

PRINCIPLES OF CAREGIVING: AGING AND PHYSICAL DISABILITIES

CHAPTER 8 – DEMENTIA SPECIFIC CARE

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OBJECTIVES

1. Identify and describe dementia-specific care related to:
 - a. the types and stages of dementia,
 - b. communication,
 - c. importance of activities,
 - d. managing difficult behaviors, and
 - e. safety issues.
2. Identify and describe the activities of daily living issues related to dementia-specific care.
3. Demonstrate selected personal care skills as they relate to dementia-specific care.

KEY TERMS

Alzheimer's disease	Pharmacological
Dementia	Reversible dementia
Irreversible dementia	Sundowning
Life Story	Wandering
Non-pharmacological	

This part of the training is intended to introduce the student to dementia-specific care. It is intended to be an overview of the topic.

The Alzheimer’s Association, Desert Southwest Chapter, has developed a module by a committee of professionals in the field of dementia-related care that provides in-depth training on care and treatment options.

Anyone who provides care for individuals with cognitive impairments and dementia is encouraged to attend the *Principles of Caregiving: Alzheimer’s Disease and Other Dementias* module training.

A. DEMENTIA OVERVIEW

Dementia is a progressive cognitive (thinking, reasoning, remembering) decline that impairs daily functioning. Often a group of symptoms may be present with certain diseases or conditions.

Normal, age-related forgetfulness or dementia?

As a person ages, it is common to walk into a room and think, “What did I come in here for?” Individuals may experience these momentary memory lapses, which include forgetting where they put their keys or where they parked the car at the mall. These are a normal part of aging. Even finding it difficult to remember phone numbers or the names of a recently introduced person are normal, age-related forgetfulness.

With dementia, the individual may forget family members’ names, or the person may not only misplace the keys, she may actually put them in the refrigerator. With dementia, it is not just memory that is affected, but reasoning and judgment as well.

With normal forgetfulness a person may forget the details of an event. A person with dementia may forget the entire event, insisting that it never happened. Normally, a person will be bothered by a memory lapse. A person with dementia seems to not be bothered by memory lapses.



Symptoms

Symptoms of dementia may include:

- Decline in memory, thinking, and reasoning.
- Changes in personality, mood, and behavior.
- Difficulties in language, visual recognition, and executing activities.

Types of dementia

Dementias may be reversible or irreversible. Some dementias may be resolved with appropriate medical care. Others, often caused by disease, are incurable.

Reversible

- Medical conditions such as dehydration and infections.
- Chronic medical condition being out of control (e.g., thyroid problems).
- Reaction to medication.
- Overmedication, mismanagement, withdrawal.
- Psychiatric causes such as depression, lack of sleep, stress, etc.

Irreversible

- Alzheimer's disease, the most common form of dementia.
- Vascular (multi-infarct) dementia, caused by strokes.
- Lewy body dementia, in which the person may have fluctuations in memory, hallucinations (anti-psychotics may make condition worse), rigidity in movements.
- Parkinson's disease.
- Pick's disease, a dementia involving the frontal lobes of the brain, causing behavior changes and aggressiveness.
- Huntington's disease, an inherited illness defined by uncontrolled movements and decreased physical and mental functioning.
- AIDS.
- Other rare forms such as Creutzfeldt-Jakob disease.

Depression and dementia

Depression is a chemical imbalance in the brain that can cause symptoms such as memory impairment, inability to think clearly, lack of motivation and loss of interest in activities that were once pleasurable. These same symptoms can be found with someone who has dementia. Some of the ways you can determine the difference is that individuals who are depressed usually can score very well on mental status exams and other tests that evaluate cognitive function. They may also complain about their memory loss. However, individuals with dementia score poorly on cognitive function tests and often deny any memory problems.

People who have dementia are also at a higher risk for the chemical imbalances that cause depression so individuals may have dementia and depression. If the person just has depression and responds well to treatment, the symptoms should go away. If the person is depressed and has dementia, proper treatment may make the symptoms better but they will not completely disappear.

In order to obtain the proper diagnosis and treatment, individuals exhibiting signs of depression or dementia need to be evaluated by a physician.

B. ALZHEIMER'S DISEASE

Alzheimer's disease (AD) is a progressive, degenerative disease affecting the brain. The symptoms gradually worsen over a number of years. In its early stages, memory loss is mild, but with late-stage Alzheimer's, individuals lose the ability to carry on a conversation and respond to their environment.

Although the exact cause or causes of Alzheimer's disease are not known, most experts agree that Alzheimer's, like other common chronic conditions, probably develops as a result of multiple factors rather than a single cause. The greatest risk factor for Alzheimer's disease is advancing age, but Alzheimer's is not a normal part of aging. Most Americans with Alzheimer's disease are aged 65 or older, although individuals younger than age 65 can also develop the disease. Heredity is believed to play some role.

- Sticky protein patches (amyloid plaques) form in the brain and nerve cells die.
- Nerve fibers twist into a tangle, not allowing conduction of impulses.
- Alzheimer's affects more women than men. The longer a person lives the more likely he or she is to develop the disease.
- Average life expectancy after diagnosis is 3-20 years.
- 7 out of 10 persons with dementia live at home, with much of their care falling to family members.
- **Caregiver stress is a major reason why service is requested.** 80% of caregivers report higher levels of stress, and 50% suffer from depression.

Currently, among Alzheimer's disease professionals, there is a greater urgency to educate people to get early screening and treatment. With early detection, a person:

- May get the maximum benefit from medications.
- Have more time to plan for the future.
- Get more care and support for the person and their family members.

Stages of Alzheimer's disease

People with AD usually do not fall neatly into one stage. They may even have some variable symptoms (good days and bad days).

Early stage

- Short term memory loss.
- Difficulty handling checkbook, finances, organization.
- Poor judgment and personality changes.

Mid stage

- Memory worsens.
- Increased difficulty expressing oneself.
- Difficulty using objects correctly (toothbrush, silverware).
- Disorientation to time and place.
- Restlessness or pacing.
- Behavior changes, loss of impulse control.
- Self-care abilities more impaired.

Late stage

- Limited or nonsense verbalization, or no speech.
- Oriented only to self.
- Incontinent bladder and bowel.
- Needs maximum assistance walking, unable to walk, or bedridden.
- Requires total assistance for all ADLs.

Terminal stage

- Late stage criteria *plus*:
- Difficulty chewing/swallowing.
- Infection/recurrent fever in past 12 months.
- Pressure ulcers.
- Weight loss.

C. COMMUNICATION STRATEGIES

The use of appropriate verbal and non-verbal strategies is extremely important when providing care for a person with dementia. The two most important factors are your actions and reactions (both verbal and non-verbal) to the individual and his/her behavior.

The following tips also work well in dealing with clients who do not have dementia but have some other behavioral problem. Also, refer to Chapter 3, Communication in the *Principles of Caregiving: Fundamentals* course manual for more information.

The Life Story

The life story lists some of the unique aspects of that person's life. It can give caregivers valuable cues for:

- What to talk about when trying to use distraction.
- Activities that engage the client.
- Music that the person would enjoy.

The person may help you create a life story as part of reminiscing, or you might ask the family to assist in completing a life story.



My Mom has Alzheimer's

My Mom lived with me for a couple of years after my Dad passed away. Mom loves people. She made the choice to move to a retirement home because she wanted to be around people all the time and pretty soon she knew she would have to give up driving. In a time of only six years I saw Mom go from the retirement center, to the assisted living center, and now she is in the memory unit. It is a roller coaster of a ride with emotions. This is the Mom I used to talk to about problems and we would come up with solutions to solve the world. Now our conversations are about when Dad is coming home. This conversation usually happened around 6 p.m. I remember someone telling me about "sundowners." This is the time when people who have been diagnosed with dementia or Alzheimer's would get upset or confused. One time, Mom was really upset and she would not eat because she said she had dinner all ready and was waiting for Dad to come home. Mom was truly upset, nervous, and wondering where he was. At first, my heart broke to hear her ask me this question, since Dad died many years ago. But I learned to be creative about answering her. "Mom, remember how Dad has to travel with his job? Well he was in a snow storm and he won't make it home tonight." My Mom looked at me with a great sigh of relief and kept saying, "Well, thank God he is alright. Thank God he is alright!" She then asked me what she should do with the dinner she made. I told her I would put everything away. I was amazed how she just smiled and relaxed, and then she went to eat her dinner. When I left that day, I thought to myself is it really sad to be in a place where Mom is so happy? Now I almost feel comfortable being where Mom is on those days when she is living in the past. When Mom is living in the past I tell her how much Dad loves her and I love to see her smile. I remember someone saying to me that I needed to go to my Mom's world and not try to make her be in my world. Now I understand.

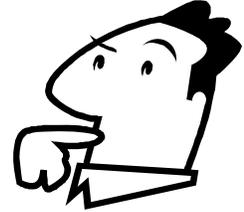
–Daughter of a Person with Alzheimer's disease



D. CHALLENGING BEHAVIORS

Persons with dementia may present challenging or difficult behaviors for the caregiver. Causes may be the effects of Alzheimer’s disease on the brain, confusion, fatigue, pain, understimulation or boredom, or a lack of routine. Over-stimulation may also be a factor in difficult behavior.

The caregiver’s approach and reaction to the behavior can either aggravate or defuse a challenging encounter.



Types of behaviors

- Combativeness and aggression.
- Wandering and rummaging.
- Physical restlessness (pacing).
- Sundowning, becoming more confused/agitated in the late afternoon and evening.
- Inappropriate sexual behavior.

Tips for managing challenging behaviors

The approach used by a caregiver can significantly impact problem behaviors in a person with dementia. The caregiver can escalate a problem, or can calm the person by using the correct approach.

- Introduce yourself at each encounter.
- Use touch as appropriate.
- Try to determine the cause of the behavior (boredom, pain, anxiety, etc.) and then try to reduce or eliminate it. Causes may be:
 - Boredom. Try a functionally appropriate activity.
 - Pain. Try the appropriate non-pharmacological treatment first (see Section H in this chapter).
 - Anxiety. Try reassurance and diversion.
- Use a soft approach:
 - Smile, use a warm demeanor.
 - Use pleasant voice tones.
 - Go slow.
 - Talk in short, simple sentences.
 - Avoid correcting or confrontation.
 - Appeal to the emotion and let the person know you will keep him/her safe.
 - Be flexible in getting tasks accomplished.



Tips for Working with Difficult Behaviors Associated with Dementia

1. **Keep calm.** If the person is excited and you become excited, the situation will only get worse. Instead, maintain a calm voice and stature.
2. **Take the person away from the present environment or try to focus on something else (*diversion or redirection*).** Changing the subject or the environment can often be helpful. Try a different scene, such as a backyard patio, to see if the agitation decreases. Talk soothingly about something you know the person enjoys, such as their family, or involve the person in an activity he/she likes to do, such as drawing.
3. **Talk and move slowly so that the person does not feel threatened.** If the person is already feeling insecure or frightened, it will not help if someone else rushes in or speaks in a loud voice. Instead, stay relaxed and try not to upset the person further.
4. **Try soothing touch.** For some people, a gentle arm around the shoulders, holding hands, or a gentle back scratch can be reassuring and soothing. Be sure this is appropriate for your client, or it may have disastrous results.
5. **Do not try to correct the person.** Because of the brain damage, it will not help to correct a person with dementia about reality. Instead, try to "go with the flow" and let the person say whatever she/he wants to, even if you know it is not true.
6. **Respond to the emotions of the person.** Regardless of what caused the agitation, the person is upset. Try to focus on what the person is feeling or what emotions he or she is displaying, instead of the actual words being used.
7. **Always treat individuals with respect and dignity.** Never forget that the person is an adult, despite their behavior. **Don't punish them or talk to them like a child.**

Adapted from "Alzheimer's Disease: Pieces of the Puzzle" produced by Arizona Long Term Care Gerontology Center (now the Arizona Center on Aging) at the University of Arizona.

E. DEMENTIA AND SEXUALITY

Changes in sexual behavior in a person with dementia can be very upsetting for family members and the DCW. Some behaviors that might be exhibited:

- Flirtatious behavior. The person may forget marital status and begin to flirt with others, including the DCW.
- Unreasonable jealousy or paranoia.
- Exposing or fondling self inappropriately.
- Misinterpretations, making sexual advances to another person, including the DCW, because he/she believes the person is the spouse.

Try to determine if there is a cause for the behavior. If the person is fondling him/herself, the person may need to use the bathroom. If the cause cannot be corrected, gentle diversion usually works. However, DCWs who feel threatened or need advice should call their supervisors.

F. ASSISTANCE WITH ACTIVITIES OF DAILY LIVING

As dementia progresses, there will be a decline in the ability to do activities of daily living (ADLs) independently. Unfortunately, this trend cannot be reversed, but you can improve a person's quality of life by making the person feel as productive and independent as possible. The following are some guidelines to follow when providing assistance with ADLs for a person with Alzheimer's disease. As always, clients need to be offered choices and preferences. DCWs will meet less resistance if the person retains a sense of control.

- **Establish and maintain a routine.** Establishing and maintaining a routine is very important when assisting with ADLs. A routine does not rely as much on memory, especially if it has been done throughout the person's adult life. Ask the person or family for input. Try to do the various ADLs such as bathing at the same time and in the same manner each time.
- **Have the person help.** Losing the feeling of being productive can be troubling to some people. Allow the person to help with such things as washing dishes (even if you have to re-wash them later) or folding towels. A man could water plants outdoors. Other things that the person could help with are clipping coupons, sorting laundry, setting the table, etc. Ask the person or family what the person likes to do, and arrange activities where he or she can help.
- **Specialized clothing.** Shoes with Velcro fasteners, tube socks, pull-on shirts and pants all make it easier to dress and undress (and also help when trying to get to the bathroom on time). In the mid to late stages of the disease you may need to use clothing that is harder for the person to remove, if inappropriate undressing becomes a problem.

Bathing strategies

Behaviors that may occur

- Fighting/resisting the caregiver.
- Yelling/swearing/biting.
- Crying/moaning.



Why behaviors occur

- Person may be frustrated.
- Person may be experiencing discomfort and/or loss of dignity.
- The person is trying to say “NO!”

Caregivers need to re-think the bathing situation, and see these behaviors as self-protective, rather than combative or resistant.

Steps to successful bathing

Re-think the bathing experience

- Ask the family about the person’s bathing preferences prior to dementia such as shower or bath, how often and what time of day is preferred.
- Use bathing preferences and rituals that have been pre-established.
- Keep in mind the goal is to create a comfortable and pleasurable experience for the person with dementia.

Approach Strategies

- Always use the soft approach and try a variety of techniques.
- Don’t ask the person if she wants a bath or shower if you are not willing to accept no for an answer!
- If the person refuses you, leave and come back again in a few minutes.
- Change the term bath or shower to “getting freshened up.”
- Focus on a reason for the person to get clean (for example, going to an appointment or going to see a relative).

Be Organized!

- Have the room ready to go! Bathing area should be warm, well lit, with all the supplies ready.
- Position the person comfortably.
- Have enough bath blankets/towels to keep the person covered at all times.

Helpful Tips

- Remember to keep the person covered at all times.
- Lift the blanket or towel as you bathe the person and then replace (some of the resistance may come from being uncovered).

- Begin bathing the least disturbing area first, the feet, and move up from there, saving the genital area and face until last.
- Utilize distraction techniques. Play music or sing, if the person has a preference. Use the person's life story to stimulate a conversation.
- Give the person something to hold or to eat or drink (something sweet?).

Shampooing

Save washing the hair until last, *or* separate it from the bath completely. Try shampooing hair in a chair using washcloths and rinseless soap. If it remains a problem, consider making arrangements for a beauty shop/barber instead of trying to do it at home. This is especially good for people who enjoyed regular beauty shop/barber appointments when they were younger. Make it a special outing with a stop at a favorite diner.

G. PLANNING ACTIVITIES

Activities provide opportunities for social interaction, encourage creative self-expression, increase feelings of achievement and enjoyment, and decrease agitation, boredom, and isolation.

Gear activities to the *functional abilities* of the person. If the activity is too difficult, the person may become overwhelmed. If it is too easy, the person may become bored. Both can lead to problem behaviors.

Possible Activities

- Give the person something meaningful to do, like folding towels.
- Look at picture books and magazines and make a card or cut out pictures.
- Play music of the person's preference or try singing old favorites.
- Watch TV programs only if the person shows interest (for example, nature programs, musicals and Lawrence Welk, old comedies like I Love Lucy).
- Offer frequent snacks and fluids.
- Use lotion to give a 1 to 2 minute hand or foot massage. Consider adding an essential oil for aromatherapy.
- Read a poem, prayer, or scripture verse.
- Exercise
 - Accompany the restless person on a walk, just to look at flowers on the patio.
 - Designate a safe area where the person can walk.
 - Take a person who uses a wheelchair for a walk.



H. PAIN MANAGEMENT TECHNIQUES

A person with dementia may not be able to tell a caregiver that he/she is in pain. It is very important that the caregiver be alert to changes in the person's behavior that might signal the person is in pain. Try to provide one of the non-pharmacological approaches first.

Non-pharmacological

Non-pharmacological means not using medication. Caregivers can do these measures without a physician's order:

- Try a change of position or a walk.
- Offer to take the person to the toilet.
- Offer snacks/fluids.
- Give a lotion massage.
- Reduce stimulation in environment and allow for quiet time.
- Listen to music.
- Adjust body temperature. The person may be too hot or too cold, you may need to adjust clothing or thermostat.



Pharmacological

Pharmacological remedies involve the use of medications. If the non-pharmacological strategies do not work, report this to the family and your supervisor. The person's physician may prescribe a medication that will relieve pain. Helpful points to remember:

- A non-aspirin pain reliever such as Tylenol usually works well.
- Narcotics are usually not tolerated well in elderly individuals.
- Anxiety in an elderly person with dementia is not always well-managed by anti-anxiety agents.
- Pills don't always work and some may have serious side effects.

Adapted from: Palliative Care for Advanced Dementia, Train the Trainer Program, Alzheimer's Association, Desert Southwest Chapter.

I. SAFETY CONCERNS

Safety is the primary responsibility when caring for a person with dementia. Make sure that basic fall-prevention measures are used (for example, clear pathways, no scatter rugs, etc.). Refer to the Section C, Falls, in Chapter 9 of the *Principles of Caregiving: Fundamentals* course manual.

Wandering

It is estimated that 50% to 60% of people with Alzheimer’s disease will wander. This means that the person may try to leave the building alone. The danger is that the person may get lost. A person with dementia may not be able to ask for help or even remember his/her address. The Alzheimer’s Association website contains more information on wandering. Go to www.alz.org/living_with_alzheimers_wandering_behaviors.asp

Safe Return® program

The MedicAlert + Alzheimer’s Association Safe Return® program is a nationwide emergency response system offered through local Alzheimer’s Association chapters. A person at risk for wandering can be enrolled and receive a bracelet with information engraved. Anyone finding a person who is lost can call the phone number on the bracelet to get help. For more information, visit www.alz.org/safereturn.