

Caring for the Person with Alzheimer's Disease

(3 credits)

After completing this section, you should be able to:

1. Define dementia and list related terms
2. Describe the progression Alzheimer's disease may follow
3. Identify helpful attitudes when caring for people with Alzheimer's or any dementia
4. List strategies for better communication with people who have Alzheimer's
5. List difficult behaviors in people with Alzheimer's and describe ways to manage each

1. Define dementia and list related terms

Dementia is a serious loss of mental abilities such as thinking, remembering, reasoning, and communicating. As dementia advances, these losses make it difficult for a person to perform activities of daily living (ADLs). Examples of ADLs include eating, bathing, dressing, communicating and toileting. Dementia is *not* a normal part of aging.

The following are a few of the common causes of dementia:

- Alzheimer's disease
- Multi-infarct or vascular dementia (a series of strokes causing damage to the brain)
- Parkinson's disease
- Huntington's disease

Here are some terms related to dementia; you should be able to recognize and understand them:

Progressive: Once they begin, progressive diseases continue to advance and tend to spread to other parts of the body and affect many body functions.

Degenerative: Degenerative diseases get continually worse, eventually causing a breakdown of the body system(s). Degenerative diseases can cause death. They cause lower and lower levels of mental and physical health.

Onset: The onset of a disease is the time when the signs and symptoms begin to appear.

Irreversible: An irreversible disease or condition cannot be cured. Someone with irreversible dementia, such as Alzheimer's, will either die from the disease or die with the disease.

Infarct: The death of tissue resulting from a sudden loss of blood supply. This loss of blood supply is often caused by a blood clot.

2. Describe the progression Alzheimer's disease may follow

Alzheimer's disease (AD) is a progressive, degenerative, and irreversible disease. It causes tangled nerve fibers and protein deposits to form in the brain, eventually

causing dementia. People with Alzheimer's disease will never recover. They will need more care as the disease progresses.

Alzheimer's disease generally begins with forgetfulness and confusion. It progresses to complete loss of all ability to care for oneself. Each person with Alzheimer's will show different symptoms at different times. For example, one person with AD may be able to read, but not be able to use the phone. Another person may not be able to read, but is still able to do simple math. Skills a person has used constantly over a long lifetime are usually kept longer (Fig. 1-1). Thus some people with AD can cook or play a musical instrument with some help long after they have lost much of their memory.



Fig. 1-1. Even when a person loses much of her memory, she may still keep skills she has used her whole life.

Remember that each person with Alzheimer's is an individual and may show symptoms from one or two stages at once and may never show certain symptoms at all.

General Progression of Alzheimer's Disease

Stage I

- recent (short-term) memory loss
- disorientation to time
- lack of interest in doing things, including work, dressing, recreation
- inability to concentrate
- mood swings
- irritability
- petulance: peevish, ill-humored, rude behavior
- tendency to blame others
- carelessness in personal habits
- poor judgment

Stage II

- increased memory loss: may forget family members and friends
- slurred speech
- difficulty finding words, finishing thoughts, or following directions
- tendency to make statements that are illogical
- inability to read, write, or do math
- inability to care for self or perform ADLs without assistance
- incontinence
- dulled senses (for example, cannot distinguish between heat and cold)
- restlessness, wandering, and/or agitation (increase of these in the evening is called "sundowning")
- sleep problems
- lack of impulse control (for example: swears excessively or is sexually aggressive or rude)
- obsessive repetition of movements, behavior, or words
- temper tantrums
- hallucinations or delusions

Stage III

- total disorientation to time, place, and person
- apathy
- total dependence on others for care
- total incontinence
- inability to speak or communicate except for grunting, groaning, or screaming
- total immobility/confinement to bed
- inability to recognize family or self
- increased sleep disturbances
- difficulty swallowing, which produces risk of choking
- seizures
- coma
- death

3. Identify helpful attitudes when caring for people with Alzheimer's or any dementia

The following attitudes will help you provide better care for people with Alzheimer's disease or any dementia:

People with AD are individuals.

AD develops differently in different people. One care plan cannot serve all people with dementia. Take an interest in each individual. Knowing people's likes and dislikes helps you manage their behavior. Be an expert on the people for whom you care.

Do not take it personally.

Always remember that people with Alzheimer's do not have control over their words and actions. They may often be unaware of what they say or do. If a person with Alzheimer's does not recognize you, does not do what you say, ignores you, accuses you, or insults you, remember that it is the disease, not the person.

Put yourself in their shoes.

AD is a devastating mental and physical disorder that affects everyone who surrounds and cares for the one with AD. Think about what it would be like to have Alzheimer's disease. Imagine being unable to perform ADLs. Be understanding and compassionate. Assume that people with AD have insight and are aware of the changes in their abilities. Provide security and comfort. Treat clients and residents with AD with dignity and respect, as you would want to be treated.

Work with the symptoms or behaviors that you see.

People with AD show different symptoms from day to day. Focus on the symptoms and behaviors you see, rather than on the disease. Notice changes in behavior, mood, and independence and report your observations.

Work as a team.

People with AD may not distinguish between aides, nurses, administrators, etc., so be prepared to help when needed. Share insights and observations with your team. Part of AD care is noticing changes in behavior or physical and emotional health. Symptoms and behavior change from day to day. You are in a great position to notice and report these changes (Fig. 1-2).



Fig. 1-2. Observing and reporting change is one of the most important tasks you'll have.

Take care of yourself.

Acknowledge that caring for someone with dementia can be emotionally and physically demanding. Be good to yourself physically, emotionally, and spiritually (Fig. 1-3). Be aware of your body's signals to slow down or to eat better. Remember that your feelings are real and you have a right to them. Share your feelings, especially with those experiencing similar situations. Do not worry about mistakes. Use them as learning experiences.

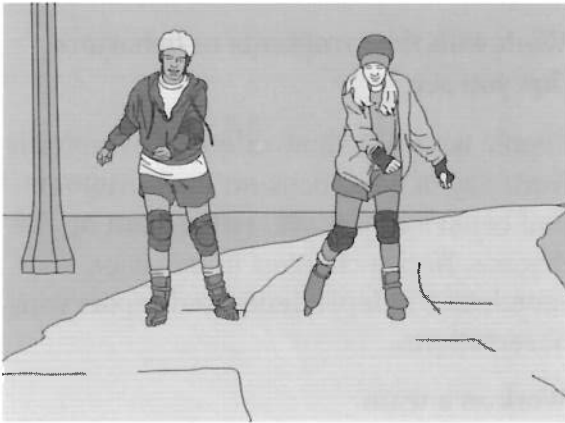


Fig. 1-3. Regular exercise is a good way to take care of yourself.

Work with family members.

Family members can be a wonderful resource. They can help you learn more about the person with AD. Family may know things you would have to learn by trial and error. Family members can also be of great comfort to dementia victims, helping you provide excellent care. Suggest environmental changes or modifications as appropriate to the person with AD.

Remember the care program goals.

In addition to the practical tasks you will perform, the care plan will also call for the following:

- Provide security and comfort.

- Maintain dignity and self-esteem.
- Promote independence.
- Provide assistance with appropriate care and interventions during each stage of the illness.

4. List strategies for better communication with people who have Alzheimer's

Some good communication tips for any situation include the following:

- Always approach from the front so you do not startle the person.
- Determine how close the person wants you to be.
- If possible, communicate in a calm place with little noise or distraction.
- Always identify yourself and use the person's name.
- Speak slowly, using a lower voice than normal. This is calming and easier to understand.

The following are good communication techniques to use with people who have dementia:

If the person is frightened or anxious, you should:

- Move and speak slowly.
- Try to see and hear yourself as they might. Always describe what you are going to do.
- Use simple language and short sentences. If performing a procedure or assisting with self-care, simplify and list steps one at a time.
- Check your nonverbal language; are you tense or hurried?

If the person forgets or shows memory loss, you should:

- Use the same words if you need to repeat an instruction or question. However, you may be using a word the

person does not understand, such as “tired.” Try other words like “nap,” “lie down,” “rest,” etc.

If the person has trouble finding words or names or substitutes sound-alike words, you should:

- Suggest what you think the word is. If this upsets the person, learn from it and try not to correct him or her. As communicating with words (written and spoken) becomes more difficult, smiling, touching, and hugging can help communicate love and concern. But remember that some people find touch frightening or unwelcome.

If the person seems not to understand basic instructions or questions, you should:

- Ask the person to repeat your statements. Use short words and sentences, allowing time to answer.
- Pay attention to the communication methods that are effective and use them.
- Watch for nonverbal communication as the ability to talk diminishes. Observe body language—eyes, hands, facial expressions.
- Use signs, pictures, labels, written messages, or gestures to communicate.

If the person repeats phrases or questions over and over, you should:

- Answer the questions the same way each time. This is part of the disease. Even though responding over and over may frustrate you, it communicates comfort and security.

If the person wants to say something but cannot, you should:

- Encourage people to point, gesture, or mime. If they are obviously upset but

cannot explain why, offer comfort with a hug, a smile, or distraction techniques. Attempting to verbalize may be more frustrating.

If the person is disoriented to time and place, you should:

- Post reminders, such as calendars, activity boards, pictures, and signs on doors. Prior to the final stage of dementia, signs and labels can sometimes help with orientation. However, reality orientation does not help in the later stages of Alzheimer’s.

If the person does not remember how to perform basic tasks, you should:

- Help by breaking each activity into simple steps. For instance, “Let’s go for a walk. Stand up. Put on your sweater. First the right arm...” Encourage people to do what they can for themselves.

If the person reminisces or lives in the past, you should:

- Encourage reminiscing if it seems to give pleasure. It is an opportunity to learn more about the person.

If the person insists on doing something that is unsafe or not allowed, you should:

- Try to limit the times you say “don’t.” Instead, redirect activities toward something constructive.

If the person hallucinates, is paranoid or accusing:

- Do not take it personally. Try to redirect behavior or ignore it. Because attention span is limited, this behavior often passes quickly.

If the person is depressed or lonely, you should:

- Take time, one-on-one, to ask how the person is feeling (Fig.1-4). Really listen.

Try to involve the person in activities.
Report depression to your supervisor.

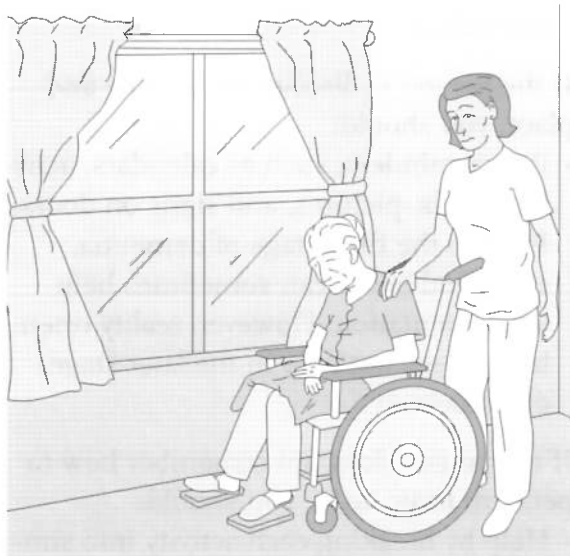


Fig. 1-4. Be understanding and respectful when caring for someone with AD.

If the person is verbally abusive or uses bad language, you should:

- Remember it is the dementia speaking and not the person. Try to ignore the language or redirect attention to something else.

If the person has lost most verbal skills, you should:

- As speaking abilities decline, use non-verbal communication. People with AD will understand touch, smiles, and laughter much longer than they will understand the spoken or written word.
- However, remember that some people do not like to be touched. Approach touching slowly. Be gentle, softly touching the hand or placing your arm around the person. A hug can express affection and caring. A smile can say you want to help.
- Even after verbal abilities are lost, signs, labels, and gestures can reach people with dementia.

- Assume people with AD can understand more than they can express. **Never talk about them as though they are not there.**

5. List difficult behaviors in people with Alzheimer's and describe ways to manage each

Below are some common difficult behaviors that you may face when working with people with AD. Remember that each person is different. Work with each person as an individual. Report behavior in detail to your supervisor.

Agitation: A person who is excited, restless, or troubled is said to be **agitated**. Situations that lead to agitation are **triggers**. Triggers may include change of routine or caregiver or new or frustrating experiences. Even watching television can cause extreme anxiety as people with AD lose their ability to distinguish fiction from reality. Try to recognize triggers and eliminate them. Once behavior like this begins, your calm response and slow, soothing tone can help minimize the behavior.

Catastrophic Reactions: When a person with AD reacts to something in an unreasonable way, it is called a **catastrophic reaction**. Many situations can cause these reactions, and they differ from person to person. As a general rule, these reactions are caused by four things:

- Fatigue
- Change of routine, environment, or caregiver
- Overstimulation, including noise, too much activity, difficult choices or tasks
- Physical pain or discomfort, including hunger or need for toileting

Again, it is important to get to know the people you care for. This allows you to avoid situations that cause these reactions and to redirect them to activities you know they enjoy. You can respond to catastrophic reactions as you would to agitation. For example, remove triggers.

Pacing and Wandering: A person who walks back and forth in the same area is **pacing**. A person who walks aimlessly around the house, facility, or neighborhood is **wandering**. Pacing and wandering can have many causes: restlessness, hunger, disorientation, the desire to use the restroom, pain, constipation, too much daytime napping, lack of exercise, or even forgetting how or where to sit down (Fig. 1-5).



Fig. 1-5. Pacing and wandering may have many causes, including hunger, the need for toileting, and a lack of exercise.

Eliminate causes when you can. For example, provide nutritious snacks, encourage an exercise routine, and maintain a toileting schedule. Nighttime wandering might be reduced by minimizing daytime napping. Let people pace and do not restrain them, but do keep an eye on them. Pacing is dangerous when it takes

people outside the safe environment. If people attempt to leave, redirect their attention to something they enjoy.

To reduce the chance of wandering outside the home or facility:

- Create a safe place for pacing. Remove clutter and create clear paths, making certain floors are not slippery. Remove throw rugs that are not secure.
- Place stop signs or “sorry we are closed” signs on doors to remind them not to exit, or have alarms on exits to indicate the door has been opened. Locks placed either very high or very low may prevent exiting. Remember to keep a key nearby in case of emergency. Never leave a person alone in a locked house or room.

In the event someone does wander away:

- Have a current photo to help identify the person.
- Make certain neighbors have a photo and a number to call if they see the person.
- Have identification cards or bracelets and clothing labels on every person with AD.

Sundowning: When a person with AD becomes restless and agitated in the late afternoon, evening or night it is called **sundowning**. Sundowning may be triggered by hunger or fatigue, a change in routine or caregiver, or any new or frustrating situation (Fig. 1-6). The best ways to reduce this restlessness are to:

- Provide adequate lighting before it starts to get dark.
- Avoid stressful situations during this time, limit activities, appointments, trips, and visits.
- Play soft music.
- Set a bedtime routine and keep it.

- Recognize when sundowning occurs and plan a calming activity just before that time.
- Eliminate caffeine from the diet.
- Give a slow back massage.
- Try to redirect the behavior or distract the person with a simple, calm activity like looking at a magazine.
- Maintain a daily exercise routine.



Fig. 1-6. Sundowning is a word that is used to describe confusion, restlessness, and agitation that happens in the late afternoon or evening.

Perseveration or Repetitive Phrasing: A person who repeats a word, phrase, question, or activity over and over is perseverating. Repeating a word or phrase is also called repetitive phrasing. Such behavior may be caused by several factors, including disorientation or confusion.

People may also repeat an action or task, such as licking lips, tapping fingers, or folding or cleaning things. Be patient with these repetitious behaviors; remember that the person is probably unaware of what he or she is doing. If questions are asked repeatedly, respond each time using the same words.

Suspicion: As people with AD begin to deal with their illness, they often become suspicious or paranoid. Do not argue with them, as this just increases defensiveness. Instead, offer calm reassurance. Be understanding.

Hallucinations or Delusions: A person who sees things that are not there is having **hallucinations**. A person who believes things that are not true is having **delusions**. Most hallucinations and delusions are harmless and can be ignored (Fig. 1-7). Reassure a person who seems agitated or worried. Do not argue with a person who is imagining things. Remember that the feelings are real to him or her. Redirect the person to other activities or thoughts. Be calm. Reassure the person that you are there to help.



Fig. 1-7. Hallucinations and delusions are real to the person with AD. Be calm and supportive.

Violent Behavior: A person who attacks, hits, or threatens someone is **violent**. Violence may be triggered by many situations, including frustration, overstimulation, or a change in routine, environment, or caregiver. If someone becomes violent, stay out of the way. Block blows but never hit back (Fig. 1-8). Step out of reach. Call for help if needed. Violent behavior usually subsides quickly. Always report this behavior.

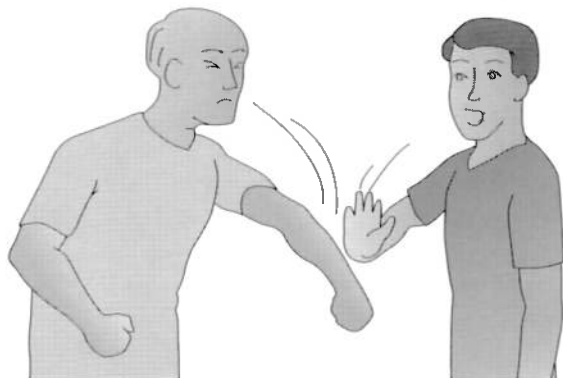


Fig. 1-8. Block blows but do not hit back.

Depression: It is understandable that people who are losing independence and the ability to manage their lives become depressed. Feelings of failure and fear can cause them to become withdrawn. Be aware of these behavior and mood changes. Report depression to your supervisor, as medications may help. Try to note the triggers or events that cause changes in mood. Always encourage and reward activities that improve moods and attempt to reduce situations that cause withdrawal. Find ways to help foster social relationships, such as group activities. Listen to them, as they will often share their feelings. Respect the right to feel sad; offer comfort and concern.

