are obvious hazards.
- Remain calm and reassuring instead of controlling.
- Avoid negative commands such as, "Don't go out there!"
- Avoid arguing with the person.
- Use a barrier to mask the door, such as a curtain, stop sign, or "do not enter" sign.
- Paint a door to look like a piece of furniture.
- Place a large "Do Not Enter" sign on exit doors.
- Paint a black space on the front porch floor that may appear to be an impassable hole.
- Add "child-safe" plastic covers to doorknobs.
- Do not lock a person with dementia in the home or car unattended.
- Install a home security system or monitoring system, such as a GPS tracking device.
- Put away items such as the person's coat and purse.
- Sew ID labels in the person's clothes, or have the person wear an ID bracelet.
- Inform neighbors about the wandering behavior and provide them with a telephone number.
- Have a current photo available should the need arise to report the person as missing.

Caregivers can also leave a copy of the person's photo on file at the police department or register the person with the **MedicAlert + Alzheimer's Association Safe Return** program, a nationwide emergency response service for individuals with Alzheimer's or a related dementia (FCA, 2021b). (See also "Resources" at the end of this course.)

Sleep Issues and Sundowning

Restlessness, agitation, disorientation, and other troubling behavior often worsen at the end of the day and sometimes continue through the night. This behavior is referred to as *sundowning*.

Possible contributing factors to sleep disturbance include:

- Mental and physical exhaustion
- Biological clock upset, causing a mix-up between day and night
- Reduced lighting, causing misinterpretation of what is seen
- Disorientation due to inability to separate dreams from reality when sleeping

The following are some **strategies** to help manage sleep issues and sundowning:

- Schedule major activities in the morning or early afternoon hours.
- Encourage a regular routine of waking up, meals, and going to bed.
- Include walks or time outside in the sunlight.
- Identify triggers for sundowning events.
- Reduce stimulation during the evening hours.
- Offer a larger meal at lunch and lighter evening meal.
- Keep the home well-lit in the evening to reduce confusion.
- Avoid physically restraining the person.
- Identify activities that are soothing, e.g., listening to music.
- Discuss with the provider about best times of day for taking medications.
- Limit daytime naps.
- Reduce or avoid alcohol, caffeine, and nicotine. (Alzheimer's Association, 2021a)

Perseveration and Compulsive Behaviors

Repetitious speech or actions are those that occur on a continuous basis and generally serve no functional purpose. They may include:

- Checking locks, doors, or window coverings over and over
- Having rigid walking patterns, including pacing
- Collecting or hoarding items

- Counting or organizing objects repeatedly
- Going to the toilet frequently
- Selective eating habits
- Asking the same questions repeatedly

Consider whether the person might have a need they are not able to express, such as boredom, hunger, insecurity, or need to use the toilet. It may be of benefit to substitute the behavior with another activity, such as folding laundry. Remove or hide objects in the environment that might trigger the behavior.

Repetitious activity often has a basis in the person's past, such as going to work. Helpful measures to consider may include:

- Distract with a snack or activity.
- Avoid reminding the person that they just asked the same question.
- Ignore the behavior or question, and refocus the person into an activity such helping with a chore.
- Don't discuss plans until immediately prior to an event.
- Learn to recognize certain behaviors (e.g., pulling at clothing to indicate a need to use the bathroom).

When the person is very rigid and resistant to any interference with the activity, avoid provoking an aggressive reaction.

- Use a calm, matter-of-fact tone of voice.
- Do not become bossy or condescending.
- Distract the person with something appealing to them. (UCSF, 2021; FCA, 2021b)

Shadowing is a repetitive behavior in which the person constantly follows their caregivers around since caregivers represent security and protection. Helpful suggestions include:

- Establish and maintain a daily routine to help the person feel more secure.
- Speak reassuring words every day and often, such as, "You're safe."
- Avoid moving household furnishings or other items around or rearranging them.
- Use a simple white board to indicate today's date or to let the person know when the caregiver will return.
- Involve and engage the person in familiar household activities.
- Play favorite musical selections.

- Play a recording of the caregiver's voice or any reassuring familiar voice.
- Play a videotape of recent events or familiar movies.
- Consider using a day center or hiring a professional caregiver. (Alzheimer's Association, 2021a)

Inappropriate Sexual Behaviors

Because of dementia, many individuals lose the ability to determine the appropriate time, place, or manner to express sexual needs. Inappropriate behaviors may include undressing in public, making lewd remarks or unreasonable sexual demands, and sexual aggression, such as fondling, exposing genitals, or attempting to engage in sex acts with people other than their partners.

Persons who masturbate in public places should be gently led from the public area to their room. If persons have truly problematic sexual behaviors, visitation should take place in the person's room, and once the family leaves, the person should immediately be involved in some activity.

Every attempt should be made to determine whether the person is suffering from pruritus, an infection, or a chronic stress condition. Undressing in public may also be due to being too warm or frustration about trying to remember how to dress and undress. Clothing that closes in the back makes disrobing difficult in inappropriate settings.

Forewarn family and friends of the person's behaviors to better prepare them with what to expect and how best to respond.

If the person is disruptive or making someone else uncomfortable, make eye contact and say, "Stop," with a calm but firm tone of voice, and then distract.

If it is thought that the person is seeking more physical affection or intimacy, consider pet therapy, a stuffed animal, and socially appropriate touching such as hand-holding, dancing, back rubs or massages, manicure/pedicure, or brushing/combing hair (UCSF, 2021).

COMMUNICATION STRATEGIES

As Alzheimer's dementia progresses, the person's ability to communicate begins to deteriorate, and the following changes may occur:

- Difficulty finding the right words
- Repetitious use of familiar words
- Describing familiar objects rather than calling them by name
- Inventing new words for familiar objects
- Losing one's train of thought

- Reverting to one's native language
- Problems with organization of words
- Reduced efforts to speak
- Relying on gestures more than speaking

The following are means to communicate more effectively with someone in the **early stage** of Alzheimer's:

- If the individual has a vision and/or hearing deficit, make certain they wear their glasses and/or hearing aids.
- Avoid making assumptions about the person's ability to communicate.
- Do not exclude the person from conversations.
- Speak directly to the person rather than to their caregiver or companion.
- Be patient and take time to listen to the person express their thoughts, feelings, and needs.
- Give the person time to respond and do not interrupt unless the person requests help.
- Ask the person what help may be needed.
- Discuss which method of communication is most comfortable, which may include faceto-face conversation, email, or phone calls.
- Use humor to lighten a mood and make communication easier.
- Don't pull away; honesty, friendship, and support are important to the person.

In the **middle stage** of Alzheimer's, as the disease progresses, the person will have more and more difficulty communicating. It is helpful to:

- Engage with the person in one-on-one conversation in a quiet place with minimal noise and other distractions.
- Speak slowly and clearly, keep sentences simple focusing on one idea at a time.
- Face the person, maintain eye contact.
- Give the person adequate time to respond.
- Ask one question at a time.
- Ask yes or no questions; avoid open-ended questions.
- Avoid correcting or criticizing.
- Repeat what the person has said for clarification.
- Make statements rather than ask questions.

- Avoid arguing.
- Offer clear, step-by-step instructions for tasks.
- Give visual cues or demonstrate tasks to encourage participation.
- Attempt written notes when spoken words seem confusing.

In the **late stage** of Alzheimer's, the person may rely on nonverbal communication such as facial expressions or vocal sounds. At this time:

- Approach the person from the front and identify yourself.
- To understand what the person is saying, ask them to point or gesture.
- Use touch, sights, sounds, smells, and tastes as a form of communication.
- Consider the feelings behind words or sounds.
- Avoid talking down to the person and do not talk to others about the person as if they were not present.
- Use positive body language.
- Repeat your message as often as necessary.
- Distract the anxious or agitated person. (Alzheimer's Association, 2021a)

As dementia progresses, nonverbal communication may become the main way a person communicates. Consider that the person with dementia will read and interpret others' body language, and make sure body language and facial expression match what is being spoken. Visual prompts are helpful for the person with dementia, including cue cards or a book with pictures to point to for communicating needs and wants. Careful observation of the person's facial expressions, eye contact or lack of eye contact, and body language can help the caregiver assess comfort or pain, anger, hostility, and misunderstanding.

Persons with Alzheimer's may ask the same question repeatedly because they do not remember the answer given. Respond to the question, and then try to distract the person with an activity or a change of topic or a change of scene (Alzheimer's Society, 2021).

CONCLUSION

The risk of developing Alzheimer's dementia increases with age, and as the population continues to age, the number of persons with Alzheimer's disease will also increase. Healthcare professionals must become educated about this disease and its impact in order to effectively care for these individuals and their loved ones. This includes learning strategies to manage difficult behaviors.



RESOURCES

Alzheimer's Association https://www.alz.org

Alzheimer's disease and related dementias (National Institute on Aging) https://www.nia.nih.gov/alzheimers

Family Caregiver Alliance https://www.caregiver.org

Home safety checklist https://www.alz.org/media/Documents/alzheimers-dementia-home-safety-checklist-ts.pdf

24/7 wandering support https://www.alz.org/help-support/caregiving/safety/medicalert-safe-return

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TEST

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- **1.** For which purpose is laboratory testing primarily conducted in diagnosing Alzheimer's disease?
 - a. Screen for and detect early stages of dementia
 - b. Rule out other reversible forms of cognitive impairment
 - c. Differentiate between stages of the disease
 - d. Distinguish Alzheimer's disease from other forms of dementia
- **2.** Which statement is **accurate** regarding pharmacologic treatment for patients with Alzheimer's disease?
 - a. Medications can improve a patient's cognitive and functional status.
 - b. There is one medication that can cure Alzheimer's if prescribed early in the disease's progression.
 - c. Medications often increase a patient's behavioral and psychological symptoms.
 - d. There are no medications that help lessen symptoms such as memory loss and confusion.
- **3.** Which ability is the first to decline in persons with Alzheimer's disease?
 - a. Maintaining nutritional well-being
 - b. Bathing and personal hygiene
 - c. Recognizing signals to void or defecate
 - d. Performing instrumental activities of daily living
- 4. Which "three Rs" should be used to calm an agitated patient with Alzheimer's disease?
 - a. Respond, restore order, and restart the activity
 - b. Remind, reprimand, and restrain
 - c. Repeat, reassure, and redirect
 - d. Rewind, relax, and resume
- 5. Which response should be made when a person with Alzheimer's disease has asked the same question several times even after it has been answered?
 - a. Ask the person to try to remember what was said before.
 - b. Ignore the question and leave the room.
 - c. Respond to the question and then try to distract the person.
 - d. Tell the person the question has already been answered and walk away.