Dementia, Level 1

Dementia Capable Caregiving

Home and Community Living Administration

DSHS
WASHINGTON STATE
Department of Social
and Health Services

This curriculum was developed from feedback and input gathered from stakeholders across the state. Primary stakeholder groups included facility owners/providers, managers, supervisors, caregivers, trainers, families, clients/residents, DSHS staff, long term care ombudsman and advocacy group representatives.

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Lesson 1
Introduction to Dementia

Objective:

The caregiver will review common signs, symptoms and types of dementia and identify the difference between dementia and conditions that might look like dementia.

Overview

It is important as a caregiver to understand how dementia affects a person's body and mind. Learning about dementia allows you to create a deeper level of compassion for the individual(s) you care for. This basic understanding is the foundation on which you will build the skills and confidence you need to provide the best care for people with dementia.

It is essential to recognize the difference between dementia and other conditions that might look like dementia. Conditions that resemble dementia might require immediate intervention, while others might justify changes to the care you provide or changes to the environment.

It is critical to recognize that people with dementia are people with feelings and that dementia is caused by diseases that affect the brain. Recognizing this can help you to understand that the individual you are caring for is not being difficult, mean, angry, forgetful, etc. on purpose and that the disease is not their choice. It is you, the caregiver, who must be empathetic and adapt to provide a safe, compassionate environment and create the highest quality of life for the individual with dementia.

Step into Dementia

It might be difficult to understand what someone with dementia is going through. Try to imagine how you would feel or act if you or someone you close with were in the same situation. Think about someone very close to you (parent, grandparent, best friend…). If this person had dementia, how would you want them to be cared for?

Media

Video: ABC NIGHTLINE Tells America About the Virtual Dementia Tour® (6:50) https://www.youtube.com/watch?v=QEmBmokHU3Q

Have you ever heard of a Virtual Dementia Tour? If so, have you experienced one?

After watching this video, does it change how you would want someone very close to you cared for?

Some Facts

According to the Alzheimer's Association (2023):

Approximately 6.7 million Americans aged 65 and older are living with dementia, and this number is projected to increase as the population ages.

In Washington, around 130,000 people are living with dementia, with estimates suggesting this number could rise to over 200,000 by 2030 due to the aging population.

Dementia not only affects individuals, but also significantly impacts caregivers, with many caregivers reporting high levels of stress and challenges providing care.

These numbers highlight the growing need for awareness, support, and resources for both the person living with dementia and their caregivers.

For the most current information, refer to the Alzheimer's Association and the Washington State Department of Health websites.

Definition

What is NOT dementia?

Before learning what IS dementia, you should learn about what is NOT dementia.

Forgetfulness

Do you ever forget what you are doing? For example, do you go into a room and forget why you went there? Do you forget where you put your keys? Most people experience some forgetfulness. We forget a person's name, an appointment or where we left our cell phone. We all forget things. The difference is we remember it again at some point in the future. Forgetfulness is more common when we are physically ill, tired, stressed, distracted or depressed. Forgetfulness is NOT dementia.

Forgetfulness might look like: Where did I put my car keys?

Dementia might look like: What are these shiny things for?

Conditions That May Resemble Dementia

While most changes in the brain that cause dementia are permanent and worsen over time, there are some thinking and memory problems caused by other conditions that resemble dementia. These conditions may improve when the condition is treated or addressed.

Some of these conditions are:

- Depression
- Delirium
- Urinary Tract Infection (UTI)
- Mild Cognitive Impairment (MCI) and age-related cognitive decline
- Medication side effects
- Excessive use of alcohol
- Thyroid problems
- Vitamin deficiencies
- Other infections (meningitis, syphilis)

If you see any of the symptoms associated with these conditions, get the person to a medical professional as quickly as possible. An accurate diagnosis needs to be made and appropriate treatment initiated.

Depression

Depression is a serious, but treatable, mood disorder that involves the body, mood, and thoughts. It affects the way the person eats and sleeps, feels about self, and the way the person thinks about things.

Depression is not the same as a passing sad mood. It involves serious symptoms that last for at least several weeks and make it difficult to function normally.

It is important to know if a person with dementia is also depressed because untreated depression may make the effects of dementia worse and may be life threatening.

Symptoms of depression

- Loss of interest and pleasure in activities
- Difficulty sleeping or sleeping too much
- Lack of energy
- Loss of appetite and weight
- Being unusually emotional, crying, angry, or agitated
- Expressing feelings of sadness or worthlessness
- Increased confusion
- Aches and pains that appear to have no physical cause
- Expressing thoughts of death or suicide

For more information on Mental Health topics, refer to the Mental Health, Level 1 course.

You have been caring for Mr. Miley for nearly six months. For the first several months, he was generally in a good mood and you would often find him gardening and visiting with his friends and family. Over the last two months, you notice he is sleeping more than usual and has gradually lost interest in gardening. He spends most of his time in his room. He is refusing visits with friends and family. You notice that over the last two weeks he is becoming increasingly angry and agitated toward others.

What are the symptoms that might look like depression.

Notes

Delirium

Delirium can look like dementia and is sometimes mistaken for dementia. Delirium is a medical condition characterized by severe confusion that starts quickly (also called sudden onset). It varies in severity and may be worse at night or when waking up.
It is most likely caused by physical illnesses, trauma or a reaction from a medication. Delirium can be reversed with appropriate treatment. The type of treatment the person will receive depends on what is causing the delirium. If you suspect that a person may be experiencing delirium, seek **immediate** medical attention. Death can occur if the delirium goes untreated.

Learn More About Delirium:

Symptoms of delirium

- Acute and sudden changes in memory
- Reduced awareness of the environment or becoming very alert
- Agitation because of confusion
- Difficulties with attention and focus
- May display a wide range of emotions, including anxiety, sadness, or extreme happiness
- Changes in the person's sleep-wake pattern
- Visual hallucinations
- Delusions (false thoughts or beliefs – more information in lesson 2)

Causes of delirium

- Dehydration from diuretics, low fluid intake, or hot weather
- An infection, inflammation, or virus, such as a urinary tract infection or pneumonia
- Fever or low body temperature
- Medications, including getting too much medication, taking medications that react with other medicines, or medication side- effects
- Withdrawal from stopping drinking alcohol or using drugs
- A reaction to mixing over-the-counter cold, sleeping, or pain remedies with prescribed medications
- Multiple, severe, and unstable medical problems
- Physical injury, such as fractures
- Diseases or illnesses such as liver or kidney disease, thyroid-disorders, or poorly controlled diabetes

Ms. Zellmer enjoys participating in activities and taking walks. She is usually in a good mood with occasional times of unhappiness. During this morning's activity, she suddenly becomes agitated and confused about where she is and what she is doing. Frantically, she swings her arms in front of her as if she were hitting at something. You know she just started a new medication.

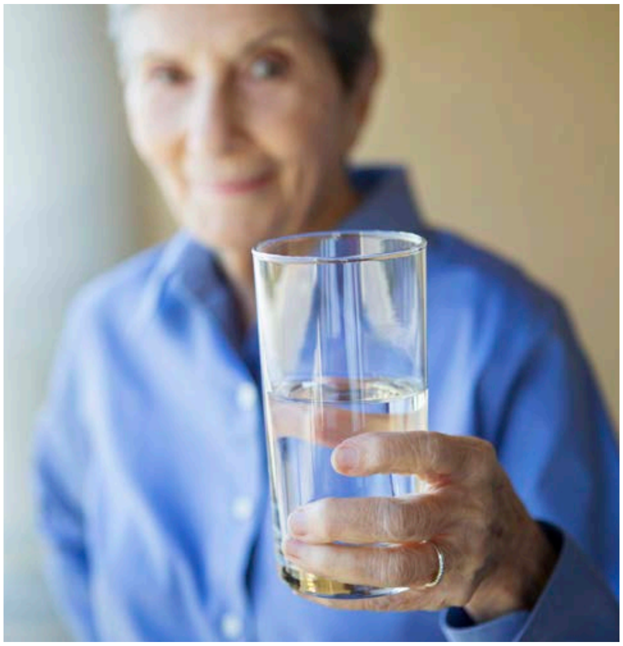
Highlight the symptoms that might look like delirium.

Notes

Urinary Tract Infection, a common cause of delirium

Urinary Tract Infection (UTI) is an infection caused by bacteria in part of the urinary tract. Sometimes a UTI can also lead to a bladder or kidney infection. UTIs are the second most common infection type. UTIs are easy to cure. If left untreated, the infection can become serious and spread in the body. UTI is the leading cause of sepsis, a potentially life-threatening infection of the bloodstream. For people with dementia, it will often make the symptoms temporarily worse.

Dehydration is a common cause of UTIs, so it is important to monitor fluid intake, prompt bathroom visits several times each day and support good hygiene.



Symptoms of UTI?

- Sudden change in behavior, confusion or worsening of confusion
- Fever or hypothermia
- Poor appetite
- Lethargy
- Change in mental status
- Urinary incontinence
- Confusion
- Burning during urinating
- Urge to urinate frequently
- Pain
- Nausea and vomiting

Symptoms change with age. Because of a change in the immune system, the most prominent symptoms you might see are increased confusion, agitation, withdrawal, and behaviors such as restlessness, hallucinations and delusions.

What are the causes of UTI?

- Bacteria or infection and inflammation of the bladder or urinary tract

Claudia Combs, a 91-year-old woman with dementia complains of dizziness and you notice she has less energy than usual. One day you notice she takes an unusually long nap. When she wakes, she is more confused than usual and unable to dress herself.

Highlight the symptoms that might look like UTI.

Notes

To minimize the chances of a UTI, and to help when a client has a UTI, encourage 6-8 glasses of water per day, prompt bathroom visits several times each day and maintain good perineal hygiene.

Mild Cognitive Impairment

Mild Cognitive Impairment (MCI) causes a slight but noticeable and measurable decline in cognitive abilities. This includes memory and thinking skills. The changes are serious enough to be noticed by the individuals experiencing them or to other people, but not severe enough to interfere with daily life or independent function. Some people will get better, but there is an increased risk of developing dementia.

There are two types of MCI, and the difference is the type of thinking skill that is affected.

Symptoms of MCI

- Amnestic MCI affects memory. A person may start to forget important information that would previously have recalled easily, such as appointments, conversations or recent events.
- Non-amnestic MCI affects thinking skills other than memory. Thinking skills may be affected such as the ability to make sound decisions, judge the time or sequence of steps needed to complete a complex task, or visual perception.

What IS Dementia?

Dementia is a general term used to describe a decline in cognitive function severe enough to interfere with daily life.

Dementia is not a disease itself. Dementia is caused by many diseases. Alzheimer's disease is the most common type of dementia, but there are several others, including vascular dementia, Lewy body dementia, and frontotemporal dementia.

Dementia is Not a Normal Part of Aging and it is Not a Disease Itself.

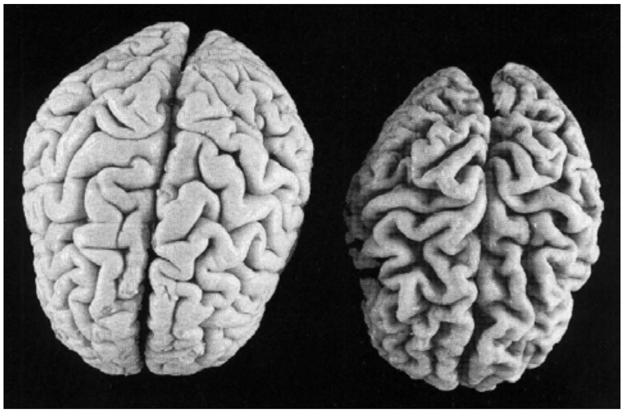
The diseases, injuries, and illnesses that cause dementia damage the brain and destroy brain cells. Because cells are dead or dying, the overall size of the brain shrinks and holes develop in certain parts of it. In the picture of the two brains, notice that the brain on the left- is a typical, healthy brain. The brain on the right is a brain affected by dementia.

Symptoms

At least two core mental functions must be significantly impaired to be considered dementia, such as:

- Memory
- Communication and language
- Ability to focus and pay attention
- Reasoning and judgment
- Visual perception

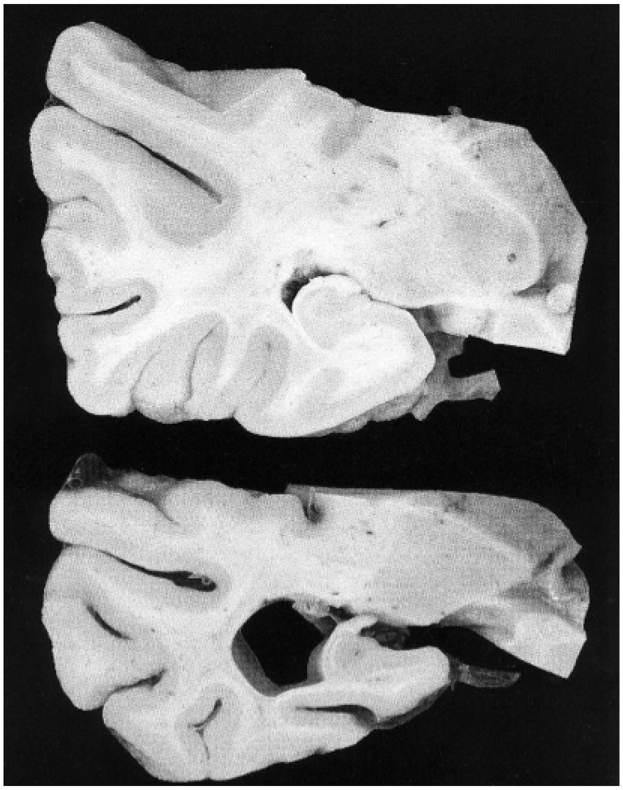
These symptoms are common across all types of dementia. There are unique symptoms associated with specific types of dementia identified later in this lesson.



Though different diseases cause damage to different parts of the brain, some damage is universal to all types of dementia. For example, there is memory loss with all types of dementia.

A person with dementia may:

- Forget things
- Have trouble understanding words
- Forget how to do things they have done for years
- Become disoriented
- Have ideas or perceptions that are not real
- Become frustrated easily
- Ask the same questions or tell the same stories over and over
- Have personality changes



A person with dementia may not be aware of his or her changed behavior and is not doing things intentionally to be difficult. If you find that you are taking it personally or having a negative emotional reaction, stop and take a deep breath. Remember, the person's brain is no longer working the way it used to.

Never argue, shout, lecture, make fun of, or force a person with dementia to do something they do not want to do. Focus on the strengths of each person and be compassionate toward them. Your attitude will influence the outcome of any interaction.

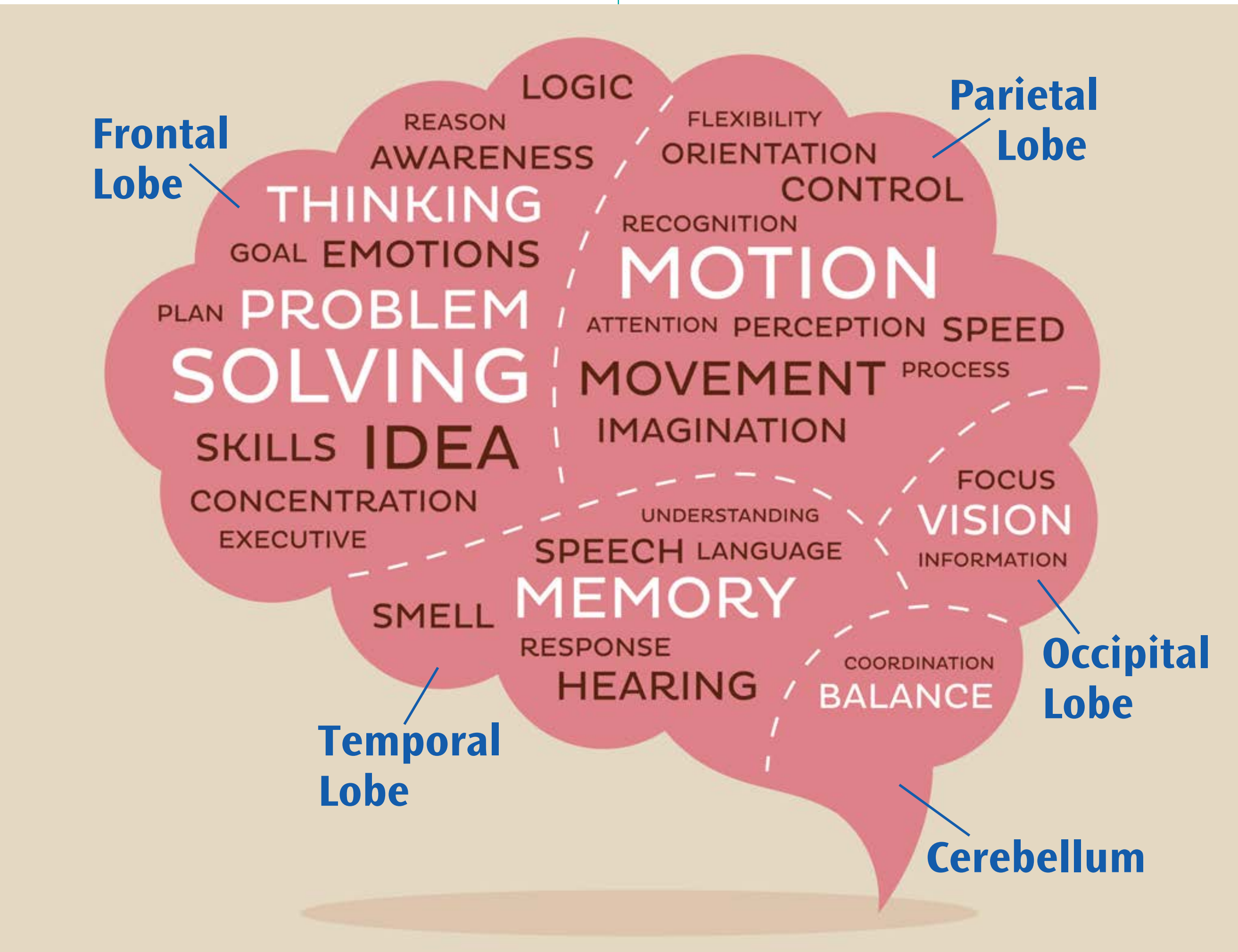
Causes

Dementia is caused by damage to brain cells. Thinking, behavior and feelings may be affected when brain cells cannot communicate with each other. Research is ongoing and there are many different theories as to why some people get dementia and others do not.

The brain has many distinct regions, each of which is responsible for different functions (for example, memory, judgment and movement). When cells in a region are damaged, that region might not carry out its functions normally.

Media

Watch Video: Understand Alzheimer's Disease in 3 minutes (3:14) https://youtu.be/Eq_Er-tqPsA



Parts of the Brain

- **Frontal Lobe:** Movement, thinking initiation, reasoning and judgement, behavior (emotions), memory, speaking
- **Parietal Lobe:** Perception, making sense of the world, knowing right from left, sensation, reading, arithmetic, spelling, understanding special relationships
- **Occipital Lobe:** Vision, color blindness
- **Cerebellum:** Balance, coordination, fine muscle control
- **Temporal Lobe:** Memory, understanding language, behavior, memory, hearing

Diagnosis

Your role is to provide care. Your role is not to diagnose. Diagnosis of any type of dementia must be made by a physician, nurse practitioner, or physician's assistant using a history, laboratory tests, brain imaging and often neuropsychological tests.

Types of Dementia

Dementia is caused by about 60 different diseases. Each has different symptoms. Remember that at least two core mental functions must be significantly impaired to be considered dementia.

Alzheimer's is the most common cause of dementia.

The second most common cause of dementia is Vascular Dementia, which is caused by strokes or other vascular problems.

Dementia with Lewy Bodies is caused by a buildup of protein deposits in the brain and might present itself through visual hallucinations and movements similar to Parkinson's.

Frontotemporal Dementia occurs between ages 45-65 and may present as changes in personality and behaviors with difficulty with language and judgement.

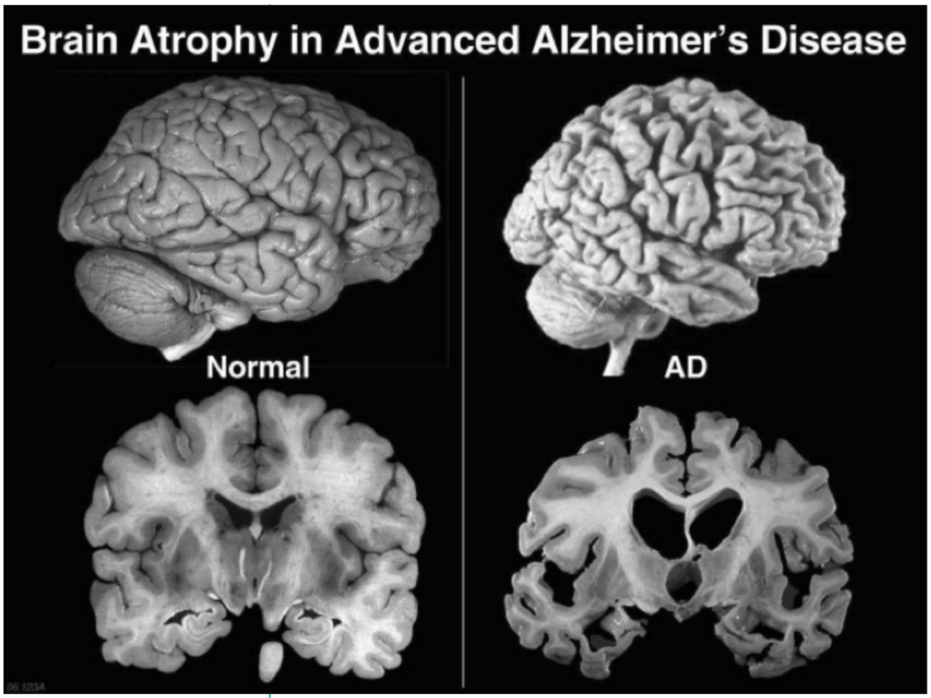
Find more information on these types of dementia on pages 10.

The most important points to remember are:

- Memorizing these types of dementia is less important than how you care for a person.
- Think about how you might approach each individual with kindness and compassion while considering the behaviors that might be associated with the disease.
- Dementia is caused by damage to the brain cells.
- There is no cure for any type of dementia.
- Dementia is not a normal part of aging.
- Most of all, be present, be flexible, be simple (but not simplistic).

Alzheimer's Disease

Alzheimer's disease is a progressive, degenerative brain disease. Lesions clog and prevent communication between brain cells and destroy the brain from the inside. Onset is gradual and irreversible, ending in death. Notice in Image 4 that the brain on the left is a "normal" brain weighing around 3 pounds. The brain on the right has holes and weighs around 1.5 pounds.



Might look like:

- Difficulty remembering things
- Difficulty finding familiar places
- Short attention span
- Poor problem-solving
- Difficulty finding the right words
- Wandering behavior
- Repeating questions or stories
- Collecting behavior (might collect dishes, napkins, briefs, etc.)
- Eating often or forgetting to eat
- Shuffle/unsteady walking
- Confusion
- Forgetting names of people or places
- Personality changes
- Mood swings
- Trouble learning new information
- Sun downing (Sun downing is when confusion and agitation worsen in the late afternoon and evenings, or as the sun goes down.)
- Combativeness

Research continues and there is always hope to find more information and insight on Alzheimer's disease and possible cures.

Vascular Dementia

Vascular Dementia is the second most common cause of dementia. It is caused by brain damage from cerebrovascular or cardiovascular problems (strokes) or other problems that impact vascular function such as long-standing diabetes, irregular heartbeat, or unmanaged high blood pressure.

Might look like:

- Symptoms like Alzheimer's Disease
- Abrupt onset, particularly with coordination and the ability to walk.
- Patchy intellectual loss
- Evidence of cerebrovascular disease, hypertension, or diabetes
- Lesions frequently visible on brain imaging
- Personality and emotions affected late in the disease
- Can occur along with Alzheimer's Disease
- Visual field loss

Dementia with Lewy Bodies

Caused by the buildup of tiny protein deposits in the brain. The presence of these deposits, or Lewy Bodies, disrupts the brain's normal functioning and interrupts the action of important chemical messengers.

Might look like:

- Abilities changing daily or hourly
- Visual hallucinations
- Shuffling and difficulties with balance
- Very slow movements
- Muscle stiffness
- Loss of facial expression ("flat affect")
- Fainting and/or falls
- Nightmares
- Problems sleeping
- Spatial disorientation
- Typically does not respond well to antipsychotic meds

Frontotemporal Dementia

Linked to degeneration of nerve cells in the frontal and temporal brain lobes and many have a family history of the disease. Frontotemporal Dementia may also be called Pick's disease.

Might look like:

- Usually occurs ages 45 – 65
- Changes in personality and behavior
- Difficulty with language – speaking, writing and comprehension.
- Judgment and social behavior problems such as stealing, neglecting responsibilities, increased, compulsive behavior
- Eventual motor skill problems and memory loss

Mixed Dementia

When more than one type of dementia occurs at the same time. Most often, Alzheimer's and vascular dementia or dementia with Lewy Bodies.

Other Disorders Linked to Dementia

- **Wernicke-Korsakoff Syndrome:** is a chronic memory disorder caused by severe deficiency of thiamine (vitamin B-1). The most common cause is long-term alcohol misuse. Memory problems may be strikingly severe while other thinking and social skills seem relatively unaffected.
- **HIV-associated Dementia:** is due to infection of the brain with HIV virus; symptoms include impaired memory, apathy, social withdrawal, and concentration problems.
- **Huntington's Disease:** is a heredity disorder caused by a faulty gene and children of a person with the disorder have a 50% chance of getting the disease; symptoms begin in 30 to 40-year-old people with personality changes such as anxiety, depression and progress to show psychotic behavior severe dementia and chorea. Chorea is involuntary jerky, arrhythmic movements of the body.
- **Dementia Pugilistica:** is also termed Boxer's syndrome, is due to traumatic injury (often repeatedly) to the brain; symptoms commonly are dementia and parkinsonism (tremors, gait abnormalities) and other changes depending on where brain injury has happened.
- **Corticobasal Degeneration:** is a progressive nerve cell loss in multiple areas of the brain; symptoms begin at about age 60 on one side of the body and include poor coordination and rigidity with associated visual-spatial problems that can progress to memory loss, hesitant speech and difficulty swallowing (dysphagia).
- **Creutzfeldt-Jakob Disease:** is the most common human form of a group of rare, fatal brain disorders affecting people and certain other mammals. A variant of this disease is called mad cow disease and occurs in cattle, and has been transmitted to people under certain circumstances. Rapidly fatal disorder that impairs memory and coordination and causes behavior changes.
- **Secondary Dementias:** These dementias occur in people with other disorders of movement such as Parkinson's Disease or Multiple Sclerosis. These dementias may share symptoms with any of the above mentioned dementias but researchers are unsure if this is due to disease overlap or other causes.

Lesson Summary

- Learning about dementia allows you to create a deeper level of compassion for the individual(s) you care for, build skills and confidence to provide the best care.
- Adapt to provide a safe, compassionate environment and create the highest quality of life for the individual with dementia.
- Some conditions may resemble dementia. Stay alert to conditions that may be treatable.

Notes

Checkpoint

Read the scenarios that follow. Based on the information given could it be dementia? Or could these symptoms be related to a condition that is NOT dementia? Place a checkmark in the most appropriate box.

Scenario	Dementia	NOT Dementia
Name: Babette Capuano | Age: 67 **Symptoms:** Taking longer to complete tasks than usual, occasionally forgetting steps in a sequence – today she put her shoes on before her socks and then realized what she did and then took her shoes off to put her socks on before her shoes.		
Name: Bart Uhrich | Age: 82 **Symptoms:** Difficulty understanding words and frequently stumbles on his words when speaking, frequently unable to recall recent events.		
Name: Cristi Struck | Age: 90 **Symptoms**: Very alert, sudden confusion and sudden displays of a range of emotions that are not usual for her.		
Name: Geraldo Bruce | Age: 78 **Symptoms:** Low energy, loss of appetite, feelings of sadness, sleeping more than usual.		
Name: Zachary Yard | Age: 54 **Symptoms:** Gets lost when walking to his room, repeats questions when getting ready for the day, usually forgets your name but seems to recognize your face, argumentative toward you.		

Notes

Lesson 2
Hallucinations and Delusions

Objective:

The caregiver will identify common hallucinations and delusions a person with dementia may exhibit, and identify physical, emotional, and environmental causes of hallucinations and delusions.

Overview

People with dementia experience hallucinations and/or delusions frequently. They may hear or see things that we do not. Delusions and hallucinations may be a way for a person with dementia to make sense of their world. They may experience false beliefs based on misinterpretation of events. Attempting to correct their interpretation of these experiences may cause emotional harm as well as physical or verbal outbursts or social withdrawal. It is important not to ignore or fear the hallucinations or delusions.

By learning the cause(s) of these experiences, you can respond in a way that supports the person as an individual and keeps them safe without adding to behavior challenges caregiving. Remember - you cannot change how a person thinks or feels but you can anticipate these experiences based on the person's past and creatively respond.

The key distinguishing factor between hallucinations and delusions is that hallucinations usually involve the senses (hearing, tasting, smelling or feeling things that are not there), while delusions are false thoughts and beliefs.

There should be no assumption that the person is having delusions. Do not overlook or dismiss that the claim could be real.

Baseline

A baseline is a term meaning the person is functioning at their typical level of functioning. Identifying what a person's baseline looks like can help you to recognize when a behavior is not usual for that individual.

If behaviors are unusual, different, or altered pay attention to possible reasons. Before reporting to the doctor, check with other staff and family members and see if the behaviors are common and should require medical attention. Rule out physical causes or medical issues such as urinary tract infection (UTI), physical problems, eyesight or hearing problems or medication side effects.

Keep in mind any cultural considerations when interpreting the person's behavior. For example, a person may have a belief and practice of talking to "ancestor spirits." It is your responsibility to be respectful of these beliefs and not judge.

Hallucinations

A hallucination is a false perception of objects or events involving the senses that can only be verified by the person experiencing them. Some people with dementia may experience hallucinations. They may see the face of an old friend in an object or see something crawling on them. A person may have conversations with people that are not there. Hallucinations seem very real to the person with dementia and can cause them extreme anxiety or even panic. Hallucinations may be from changes in the brain resulting from dementia.

The important thing to remember is not to argue with people. Avoid responding with "No, you do not see that. It is not really happening.", "Your kids are grown up" or "I do not see what you are talking about – that isn't real."

This is called reality orientation and it may contribute to mood and self-esteem problems. Insisting on orienting someone living with dementia who is having hallucination may cause undue stress or worry.

Visual Hallucinations

Visual hallucinations are when a person sees a person or object that is not there. These are the most common type of hallucination in dementia. People with Lewy body dementia are more likely to have persistent visual hallucinations.

Visual hallucinations can start when a person misinterprets what they are seeing. For example, a person may think they see faces or objects in swirling patterns on fabrics or in the shadows in a room. The person may also see people or objects that are not there - sometimes involving complicated scenes or unusual situations.

Many people with dementia who experience visual hallucinations only experience them occasionally. Sometimes they only last a few seconds. However, sometimes they are more persistent and troublesome.

Causes

Possible causes of visual hallucinations in a person with dementia include:

- Physical illness such as infections or physical problems like dehydration or delirium
- Side-effects of some types of medication
- Extreme stress
- Long standing mental disorders
- Poor eyesight
- Poor lighting or shadows
- Changes that are occurring in the brain as the dementia progresses

Example: John sees his wife's face in the mirror when she is not around.

Auditory Hallucinations

Auditory hallucinations occur when a person hears voices or noises that do not exist.

There are several signs you may see that a person with dementia is experiencing an auditory hallucination. They may:

- Talk to themselves and pause, as though waiting for someone else to respond before continuing.
- Shout at people who are not there (although many people with dementia may do this and may not be having an auditory hallucination).

A person with dementia who is experiencing hallucinations may react in different ways. The person may:

- Become suspicious
- Realize that their imagination is playing tricks and pay no attention to the hallucination
- Find it difficult to decide whether the hallucination is real
- Become convinced that what he or she is hearing or seeing is real
- Get frightened

Causes

Possible causes of auditory hallucinations are identical to those for visual hallucinations and include hearing loss or a hearing aid not working correctly. It is important to rule out physical causes and have the persons hearing and hearing aid (if they have one) checked.

Example: Ruth claims that she speaks with her dead husband and she hears him speak back.

Be careful not to discount cultural differences that may look like hallucinations.

Delusions

A delusion is a fixed false idea, sometimes based on a misinterpretation of a situation. Delusions are common with dementia and ingrained into the dementia itself. The person living with dementia is trying to make sense of a chaotic world. Most delusions, then, are just the best understanding of any given situation and they happen almost seamlessly. A person with dementia who is having delusions may sometimes become overly suspicious and develop distorted ideas about what is happening.

Many delusions in people with dementia are rooted in the belief that the person is somehow in danger or other people want to harm them. No evidence to the contrary will convince them it is not true. Likewise, many delusions arise from the person with dementia trying to make sense of what is going on.

A person with dementia may believe his or her:

- Partner is being unfaithful
- Close relative has been replaced by an imposter who closely resembles them
- Food is being poisoned
- Heater is releasing poisonous gases
- Their caregiver is trying to harm them
- Staff is stealing their things

Example: Rose is convinced that her caregiver is stealing her toothpaste and underwear.

Other causes of delusion-like behavior

There should be no assumption that the person is having delusions. Do not overlook or dismiss that the claim could be real. Sometimes a person with dementia cannot easily communicate and someone might be stealing from them, doing something to them, or coming into their room when they should not be.

There are times when things that appear to be delusions have other explanations.

- Is there another explanation for what the person may be experiencing?
- Is there an alteration of the environment that would make it better?

The problems with memory that occur with dementia may contribute to suspiciousness, paranoia, and false ideas.

People with dementia who are unaware that their memory is poor will often misinterpret what is happening in the present and create a situation where someone or something else is at fault. This is understandable when they have no memory of recent events or previous explanations are forgotten and current conversations do not make sense.

For example, people with dementia may:

- Believe someone has taken their belongings - which they misplaced, never had, or had in the past
- Create a false idea to make sense of the present reality - For example, they say they lost their leg in WWII to explain a leg that was recently amputated
- Say that family has abandoned them - because they don’t recall recent family visits
- Believe that what is happening on a TV show is real
- Want to go home – believing that their spouse, child or friend is picking them up
- Believe that a caregiver or other individual is their family member or past friend
- See small children or animals (common with Lewy body dementia)

For more information on how to respond to hallucinations and delusions, see Module 4: Creative approaches to challenging behaviors.

Lesson Summary

- People with dementia experience hallucinations and/or delusions frequently.
- Delusions and hallucinations are a common way for a person with dementia to make sense of their world.
- By learning the cause(s) of these experiences, you can respond in a way that supports the person as an individual and keeps them safe.
- Hallucinations usually involve the senses (hearing, tasting, smelling or feeling things that are not there).
- Delusions are false thoughts and beliefs.
- Baseline is a term meaning the person is functioning at their typical level of functioning.
- There are times when things that appear to be delusions have other explanations.
- Avoid making assumptions about experiences being real or not.

Checkpoint

Read the scenarios below. Put a checkmark in the box with the best answer - if it is a visual hallucination, auditory hallucination or a delusion. Discuss what could be happening.

Name: Gwen Mooring | Age: 87 | Diagnosis: Dementia, Alzheimer's After breakfast, you see Ms. Mooring sitting on the couch in front of the radio. The radio is off but she is laughing and nodding her head in the direction of the radio. **What could be happening?**	**Choose one:** ☐ Visual Hallucination ☐ Auditory Hallucination ☐ Delusion
Name: Evan Copeland | Age: 87 | Diagnosis: Dementia, Vascular Mr. Copeland's daughter comes to visit him every Wednesday. Today she arrived late because she got stuck in traffic. When she went to greet him with "hi dad", he yells at her – you are not my daughter! **What could be happening?**	**Choose one:** ☐ Visual Hallucination ☐ Auditory Hallucination ☐ Delusion
Name: Devin Stickler | Age: 83 | Diagnosis: Dementia with Lewy Body You notice Mr. Stickler shuffling down the hallway towards the front door. He looks upset. You approach him and ask if he needs anything. He said he saw a cat in his room and he is chasing the cat outside. **What could be happening?**	**Choose one:** ☐ Visual Hallucination ☐ Auditory Hallucination ☐ Delusion

Lesson 3
Setting the Tone

Objective:

The caregiver will distinguish between positive and negative interactions and ways to enhance quality of life for the individual.

Overview

How you provide care is very important to the individuals you care for. Your gentle approach, compassion, and understanding of the individual's current abilities as well as your habits and experiences all play a huge part in ensuring the person has a quality life.

You can set a tone in your working environment through positive interactions. A positive tone creates an environment that makes it safe and encourages everyone to play an essential role in the care of the person with dementia. Ultimately working relationships between you, family members, and other staff assures the best quality care for a person with dementia. By setting a positive tone for success, you ensure that the individual enjoys contributing to the environment and experiencing positive moments. Caregiving for people who have dementia is not "doing for" but rather "doing with". It is important to get to know each individual as they are now and honor their past so that common life themes can be infused into a daily routine.

Studies show that people who remain active and involved in worthwhile endeavors may have less depression and an increased overall satisfaction with life. Likewise, a homelike, safe, calm environment allows for self-exploration and encourages overall well-being. A person's environment, and all that goes on in the environment, determines the day's tone.

The Caregiver

Caring for an individual with dementia can be challenging, and at times, it can feel overwhelming and frustrating. How you present yourself and respond during uncontrollable circumstances can set the tone in your environment. Be judgment free. Try to understand what it is like to be in their place. If someone you are caring for is becoming agitated, then step back and try to understand what is creating the agitation and help them understand how to de-escalate it (if they are able) – how are your actions influencing the situation? Be kind, be gentle. Provide the best possible care. Allow the person with dementia to do as much for themselves as possible. Do not expect perfection.

You and Caregiving

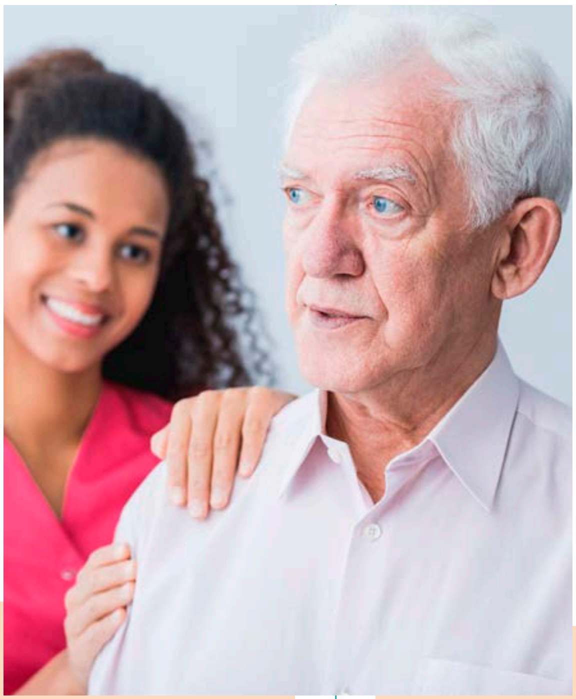
Take a moment and look at yourself. Look at how you engage with the individuals you care for. Look at how you interact with others. Look at how you dress and how you talk. Look at how creative, silly or compassionate you are. Just as these characteristics make you who you are – the individuals you care for are just as diverse.

As these characteristics are a part of who you are, some basic characteristics that effective caregivers possess are empathy, dependability, patience, strength, flexibility and creativity.

Look at yourself, the environment, others and the individual(s) with dementia. Think of some ways you can set a positive tone for success and safety in these areas.

Empathy

Empathy is the foundation for every caregiver who provides quality compassionate care. Empathy is the ability to understand and share the feelings of another. Interacting with the individual with dementia means taking the time to sit with a person and really get to know and understand them and their feelings – even when they are unable to verbally tell you.



Reflect: How would I want to be treated and cared for if I was living with dementia?

Dependability

Being dependable is being capable of being relied on; worthy of trust and stable. People with dementia have lost some degree of independence and must rely on you for some level of care.

Reflect: How would I feel if I was unable to get my own meals, bathe myself, get dressed or go to the bathroom myself? Now imagine not having anyone to count on when you need help. How does this make you feel?

Patience

The ability to have patience is the capacity to accept or tolerate delay, trouble, or suffering without getting angry or upset. The individual with dementia is dealing with memory loss and loss of the ability to process information. It takes more patience to provide care when you are in a hurry and the person you care for needs extra time to process or understand what you are trying to do. A person with memory loss might ask the same questions repeatedly and to them each time is the first time they ask.

Reflect: How would I feel if I were unable to do the things I used to at the same pace or felt confused by what my caregiver is asking of me? What if my caregiver tried meeting me where I am?

Strength

Having strength in this context is having mental power, moral power, and courage. Caregiving is a difficult job and there are times when you may have a bad day, have a lot going on outside of work, you feel burnt out or the individuals you are caring for have a bad day. It is a strength to recognize when you need to ask for help, make changes to the care, take a time out or tap into your patience. Sometimes taking a deep breath and coming back in 15 minutes with a smile can make a world of difference.

Reflect: What can I do if I am feeling frustrated and exhausted and realize my mood is influencing the individual I am providing care for?

Flexibility

Flexibility is the ability to have willingness to change or compromise. Life is change. The world of caregiving is constant change. You must be flexible to adapt quickly to changes in health, personality, behavior, and schedules. What worked before might not work this time or the next time.

> Reflect: How would I feel if I were used to doing things a certain way – from wake up to breakfast and my caregiver wanted me to do it a different way to fit their schedule?

Creativity

Creativity is the use of the imagination or original ideas, especially in the production of an artistic work. Caregiving requires you to be creative in approach and look for new ways to accomplish the same tasks.

> Reflect: Think of a time when you were frustrated by a situation and had to think of a creative way to get through the situation. What was the outcome? Did you try it again later and did it work the same as before? If not, what did you do?

Self-Care

There are many rewards to caregiving. Caregiving can build self-esteem and a sense of self-worth. While it is rewarding, it can also be emotionally and physically challenging and require special attention to self-care. You are part of the environment and need to have self-care because you influence the environment.

Before you travel on an airplane, the flight attendant walks you through how to locate the exits, the emergency procedures, and how to use the oxygen mask. The attendant instructs you that you must first put your own mask on, and then you assist others. If you try to put an oxygen mask on someone else first, there is a chance you will lose consciousness, and you will be unable to assist others or even yourself. The only way you can ensure that you can help those around you is to help yourself first.

Caring for yourself is the most important and most forgotten thing you can do as a caregiver. Caregivers often have difficulties managing their own well-being while managing caregiving responsibilities. How can you help others if you do not help yourself first?

Common difficulties among caregivers might include:

- Not getting enough sleep, or poor quality sleep
- Eating junk foods or processed foods, skipping meals, and/or not eating regularly; difficulty planning meals.
- Not getting enough exercise
- Not feeling able to rest or stay home and rest when ill
- Postponement of or difficulty making medical appointments for themselves

The task of giving individualized, affectionate care to people with dementia can place heavy psychological, emotional, and physical demands on you. You might experience demands that are too great or difficult to handle. You may find it hard to cope.

Often caregivers struggle with

- Feeling that they can never do enough
- Feeling undervalued and inadequately compensated
- Juggling multiple roles with limited time and resources
- Handling new or challenging behaviors
- Managing the unpredictability of the disease process and behaviors associated with dementia
- Knowing how to respond to constant and repetitive questions

Reduce Personal Stress

Try to remember that you cannot control how others behave in difficult circumstances; you can only control how you react to the situation. Recognize when you are feeling stressed. Signs might include irritability, sleep problems, and forgetfulness. Make changes to reduce your stress early – do not wait until you are overwhelmed.

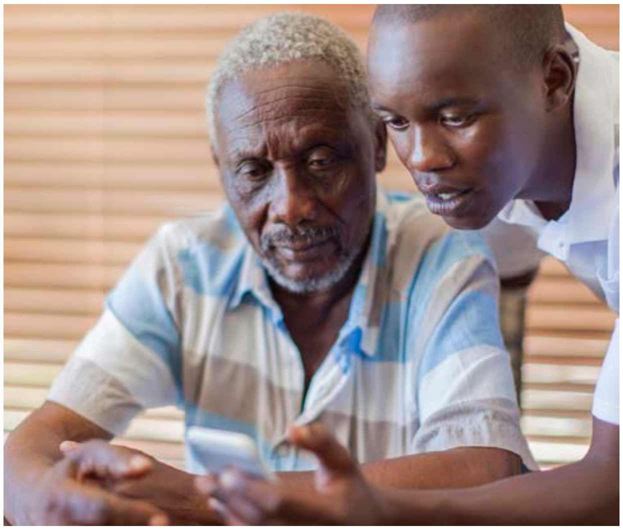
Ask yourself

- What is causing the stress?
- What do you have control over that you can change?

What you can do:

- Remember you can only change yourself. You cannot change another person – especially a person with dementia who is unable to change their circumstances or the changes in their brain.
- Take action. Taking action gives you a sense of control and may reduce stress.
- Walk it out, talk it out, meditate, do something you enjoy.
- Seek solutions – what is the problem and what are some possible solutions?

Think about ways you have reduced stress in the past that worked. Write them down and refer to them later if you are feeling stressed.



Setting Goals

Setting goals on what you want to accomplish over three to six months is important in self-care. Set goals to take time participating in activities you enjoy that make you feel healthier.

Think about a time you set a personal goal and achieved it. How did that achievement make you feel?

Communicate Effectively

Communicating effectively will help you get the help and support you need. Communicate your needs or concerns using “I” rather than “you”. Such as "I feel hurt when you yell at me" instead of "You always yell at me!" Respect the rights and feelings of others. Be clear and specific. Ask for clarification – do not assume. Be a good listener. (More information on communicating in Lesson 8.)

Think of a time when you had a misunderstanding with someone. Write down what you did that could have been better and write down what you did that went well.

Asking for and Accepting Help

Know when to ask for help and accept it. Find help from your coworkers, managers, families of the individuals you care for, join a support group.

Know that it is also ok to say no to the demands of others if you are feeling overwhelmed or need a break. Do not feel guilty for saying no.

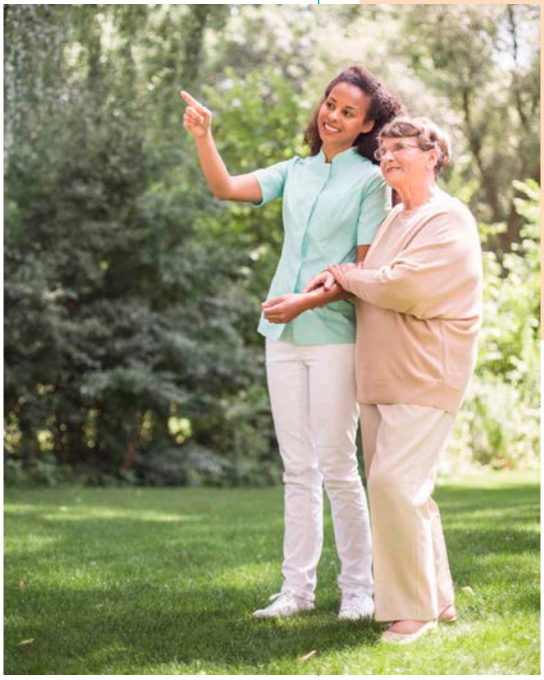
Think of a time when you knew you needed help but did not ask. How could you have asked for help now? Or is there something you can plan next time to ask for help?

Exercise

Exercise promotes better sleep, reduces stress, depression, increases energy, and alertness. As part of your self-care routine – make sure you are getting regular exercise.

Ways you can incorporate daily exercise:

- Stretching Exercises
- Find activities you enjoy
- Gardening
- Household chores
- Join a gym
- Take walks with the individual(s) you care for
- Walking – on the job, around the mall, to the store, around the block
- Play – active play with kids can get your heart pumping while having fun



List some physical activities you enjoy. Plan to spend 20 minutes this week doing something from your list.

Nutrition

Healthy eating plays a big role in your ability to deal with stress. Stress or eating processed foods may weaken your immune system. A balanced diet will help you maintain the nutrients you need to keep you focused, alert, energetic and healthy.

Ways you can incorporate healthy foods:

- Watch a cooking show online and follow the recipe.
- Plan and cook meals with your family.
- Shop on the perimeter of the grocery store, where the freshest foods are usually displayed (fruits, vegetables, dairy, and protein).
- Try at least one fresh fruit or vegetable you've not eaten before.

Think of a time when you knew you needed help but did not ask. How could you have asked for help now? Or is there something you can plan next time to ask for help?

Set a goal to choose healthier foods this week. Write down foods you like to eat that are healthy.

Learning from Our Emotions

Learn to listen to your emotions and what they are telling you. Caregiving involves a range of emotions. You may feel guilt, resentment, anger, worry, loneliness, sadness, grief, fear or defensiveness. You may also feel happy, excited, tenderness, joy, or hope.

Emotions influence your thinking, behavior and actions. Fear based emotions that are long term can cause damage to the immune system and other systems in your body. Understanding where these emotions are coming from and how they are affecting the environment are important in your role as a caregiver.

Focusing on gratitude can help you to set a more positive tone. List three things you are grateful or thankful for today.

Support

Providing care for a person with dementia can be physically and emotionally demanding.

Feelings of anger, frustration, and worry are common.

If you are a caregiver for someone with dementia:

- Take care of your physical, emotional and spiritual health
- Learn as much about the disease as you can
- Find connections with other caregivers
- Network with your peers and management
- Join a support group

Consider sharing your contact information with people in the class so you can build a support system.

The Environment

The environment can influence "the feeling" of a space. A homelike environment can impart feelings of comfort and relaxation, while a cluttered or noisy environment might bring about feelings of worry or unease.

Look at the environment – assess the visual/auditory/sensory stimulation: how loud, quiet, or visually distracting is the room? How cluttered is the space? Are the bathroom and kitchen accessible? Is there access to outdoor areas?

Some things that might affect the environment:

- Your emotions
- Using your cell phone or being busy with other tasks instead of being present with the person/people you care for
- Noise, sounds
- Aroma / smells
- Lighting
- Temperature
- Colors
- Patterns on objects
- Pictures
- Signs (to help people find rooms, bathrooms, kitchen, etc.)

Be aware of the environment. Is it safe and positive? Avoid making unnecessary changes – it can add confusion.

The individual with dementia might have altered senses. They might experience changes in vision, hearing, sensitivity to temperature, depth perception.

Some common issues with dementia and the environment:

- Often, individuals with dementia have trouble with color contrast.
- Patterns on the floor might confuse them into thinking there is a hole or water on the floor or something they may need to step over or pick up.

Enhancing the Environment

Use the environment to encourage community, maximize safety, support caregivers, cue specific behaviors and abilities, and redirect challenging behaviors. Provide a variety of activity spaces with a variety of tasks and activities through careful schedule planning.

Be aware of safety features in the environment such as hand sanitizer, personal care items and household cleaners and detergents. While it might be a reasonable product in a lot of places, it is of concern when working with clients living with dementia because their cognition might impair their ability to realize what this product is and how to use it.

Other common environmental features such as a coffee bar could be somewhat concerning with residents who have dementia because the person might have lost safety awareness regarding hot foods and liquids.

Schedule Planning

Careful schedule planning should consider each person's strengths and preferences, especially regarding familiar routines and daily habits. When planning - allow plenty of time and be flexible. Document any effects of changes in the routine and consider issues that might disrupt routines – such as pain, fatigue, illness.

Variety

Having a variety of spaces available provides choices for individuals with a variety of needs and interests. Likewise, providing a variety of available tasks or activities can enhance an individual's experience to support a higher quality of life.

Others

Other people who interact with the individual with dementia can also influence the tone. Look at others - staff, visitors, other individuals in the environment. Encourage a positive tone among others who come into your environment.

The Individual with Dementia

People with dementia who remain active and involved in personal interests and worthwhile endeavors may have less depression and an increased overall satisfaction with life. Get to know each person and their rich history and personality. Get to know what they like and dislike, look beyond the surface and encourage participation in activities that give their life purpose and worth.

You must meet the person in the place they are. If they are having a rough time, you need to comfort and talk them through it. It does not matter if what they perceive is real or not. If they are agitated, step back and try to understand how to de-escalate the agitation.

While an individual's hobbies and personal interests can be added to their daily routine, also consider some household chores or life-long work-related activities the person might enjoy. These might include sweeping, feeding the birds, gardening, sewing, minor equipment repairs, laundry, or more.

List some tasks, chores and activities you enjoy.

Make a point to find tasks, chores and activities that the individual you are caring for enjoys and try to incorporate more of these into their day.

Lesson Summary

- A positive tone creates an environment that makes it safe and encourages everyone to play an essential role in the care of the person with dementia.
- Ultimately working relationships between you, family members, and other staff assure the best quality care for a person with dementia.
- Caregiving for people who have dementia is not "doing for" but rather "doing with". It is important to know each individual as they are now and honor their past so that common life themes are infused into a daily routine.
- Characteristics an effective caregiver possesses are empathy, dependability, patience, strength, flexibility and creativity.
- Remember that although you cannot control how others behave in difficult circumstances, you can only control how you resoond the situation. Recognize when you are feeling stressed.
- Use the environment to encourage community, maximize safety, support caregivers, cue specific behaviors and abilities and redirect challenging behaviors.
- People who remain active and involved in worthwhile endeavors may have less depression and increased overall satisfaction with life.

Checkpoint

Read the caregiver behaviors below and indicate by placing a checkmark next to "positive" if the behavior will keep the environment calm and positive or "negative" if the behavior will create negativity in the environment.

Caregiver Behavior	Positive	Negative
1. Be dismissive		
2. Be patient		
3. Provide safe and calm environment		
4. Engage and listen		
5. Get frustrated		
6. Ignore who a person is		
7. Know the individual – what they did as a child or as an adult		
8. Lack awareness of chaos in the environment		
9. See or experience a person's point of view		
10. Talk down to individuals		
11. Treat people with respect and dignity		
12. Treat them like adults		
13. Treat them like children		

Lesson 4
Working With Families

Objective:

The caregiver will recognize common emotions family members experience with a loved one who has dementia, identify some difficulties family members may experience or express about their loved one's care and provide resources for families.

Overview

Dementia has a huge impact on families. Many family members experience guilt, anger, sadness, and/or depression when seeking and obtaining care for their loved one. Others experience relief and appreciation towards those who care for their family member. By better understanding what a family goes through, you are better prepared to interact and respond to family concerns and complaints.

Interacting with families is an important aspect of your job. Sharing both good stories and incidents takes tact and professionalism along with compassion. There is only so much that we can see about a person on the surface. It is important to learn what is beneath the surface and not judge the person or the situation.

The way you and others interact with families will affect the overall mood of the environment and the satisfaction of the families. Negative talk and attitudes from the family can be difficult and sometimes hurtful; appropriate response and the ability to share your experience with a supervisor or another trusted person is imperative to minimizing burnout.

How would you feel if you had to place a loved one with dementia in the care of someone else? What if this loved one has always told you to never put them into this type of care? Would you feel guilt? Shame? Sadness?

Understanding the Family Unit

Many people contribute to the support of a person with dementia. The family unit might expand beyond what you think about as the traditional family unit of spouse and adult children.

Common family units can include:

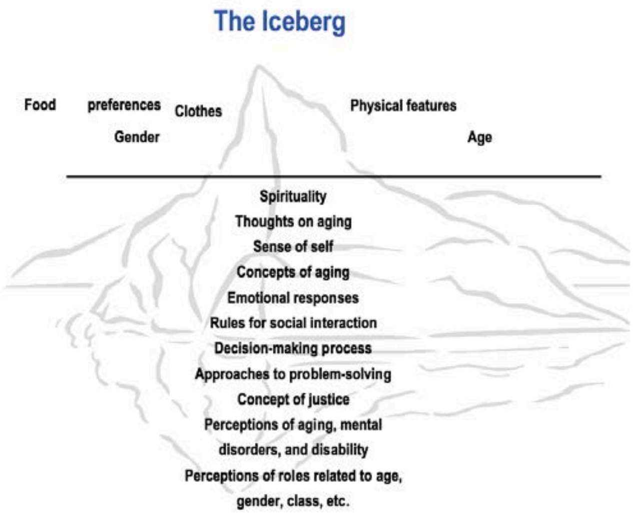
- Stepchildren of a remarried father or mother
- A newly married spouse
- An unmarried partner
- Adult siblings
- Nieces and nephews

- A same-sex partner
- Families of choice
- Kinship relationships
- Close friends
- Grown grandchildren
- Cherished pets

Getting to Know the Person with Dementia's Family

The family is central and an important source of support in the care of a person with dementia. Family offers a person with dementia a sense of belonging and provides them with stimulation, affection, and fun.

You should be encouraged to get to know the person's family. Family is also an important source of information that will help you provide individualized quality care for their loved one.



The Iceberg

The Iceberg represents many different parts of a person based on cultural differences, perspectives, values, and beliefs. Often, it is the tip of the "iceberg" that is considered when getting to know a person with dementia or family members.

The tip of the iceberg does not represent the entire person. The tip represents what you see on the surface. This might include – physical features, age, gender, clothing and food preferences.

If you take time to get to know the whole person, you will find much more below the surface, such as spirituality, thoughts on aging, sense of self, emotional responses, how they make decisions, mental disorders, and more.

At times – the family might bring a negative view of the individual with dementia. The family member might have resentment and anger towards the individual and the life they had prior to the dementia. As a caregiver, it is your job to get to know the individual and give them the best possible care and refrain from passing judgment on past behaviors or someone else's perception.

Working with Family Members and Friends

The entire family experiences dramatic changes when a loved one has dementia. The family may go through an extremely difficult time and may look to you for support.

The single most important thing that families need and want is that you provide quality care for their loved one. They trust that you will see their loved one as a unique person and that care is provided with love and respect.

Each family is unique. However, most families need:

Good communication with caregiving staff members – Families need to know caregivers well enough to trust them. They need to know who to talk to for information, who to complain to, and who to give information that will help in care. They need to know you will communicate issues – both good and bad.

Understanding rather than criticism for their coping strategies – Though many families cope well with the emotional demands of having a family member with dementia, others may react with denial, withdrawal, anger, frustration, loss, or guilt for having to seek care or needing assistance or not honoring the person's wishes. Families may also feel relief and appreciation for your help. Sometimes these emotions can result in negative behaviors directed at you – such as blaming care staff out of guilt or frustration for issues.

Issues such as

- Not fixing mom's hair the way she used to wear it
- Not dressing her in the proper clothes for church
- Offering her foods that she used to not like

Understand that the emotions are part of the process and know that you can get help from your supervisor if needed. These families need time, understanding, and support. You need patience with, and acceptance of, those who are having difficulty.

When working with families consider that family members may:

- Have their own issues and needs they are dealing with. For example, the family member might be feeling a need for approval from a parent who was very critical.
- Be experiencing their own health problems.
- Disagree about what care is provided and how much each family member should be doing. Remember to not take sides but help the person with dementia get his or her needs met.
- Feel emotionally or physically exhausted or overwhelmed. Depression is common.
- Feel guilty about problems in their family history or things they did and did not do.
- Have varying abilities to cope. Sometimes it may seem like a person is in denial, when he or she is just unable to accept the severity of the person's dementia.
- Be experiencing loss. The losses family members might experience include:
  - The person's companionship
  - A source of emotional support
  - Someone to talk with and confide in
  - Their hopes and dreams for the future

Finally, remember the family's experiences, beliefs, expectations, values, religion, nationality, age, race, or sexual orientation influences how they view and react to a situation.

Helpful Ideas for Supporting Family Members

- Welcome family members and friends when they approach you. Be friendly and open. If you are rushed, give a quick greeting and tell the family that you will connect with them soon.
- Invite the family to offer input into their loved one's plan of care.
- Ask family members about the person's preferences and routines and what they have found to be effective in working with the person. If their approach works, you should respect it and try to follow their lead.
- Listen. Sometimes, families just need to talk with someone. Ask family members how they are doing and show interest in what they have to say. You do not need to provide all the answers, just be a compassionate listener.
- Encourage family members to take care of themselves. Pass along useful information, such as where to find more information or support groups.
- Remind the family of their strengths and successes.
- Be gentle with yourself and with family members. Neither they nor you created the situations faced. Give yourself or a family member some quiet time if either are close to losing their cool.
- Help family members accept the progressive nature of dementia. Let them know that the person will need more help over time, but that does not mean they should give up. Help the family to know and focus on what the person can still do and build on that.
- Help the family to understand that the person with dementia is doing the best he or she can with a brain disease.

What you can share with families

- Fun things you have done with their loved one
- What has worked and not worked when interacting with their loved one
- Changes, as they occur
- The value of their visits
- Strengths you see in the person
- Relationships the person has developed

What you might ask the family to share about the person with dementia

- Cultural and educational background
- Previous occupations and hobbies
- Spiritual beliefs
- Family information
- Special abilities and qualities of the person, past and present
- Likes, dislikes, and preferences
- Attitudes and how they cope with changes
- Techniques that have worked well for them

Building Trust

Trust is essential between you and the family. Each setting (home, facility, etc.) should have policies and procedures that are clearly documented to avoid confusion and build trust. The policies and procedures include how to obtain a person's history, giving family information, the family role, how you should respond to a distressed family member, how to handle certain challenging behaviors, and other relevant topics.

Consult your manager if you are not familiar with these policies.

Some ways you can build trust are:

- Lead by example
- Communicate openly
- Do not place blame
- Be honest
- Be reliable

Lesson Summary

- Interacting with families is an important aspect of your job.
- The way you and others interact with families will affect the overall mood of the environment and the satisfaction of the families.
- The family is central and an important source of support in the care of a person with dementia.
- You should be encouraged to get to know the person's family.
- The entire family experiences dramatic changes when a loved one has dementia.
- The family may go through an extremely difficult time and may look to you for support.
- The single most important thing that families need and want is that you provide quality care for their loved one.

Checkpoint

Read the scenario below and select the best answer option.

You have been providing care for Rosella Borowski, a sweet woman with dementia. You have noticed that her dementia is progressing more rapidly lately. Today, her daughter Nichole came to visit her mother as she does often. You know that they have a very close relationship and always have. As Nichole enters the room, Rosella does not recognize her daughter and instead calls out to you using the daughter's name. Nichole becomes upset and cries.

How might you respond?

a. Tell Nichole that her visits with her mother are valuable.

b. Help Nichole to understand the progressive nature of dementia and that her mother is doing the best that she can.

c. Reassure Nichole that you are there for her.

d. All the above

Notes

Module 2: Living with Dementia

Lesson 5: Sexuality and Intimacy

The caregiver will identify safe and unsafe expressions of sexuality and steps to take in the best interest of the individual.

Lesson 6: Medications, Treatments and Therapies

The caregiver will identify possible medication side effects, ways to respond to side effects and recognize non-drug therapies to alleviate some symptoms of dementia.

Lesson 7: Activities of Daily Living

The caregiver will identify ways to assist with activities of daily living while focusing on an individual's strengths.

Lesson 5
Sexuality and Intimacy

Objective:

The caregiver will identify safe and unsafe expressions of sexuality and steps to take in the best interest of the individual.

Overview

Sexuality is a topic that most Americans do not discuss in the workplace. Sexuality is a life-long reality and sometimes individuals with dementia choose partners that, had the person not had dementia, they would not have chosen. Sex and sexual activity (including touching, talking, and masturbation) are not wrong or dirty but rather, in a positive environment where both adults are capable of consenting, can result in improved mood and life satisfaction. You must be aware of your own personal biases about sexuality, and must be diligent and attentive to determine how, when, and why to intervene on sexual expressions. When you care for the individual with dementia, concerns may arise around consent, competence, and privacy. There are appropriate and respectful ways to intervene in sexual behavior when necessary.

Sexual behavior may change as dementia advances. Memory and thinking are affected as well as social norms. Some situations of sexual expression may or may not be okay.

Unacceptable sexual behaviors including stalking, forcing another to perform sexual acts, coercion, sexually explicit photography, and touching without consent may arise.

It is important that you remember that you are caring for adults who have memory loss and are most often living in a communal environment. Because sexuality does not go away with age or with the diagnosis of dementia, the topic of sexuality is likely to come up. It is time to become comfortable with it, learn about the topic without judgement, and recognize that sexuality is a normal human need.

Sexuality & Intimacy

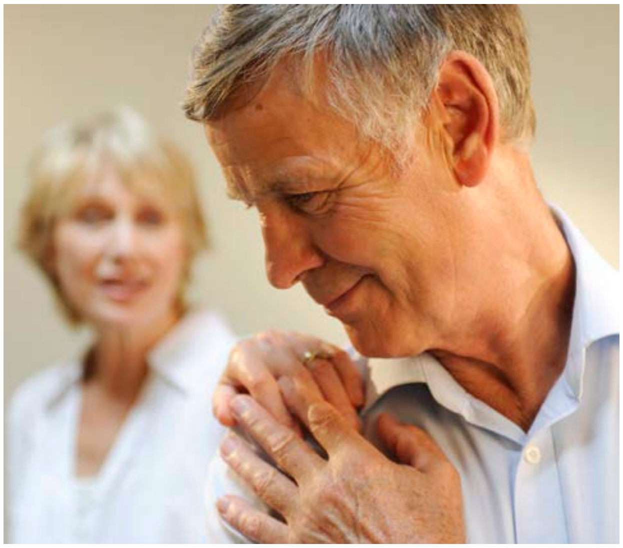
Sexuality is a basic human need that starts at birth and continues throughout our lives. Every individual has a need for love, touch, intimacy, and companionship. The sexual needs of older adults are similar to those of younger individuals but with variations in frequency, intensity and mode of expression. Healthy relationships can enhance the quality of life and contribute to longevity.

Sexuality is the feeling of sexual desire and its expression through sexual activity. It is a central and natural part of who we are throughout our lifetime. It includes sex drive, sexual acts, gender identities, roles, sexual orientation, eroticism, pleasure, intimacy, and reproduction. Expressions of sexuality in long-term care have included a range of actions including sexual intercourse, flirting, showing affection, giving compliments, closeness, physical contact, and physical appearance.

Intimacy is the giving and receiving of love and affection. It is a close, familiar, and usually affectionate or loving personal relationship with another person or group, which can include caring touch, empathic understanding, comfort and a feeling of safety in the relationship. The desire for intimacy does not decrease with age, and there is no age where intimacy is inappropriate.

A person diagnosed with dementia does not lose his or her sexual identity or the need for intimacy. The person continues to need loving, safe relationships and caring touch. As dementia progresses, sexual and intimacy needs and the way they are expressed may change.

Often, people with dementia exhibit behaviors that are misinterpreted as being sexual in nature. These behaviors are usually related to something else that the person cannot directly express because of the effects of dementia. The behaviors seldom involve sexual arousal.



Sexualized Behavior

Unusual sexual behavior may be part of the illness. The person with dementia may no longer know what to do with sexual desire or how to communicate a need for comfort, touch, and intimacy.

Sexual behaviors, including those directed at you, are usually not personal. These behaviors are often an expression of a need or desire. Therefore, they are not sexual behaviors but sexualized behaviors. Sexualized behaviors are behaviors that appear sexual in nature, however when examined closely reflect a need for touch, intimacy, or something else.

Other times, a man or woman who was always a flirt in their younger years may continue this behavior. Sometimes these behaviors are labeled as inappropriate or bad when they are just continuing past habits and behaviors.

Do No Harm

Your guiding principle is “do no harm”. Do no harm means that the person’s well-being is your primary consideration. When both residents are capable of consent and quality of life is enhanced, the couple should be free to engage in sexual activity. In many cases, a relationship among older people is not a problem for the couple, but is an issue for caregivers and/or family and relatives of the couple.

The key to approaching sexual behaviors is the same as the approach to all other care. Consider the person and their feelings and needs first. It is also important for you to consider that a person with dementia has the same rights as all other people.

A person with dementia has the right to be sexually active if they wish if it is not harming others, regardless of age, ability, or sexual preference.

Sexuality is a basic need that people with dementia should be able to express without fear or disapproval. All adults have the right to make choices about their relationships and private life, even if those choices are not the same as what you would make.

This MUST be in context of their capacity to consent, otherwise it will be considered sexual abuse. You will want to work with your supervisor to evaluate each person’s ability to consent, and plan for that evaluation to continue as capacity can change with time and circumstances.

Attitudes

Some people may hold negative attitudes toward sexual expression in late life. Often there is an assumption that older adults are asexual (a person who has no sexual feelings or desires), incapable of sex or sexually undesirable - especially those living within care facilities. General perception and prejudice is that sex in older people is disgusting, funny or does not exist. Many view late-life sexuality as a problem that should be prevented or eliminated. This attitude can cause younger people to hold misconceptions about aging and may be harmful to older adults because it can cause conflicted feelings or guilt about their sexuality.

Historically, stigma has occurred between same-sex activities more than opposite-sex activities. A **stigma** is a mark of disgrace associated with a specific circumstance, quality or person. The combination of dementia and individuals from the LGBTQIA+ (lesbian, gay, bisexual, Transgendered, queer, questioning, intersex, asexual) community can at times result in negative experiences for the individual. Because dementia robs people of their most recent memories, they might experience fear or feeling unsafe because they must come out all over again in a new group of people. Improving attitudes and reducing stigma about sexuality and dementia is important.

It is your job as a caregiver to look beyond your own bias, and find balance between protecting from harm, evaluating the individual's capacity to consent to sexual activity, maintaining privacy and promoting independence.

Maybell Wiggin is 77 years old and has Vascular Dementia. She recently moved into an assisted living facility because her husband could no longer provide the care she needed. Maybell does not recognize her husband and has recently shown interest in Lance, a male resident at the facility. Earlier today you found the two cuddling and kissing in Maybell's bed. How might you deal with this situation?

Notes

Changes

Dementia causes many changes and this includes changes in sex and intimate relationships. Changes occur with dementia that affect thinking, memory and social norms. Depending on the parts of the brain has been damaged and medications they might be taking, a person with dementia could experience changes such as reduced or increased interest in sex, increased or decreased ability to perform sexually, changes in sexual manners or levels of inhibition.

Reduced Interest

Some people with dementia seem to lose or have less interest in sex at an early stage and may become withdrawn. Being caressed, hugged or cuddled may give them reassurance, but they might not be able to initiate any affection themselves.

Increased Interest

Although it is rare, people with dementia can show excessive interest in sex. They may appear to be sexually aggressive, demand repeated sex from partners, and attempt to have sex with people other than their partners, masturbate frequently, or try to touch other people inappropriately.

In extreme situations where sexual aggression occurs, it may be difficult to manage. The healthcare provider needs to be notified. A caregiver may have to seek help from a supervisor to keep themselves and those around them safe in situations where the person with dementia is violent or persistent.

Sexual Aggression

In rare cases, some people with dementia may experience a phase of being sexually aggressive. Sexual aggression might look like being forceful or overly assertive toward another person. It may stem from the person's interpretation, feelings or perception about a situation. The individual may make repeated demands for sex from their partner or other people. In some cases, if the person with dementia is a strong person, the level of physical force may be difficult to manage. For some people, the aggression may be part of their past behaviors and is worse with dementia.

It is your job not to take the behaviors personally. Remember it is the illness and not necessarily the person causing the behavior. You should always look out for your own safety and the safety for others around you. If you or others feel at risk of violence, aggression or verbal abuse, talk with your manager and follow your policies and procedures. Individuals who exhibit this type of behavior should have it addressed in their service plan, along with suggested steps that you can take to work with these behaviors. Never be afraid to call 911 if you feel that you or others are in an unsafe situation.

Inhibitions

Dementia might reduce a person's inhibitions, which may uncover their private thoughts and they might not be able to hide feelings and control behaviors as they once did. This includes thoughts, behaviors and feelings around sex. Some individuals with dementia might make sexual advances, undress or touch themselves in public. They may use language that people have never heard them use or is out of character for the individual. Sometimes the person with dementia might feel confused, distressed or frustrated by these situations, especially if they do not understand why others consider their behavior inappropriate. These behaviors rarely involve sexual arousal and sometimes might be a sign of something else such as:

- Needing to use the toilet
- Discomfort from clothing (too itchy, too tight, too hot)
- Boredom or agitation
- Need to be touched or needing affection
- Misunderstanding other people's needs or behaviors
- Mistaking someone as their current or previous partner

Coping and Frustrations

There are several ways to relieve pent-up sexual tension. Exercise, other physical activities or masturbation can help reduce physical tension. Sometimes sexual desire can be confused with a need for closeness, touch, belonging, security, acceptance and warmth or a need to feel special to another person. Close platonic friendships can help meet some of the need for emotional intimacy. Therapies such as massage and reflexology involving physical contact can be very relaxing.

Sonny Tricket, who has been in your care for the last two years, was diagnosed with Alzheimer's disease at age 76. His disease has progressed quickly over the last few months since his wife passed away. One evening, Mr. Tricket is shifting in his seat and pulling at his pants. He begins to pull his pants down. What are some possible reasons he may be behaving in this way that do not involve sexual arousal?

Notes

Essentials

Client Rights

Everyone has the right to express his or her sexuality without fear of judgment.

Considerations in general around sexuality:

Right to be:

- Who they are (gender identity, sexual orientation) – even if that is different from how they were before dementia)
- Sexually active
- Free from acting under duress

Right to:

- Privacy
- Choose and reject partners
- Engage in behaviors different from past behaviors (gender, sexual orientation)

Additional considerations involving individuals with dementia and sexuality:

- Your guiding principle should be "do no harm"
- Consent may fluctuate or change from minute to minute, hour to hour, day to day
- Consider the person's decision-making capacity

You have a responsibility to protect these rights:

- Evaluate and make sure no one is being harmed
- Be familiar with your employer's policy around sexual expression
- Look at and resolve any misconceptions or biases you may have

Consent

Consent is permission for something to happen or agreement to do something. In the context around sexuality, both individuals involved in any sexual or intimate activity must consent. When one or both individuals have dementia, the levels of dementia might affect the ability to consent. In the world of dementia, this is always changing.

Decision making capacity can be defined as the ability an individual has to make their own decisions. Is the person with dementia able to make decisions in his or her best interest? There are times when friends and family of the individual believe that the person cannot make decisions. This may not be the case and requires careful consideration.

Confirmation should be made that consent was and continues to be given and that the safety of all involved is a priority.

Abuse and Other Unacceptable Sexual Behaviors

There can be times when a person with dementia can experience abuse.

- Physical or emotional abuse
- Stalking
- Coercion or duress is the practice of persuading someone to do something by using force or threats. This can include continued pressure or persistent harassment that may not be directly forceful or threatening, but still unwanted.
- Touching without consent
- Photographing or video recording

You must always make certain that a person with dementia is safe and not at risk of harm. Once the safety of the person with dementia is secure, those involved in their support and care will need to determine a number of things.

Family and close friends of the person with dementia will want reassurance that there is no intimidation or manipulation of their loved one.

Ask if the person with dementia is:

- Comfortable with the relationship?
- Able to avoid being treated unfairly or exploited?
- Capable of saying no?
- Being treated with respect, dignity, and is given privacy?

If a person with dementia is unable to make decisions to protect themselves, there are procedures that allow family members to act on his or her behalf. A family member or another concerned person can also seek a protection or guardianship order.

The person's rights must always be considered when determining the need for protection.

Talking to Families about Sex

Although it is critical that you safeguard a person with dementia's right to confidentiality, there may be times when family members need to be made aware of sexual or intimacy concerns.

You should talk with your supervisor before approaching the family and follow any policies in place for these types of conversations.

Talking about sexuality can be uncomfortable or cause anxiety for many people —including caregivers and family members. If you and your supervisor decide to talk with family, you can assist families by reminding them that:

- It is important to honor and acknowledge the person with dementia as a vital and sexual being.
- People with dementia have been sexual beings for much longer than they have lived with dementia.
- Many behaviors that appear sexual may be an expression of a need for touch and intimacy.
- Maintaining a healthy sex life can improve overall quality of life for people with dementia.

- People with dementia have the same rights as any other person.
- People with dementia can be at risk for sexually transmitted infections (STIs). Families may need support and assistance in assuring the health and safety of their family member.
- The risk of STIs does not diminish with age. Managers should create a policy, if one does not exist, for addressing the risk of STIs. STIs are a potential danger to anyone sexually active—including people with dementia.

Cristi Stuck, a 90 year old woman with vascular dementia has been affectionate on and off with a male resident, also with vascular dementia. They both seem to be at the same stage of dementia. Their emotions seem to change daily and at times, one or both do not recognize each other. How do you manage this relationship?

Notes

Caregiver Responsibility

You should be familiar with your employer's policy around sexual behaviors. Talk with your supervisor even if it is not a concern with individuals you care for currently. You need to be prepared and know what is expected of you in these situations before something happens.

Your responsibility is to be the advocate for the person with dementia. You need to remember the capacity of a person with dementia can change from one minute to the next.

You must continuously reassess the situation and ensure that no one is being harmed. If you remain satisfied that the person consented and was not acting under duress, then do not attempt to interfere.

The need for intimacy and closeness is a very important and a natural part of people’s lives, including people with dementia. Find ways to include different forms of touch in your everyday caregiving routines so a person with dementia continues to get some physical contact. Massage, holding hands, and sharing hugs are ways of continuing to provide loving touch and may help meet the need for intimacy.

Before touching a resident, make sure they are comfortable with your touch. Everyone may have different feelings about personal space and touch.

What You Can Do

When dementia affects the person’s understanding of social situations and his or her ability to behave as might be expected.

Even though some people with dementia display sexualized behaviors, it is rare. If sexualized behaviors do happen, remain calm and do not communicate anger, shame, or distress to the person with dementia. You will need to:

Focus on the Behavior – Consider all possible reasons for the behavior. This could include needing to go to the toilet, discomfort, or boredom. Try to identify the circumstances in which the behavior is likely to happen. Are there cues? Try to consider the person and their dementia and not sexualize the behavior.

Provide Privacy – Lead the person with dementia away from the situation, calmly and gently or cover the person with a blanket to limit exposure. Do not physically restrain the person, as this may cause them to become frustrated and it is against the law.

Examine Your Behavior – Consider how you may appear to the other person and how your body language and non-verbal communication can be interpreted.

Distract the person – Redirect them to another activity.

Involve Family – If approved by your supervisor and policy, speak to family about understanding and dealing with situations. This can be tricky to involve family and sometimes backfires because the adult daughter or son say they are not okay with the activity. It is not their choice. It is based on the facility determination that the person with dementia is able to consent, and that the individuals are at about the same level of dementia to minimize the likelihood of one resident overpowering another.

Seek Advice – Ask health care professionals and other care providers for practical advice for dealing with sexualized behaviors.

The following are behaviors you may see in the person with dementia that may appear to be sexualized.

Dementia and Sexualized Behaviors

Behavior	Dementia Considerations	Care Tips
Bold Behavior • Flirtation • Inappropriate sexual advances towards others	• The person may have forgotten their marital status • Person may be expressing a need for touch	• Don't take it personally • Remember, it is often the disease and not the person
Disrobing • Taking clothes off in public or unusual places. • Opening zippers, snaps or buttons	• Expressing a need to go to the bathroom • May be bored • May be frustrated • Clothing may be restraining irritating or uncomfortable	• Be attentive to toileting needs • Assess for pain and discomfort • Redirect behaviors and provide opportunities for engaging in other activities
Fondling/Masturbation • May fondle him or herself in public places • May masturbate in public places	• May have forgotten social rules or etiquette • May not understand that the behavior is inappropriate in public • May be unaware of others reactions to the behavior • May be doing this because it feels good, self-satisfaction	• Do not overreact • Approach the person in a calm manner and re-direct the behavior • Provide privacy. You may choose to take the person to a private area or cover the person with a blanket to limit exposure
Inappropriate Touching of Others • Seeks hugs and kisses from staff and strangers • May grope staff or others	• May be confused • Advances may be directed toward someone that resembles a spouse, lover, or companion • May misinterpret other person's actions and behavior as wanting to be touched	• Do not judge the person • Re-direct any inappropriate behaviors • Set limits if behaviors are sexually inappropriate • View all behaviors as a way that the person is trying to communicate a need • Always consider client rights

Reporting Non-consensual Sexual Conduct

As defined by Washington State law, it is your obligation to protect the health and safety of individuals by reporting all concerns of suspected non-consensual sexual conduct and/or relationships.

When there is reason to suspect sexual conduct and/or relationships is non-consensual or there is any sexual conduct between a resident and a staff member, a report must be made pursuant to Chapter 74.34 RCW.

Talk with your supervisor and become familiar with policies. If non-consensual sexual conduct and/or relationships have occurred and the report is not made, the facility may be faced with significant fines and other enforcement actions, including, but not limited to, stop placement.

Pursuant to Chapter 74.34.035 RCW, when there is reason to suspect that sexual assault has occurred, mandated reporters shall immediately report to the appropriate law enforcement agency and to the department.

Lesson Summary

- Sexuality is a life-long reality and an important part of life.
- Sex and sexual activity (including touching, talking, and masturbation) are not wrong or dirty but rather, in a positive environment where both adults are consenting, can result in improved mood and life satisfaction.
- You must be aware of your own personal biases about sexuality, and must be diligent and attentive to determine how, when and why to intervene on sexual expressions.
- Sexual behavior may change as dementia advances.
- If neither party is being harmed and their quality of life is enhanced, the couple should be free to engage in sexual activity.
- The key to approaching sexual behaviors is the same as the approach to all other care – consider the person and their feelings and needs first.
- As defined by Washington State law, it is your obligation to protect the health and safety of individuals by reporting all concerns of suspected non-consensual sexual conduct and/or relationships.

Checkpoint

Read the behavior scenarios below and indicate the letter next to it for what you should consider about this individual who has dementia. Choose the best answer.

_____ 1. Maybell Wiggin just celebrated her 78th birthday and has Vascular Dementia. She is married and has been living in an assisted living facility for over a year. When she moved into the facility she showed interest in Lance, a male resident at the facility. Lately, she has been flirting a lot with other males in your care.

_____ 2. Sonny Tricket, now age 76, has been experiencing more frequent changes in his behaviors related to Alzheimer's disease. For the last few days, he has been taking his pants off routinely in the dining room.

_____ 3. Zachary Yard is 54 with middle stage Alzheimer's. Earlier this year, he started following another resident around asking her to kiss him and fondle his genitals. Recently you have found him masturbating in public spaces.

a. Clothing may be restraining or painful

b. May have forgotten social rules or etiquette

c. The person may have forgotten their marital status

Notes

Lesson 6
Medications, Treatments and Therapies

Objective:

The caregiver will identify possible medication side effects, ways to respond to side effects and recognize non-drug therapies to alleviate some symptoms of dementia.

Overview

Medication management is a big part of caring for an individual with dementia. There are many prescription and non-prescription medications (over the counter medications, vitamins, food supplements, and herbal remedies) given to older adults for common health problems. Medications are commonly prescribed for diagnoses such as high blood pressure, heart disease, mental illness, diabetes, pain, seizures and other health conditions.

Medications should only be one part of a person's overall care. Non-drug treatments, activities and support are just as important in helping someone live well with dementia. When you understand that there are many possibilities to manage care, you will understand that not all methods work for every individual all the time. While a licensed medical professional manages pharmaceutical drugs, it is your job to watch for side effects. It is also your job to be creative, patient and flexible. Be mindful that you can do more to provide a higher quality of life for those you care for.

Become familiar with any policy and procedure your setting has around medication management.

Conventional Medicine

Conventional medicine generally uses pharmaceutical drugs as a form of treatment. There are no drug treatments, at this time, that can cure Alzheimer's disease or any other type of dementia. Medications might be prescribed if a person is experiencing symptoms of dementia such as memory loss, agitation, depression, anxiety, hostility, delusions, or hallucinations. Some medications might alleviate symptoms or slow down the disease progress. Not all medications will work for everyone and there is no cure.

The following are basic rules that must be followed whenever a medication is prescribed to a person with dementia.

- Only a licensed health care practitioner can determine and prescribe what medication to use, how often, and in what dosage.
- Medications must be taken exactly as prescribed unless you have permission from a licensed practitioner to change it.
- Never stop giving medication unless you have permission from a licensed health care practitioner. Often, when medications for dementia are stopped, there can be undesirable side effects and drastic changes in the person's abilities. Many of these medications must be tapered down before they can be stopped.
- Monitor the person closely to ensure the medication is working as intended. Watch for physical or behavioral signs that the person is uncomfortable or in pain.

- Always be aware of each medication’s side effects or possible adverse reactions. An adverse reaction is a harmful or unpleasant reaction.
- Report any side effects or adverse reactions to a licensed medical practitioner. Examples of adverse reactions include a drug overdose, drug and food interactions, intolerance, or an allergic response. Some people with dementia may not be able to communicate that they are experiencing side effects or having difficulty with medication; your observations of changes, then, are important to share with the prescriber.
- If the person refuses to take their medication, stop and consider trying again later. Never try to force a resident to take their medication. Residents have a right to refuse medications and treatments.

Is there a cure for Alzheimer’s disease or other common types of dementia?

Medications Used with People Who Have Dementia

Medical research continues to increase the number of medications available.

Most of the major Alzheimer’s websites have current information on new medications for dementia. For example, visit www.alzinfo.org and click on drug treatment.

The medication information that follows can act as a resource, but you do not need to memorize this information.

General Dementia Medications

Cholinesterase Inhibitors (donepezil, rivastigmine and galantamine)

Donepezil, rivastigmine and galantamine all prevent an enzyme called acetylcholinesterase from breaking down acetylcholine in the brain. Increasing the acetylcholine increases communication between nerve cells and may temporarily alleviate or stabilize symptoms.

Common names

- Aricept (donepezil)
- Exelon (rivastigmine)
- Razadyne (galantamine)

Side effects

- Loss of appetite
- Nausea
- Vomiting
- Diarrhea
- Muscle cramps
- Headaches
- Dizziness
- Fatigue
- Insomnia

Memantine

Memantine protects brain cells by blocking the effects of glutamate. Glutamate is a chemical that helps send messages between nerve cells. It is released in excessive amounts when Alzheimer’s disease damages the brain cells.

Common names

- Namenda

Side effects

- Dizziness
- Headaches
- Tiredness
- Raised blood pressure
- Constipation

Other Drugs Used With People Who Have Dementia

Antidepressants

Depression is very common among people with dementia. One way to treat depression is with medications called antidepressants. For people with dementia, Zoloft (Sertraline) may be effective in reducing symptoms of depression.

Other medications used to treat depression may include:

- Prozac (Fluoxetine)
- Paxil (Paroxetine)
- Celexa (Citalopram)

Antipsychotics

Antipsychotic medications are sometimes used to treat mental distress, agitation, aggression, and certain conditions or disorders, such as psychosis. Psychosis is a disorder that typically includes delusions and hallucinations. Antipsychotic medications are prescribed to treat the hallucinations and delusions of psychosis.

You may also see medications used to treat symptoms associated with dementia such as pacing, sleeplessness, or sundowning.

Any situation where these antipsychotic medications are used must be closely monitored to ensure that they are never used as a chemical restraint.

Recent studies have been inconclusive on the effectiveness of antipsychotic medications and have found them to be less effective than other treatments that have fewer side effects.

Some antipsychotic medications include:

- Haldol (Haloperidol)
- Seroquel (Quetiapine)
- Zyprexa (Olanzapine)
- Risperdal (Risperidone)

These medications must always be used cautiously due to their serious and potentially life-threatening side effects. The federal government, long term care professional organizations, as well as the state ombuds program all share grave concerns about the use of anti-psychotic medication amongst older adults who have dementia. It is important to talk to your supervisor about a resident starting these medications. There may need to be additional conversations with family members and the prescriber beforehand. Behavioral interventions are the preferred method to deal with psychosis associated with dementia.

Anticonvulsants

Tegretol (Carbamazepine) is a medication used to treat seizures. It may also be used as a mood stabilizer in treating and decreasing behaviors such as severe agitation, aggression, or extreme excitability in people with dementia.

Other medications used to treat seizures may include:

- Dilantin (Divalproex)
- Lamictal (Lamotrigine)

There is no evidence that supports that these medications improve mood or behavior.

Medication Side Effects

You do not have to be an expert at medications, but you do need to be an expert at monitoring effects, side effects and changes you see. Be a good observer. All medications can cause side effects. Nonprescription medications, such as over-the-counter medications, vitamins, food supplements, and herbal remedies can also cause side effects.

These side effects can make the person sick or lead to further cognitive impairment. Side effects may also be mistaken for a new illness or the progression of dementia.

Unintended side effects may be caused by interactions with other medications, other diagnoses, such as heart disease or diabetes, and/or toxic effects from the accumulation of medications in the person's blood. It is important to know that:

- There is a higher risk of side effects occurring if a medication's dosage is increased.
- Side effects might be worse if a medication is not taken exactly as prescribed.
- Side effects may increase if the individual is taking more than one medication and will be more difficult to evaluate.
- Side effects can be lessened to reduce discomfort by working with the person's medical practitioner.

The person's licensed medical practitioner must review a complete list of all prescription and non-prescription medications routinely. It is also beneficial to have a medication regimen reviewed by a pharmacist regularly. Medications must be reviewed for dosage, continued need, possible duplication, medication interactions, and/or medication with food interactions.

Reporting Side Effects

Report any side effects or adverse reactions to the appropriate person where you work. The person's licensed medical practitioner should be involved to make changes to the medication or prescribe another medication if the side effect(s) do not improve or are causing a great deal of discomfort.

Life threatening side effects include:

- Trouble breathing
- Trouble swallowing
- High fever
- Bleeding
- Seizures
- Delirium

Any life threatening drug reaction or side effect should be treated as a medical emergency—call 911.

Earlier this week, Jacquline Pool started an increased dose of Donepezil for her Alzheimer's. Yesterday she started complaining about her stomach and holding her stomach area. She is having diarrhea and refused to eat breakfast and lunch today. What should you do?

Chemical Restraints

Chemical restraint is considered abuse in the state of Washington. Chemical restraint means the administration of or assistance with any drug to manage a vulnerable adult's behavior in a way that reduces the safety risk to the vulnerable adult or others, has the temporary effect of restricting the vulnerable adult's freedom of movement, and is not standard treatment for the vulnerable adult's medical or psychiatric condition. Sec. 1 RCW 74.34.020(3).

Refusal

Individuals have the right to refuse medication. Follow your employer's policies and procedures when residents choose not to take their medications. This may include reporting the refusal to the resident's doctor.

Non-drug Therapies

Pharmaceutical medications are not the only option for managing dementia. Non-drug therapies can also alleviate some symptoms of dementia. Remember you can modify the environment; how you respond to a person or behavior, and even modify tasks. Some individuals might also benefit from including natural medicine, vitamins, supplements, holistic therapies and better nutrition into their routine. Just as you did with conventional medications – you must be observant and watch for any adverse reactions and side effects.

Natural Medicine

Natural medicine includes vitamins like B, E, and D and omega 3 fatty acids.

Alpha-lipoic acid (ALA) is a vitamin-like chemical called an antioxidant. Yeast, liver, kidney, spinach, broccoli, and potatoes are good sources of alpha-lipoic acid. It is also made for use as medicine. Alpha-lipoic acid seems to work as an antioxidant, which means that it might provide protection to the brain under conditions of damage or injury. Some people may use this for memory loss.

Astaxanthin naturally occurs in certain algae, salmon, trout, lobster, shrimp and other seafood. It is used for Alzheimer's disease, Parkinson's disease, stroke and other conditions. Astaxanthin is also an antioxidant.

Coenzyme Q10 is an antioxidant that helps protect the body from damage. It is found in small amounts in organ meats (heart, liver, kidneys) as well as soy oil, sardines, mackerel, and peanuts. It is used for energy production in cells and has shown some beneficial results in animals with Alzheimer's.

Ginkgo biloba may improve blood flow to the brain and acts as an antioxidant. Several studies have shown that it can help with memory problems caused by dementia or Alzheimer's disease. It seems to help prevent the progression of dementia symptoms, especially when the dementia is a result of vascular disease. It does not prevent dementia or Alzheimer's.

Omega-3 fatty acids are found in certain fish, nuts and seeds. Some research suggests that omega-3s may help protect against Alzheimer's disease and dementia, and have positive effect on gradual memory loss linked to aging, but it is not certain yet.

Vitamin B6, B12 and folic acid (B9) may help slow the progression of the Alzheimer's disease. B6 can be found in a diet with eggs, bananas, fish and spinach. B12 is found in fish and eggs. Folic acid is found in beets, dates and avocados.

Vitamin E is commonly found in eggs, fruits, and vegetables and available as a supplement. Some people use vitamin E for diseases of the brain and nervous system including Alzheimer's disease and other dementias.

Vitamin D facilitates nerve growth in your brain. Some researchers believe that optimal vitamin D levels helps brain function. Vitamin D can be found through sensible sun exposure, light therapy and supplements.

Cannabis

Cannabis, also known as marijuana comes from a plant and is used as a psychotropic drug. In April 2015, DSHS issued guidance for AFHs and ALFs on cannabis.

"The use of medical and recreational cannabis is still illegal under federal regulation. Consequently, federal funds such as Medicaid cannot be used directly or indirectly for activities or expenses related to the use of cannabis.

…RCS encourages providers to develop their policies on cannabis even if it is not a current issue in their home/s. Doing so will ensure current and new residents are aware of the policy. When developing policies and procedures around cannabis use, please consider the following points:

- Residents who wish to use cannabis in smoked form need to be assessed in a manner similar to tobacco use. Please refer to applicable chapters of WAC and your employer's policies and procedures regarding resident safety and smoking.
- Cannabis, like any other substance that can be harmful, must be kept out of reach of residents who might endanger themselves with it. Please refer to the applicable WAC sections that address the storage of medication and chemicals.
- Keep in mind that a person under the influence of cannabis may require additional supervision.

- Because marijuana is federally illegal, and there is no “prescription” for marijuana products (a prescriber can recommend its use, but not prescribe it), staff should not assist a client to take marijuana, nor should it be stored in a medication cart or room?
- If a person is using cannabis products, the details of how the person receives it, uses it, and is supervised, must be documented in their Negotiated Care Plan.

RCS notes that state and federal laws and rules surrounding both medical and recreational cannabis are changing rapidly; therefore, information in this document must be supplemented with consideration of current rule, law, and code. Providers and settings are responsible for keeping abreast of new developments in this area. To follow the latest development on cannabis laws as they apply to both medicinal and recreational use, please refer to the Department of Health Website at: www.doh.wa.gov/YouandYourFamily/Marijuana.”

Be familiar with your policy and expectations in your setting.

Holistic Therapies

Holistic medicine is a form of healing that considers the whole person – body, mind, spirit and emotions in the quest for optimal health and wellness. The ideas below might be used individually or in combination with each other. Like conventional medication, these therapies may not work for everyone and it is important to monitor for side effects or changes in the individual you care for.

- **Aromatherapy** uses essential oils from plants that are applied to the skin through a lotion, added to a bath or inhaled for improved physical and mental health. There is some evidence that aromatherapy may help individuals with dementia relax and certain oils may improve cognition. Lemon balm may improve cognition and mood in the treatment of Alzheimer’s disease, and lavender oil may relax or calm. Always be sure the person does not have an allergy to any essential oils in use.
- **Acupuncture** practitioners insert very fine needles into the skin to stimulate various nerves and prevent or relieve pain, nausea and fatigue.
- **Massage therapy** involves a hands-on manipulation of the body’s soft tissue by a practitioner. Massage might help manage symptoms associated with dementia, such as anxiety, agitation and depression.
- **Bright light therapy** occurs when a person sits in front of a light box that provides about 30 times more light than an average light for a set amount of time each day. One study showed promising effects of the therapy on restlessness and disturbed sleep for people with dementia.
- **Music therapy** is powerful for individuals with dementia. Even in late stages of dementia, music can alter the mood, manage stress-induced agitation and help with cognitive function and motor movements. Some individuals will find that music devices programmed with individualized playlists, singing, or other music related group activities will sooth and improve quality of life.

- **Pet therapy** can benefit individuals with dementia by reducing agitation and increasing pleasure, increase the physical activity, and may engage in playful activities with the animal. Animals are non-judgmental and can be perfect therapists and companions. They can provide a tremendous source of social support and unconditional love. Realistic, life like «toy» pets (dogs and cats) to hold and pet can be comforting to some residents.
- **Sleep** can be a common problem with individuals with dementia and sleep is very important for good health and well-being. Non-drug treatments for sleep aim to improve sleep routine and sleeping environment and reduce daytime napping. Some of these treatments include maintaining regular mealtimes and bed times, sunlight exposure, regular exercise, finding a comfortable temperature in the room, providing nightlights and other security objects. You should also remember that not everyone sleeps at night. Some individuals who have had a long history of working nights might be more comfortable with a less typical sleep schedule.

- **Qigong** is an ancient Chinese health care system that integrates physical postures, breathing techniques and focused intention. Pronounced chee-gung, it means cultivating energy and is practiced for health maintenance, healing and increasing vitality. The movements of Qigong are said to reduce stress, build stamina, increase vitality, and enhance the immune system.
- **Child representational therapy** is therapy that provides people with dementia an opportunity to interact with a life-like baby doll. The most value is found when the individual is at a stage in their dementia where they perceive the doll as a real baby. This can provide an opportunity to express emotions, provide meaningful communication opportunities through the interaction, provide validation and purpose, provide opportunities to reminisce about the past and provide tactile/sensory experiences that provide comfort and security. For some, the baby doll could become a friend that they are able to share with and not feel judged.

- **Intergenerational care** occurs when adult care is combined with childcare so adults and children can interact together on a regular basis. Intergenerational care can benefit both the youth as well as the person with dementia. Some studies have noted that people with dementia had a higher level of positive engagement when interacting with children. Attentive supervision is necessary to ensure the safety of both parties.
- **Technology** such as iPads, and other music devices might benefit individuals with dementia. These devices might provide new means of communication for individuals who cannot express themselves, can help with reminders and appointments, used to monitor movements and habits, personalized with music and photos, encourages socialization with others with games, creative apps and helps individuals connect with family.

Media

Play Video: Henry and his reaction to hearing music from his era. (6:29) https://www.youtube.com/watch?v=fyZQf0p73QM

Nutrition

Eating is a social activity. Diet and nutrition play an important role in maintaining health and wellbeing. Diet is what we eat and drink, and it is considered a lifestyle. Nutrition is the process of ingesting and digesting foods and absorbing the nutrients.

Some terms to be familiar with

- **Malnutrition** is comprised of both overnutrition (excess food/calorie intake) and undernutrition (depletion of energy and loss of body mass).
- **Macronutrients** are proteins, carbohydrates and fats.
- **Micronutrients** are vitamins, minerals and antioxidants. Many of these nutrients are essential and the body cannot create them in adequate amounts. It is important that micronutrients come from diet.

The best diets for health and longevity

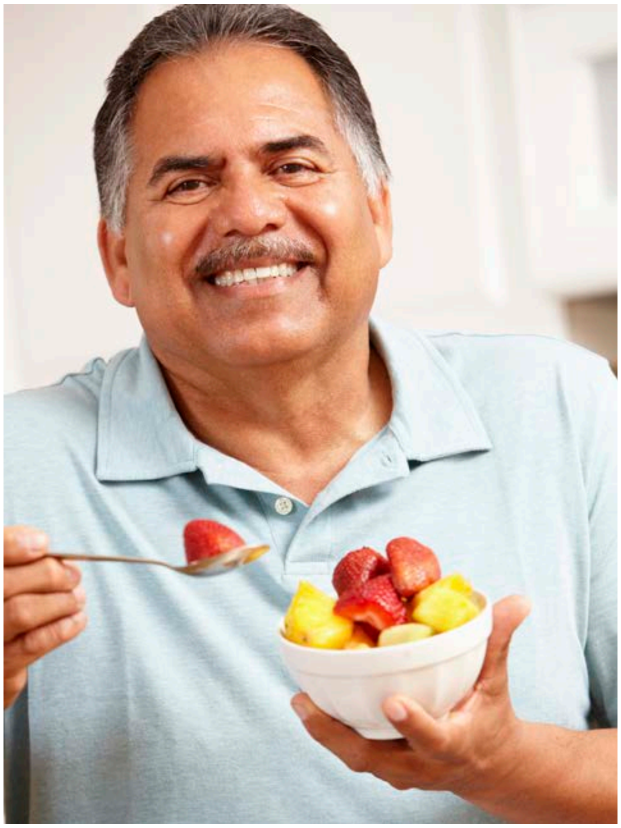
- More vegetables and fruit. A study in the July 2014 American Journal of Clinical Nutrition that followed 73,000 adults in mid to late 50s found that the greatest benefits were obtained eating 7 to 13 servings of fruit and vegetables per day – about 3 to 6 cups. Extended long-life expectancies are found in vegetarian groups because lower rates of life-threatening diseases are associated with eating more fruits and veggies and less meat.
- Coconut oil continues to get a lot of attention for improving dementia if eaten on a regular basis. Coconut oil is free of cholesterol and trans-fats and provides other health benefits of improving the body's use of insulin, improves good cholesterol, boosts thyroid function and increases energy, acts as an antioxidant and natural antibiotic and improves overall health of skin and hair. Some people will add this to their coffee or oatmeal for the flavor and possible health benefits.
- Mediterranean diet. Many studies show that individuals living the longest and staying the healthiest have a diet of whole grains, plant fats and oils, fruits, vegetables, nuts, beans, and peas that resembles the Mediterranean Diet. A study in the February 2012 Archives of Neurology found that older people eating Mediterranean diets had fewer markers of vascular damage in their brains.

Nutrient rich foods that promote brain health

- Asparagus
- Avocados
- Blueberries and strawberries
- Coffee
- Colorful fruits and vegetables
- Extra virgin olive oil
- Fruit juice
- Lentils and other legumes
- Nuts and seeds
- Red wine
- Spinach
- Green tea
- Whole grains

Lesson Summary

- A combination of conventional medications, behavior management, natural medicines, nutrition and holistic therapies are used to treat and support a person who has dementia.
- Non-drug treatments, activities and support are just as important in helping someone live well with dementia.
- There are no medications or other treatments, at this time, that can cure Alzheimer's disease or any other type of dementia.
- Always be aware of medication's side effects or possible adverse reactions.
- You do not have to be an expert at medications, but you do need to be an observer and monitor effects, side effects and changes you see. Nonprescription medications, such as over-the counter medications, vitamins, food supplements, and herbal remedies can also cause side effects. Any life-threatening drug reaction or side effect should be treated as a medical emergency – call 911.
- Chemical restraint is abuse.
- Individuals have the right to refuse medication.



Checkpoint

	True	False
Read the statements below and indicate if they are true or false.		
1. Potential side effects of some dementia medications might include loss of appetite, nausea, vomiting, muscle cramps and fatigue.		
2. If someone does not want to take their medication, you should hide it in their food or drink.		

3. Name at least three side effects that are considered life threatening and require calling 911 immediately.

1.

2.

3.

4. Name at least three alternative non-drug therapies to alleviate some symptoms of dementia:

1.

2.

3.

Notes

Lesson 7
Activities of Daily Living

Objective:

The caregiver will identify ways to assist with activities of daily living such as bathing, dressing, eating, oral care and toileting while focusing on an individual's strengths.

Overview

Activities of daily living (ADL) refer to the basic tasks of everyday life. ADLs are a big part of every individual's day. These activities include, but are not limited to bathing, dressing, eating, oral care, toileting, and mobility. When people have difficulty performing these tasks, they might need help from you, from others or even from mechanical devices or both. Dementia changes a person's life and ability to complete ADLs the way they used to before the disease. It is your job to assist with these activities while recognizing what the individual's strengths, abilities and moods are and allow them the time and freedom to do as much of the task as they can on their own. Individuals who perform their ADLs independently or with minimal assistance through cueing, prompting, reminding and encouragement will remain independent for longer and have a better quality of life.

ADLs should be about going through a day with the individual and providing companionship. Activities are important because they help a person with dementia to experience a sense of independence and control. It gives them an opportunity to have meaningful contact with other people. Activities allow people to continue to participate in life-long patterns or routines and to stay active. It also provides an opportunity for people to feel productive and contribute in some way.

Think about your own personal daily routine. Consider the aspects of bathing, dressing, eating, oral care, toileting and mobility. Reflect on how you would feel if someone else were to assist you with these tasks or do them for you completely.

Helping with Activities of Daily Living

When we are healthy, we often take for granted the importance of completing routine tasks in our day. We are so excited to get to the next, more important parts of our day that we forget to be thankful for the ability to complete these tasks without assistance. An individual with dementia has many changes going on with their brain because of the disease. This might limit capabilities and feel isolated or incompetent or less valued because they cannot complete the daily tasks that they once were able to do with ease. By using your skills in empathy, patience, flexibility, creativity – you can make activities more person centered rather than task oriented. Mindfulness in your approach will make people feel good about themselves.

Dementia care activities are about all the interactions that go into the process of doing an activity. A meaningful process includes activities that provide the person with dementia the opportunity to:

- Use his or her retained skills
- Experience and be reminded of past familiar roles such as, homemaker or business person
- Continue to interact with others in personally satisfying ways
- Feel supported by the people around them
- Build self-esteem
- Stimulate physical senses

Each person has rituals and habits that should be learned and followed. To provide meaningful, individualized activities with these goals in mind, you will need to know about the person's background, interests, and what the person enjoys.

Spend time talking to the person and learn:

- Past interests and skills
- Work-related past
- Important relationships
- Spiritual or religious traditions
- Remaining physical skills

The person will also have a lifetime of routines and daily habits. Examples might include always starting the morning with a cup of coffee and the newspaper, taking a walk after dinner, or an evening prayer. Some individuals may be used to getting their hair done weekly at the salon or dress weekly for church.

Continuing with these routines provides a sense of comfort and security for people with dementia. This is very important. You will therefore want to learn as much as you can about the person's routines and do what you can to help continue them.

If the person is no longer able to give you this information, you may have to rely on family or friends to tell you. The Negotiated Service Agreement or Negotiated care plan also includes this type of information. Always consult these resources before planning activities.

Above all, remember that safety comes first and the care you provide should be focused on each person as an individual. Recognize that timing and level of endurance may vary. Some individuals might get tired quickly and need rest. Knowing what is best for each individual and that it can change are important parts of your job. Be flexible. It may not get done now, but it will get done. It is not a reflection of you or how you are doing your job. Dementia is fluid. Some tasks require extra flexibility and some require structure.

Self-directed and Staff-directed Activities

Self-directed activities are activities the person can do on their own. Some staff set-up is normally needed. For example, staff may set out a laundry basket full of socks or towels to provide an opportunity to match socks or fold towels. A person who was an avid gardener may enjoy a raised bed where they can plant flowers, pull weeds, or water the flowers.

Some people may have difficulty initiating activities because of dementia. They may need prompting and encouragement to take part in activities and to interact with others.

It is also important to provide activities directed by staff. Staff-directed activities should include both tasks that the person does in the normal course of the day and activities that are special for that person.

Creating an Environment to Support Activities

People with dementia are sensitive to things going on in their environment. When providing opportunities for activities, create an environment that:

- Is calm and quiet – hectic, noisy surroundings may confuse, frighten, or agitate a person with dementia
- Provides a balanced amount of stimulation – too much activity, people, and visual stimulation create overload
- Provides consistent structure
- Provides space for both privacy and opportunities to socialize
- Uses contrasting and color-coded areas. For example, paint the walls blue in the activity area to stimulate recognition of the blue room with activities
- Uses memory “props”
- Provides adequate lighting without glare
- Provides space for exploration and exercise
- Is free of potential hazards, such as sharp instruments or scalding hot water

Most people with dementia retain some ability to perform ADLs as the dementia progresses. Because ADLs have been so much a part of a person’s life, they retain some awareness that these activities are a vital part of day-to-day life.

Encouraging and supporting a person with dementia to participate in ADLs is an essential and meaningful activity. It can help the person feel more independent, more connected to the task, and build self-esteem. Never underestimate the importance of keeping the person actively involved in ADLs for as long as possible.

As a person’s dementia progresses, they may no longer be able to do all of a task. You still want to encourage the person to do as much as he or she can. For example, if doing laundry is too complex, maybe folding socks or dish towels would be a wonderful activity for the person to work on.

When doing a single task becomes too difficult, simplify the task. Break it down to its smallest possible steps and give one step instructions at a time. This is sometimes referred to as “task analysis”. People with dementia may be confused by multiple tasks but might be able to do many steps if broken down into manageable pieces.

Remember stepping into dementia in lesson 1 and trying to imagine having to complete the five tasks? If the tasks were broken down and given in manageable pieces, do you think the outcome would look different?

Sometimes demonstrating the step or task can also be helpful. For example, if allowed in your community, when the person is having difficulty with eating, eat with them so he or she can they can follow your lead.

Always be positive and give positive feedback in a genuine way. It is important to celebrate what the individual can do rather than focusing on what they cannot do.

Assisting with Challenging ADLs

It is not uncommon for a person with dementia to resist doing certain ADLs. Often, the person cannot tell you what is wrong or what he or she needs. There may be several things going on. The challenge is to try to figure out what the underlying cause(s) of the person’s resistance is and find ways to address it.

Pain may contribute to a reaction from the individual during bathing, dressing, transferring, or dental care. Be aware of any possibility of pain and address and report the pain.

It is always good to try different strategies. Something that works one day may not work the next. You will also want to pass along anything that has been successful to other caregivers who work with that person.

Strategies

Some helpful strategies to help you to provide excellent care during activities of daily living:

- Individualize tasks and activities for each person based on history.
- Select the best time of day for each person for each ADL.
- Be flexible with schedule, routine and attitude to create the best environment for each individual.
- Enable and encourage each person to do as much as they can in a stress free environment to support competence and self-esteem.
- Use cues as a person has difficulty understanding what is happening. Use focused and relevant cues. Talk about the process and orient people often because they forget quickly.
- Use touch to communicate affection and guide an individual. Gentle touch to a specific body part can encourage them to use it.
- Use imitation to show by doing.
- Use reminders, lists and signs when appropriate. Sometimes a letter from family about where an item is located or a calendar on the wall to record visits, schedules, and activities might be helpful.
- Use diversion and distraction to cue someone to do something else (when the individual is calm.)
- Use predictability to help a person feel more in control of what will happen next to meet a person's need for sameness.
- Create context by creating a homelike environment to provide a more familiar feeling for the individual.
- Make goals obvious for individuals who will be able to understand. For example, the goal of walking down the hall is so that we can eat breakfast.
- Plan to make sure you have all the supplies you need and if your original plan does not work, is there a backup plan?

Select five strategies that you think are important and list why you chose these.

1. ______________________________

____

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2. ______________________________

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3. ______________________________

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4. ______________________________

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5. ______________________________

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Assisting with Bathing

Keep in mind that bathing involves many stressors for a person with dementia. Because of dementia, the person is less able to deal with stress. Most problems are caused by over stimulation, a feeling of intrusion into personal space and anxiety. Being undressed and washed by a stranger may be a humiliating, frightening, and a potentially traumatic experience for the person. You may appear as a stranger even if the person recognized you before. Fight or flight is a natural human reaction to perceived threats or unpleasant sensations. If the person feels they are in danger, the person may try to fight you off or try to get away. For example, a person with dementia thinks you are a stranger trying to take off his clothes and resists your help when you are helping him get ready for a bath.

Bathing could be painful to the person. Stay alert for expressions of pain. The person may have arthritis or other physical problems that makes movement and/or touch difficult or painful. The feeling of a shower head spraying down on the person could feel harsh.

Things are not always as they seem. A tub might appear to be 50 feet deep to a person with dementia or the lighting in the room could create a problem. Lights shining off ceramic tiles or a white surface causes glare and can be distressing to a person with dementia. Lighting should be bright enough for the caregiver but low enough to not startle the person being bathed.

Before the bath:

- Get to know and incorporate the person’s past personal routines and preferences for bathing.
- Be aware of time or time of day that best suits the individual’s present daily routine for bathing. If they are used to bathing on Saturday night before church on a Sunday, use that to your advantage. Do keep in mind that energy levels generally drop as the day goes on.
- Be sure that the bath area is prepared before the person arrives. Keep everything warm, including the room, water, and towels. Arrange bath items in the order in which they will be used.
- Approach the bath as a special time for the person. Use it as an opportunity to communicate that it is time to prepare for the day, get ready for a meal, or just freshen up.
- Do not pressure the person. Allow the person to be in control.
- If the person tries to resist taking a bath, gently remind the person who you are and that you are there to help. Reassure the person that his or her wishes will be respected during the bath.
- If the person does not want to take a bath, offer an alternative to bathing, such as a sponge bath.
- Use the language they are more familiar with for bathing. (“freshen up”, “sponge bath”, “clean up”, etc.)

During the bath:

- Talk about the process. Give simple directions, one step at a time.
- Encourage the person to do as much as they can do.
- If the shower spray intensity bothers the person, try putting a towel over their shoulders to decrease the sensation while continuing the bathing.
- Concentrate on and respond to the person’s feelings and reactions. Do not talk with others while assisting with a bath.
- If the person gets agitated, bring up a pleasant topic, play music, or give the person something to hold as a distraction.
- Speak in a low, pleasant voice before and all through the bath.
- Be mindful of the person’s modesty and always preserve the person›s dignity and privacy when bathing. Use a shower cape, towel or hairdressing cape. Modesty may be a reason for behaviors that are challenging.
- Allow adequate time for bathing and work slowly.

- A hand-held shower is usually less frightening than an overhead shower.
- Use bath time to check the person's skin for any infections, rashes, sores, or swelling.
- If washing the person's hair during the bath creates a negative response, try an alternative. A trip to the beauty parlor or barber may be a more pleasant experience for him or her.
- If the person grabs at objects or you, give the person something to hold. Grabbing during transfers usually indicates a fear of falling. Give constant reassurance.

After the bath:

- Use lotion to prevent dry skin.
- Keep track of successful and unsuccessful methods for helping. Share these thoughts or notes with other caregivers.
- Celebrate small successes.

Devin Stickler has dementia with Lewy Bodies. His muscles are stiff and he is moving very slowly. Today, you are there to help him take a bath and he is resisting having any part in it. Describe three ways you could help Mr. Stickler to work through his resistance and make the experience less stressful.

Assisting with Dressing

Something to keep in mind is that dressing is a very personal and private activity. Getting undressed in front of someone may be an uncomfortable experience. Getting dressed can be a very complex and overwhelming task for a person with dementia. Some people with dementia may forget to change their clothes or forget how to dress. In the past, people did not change clothes as often as today. It is important not to impose your own values about how often clothes should be changed. Try to keep the routine the person is used to. Some people with dementia may forget if they are getting dressed or undressed. People with dementia may find making decisions about what to wear difficult. The person may no longer be able to tell you if they are too hot or too cold. Keep an eye out for signs of discomfort.

Before dressing:

- Make sure the room is warm enough.
- Remember the person's feelings when reminding the person to change clothes.
- Simplify the number of choices. For example, offer two shirts to choose between.
- Choose clothing that is easier to put on, such as slip-on shoes or pull-over shirts without buttons.
- Lay out clothing arranged in the order that they are put on.
- Lay out lightly colored clothing on a dark bedspread. Contrasting colors will make it easier for the person to clearly see the clothing.
- Let the person decide what to wear. As long as it is not harmful, the same or mismatched clothes are better than a confrontation.

While dressing:

- Always preserve the person's dignity while dressing. This might include things like shutting the door, closing the drapes, or looking away when they are putting on undergarments.
- Make dressing an enjoyable activity. Chat about what might be of interest to the person.
- Careful prompting or reminders may help the person get dressed independently. For example, touch the leg that needs to go in the pant leg.
- Give simple, one-step instructions and allow plenty of time.
- If the person resists efforts to help, stop for a while and try again later.

Bart Uhrich has frontotemporal dementia. You are there to help him get dressed this morning. Although he is normally able to participate in some dressing tasks, he was awake much of the night. He is tired and restless this morning when you arrive. Describe three things you could do to encourage and support Mr. Uhrich's strengths this morning.

Assisting with Eating

Things to keep in mind about eating is that a person with dementia may:

- Forget how to chew and swallow.
- Forget what to do with silverware.
- Have a difficult time telling what food is.
- Accept food but will not swallow it. This is often called "pocketing" food.
- Have lost safety awareness regarding hot foods and liquids

Making mealtime enjoyable:

- Keep a regular routine. Routine is reassuring for a person with dementia.
- Keep noise and activity around the table at a minimum.
- Make the dining area comfortable. If the person gets anxious around a lot of people, try serving the person in a quieter area.
- Allow plenty of time.
- Eat with the person if you are able so she or he can follow your lead.
- As the person loses the ability to use silverware, provide finger foods as much as possible and provide utensils that are easier to grasp.
- If the person needs to be fed, help the person to feel involved. For example, put your hand over his or hers and guide the food to his or her mouth.
- Make sure that food and drinks are not too hot—people with dementia often lose the ability to judge temperature.
- Serve one food at a time to reduce distraction and overwhelm.

Appetite Loss

Many people with dementia have a poor appetite or lose interest in food. This can become a serious problem. A poor appetite can result in weight loss, a lack of energy, a reduced ability to fight infections, and can make problems with concentration even worse.

Common reasons for a poor appetite:

- Depression
- Dementia affects the sense of taste
- Physical discomfort—sore gums or badly fitting dentures, clothing that is too tight
- Lack of exercise
- The person may no longer recognize food
- Difficulties with chewing or swallowing
- Constipation

Ways to deal with loss of appetite:

- Encourage healthy snacking.
- Offer sauces or seasonings that the person did not use before.
- Encourage the person to get involved and help prepare meals.
- Encourage physical activity.
- Try a small glass of juice before the meal to whet the appetite.
- Serve four or five small meals.
- Offer energy-rich foods such as protein shakes or ice cream.
- Create smells like baking bread before dinner to stimulate the taste buds.
- Talk with family about favorite foods.

Overeating

Sometimes a person with dementia will eat more food than is needed.

Common reasons for overeating:

The person with dementia may:

- Develop a constant appetite for food.
- Forget they have already eaten.

Ways to deal with overeating:

- Try giving five to six small meals per day.
- Involve the person in an activity as a distraction.
- Have low calorie snacks available.

Chewing and swallowing problems

Problems with eating may relate to the mouth.

Common reasons for chewing and swallowing problems:

- Person forgets how to chew and swallow.
- Dry mouth makes swallowing difficult.
- Discomfort from gum disease or other dental problems.
- Ill-fitting dentures make chewing difficult.

Ways to deal with chewing and swallowing problems:

Remember to consult with your supervisor about swallowing problems. A swallow evaluation might be needed to begin with.

- Demonstrate chewing.
- Moisten foods with gravies or sauces.
- Offer small portions.
- Remind the person to swallow with each bite, stroke his or her throat gently, and check his or her mouth to see if food has been swallowed. Do not give foods which are hard to swallow.
- Avoid the combination of liquids and solids, such as ready-to-eat cereals and cold milk. The two textures combined make it difficult for the person to know whether to chew or swallow.
- Have the person get a dental check-up of gums, teeth, and dentures.
- Notify the doctor if choking problems develop.

Gwen Mooring has Alzheimer's and has been in your care for almost a year. It is lunchtime and you are there to help her eat. You have noticed that Ms. Mooring is not eating well and has lost some weight. Describe three ways you could help to ensure Ms. Mooring gets proper nutrition.

Assisting with Personal Hygiene and Oral Care

Keep in mind that oral care can be difficult for someone with dementia. A mouth in poor condition can be a cause for appetite loss, digestive problems, tooth decay, and gum disease. While helping with oral care, always watch for and report:

- Sores in the mouth
- Loose or broken teeth
- Bleeding
- Bad mouth odor

The person may lose the ability to acknowledge or describe dental symptoms or pain as dementia progresses. Watch for signs of mouth problems, including the person:

- Rubbing or touching their cheek or jaw.
- Moaning or shouting.
- Rolling their head or nodding.
- Flinching when washing their face or shaving.
- Refusing hot or cold foods or drinks.
- Being restless, sleeping poorly, or being more irritable or aggressive.
- Refusing or being reluctant to put their dentures in when this was not a problem before.

Eventually, many people with dementia reach a stage where they will no longer tolerate dentures in their mouth - even if they have worn them without problems in the past. When this happens:

- Alter the person's diet to include only foods that do not need to be chewed.
- Talk to the person's doctor about getting a liquid food supplement.
- Continue dental care for the person's gums and tongue.

Let the person brush their teeth as much as possible. Be aware of how thorough of a job the person has done. You may have to assist in hard-to-reach areas. Use a soft, junior-sized brush to clean without damaging their gums. Check how easily the person can grip the toothbrush. Adaptive grips for toothbrushes are available, if needed. Make sure the person completes one step to the best of their ability before going on to the next step. Do not rush. As coordination decreases, an electric toothbrush may help maintain the person's independence. If the person needs help brushing their teeth, help the person feel involved by putting your hand over their hand and guide the brush. Remember to brush the tongue also. As the dementia progresses, seek the advice of a dentist on the best way to clean the person's teeth.

Assisting with Toileting

The damage to the person's brain caused by dementia can interfere with the person's ability to:

- Recognize the need to go to the toilet.
- Be able to wait until they get to the toilet.
- Find the toilet.
- Recognize the toilet.
- Use the toilet properly.
- Recognize when the bladder is completely emptied.

Make sure the bathroom is clearly marked—put a sign and/or picture on the door, use a night light, or leave the door open.

- Keep the way to the toilet clear and free of clutter.
- A raised toilet seat and grab bars may help the person get on and off the toilet.
- Simplify clothing—try elastic waistbands or Velcro type fasteners.
- A commode may help if the distance to the bathroom is too far.
- If the person is having trouble urinating, try giving them a drink of water or run water while the person is on the toilet.
- If the person is restless, try giving them something to hold on to or use something else as a distraction.
- If the person is urinating in inappropriate places, remove any objects which may be mistaken for a toilet.
- Some people with dementia do not see white toilets. Clearly mark the toilet seat or use a colored toilet seat.

Managing Incontinence

- Observe the person's toileting patterns. Cue the person to use the toilet at regular times that follow their pattern.

- Watch for non-verbal cues, such as pulling on clothes, agitation, or a flushed face.
- Try toileting before and after meals, first thing in the morning and before bed.
- Always respect the person's privacy and dignity.
- Incontinence can be embarrassing and humiliating. Be sensitive to these feelings and treat the person with empathy and understanding.
- Use kind, respectful words. Using the word "diaper" is humiliating. Use "brief" or other acceptable term instead.
- Accidents are bound to happen. Treat the situation in a matter-of-fact manner. Never scold or humiliate the person.

Lesson Summary

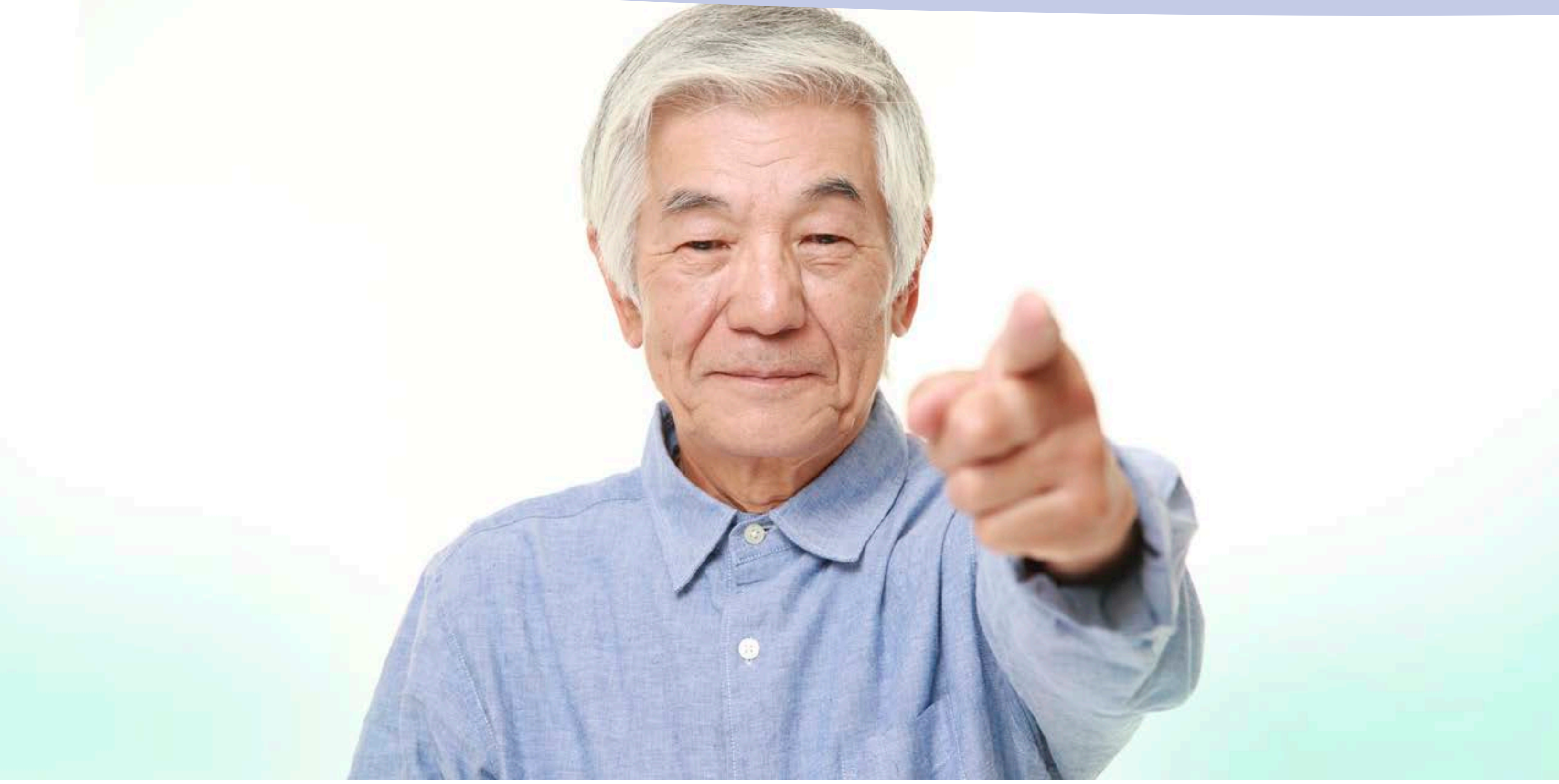
- Activities of daily living (ADL) refer to the basic tasks of everyday life. ADLs include bathing, dressing, eating, oral care, toileting, and mobility.
- ADLs should be about going through a day with the individual and providing companionship.
- Activities are important because they help a person with dementia to experience a sense of independence and control.
- By using your skills in empathy, patience, flexibility, creativity – you can make activities more person centered rather than task oriented.
- Each person has rituals and habits that should be learned and followed.
- When doing a single task becomes too difficult, simplify the task. Break it down to its smallest possible steps and give one step instructions at a time.
- It is important to celebrate what the individual can do rather than focusing on what they cannot do.

Checkpoint

Read the scenario below. Identify ways to assist with ADLs, such as bathing, dressing, eating, oral care, toileting, while focusing on Mr. Yard's strengths.

Zachary Yard, is a 54-year-old single man who has mid stage Alzheimer's disease. He wanders frequently and gets lost when walking to his room. He often repeats questions when getting ready for the day and usually forgets your name but seems to recognize your face. He is able to get dressed with cues. At times, he is argumentative toward you. As his Alzheimer's progresses, he has been flirting more with the women and displaying sexualized behaviors. He has been having trouble with his dentures and not wanting them in as he had before. He likes sweet treats and coffee.

Notes



Module 3: Fostering Communication and Understanding

Lesson 8: Communicating with People who Have Dementia

The caregiver will be able to demonstrate an ability to recognize communication styles and ways to communicate effectively.

Lesson 9: Trauma-Informed Care

The caregiver will recognize that past traumas can affect current thinking, behaviors and actions and will identify strategies to provide trauma informed care.

Lesson 8
Communicating with People who Have Dementia

Objective:

The caregiver will be able to demonstrate an ability to recognize communication styles and ways to communicate effectively.

Overview

Communication is more than a verbal exchange when caring for people with memory impairment. Even when verbal communication is difficult for a person, the person may still be able to use or read body language or sense your mood. By using effective communication strategies, you will maximize your connection with the individuals you care for.

Communication varies for each individual and the way we communicate is influenced by our past. Our past has many influences including our experiences, family, friends, work, traumatic events, traditions, culture, religion and spirituality. When you add the impact that dementia has on the brain, it adds new concerns to the communication process. Part of your responsibility working with individuals with dementia is to get to know them as a person. When you get to know people, you learn what is important to that person and how to communicate with them. As you get to know the person, you learn to communicate in a way that works for each individual and learn to recognize body language and tone of voice. This gives you the opportunity to identify possible concerns, and develop and maintain healthy relationships.

As dementia progresses, the way an individual communicates will change. Recognizing changes that occur during disease progression will also remind you that interactions are not about you. It is about the individual and that they are doing the best that they can. The person's best may look different from moment to moment, day to day, or over time. You must continue to do your best to be flexible, adjust and make changes to your approach to provide the best possible care for the individual.

Imagine you wake up in the middle of a new country where everyone is speaking a language you do not understand. How do think you would feel? How would you communicate if no one can understand your words?

Communication and Dementia

For individuals with dementia, it may feel as though they appeared suddenly in this place for the first time. They may not recognize faces, the words you speak, and they may not be able to speak the words they need to communicate with you as they had before. Luckily, there is a way to communicate. It is your job to know the individual, what works and what does not work. If something does not work, you must draw on your creativity and flexibility to try something new. You cannot expect the individual to change. You must be the one who changes for the individual.

There are two main types of communication - verbal and nonverbal.

Verbal Communication

Spoken words make up verbal communication. These are the words and sounds that we make to express ourselves.

Nonverbal Communication

Nonverbal communication is tone of voice, body language, and proximity.

- Tone of voice is how we say what we say, how we construct sentences, the sound of our words and the personality we communicate. Tone of voice includes changes in pitch and volume of your voice.
- Body language includes posture, eye contact, facial expressions and gestures.
- Proximity is the nearness in space, time, or relationship. Proximity can demonstrate aggression when too close or fear when moving back.

You are in a hurry to finish your morning ADLs with Barton Miley so you can get him to breakfast. You turn to the closet to put away some clothes and say in an aggravated tone "Can you PLEASE finish putting your shoes on so you can get to breakfast?" Even though your words are kind, your tone is not. How can you fix this?

Progression of Dementia and Communication Impact

Dementia affects the parts of the brain that control communication in different ways for different people and different types of dementia. As dementia progresses, usually there is a gradual decline in the person's ability to communicate. Changes will vary throughout the progression of dementia. In each phase, changes may occur in memory, comprehension, language skills, and social communication.

- Comprehension is the ability to understand the meaning of something. Is the message understood?
- Language skills include receptive language (the understanding of words and gestures that are received by the individual) and expressive language (how an individual expresses thoughts and feelings by using words, signals, or gestures.)
- Social communication is the ability to converse in social situations. Is there an interaction?

There are some general changes in communication you are likely to see. The person with dementia may:

- Have difficulty finding a specific word and say another word instead
- Not understand what you are saying or only understand part of it
- Speak easily but not make sense
- Talk about past events but not remember recent events
- Lose social graces, interrupt, ignore another speaker, not respond when spoken to, only talk about him or herself, or demand constant attention
- Have difficulty expressing emotions appropriately
- Have trouble with writing
- Be able to read words but may not understand the meaning

A person's language skill is not always a good indicator of understanding. Receptive and expressive language might be at two different levels. For example, the person may understand more than they can speak or speak more than they can understand.

As the dementia progresses, the person may partially or completely lose the ability to communicate verbally. It is important to remember that a person with dementia:

- Can still communicate in other ways
- Remains an important source of information
- Should be included in conversations to the greatest extent possible

The following pages explain some of the changes that occur in each phase of dementia. Remember that each phase of dementia and each individual will be different. Some interactions that would be appropriate with individuals who are in late phase dementia will not be appropriate with individuals in early phase dementia and vice versa.

Early Phase of Dementia

Memory

- May experience mild loss of recent memory.

Comprehension

- May have difficulty understanding complex conversations, talking that is too fast, and talking that takes place in noisy or distracting environments
- Understands facial expressions, gestures, and other nonverbal cues, but may be unable to understand humor and sarcasm
- Can follow directions if the directions are clearly stated
- Can understand written notes that remind or cue the person to do something. For example, "Take your heart medication at 2 pm."

Language Skills

- May have some problems thinking about what to say
- May have difficulties with words and use related words, such as "sugar" for "salt."
- Will often correct mistakes themselves
- Will continue to use good grammar if they have previously done so

Social Communication

- Changes the subject to hide that they are having difficulties
- Tend to repeat themselves
- Rely heavily on overused phrases or expressions (clichés)
- Manage to get along in most social situations
- Couples may cover for each other

Noah Granbury is sitting at the dining room table with a cup of coffee. He asks his wife, Wendy, to please pass him the salt for his coffee. She looks confused and he shakes his head and asks her for the sugar instead. Wendy is noticing that he has been having difficulty with words a lot more recently. She looks concerned and asks if he is ok. He changes the subject by asking her if she has seen the newspaper. Discuss the ways Noah's communication is impacted by early phase dementia.

Middle Phase of Dementia

Memory

- May experience moderate loss of long and short-term memory
- Remembers fewer words or concepts and less familiar names
- Will no longer be able to hide memory problems
- Learning new material becomes very difficult

Comprehension

- May have trouble understanding day-to-day conversations
- May be unable to understand when people talk too fast
- May have difficulty focusing and paying attention
- Are easily distracted by noise and other people talking
- May require repetition of simple directions
- Can read but may or may not understand the meaning
- Miss facial expressions but are still aware of their emotional meaning

Language Skills

- Lose the ability to remember names and words
- Ability to process words into ideas or ideas into words is slower
- Often use "gibberish"
- May endlessly repeat questions, words, or ideas
- May still use relatively good grammar
- Have difficulty reading and writing, use fewer words, and spelling errors are common

Social Communication

- Talking becomes unclear, empty, and not related to the conversation
- May find it difficult to start a conversation
- Ask fewer questions and seldom comment or correct themselves
- Answers to questions are often incomplete or not relevant to the question
- May forget the question that was asked
- Can still handle some casual social situations

Noah Granbury was diagnosed with Alzheimer's at age 76. He is now 79 and is now in your care. This afternoon you noticed him squinting at his newspaper and put it down with a frustrated look. The TV is on and there are people talking. He leaves the room. You approach Noah to see if you can help him. He turns away from you and starts talking about working at the grocery store. Discuss the ways Noah's communication is impacted by middle phase dementia.

Late Phase of Dementia

Memory

- Does not know the time, place, and person
- Fails to recognize self or family members (mirrors may be a problem)
- Cannot form new memories

Comprehension

- Does not understand the meaning of words
- May be unaware that someone is speaking to them

Language Skills

- May repeat things over and over or repeat what others say
- May use poor grammar
- May speak only in slang or nonsense or not talk at all
- Revert back to language of origin

Social Communication

- No longer aware of social interactions and what is expected
- May withdraw partially or completely
- May communicate in other ways

Noah Granbury is now 85 and still in your care. He often sits in his chair looking out the window. His wife, Wendy, comes to visit him often. She sits next to him and he glances at her, not recognizing her, then looks back toward the window. Discuss the ways Noah's communication is impacted by late phase dementia.

Strategies and Tips

Changes are taking place in the brain. Because of these changes, communicating with a person with dementia can be challenging. Communicating effectively may take more time, patience, and energy. It is important that you make the effort to be attentive and careful in the ways that you:

- Approach a person with dementia
- Give and receive information from the person
- Listen and interpret what the person is trying to communicate with you
- Watch for subtle and not so subtle changes in body language

The individual with dementia might ask the same questions repeatedly or repeat stories as if it was the first time telling it. Avoid saying, "you've already told me that story" or interrupting the individual. Remember that the brain is changing and the individual might not remember your answer or that they have shared a story with you. Be patient with the individual and respond positively. Ask for more information by saying, "tell me about it" or "tell me more about ______." Remember these stories so you can understand the person better as their dementia progresses and they are no longer able to share their stories.

A person with dementia may have difficulty understanding what you are saying, or react or respond in ways you are not expecting. As dementia changes the brain, the individual might become more rigid, inflexible, set in their ways or stubborn. The person may become more accusatory or seem mean when they were pleasant and gentle before. Experiences can influence how someone responds or reacts. A person with dementia might not want to interact with specific caregivers because of culture, race, nationality, gender or simply because the caregiver reminds them of someone else.

Do not take it personally.

Often a person with dementia becomes very sensitive to feelings and emotions. This means you will need to take extra care in how you approach a person with dementia and pay special attention to what you might be communicating non-verbally. Avoid arguing with the individual or needing to be right. Be willing to say you are sorry. Do your best to be kind, smile and remain positive.

Approaching a Person with Dementia

How you approach a person with dementia will set the tone of the interaction. Before approaching a person with dementia, check your attitude. If you are feeling tense or upset about anything, the person with dementia is sure to notice it. Do all that you can to be calm and relaxed.

- Show concern and support for the person.
- Approach the person slowly from the front or side. Do not approach the person from behind.
- Wait to have the person's attention.
- Introduce yourself every time you approach the person. Do not approach the person as if he or she should know you. The person may not remember you. Wearing a name badge can be helpful for someone who needs a little help remembering your name without it being obvious that they cannot remember.
- Use a friendly tone of voice and facial expressions. Smile!
- Call the person by their preferred name and tell why you are there. Know preferences on what the person likes to be called. If the individual has trouble recalling relationships, it might be helpful to use names, not relationship. (For example: Say "Hi Alice, its Mary." Not "Hi grandma, it's your granddaughter".)
- Use what you know about the person and offer support.
- Relax and go with the person's current reality.

Non-verbal gestures

Non-verbal gestures can enhance communication. Use hand gestures and facial expressions to be more easily understood.

- Touching and holding the person's hand may help keep his or her attention. Do not assume that the person likes to be touched. Ask before touching the person.
- Sit or squat beside a seated person – never stand above him or her.
- Watch your body language. The person with dementia will pick up feelings of anger, frustration or impatience.
- Use visual cues such as pointing, gesturing, demonstrating, using props.
- Do tasks with the person, not to or for the person.
- Use "social cues" that are familiar to the person. For example, sit down with two cups of coffee when you want to talk with the person. In this culture, coffee is often associated with conversation.
- Keep one hand on the person while busy doing tasks with the other hand to reassure them you are close and they are safe.
- Use soft touches and gradual movements.

Discussion: Why should you approach from the front or side? Why is body language an important part of communication?

Giving information

Giving cues or instructions on completing tasks can be a large part of your caregiving role. When you are assisting a person with dementia with personal care, this can become challenging.

Below are tips you can use to help make the task go smoother.

- Use a low tone (pitch) of voice. A raised or high-pitched voice can signal that you are upset.
- Talk slowly and clearly.
- Say less. Some people may only be able to process a few words at a time or only hear part of the words said.
- Slow down. Pause. Wait for responses. Allow time for questions.
- Point or demonstrate to help a person understand what you are saying.
- Use different words to get a point across if the person does not understand the first time.
- Use the names of people and objects whenever you can.
- Keep sentences short and simple. Focus on one idea at a time.
- Ask, rather than tell the person what to do. You will get a much better reception by not commanding or ordering the person to do things.
- Limit information to current reality and limit future date information.

Getting information

To the greatest extent possible, the person with dementia should continue to be actively involved in making decisions regarding care. Sometimes getting information from the person regarding his or her preferences can be difficult.

The following tips can help you get more information from the person.

- Allow plenty of time for the person to think about what was asked. Do not assume the person understands or agrees with you because he or she does not respond right away.
- Try not to finish the person's sentences.
- Do not talk over another person. Talk one at a time.
- If the person has difficulty finding a word, ask him or her to explain it in a different way or possibly spell it if that works for the individual.
- Avoid or reframe open-ended questions. Instead, offer alternative responses and allow for spontaneity.
- Avoid reason, logic, or the mention of time. All of these require complex thought processes that the person may no longer have.
- Ask one question at a time.

Discussion: Give some examples of ways you can give information on a specific activity of daily living. Talk about ways you can involve the person with the specific ADL.

Listening and interpreting information

Listening is more than hearing words. It is being aware of body language, emotions, movements and feelings.

- Listen for and learn to recognize the person's feelings and emotions. Use your senses, as well as your intuition, to understand what the person is attempting to communicate.
- Validate. Focus on the person's feelings being expressed rather than concentrating on what the person is saying.
- Remain still when the person is talking. It will show the person that you are trying to understand.
- Remember that you do not need to react or respond to everything the person says. Sometimes, the most appropriate response is just to listen.

Communicating respect

Respect must be given to everyone you interact with as an individual.

- A person with dementia is extra sensitive to feelings and emotions. It is important to be aware of what you say, and how you say it. Make sure that your communication is respectful.
- Keep the person's culture and beliefs in mind and know what respectful communication is in that culture. Talk to the person's family to learn more about what is respectful.
- Focus on the abilities the person still has.
- Do not talk down to the person or treat him or her as a child. Conversation should be simple, but remain on an adult level.
- Talk to the person. Do not talk about him or her as if he or she were not present. Even though the person may not understand everything that is said, it is important to preserve the person's dignity and self-esteem.
- When the person's family or friends are present, continue to interact with the person with dementia. Let the family know that the person with dementia should be a part of the conversation. Tell the family that they will also have a chance to provide information.

Discussion: Why is it important to listen to more than the words that are spoken? What are some ways that you feel respected from your perspective, culture and background?

Importance of environment

To facilitate better communication with a person with dementia, make sure the environment is favorable to good communication.

While it is difficult for anyone to carry on a conversation when there are too many other things going on, it is even more difficult for a person with dementia. A person with dementia is easily overwhelmed with too much stimulation or noise.

To make the environment more conducive to quality communication:

- Avoid competing noises. Turn the television on mute, turn down the radio, or move to a quieter location, if needed.

- Check that any problems a person may be having communicating are not due to the person's impaired vision, hearing, or poorly fitting dentures. Make sure glasses, hearing aids, and dentures are all clean, correctly prescribed and fit appropriately.
- Ensure the lighting is adequate for the person to see you but not so bright that it causes a glare.

Discussion: What are some distractions in the environment that you work in that might influence the quality of communication?

Practicing communication strategies

When working with people who have dementia, be prepared to be creative and try a variety of strategies to improve communication. If something is working, continue using the strategy until it does not work. See what else works. You may be able to go back and reuse strategies that worked before. Share these strategies with others.

Listed below are some specific tips and strategies to enhance your ability to communicate effectively with a person with dementia. These tips and strategies are not things we practice often or give much consideration to; however, when communicating with a person who has dementia, they are important. As a caregiver, you will need to:

- Avoid or reframe open-ended questions.
- Avoid reason, logic, or the mention of time.
- Ask, rather than tell the person what to do.
- Say less
- Practice "Gentle Deception"

Practice these communication strategies and consider how your approach might be specific to the person with dementia.

Avoid or reframe open-ended questions

Open-ended questions are questions that cannot be answered with a simple "yes" or "no" or with a specific piece of information. They require the person responding to give thought and make sense of what is being said. For the person with dementia, this might be difficult.

As a caregiver, you may reframe open-ended questions by:

- Suggesting an answer and allowing the person to respond.
- Asking a question in a way that allows for a "yes" or "no" answer.

Ruth is an 80-year-old woman with Alzheimer's disease in your care. Read the following scenario:

You are helping Ruth dress today. Ruth goes to the closet and opens the door, where there are many clothes with lots of choices.

You: "Okay, Ruth, I'm here to help you dress today. What would you like to wear? Would you like to wear pants or a skirt or would you prefer to wear a jogging suit?"
Ruth looks distressed.

Why might the questions be difficult for Ruth to answer?

What could you do instead?

John has Frontotemporal Dementia (Picks disease) and lives at home. You are the caregiver for him today and it is time for lunch.

How might you ask John what he would like for lunch (avoid using an open-ended question)?

Avoid reason, logic, or the mention of time

A person with dementia sometimes loses the ability to use complex reasoning and to process information logically. Time, for a person with dementia, is not always sequential. When a person has dementia, sometimes time can be the present moment, sometimes it may be the past, and sometimes it may be the future.

This means that if you ask questions or give directions using reason, logic or time, you may be asking the person to do something that is impossible for him or her to do.

You come to let Ruth know that it is time for lunch.

You: “Ruth, the morning flew by, didn’t it? Do you know what time it is?”

Ruth looks overwhelmed and frustrated.

Why could this question be difficult for Ruth?

How can you improve communication with Ruth?

Melvin has Lewy Body Dementia and lately, he wants to go outside in the snow without a jacket. You are Melvin’s caregiver and you know that he will freeze if he goes out without a jacket.

What might you say or do to help Melvin (avoid using logic or the mention of time)?

Ask, rather than tell the person what to do

Telling a person with dementia what to do can be frustrating to the person who cannot remember even the obvious "right" way to do something. "Don't do that" sounds like a parent scolding a child and can be viewed as threatening. It might also be viewed as disrespectful if a younger person tells an elder what to do. Rather than telling the person what to do, encourage the person and ask for their participation in the task.

Bill has mid stage Alzheimer's disease. You enter his room. You would like Bill to put his shoes on.

Demonstrate how you might get him to put his shoes on.

What if he resists?

You are Sue's caregiver. You enter her room where she is seated on the bed trying to put her legs through her shirtsleeves.

How might you approach Sue and help her with dressing?

Say Less

When you give complex information, the person with dementia may be unable to understand more than a small part of the conversation. That is why sentences should be kept short and simple.

You enter Bill's room, where Bill is seated peacefully on the bed.

> You: "Let's get you dressed for breakfast. There is a sing along after breakfast and this is one of your favorite activities. Let's get you dressed."

How might Bill react to this request?

What might you say or do to help Bill by saying less?

Gentle deception

Gentle Deception involves letting go of the "truth" or your reality to hear what the person with dementia is saying. The idea is to let the person say whatever they want to say without trying to persuade the person that they are wrong, incorrect, or out of touch with reality. Instead, you agree with the person and allow the person with dementia to retain their sense of reality. Offer redirection by supporting what the person is saying and asking other questions like "tell me more about it."

Ruth repeatedly states she wants to go home. Ruth's home has been sold and you know that this is not a possibility for her to go home.

> Ruth: "I want to go home. I don't know where I am. My family is probably worried about me. Get me out of here, let me go home now!"

Discuss what might happen if you tell her that her home was sold and she cannot go home.

Demonstrate using gentle deception instead.

Mrs. Hoyton's husband died several years ago. Every morning she asks staff, "Where is my husband? He is supposed to pick me up."

Using Gentle Deception, how might you respond to Mrs. Hoyton?

Pulling it all together

Tips and strategies can help you in communicating more effectively with the person who has dementia. In addition to these, there are some general things to keep in mind.

These include:

- Recognizing that each person is unique and each relationship is different.
- You may need to try several approaches to discover what works best for you and for the person with dementia.
- You may need to change your expectations if they are not realistic.
- You will communicate more effectively if you accept the values, beliefs, and reality of the person with dementia, even if it has no basis in your reality.

Many of these tips and strategies seem simple, yet when you are busy with day-to-day routines, it can be easy to forget to use these. And often, you are dealing with multiple tasks and demands so using these strategies will take practice to get them right.

Lesson Summary

- Communication is more than a verbal exchange when caring for people with memory impairment.
- Even when verbal communication is difficult for a person, the individual may still be able to use or read body language or sense your mood.
- Communication varies for each individual and the way we communicate is influenced by our past.
- As you get to know the person, you learn to communicate in a way that works for each individual and learn to recognize body language and tone of voice.
- As dementia progresses, the way an individual communicates will change in memory, comprehension, language skills and social communication.
- You must continue to do your best to be flexible, adjust and make changes to your approach to provide the best possible care for the individual.
- There is a way to communicate.

Checkpoint

You have a busy schedule and have many tasks to complete before your day is complete. You enter Bill's room. Bill needs a bath and you want him to hurry.

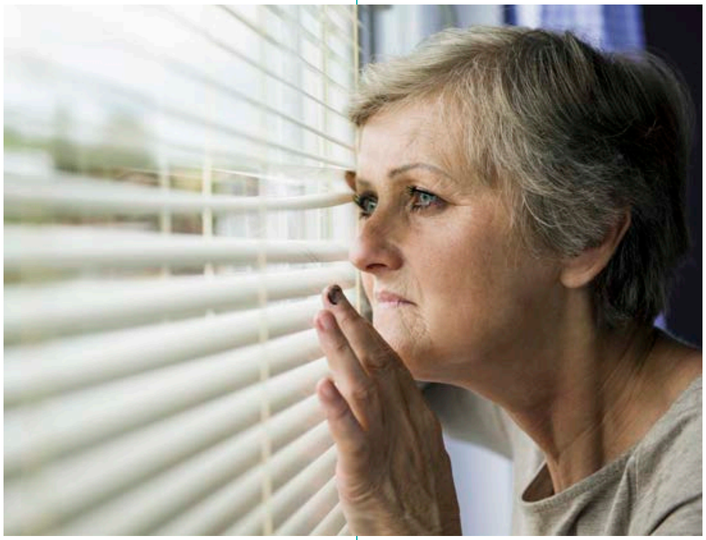
Describe how you would communicate with Bill to get his bath finished.

If Bill becomes distressed during his bath and says he will be late for school, how would you use gentle deception to communicate with Bill?

Lesson 9
Trauma-Informed Care

Objective:

The caregiver will recognize that past traumas can affect current thinking, behaviors and actions and will identify strategies to provide trauma informed care.



Overview

Trauma and adverse life events can have a lifelong impact on people. Whether that event occurred throughout childhood or as an adult, as a caregiver, you will need to understand that your past and an individual's past experiences will influence current thinking, behaviors and actions. Trauma is defined as an individual's experience of an event or enduring condition that is an actual threat or perceived as a threat to their life and personal integrity, or that of a caregiver or family member. Adverse life events are often associated with trauma responses and might include events such as physical, sexual and emotional abuse, or witnessing abuse or substance use disorder within the family. Other events such as illness, injury, accidents, hospitalizations, loss of employment or loss of a loved one might also create a trauma response. Many people have resilience to adverse life events and never develop trauma responses. Others however experience symptoms of depression, anxiety and post-traumatic stress disorder (PTSD).

The perception of trauma is subjective - meaning that each person may see trauma their own way and at different amounts of severity.

Take a few minutes to reflect on an event that occurred in your past that made you feel bad, sad, stressed or threatening to you or someone close to you. Has it influenced your life and behaviors?

Brainstorm events that might have affected the individuals you might work with. Discuss how these events might display or influence on an individual with dementia.

1. Loss of a child or spouse
2. Holocaust, or other tragic and terrible events against communities or groups of people
3. Victim of domestic violence
4. Victim of sexual abuse
5. Traumatic accidents such as train, plane crashes etc.
6. Military war experience
7. Other.

Coping Mechanisms

From these adverse life events and trauma, an individual might develop coping mechanisms. Coping mechanisms are the ways that people deal with stress and trauma. Some common coping mechanisms:

- Defense - defending from or resisting attack.
- Adaptive - tolerates the stress.
- Avoidance - keeps self away from the stress.
- Attack - diverts one's consciousness to a person or group of individuals other than the stressor or the stressful situation.
- Behavioral - modifies the way we act to minimize or eradicate the stress.
- Cognitive - alters the way we think so that stress is reduced or removed.
- Self-harm - intends to harm self as a response to stress.
- Conversion - changes one thought, behavior or emotion into another.

Impact of Culture

A person's cultural identity can include nationality, religion, income, age, education, sexual orientation, mental and physical abilities, gender, profession, and ethnicity. Culture shapes how we identify and interpret the threat of traumatic events and how we respond to or cope with these events. Culture can shape how a person experiencing the trauma reacts and responds, and it can shape how individuals and communities perceive and judge the trauma experienced by another person. If an individual, who experiences trauma, feels that society will not accept them as a victim or their culture rejects, judges, or stigmatizes them the individual may withdraw and be silent.

As a caregiver, you should be aware of your own cultural biases and try to remain non-judgmental.

- Be respectful of cultures, spiritual beliefs and routines.
- Be aware of appropriate body language.
- Say please and thank you and request permission to do tasks.

Trauma Informed Care

Trauma informed care (TIC) is an approach that aims to engage people with history of trauma, recognize the presence of trauma symptoms, and acknowledge the role that trauma has played in their lives. Many people have had some level of trauma in their past. Adverse childhood experiences (ACEs) are defined as preventable, potentially traumatic events that occur among persons aged 18 or younger and associated with numerous negative outcomes. 63.9% of U.S. adults reported at least one ACE. (2019-2020.

TIC is not about treating the trauma or symptom management. Instead, TIC is about gathering information about each person you care for and about potential trauma the individual has experienced. TIC is about remaining sensitive to issues or behaviors the individual might have related to past trauma. The focus is on what has happened to the person rather than what is wrong with the person. Instead of asking what is wrong with you? Ask what has happened to you and how can I support you. An individual with dementia may not be able to answer you, may not remember the traumatic event, or may at some point return to the time of life that they were experiencing the trauma.

TIC is a culture shift where individuals, their personal story, their history, and culture must be separated from their condition(s) and protected from physical harm and re-traumatization. A foundation for TIC will enhance the emotional well-being and quality of life for the individuals you care for. Screening should be done when an individual first comes into your care to see if there are any sensory triggers and if there are any calming or stress responses that follow.

A caregiver should initially approach the people they care for as if they have a trauma history. When you provide good trauma-informed care, you enhance physical and emotional safety, and improve relationships, and behaviors. Recognizing that an individual might be traumatized can give you a better understanding of behaviors or attitudes that may be related to the trauma. Approach all people with empathy, caring, compassion, and support. Understand that some routine care tasks might be threatening to someone who has experienced trauma. A trauma trigger is an experience that causes someone to recall a previous traumatic memory, although the trigger itself might not be frightening or traumatic and can be indirectly or superficially reminiscent of an earlier traumatic incident. Triggers might be anything from a date or anniversary, a color, a smell, something in the environment, dressing or undressing.

If you notice that a trauma is triggered, whether it is a known or unknown trauma, remain sensitive to the individual and do something about the circumstance to fix it. Be aware of the key principles of trauma informed care and implement them into your daily routine with the individuals you care for.

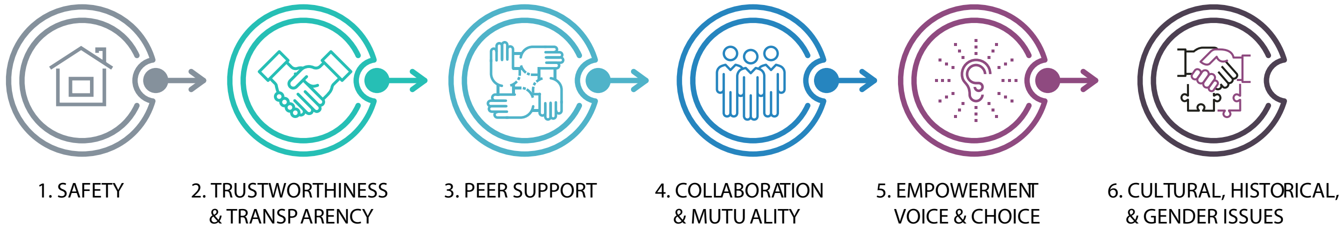
You have been hearing from others that Ms. Denner has been screaming every time someone tries to shower her. You are not looking forward to assisting with her shower today. You try to approach Ms. Denner with a smile and you use a towel around her to help with possible privacy concerns. She still screams in the shower. After talking with your supervisor and the family, you find out that Ms. Denner is a concentration camp survivor and her memory of white tiled shower rooms were gassing chambers. Discuss ways that you might handle this in the future.

Principles of trauma-informed care

Trauma informed care identifies traumatic events that an individual has experienced and views them not as past events, but as experiences that form the core of the person's identity. When caring for individuals with dementia, add the principles of trauma-informed care to your toolbox and incorporate them to develop a relationship and connection with individuals you care for.

The six key principles of trauma-informed care are:

1. Safety
2. Trustworthiness & transparency
3. Peer support & mutual self-help
4. Collaboration & mutuality
5. Empowerment, voice & choice
6. Cultural, historical & gender issues



TIC Principle	Description
Safety	People feel physically and psychologically safe
Trustworthiness & transparency	Decisions are made with transparency and the goal of building and maintaining trust
Peer support & mutual self-help	Key for building trust, establishing safety, and empowerment
Collaboration & mutuality	Recognition that healing happens in relationships and in the meaningful sharing of power and decision-making
Empowerment, voice & choice	Strengthen the experience of choice and recognizes that every person's experience is unique and requires an individualized approach
Cultural, historical, & gender issues	Move past cultural stereotypes and biases, offering culturally responsive services, leverages the healing value of traditional cultural connections and recognizes and addresses historical trauma

Strategies

To effectively work with people who have trauma, you must first take care of yourself and find a work/life balance. (See Lesson 3 on Self Care.) Your behavior and approach are essential to the well-being of the individuals you care for. Failing to understand trauma and the impact it has on behavior can have a negative impact on the individual and there might be a possibility of re-traumatization. Some generations might not complain, discuss or admit to traumatic events. Even friends or family might not know about the trauma event. Understanding that symptoms or behaviors an individual displays are attempts to cope with the adverse events they have experienced in their life may remind you to be kind and compassionate toward the individual.

Activities such as drumming, singing, dancing and yoga have shown to be effective in emotional and behavioral regulation and in easing the impact of trauma.

While some behaviors that come out of trauma are negative, there can be strategies to help people cope that can have positive outcomes. Remember to meet individuals where they are and their current ability and celebrate successes and strengths rather than holding an expectation that the individual should be able to perform at the same level as they did before dementia.

Listed below are some activities that may be useful for various individuals.

- Aromatherapy
- Bake
- Clean something
- Dance
- Drawing, doodling, scribbling
- Exercise
- Hug a pillow or stuffed animal
- Knit or sew
- Listen to favorite music
- Look at pretty things like flowers or art
- Meditate
- Paint nails
- Plant seeds
- Play a musical instrument
- Pray
- Punch a punching bag
- Read or be read to
- Rip paper
- Sing
- Spend time with other people
- Take a nap
- Take a relaxing bath or shower
- Watch favorite show
- Watch fish
- Write

Think of some other ways that might help a person might cope and write them down. Share these ideas and write down more ideas you learn from others.

Lesson Summary

- An individual's past experiences will influence current thinking, behaviors and actions.
- Many people have resilience to adverse life events and never develop trauma responses. Others experience symptoms of depression, anxiety and post-traumatic stress disorder (PTSD).
- An individual might develop coping mechanisms. Culture shapes how we identify and interpret the threat of traumatic events and how we respond to or cope with these events.
- Trauma informed care (TIC) is an approach that aims to engage people with history of trauma, recognize the presence of trauma symptoms, and acknowledge the r ole that trauma has played in their lives.
- TIC is about gathering information about people you care for and about potential trauma the individual has experienced. TIC is about remaining sensitive to issues or behaviors the individual might have related to past traumas.
- Instead of asking what is wrong with you? Ask what has happened to you and how can I support you.
- The six principles of trauma-informed care are: 1. safety, 2. trustworthiness and transparency, 3. peer support, 4. collaboration and mutuality, 5. empowerment voice and choice, 6. cultural, historical and gender issues.

Checkpoint

Read the scenarios below and write the letter of the principle that is the best fit on the line provided.

A. Safety
B. Trustworthiness & Transparency
C. Peer Support and mutual self-help
D. Collaboration and Mutuality
E. Empowerment, Voice and Choice
F. Cultural, Historical and Gender Issues

________ 1. Recognition that healing happens in relationships and in the meaningful sharing of power and decision-making.

________ 2. Decisions are made with transparency and the goal of building and maintaining trust.

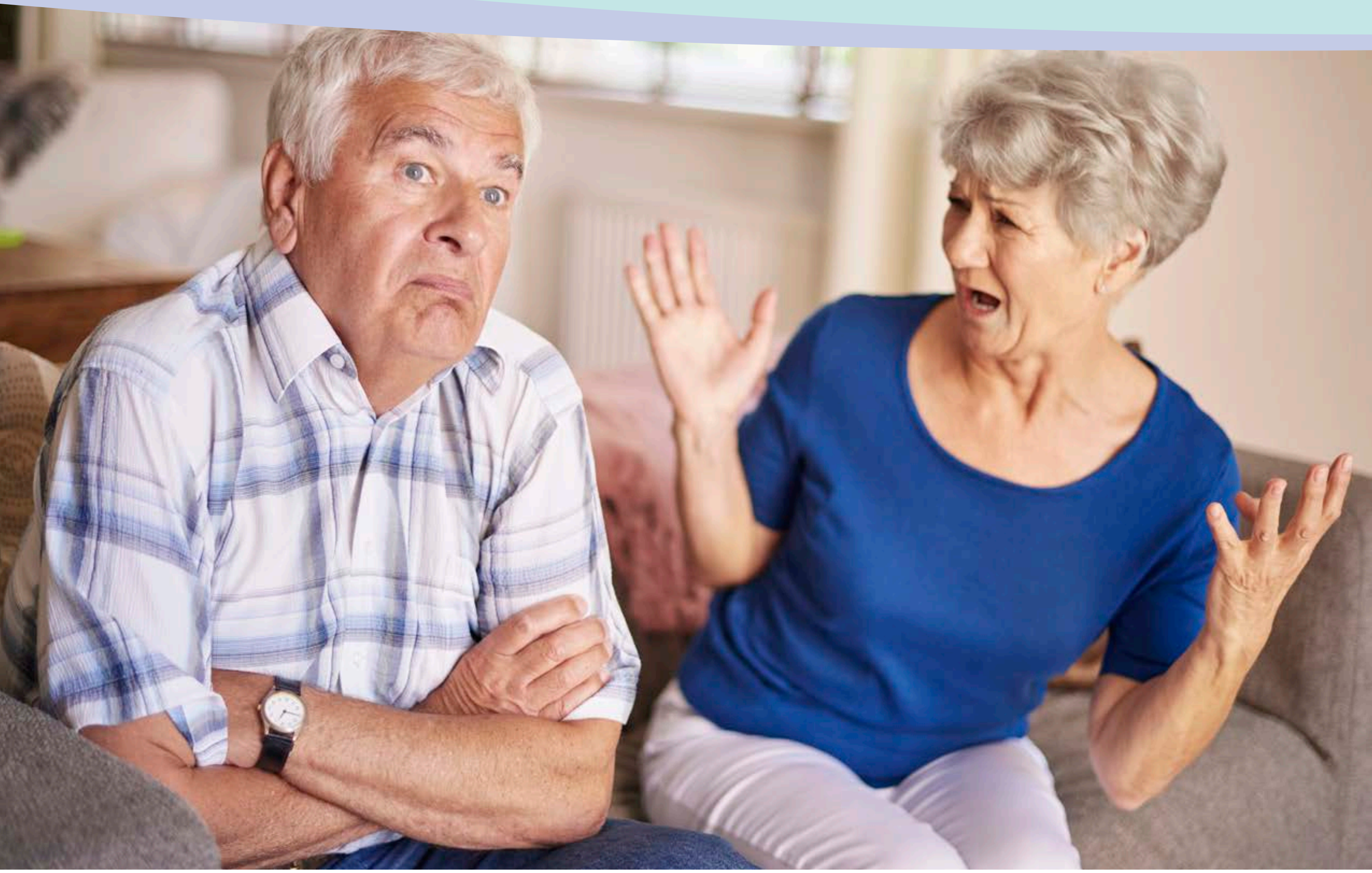
________ 3. People feel physically and psychologically safe.

________ 4. Strengthen the experience of choice and recognizes that every person's experience is unique and requires an individualized approach.

________ 5. Key for building trust, establishing safety, and empowerment

________ 6. Key for buiding trust, establishing safety, and empowerment.

Notes



Module 4: Challenging Behaviors

Lesson 10: Approaching Challenging Behaviors

The caregiver will demonstrate the sequence of steps to approach challenging behaviors.

Lesson 11: Tips for Dealing with Specific Challenging Behaviors

The caregiver will demonstrate an understanding of navigating challenging situations.

Lesson 10
Approaching Behaviors

Objective:

The caregiver will demonstrate the sequence of steps to approach challenging behaviors.

Overview

So far, you have learned that dementia is a broad term used to describe symptoms that result when the brain is damaged by disease. When brain cells cannot communicate normally – thinking, behavior and feelings are affected. You have learned about the importance of caregiving qualities to be empathetic, dependable, patient, strong, flexible and creative. You will need to use all these qualities when approaching each individual and their behaviors. Several outside factors can influence behavior beyond the disease – a person's history, medication side effects, pain, unmet needs, ability to communicate effectively and past traumas.

Individuals with dementia may behave differently than they did before dementia. They will often communicate in unique ways through their behaviors. Some refer to them as "behavioral expressions". In your role as a caregiver, when faced with a challenging behavior or situation, stop and take a step back; identify what the individual needs, and take action to meet the need.

These behaviors, when responded to in a friendly and effective manner, can help enhance your satisfaction as a caregiver and promote a better quality of life for the individual with dementia.

Imagine that you are checking into a hotel. You have been traveling all day and you are tired. You put your suitcase in the closet and crawl into one of the beds. You pull the covers over and turn the light out. It is not long before you are sleeping soundly. In the morning, you open your eyes and you roll over to find the housekeeper from the hotel trying to get you out of bed. What would you do?

Exploring Behaviors

Individuals with dementia use behaviors to communicate a personal need, feelings, and emotions. There might be many things going on with the person that may contribute to the behavior. To decide how to best respond to the behavior, you need to take a step back and try to figure out what the person's behavior may be telling you. There is no one size fits all solution when dealing with behaviors. Different people have different needs.

Strategy for Approaching Behaviors

While there are several strategies to work with behaviors, your primary role is to remain and appear calm and supportive and do not take the behaviors personally. Remember that the individual with a diagnosis of dementia is not behaving in a way to get attention or to be mean. They are expressing a need. You must know the individual's history, habits, current needs and abilities. There is no right/ wrong view of challenging behaviors.

To approach behaviors: stop, identify and take action.

1. Stop

When you are faced with an unexpected behavior, take a moment to stop yourself and take a step back from the situation. Make sure you are not reacting. Calm yourself and focus. Most behaviors that are challenging have a cause or a trigger. There is a reason for the behavior. Behaviors that are challenging are likely a reaction to something that set the behavior in motion. Having a reaction means that the individual is unconsciously, emotionally, and possibly impulsively behaving without any thought to a situation or event. It is your job to respond. Responding is acting with thought instead of just reacting.

Responding versus reacting to a challenging situation takes self-control and discipline. The best way to respond and not react is to stop before taking action unless someone is in immediate danger.

- Stop or pause even if only a few seconds
- Calm yourself

Calming techniques

If you find yourself reacting instead of responding, there are many ways to get calm and focused. Find something that works for you.

- Take a few deep breaths.
- Count to ten.
- Detach yourself from the emotions of what is happening around you.
- Separate the behavior from the person.
- Recognize it is not about you.
- Repeat a positive phrase or affirmation to yourself such as "I am calm and relaxed in every situation" "I remain calm and positive in difficult situations" "I remain calm and in control under stress."
- Get a clear picture in your mind of armor surrounding and protecting you from harm.
- Imagine a scene, person, or experience that gives you a feeling of calm.

What are other ways you can calm yourself? Take a moment to list and share.

If you are still unable to get yourself calm and focused, give yourself a brief time-out (if possible in your situation) or ask for help. It is better to walk away for a few minutes and collect yourself than to risk reacting and making the situation worse.

2. Identify

After you take a moment, it is time to use your detective skills and figure out what is happening. Identify what caused or triggered the behavior. You should know the individual's routines, preferences, and daily rhythms related to care and life history. When you see a change that concerns you, remain emotionally available to the individual.

- Show genuine interest and concern.
- Realize that your own personal feelings of stress, personal worries, and time pressures can add to any emotional tension the individual is experiencing.
- Listen to what the person is communicating through body language, words, and the emotions behind their actions.

The individual might be expressing a need or desire or there might be a trigger that is physical, environmental and/or emotional.

Expressing a need or desire

There are many reasons an individual may not be able to communicate with words what they need or want. The person with dementia may not be able to:

- Speak.
- Process things quickly enough to explain what is happening or needed in the moment.
- Understand themselves due to the disease.
- Have strength to speak words. For example, he or she may be in too much physical and/or emotional pain.

Sometimes what you may see as a behavior that is challenging may be the only way the individual can tell you that they need or want something.

Physical, environmental, and emotional triggers

The following are some common triggers to look for that may be causing the behavior.

Physical triggers such as

- Symptoms of his or her disease(s) or condition(s)
- Infection, such as urinary tract infection (UTI)
- Pain
- Medication side effects or drug interactions. This is especially important when medications are added or stopped.
- Dehydration
- Hunger or thirst
- Fatigue
- Recent injury
- Incontinence
- Constipation
- Unmet physical care needs such as needing to go to the bathroom
- Uncomfortable clothing
- Reaction to care being given

Environmental triggers such as

- Too much noise or too many people
- Intrusion into personal space
- Temperature (too hot or cold)
- Something unfamiliar being added in the environment
- Something familiar being removed or moved
- Lack of privacy
- New environment or unfamiliar people
- Too bright or too dark
- Smells
- Full moon or sun setting
- Shift change

Emotional triggers such as

- Change in routine (especially if the individual feels no control over the change)
- Recent big changes or losses
- Difficulty with family, friends, other care team members
- Need to regain a sense of control
- Depression
- Boredom
- Past or current events
- Anxiety
- Fear
- Loneliness
- Lack of intimacy
- Emotional state of other people

The perspective of the individual you are caring for is what is important when looking for possible triggers. What has triggered the individual's behavior can be very different from what would trigger yours.

Think about triggers that are physical, environmental and emotional. Take a moment to list some additional triggers for each category. Share your ideas.

Physical:

Environmental:

Emotional:

Other things to look for:

- What happened just before the behavior started?
- Were there other people involved when the behavior occurred?
- Where did it occur?
- What is happening in the person's living space?
- Is this a new behavior?
- Are there certain actions that make it worse?
- Is the individual trying to communicate a need or desire?
- Are there any patterns you can see? For example, is there a certain time of day, events such as shift changes, a particular caregiver or visitor, substances like sugar or caffeine, or after taking a certain medication that sets it off?

3. Action

Because there are no "one size fits all" formulas to handle challenging behaviors, what works in one situation may not work in another and may not work in the same situation. What works with one individual may have the opposite result with another. The best way to deal with challenging behaviors is to adapt as you go to each unique individual and situation. This means that you must be:

- Constantly aware of signals the individual is giving off.
- Ready to adapt, walk away, soothe, distract, or respectfully steer the individual away from what triggered the behavior.
- Willing to do something different if what you tried does not seem to be working.

Minimize or eliminate the trigger

If you have an idea what is causing the behavior, try to stop or minimize the trigger. If meeting an individual's need or request can minimize or eliminate the behavior, ask yourself the following questions:

- Does it hurt anyone to do it?
- Are you bothered because it
  - Makes you change or adjust YOUR schedule?
  - Might look odd or unusual to others?
  - Requires you to "think outside the box?"
  - Would be easier to do it the "regular" way or at a less busy or unusual time?
- Is the individual experiencing pain?

Adapt

Look for ways to adapt to the individual and their routine. This can include:

- Changing when or how the individual receives care.
- Breaking tasks down into smaller steps.
- Taking frequent breaks to allow the individual more time to do each step.
- Not doing certain tasks as frequently or doing them at a different time.
- Doing more prompting or cuing.
- Encouraging independence and choice in even the smallest ways.
- Using assistive devices to their fullest extent.

Common Pitfalls:

- Orient to reality.
- Correct behavior.
- Ignore the behavior.
- Argue with the person with dementia.
- Attempt to use reasoning to change the behavior.

Be aware and observant of subtle details. The answer for successfully navigating through behavior that are challenging are often in the subtle details of who the individual is as a person.

- How do you know when the individual likes or does not like something?
- What types of things, situations, or people seem to make the individual frustrated, anxious or nervous, angry, etc?
- What pace of activity is comfortable for that individual? How do you know when it is too fast or too slow?
- How does the individual communicate (both verbally and with body language) what he/she wants?
- Is there anything you can learn about the individual's general personality that gives you an overall sense of the best way to work with them?
- Is there anything unique to the individual's culture that could be contributing to the challenging behavior?

When you get to know some of these more subtle things about an individual, you can watch for early warning signs of possible problems. Take action immediately to help the individual feel calmer and more reassured (reduce or minimize the trigger, give space, calm, distract, reassure, etc.)

Give space

Ask yourself if giving the individual some space would be best. If it is safe, come back in five or ten minutes. This may give the individual time to calm down. Some quiet time may be all it takes to resolve the situation. Giving space can also mean staying with the individual and respecting his or her need for personal space. How much space does the individual appear to need around their physical body? Is the individual hypersensitive to touch? Movement? Claustrophobic? Is there a particular way you can approach the client that seems less unsettling to them? Knowing the answers to these questions can help guide you in how to approach the individual any time, but especially when the individual is highly reactive.

Tips when approaching

Pay special attention to how you approach individuals with dementia. A sense that you are invading personal space is a common trigger of challenging behavior. Remember to:

- Knock. Ask permission to enter personal space.
- Approach from the front so he/she knows you are there.
- Smile genuinely.
- Try to get the person's attention before you talk.
- Move slowly. Avoid sudden movements.
- Identify yourself and why you are there.
- Address the individual by the preferred name.
- Spend a few minutes talking with the individual before providing care. This gives you time to see how the individual is doing and gauge if it is safe to proceed with care.
- Explain what you are doing.

Soothe and comfort

- Slow down your own movements and energy.
- Try not to show any anxiety or other intense emotions. They will likely increase the reactions from the individual.
- Validate the person's feelings.
- Speak slowly, softly with a low pitch, and in a reassuring tone. Make sure the individual can hear you if he or she has trouble hearing.
- Offer things you know comfort that individual (warm blanket, rocking chair, quiet music, a cup of tea, turning on a favorite show, a favorite object, holding a pet).
- Reduce distractions or loud background noises as much as possible. Examples might be turning down the TV, asking others in the room to step out, or turning down the lights. Ask the individuals permission before doing any of these things.
- Play relaxation or anti-anxiety music or meditations.
- If touching might be comforting, offer physical comfort such as lightly stroking the individuals hand, giving a hug or a back rub. The appropriateness of comforting touch depends on the individual's and policies where you work. If offering comforting touch is allowed, ask the individual's permission first. Make sure you know preferences when it comes to touch and back off immediately if it further upsets the person.

General rule, remember that your body language is your best communication tool. This means that it is critical that:

- Your posture, facial expressions, and stance are relaxed and open.
- Your tone is respectful and calm.
- You move slowly.
- You stop what you are doing and focus on the individual.
- Your body language matches the words you say to the individual.

Reassure

- Listen! Let the individual talk about their feelings. Do not ask a lot of questions at first. Let the individual get some of the excess emotions out. Listening helps make sure the individual knows that he/she has been "heard" by you. (Remember listen to both words and body language).
- Be understanding and sympathetic. The individual will be more likely to respond favorably if you sound sympathetic rather than insincere, annoyed, frustrated or angry.
- Maintain clear boundaries if you are treated with disrespect or threatened.
- This is not the time to have a talk about the behavior. Wait until later when the situation is calmer to work through any boundary issues or concerns.

Distract or redirect

- Distract the individual by offering choices such as a calming or favorite activity such as a walk, snack, or beverage.
- Change the conversation to something positive that may redirect the person.
- Encourage the person to take several deep breaths.
- Reinforce positive behaviors.

Encourage

- Listen.
- Use praise liberally while remaining mindful that the individual is an adult. (Be careful that the praise does not become child-like)
- Reinforce positive behavior no matter how small.
- Encourage keeping happy reminders, such as family pictures or treasured keepsakes in plain view.
- Encourage the individuals to engage in healthy behaviors in diet, exercise, and socializing with others.

Protect and support others being impacted by the behavior

It can be upsetting for others to see or be part of the challenging behavior. Remember to stay aware of others in the area. Take action to support and protect others if they are impacted.

Get help

If you need help, get it. Especially when medical or other emergency help is needed. Know what your policy is on involving other individuals such as medical personnel, other team members, family, friends or guardians.

Speak up immediately if you ever feel you are at your own breaking point or limit when dealing with an individual who is exhibiting challenging behavior.

Self-care

As a caregiver, you need to replenish your emotional reserves after handling stressful behaviors. This requires good self-care. Take time to manage your feelings. Refer to lesson 3 for tips on self-care.

Rosella Borowski has been in your care for almost two years. She is now 73 and her Alzheimer's has progressed and she is now unable to remember new information for even two or three minutes. Rosella often talks to you about starting college soon. She talks about saving her money to go to school to become an artist. Today, you approach her as she is pulling items out of a drawer. She looks at you suspiciously and accuses you of stealing her paintbrushes and hiding them from her.
Use the three steps to approach this behavior.

1.

2.

3.

Prevent or minimize challenging behaviors

Once the heat of the moment has passed, you may have more time to reflect on what triggered the challenging behavior. This information helps you take steps to avoid these situations from happening again. With more time to reflect, you may see additional patterns or concerns.

De-escalation

De-escalation is the action you take to reduce the intensity or escalation of conflict, crisis or a potentially violent situation.

When an individual that you are providing care for is upset, angry, aggressive or violent, it is important to have tools to help the individual regain a level of calm or de-escalate the situation.

In any situation, the only thing you have complete control over is yourself. You cannot control the actions of others, although you can learn tools to support the individuals you care for. Caregiving is a profession that provides care for individuals who may experience an elevation of conflict, crisis or potentially violent situation.

Each individual may have events, dates or situations that trigger them to elevate. Being aware of the individuals you care for, being trauma-informed and using the three-step process for behaviors can help minimize escalating. Successful de-escalation begins with you and your attitude, beliefs and actions. You can also support the individual by making changes to the environment to prevent agitation.

Milieu Changes in the Environment

Milieu changes are changes in the environment in which something occurs or develops. This can occur within the physical or social setting. The goal is to prevent agitation. Agitation is a state of anxiety or nervous excitement. Agitation commonly comes before aggression. Aggression is hostile or violent behavior or attitudes toward another; readiness to attack or confront.

Agitation is often reflected in behaviors such as pacing, yelling or making verbal threats or threatening gestures toward others.

Verbal warning signs of violence (that are different from baseline):

- Threats or boasts of prior violence
- Confused thinking
- Bragging about losing control
- Increased pitch when speaking
- Repetitive word use, parroting and or echoing
- Forced or strained speech
- Nervous laugh or laughing at inappropriate times
- Yelling or screaming
- Non-stop profanity
- Slurred speech
- Talk of hurting animals

Non-verbal warning signs of violence:

- Personal space violation
- Standing toe to toe
- Finger pointing
- Making fists
- Staring through you
- Face flushing
- Heavy breathing
- Flaring nostrils
- Person refuses any eye contact
- Someone blocks door/way out

You can use strategies to prevent the likelihood that individuals might escalate to an aggressive behavior. Focus strategies on creating a calm environment.

- Assess the risk in the environment
- Provide supportive and calm environments such as sensory rooms
- Provide or take training programs on creating calm environments
- Build trust and confidence with the individual

Early agitation often resolves with supportive non-confrontational language and other verbal de-escalation techniques to help diffuse the interpersonal interaction.

Some non-confrontational language examples:

- Use the person’s name
- Ask “May I help you?”
- Speak slowly
- Use restatement for clarification
- Ask to take notes (if able)
- Paraphrase
- Use “what” and “we”
- Allow time for reflection
- Give options
- Ask for their idea or solution
- Use simple words
- Maintain appropriate eye contact

Avoid language or actions such as:

- Faking attention
- Rolling your eyes
- Making false promises
- Using jargon
- Agreeing with someone or taking sides
- Cutting people off
- Getting in a power struggle
- Raising your voice
- Losing your temper
- Meeting one-on-one with an angry person
- Allowing more than one person to talk
- Arguing
- Saying “calm down”

Recognizing triggers for aggressive behavior can determine prevention strategies by identifying patterns that can be addressed (certain sensory stimuli such as excessive noise can trigger aggression in some). A prevention strategy in this case could offer earplugs or headphones to the individual.

Benefits / health outcome:

- Improved quality of life, functioning or experience
- Improved therapeutic relationship
- Decreased subsequent aggressive behavior

Role-play a time when you were able to de-escalate a situation with an individual living with dementia. What went well? What could have made it better? What would you do next time?

Situational awareness

Situational awareness or situation awareness is being aware of what is happening around you in terms of where you are, where you are supposed to be and whether anyone or anything around you is a threat to your health and safety.
To be situationally aware, keep these strategies in mind:

1. Learn to predict events
2. Identify elements around you
3. Limit situational overload
4. Be aware of time
5. Actively prevent fatigue
6. Limit attention to electronic devices and increase attention to your surroundings.
7. Use your senses

At work or outside of work, you should be aware of your surroundings. There are four levels of situational awareness developed by Col. Jeff Cooper, an expert on self-defense training. Be aware of safety and the point of danger. These levels are identified by a color scale, from white being unaware of surroundings to red being aware and ready to execute a response to a threat or danger. The goal is to be around the yellow awareness level when you are at work or in public.

White

White signifies someone who is unaware, unprepared, unconcerned. Normal state of mind when we are in the safety of our own home.

Yellow

Yellow signifies someone who is alert/attentive and calm. Normal state when we are out and about.

Orange

Orange signifies someone who has heightened awareness directed at potential threat, something is wrong. Start planning a strategy should the threat become concrete and imminent and ideally avoid the situation altogether. Generally, the focus stays on the threat to either advance to red or move back to yellow.

Red

Red signifies someone who is aware that a threat/danger exists and immediate action is needed. Execute necessary response: run, hide/take cover or fight.

Close your eyes.

What color is the chair you are sitting on?

What color of shirt is the person next to you wearing?

What direction is the door from you?

Do you feel like you are aware of your surroundings?

How can you be more aware and why would it be important?

Resident rights

70.129.120
Restraints—Physical or chemical.

The resident has the right to be free from physical restraint or chemical restraint. This section does not require or prohibit facility staff from reviewing the judgment of the resident's physician in prescribing psychopharmacologic medications.

70.129.130
Abuse, punishment, seclusion—Background checks.

The resident has the right to be free from verbal, sexual, physical, and mental abuse, corporal punishment, and involuntary seclusion.

(1) The facility must not use verbal, mental, sexual, or physical abuse, including corporal punishment or involuntary seclusion.

(2) Subject to available resources, the department of social and health services shall provide background checks required by RCW 43.43.842 for employees of facilities licensed under chapter 18.20 RCW without charge to the facility.

Debriefing

A debriefing is an activity where you evaluate and discuss what happened during the event. Be aware of any policies or procedures where you work. If you do not have a process in place, here is a six-step technique to debrief:

1. Control. Regain physical and emotional control of yourself. Stop, pause, calm yourself.
   a. Are you ready to discuss what happened?
   b. What went well?
   c. What can be done differently in the future?

2. Orient. What are the basic facts of the incident? What happened? Be nonjudgmental and listen to the perspective of every person who involved.
   a. What happened?
   b. Who was involved?
   c. When did they get there?
   d. What was each person's response during the situation?

3. Patterns. Look for patterns in causes and responses.
   a. What trends did each person observe?
   b. Are there things that seem to have caused the behavior?
   c. Do staff have precipitating factors at play as well?
   d. If so what are they?

4. Investigate: What needs to change.
   a. Brainstorm options of what might be done differently next time.
   b. What things you can do to prevent the situation from reoccurring?
   c. How can you strengthen or improve individual and team responses?
   d. What resources do you have available?
   e. What skills can team members practice?

5. Negotiate. Agree on what changes and improvements to make.
   a. Make a commitment to change
   b. Agree on how to respond in the future

6. Give. Offer support and encouragement.
   a. Express trust, confidence and respect for your colleagues.

Discuss why it is important to look for patterns in causes and responses for the quality of care for an individual with dementia.

When to call 911 or other local resources

Call 911 when you or the person you care for feels at risk. If you are unsure if your situation is an emergency, call 9-1-1. The 9-1-1 dispatcher will help determine if emergency assistance is needed.
Note: Be aware of any policy in your organization on when to call 911 or other local resources.

Document and report

You may have important information to share with other team members. Others on your team need to understand and learn from what you observed, what actions you took, and what did and did not work.

There will be policies and procedures for documenting and reporting challenging situations that you must follow. Objectively writing down what happened and what actions you took gives everyone a record. This record will help make sure you do not forget even small details that, when reviewed again, might reveal important information.

Lesson Summary

- Outside factors can influence behavior beyond dementia – a person's history, medication side effects, unmet needs, ability to communicate effectively and past traumas.
- Individuals with dementia may behave differently than they did before dementia.
- When faced with challenging behavior or situation, stop and take a step back; identify what the individual needs, and take action to meet the need.
- Behaviors, when responded to in a friendly and effective manner, can help enhance your satisfaction as a caregiver and promote a better quality of life for the individual with dementia.
- Individuals with dementia use behaviors to communicate a personal need, feelings, and emotions.
- Individuals with dementia are not behaving in a way to get attention or to be mean.
- Objectively writing down what happened and what actions you took gives everyone a record that can be reviewed and might reveal important information.

Checkpoint

Read the following scenarios and using the three-step process described in this lesson, demonstrate how you would handle each situation.

Ms. Zellmer, age 73 has Alzheimer's disease. This afternoon she is showing signs of agitation. She is restless, walking the length of the hall and back at a moderate pace while wringing her hands. You try to help her but she tells you that she does not need your help and swears at you and pushes over a chair you placed in the hall.

You were able to help Ms. Zellmer this afternoon with her agitation and make her feel better. There was extra excitement in the dining room at dinnertime with some unplanned activities for Ms. Zellmer right after dinner. She is now wandering around with more confusion and agitated than usual. You try to assist her with her bedtime routine and realize based on her patterns she is sundowning.

Lesson 11
Tips for Dealing with Specific Challenging Behaviors

Objective:

The caregiver will demonstrate an understanding of navigating challenging situations.

Overview

In 2015, DSHS and an independent consulting group analyzed a data sample of 3,705 client moves across Washington State. The moves were clients living in both adult family homes and assisted living facilities who had three or more moves. The study was trying to determine why some individuals had repeated moves from one location to another. This is important because we know moves can be very disruptive to individuals both emotionally and to the physical care they receive as new caregivers must learn the best way to work with each individual.

The study found that there were 23 behaviors that were consistently linked to clients who experienced repeated moves. It is our responsibility to be aware of these high-risk behaviors and when we identify an individual with them, work to reduce the incidence of the behavior through kindness, compassion and utilization of the behavior intervention skills learned in this course. The goal is a reduction in the number of moves experienced by the individual.

As you review this lesson and learn about the specific behaviors that might be more challenging than others, think about additional ways that you might manage these behaviors. Keep in mind the three-step process from the previous lesson as you think about each behavior listed and share additional strategies with your peers, supervisors, managers, and others. Draw from your flexibility and creativity and find new solutions to improve quality of care.

Think about a time when you experienced a challenging behavior from someone with dementia. What was the behavior? What needs do you think the person may have been trying to epress? Think about how you handled it and what you might have done differently to have a better outcome. Ask a peer how they would have handled it differently.

The following behaviors list some ideas how to navigate through the behavior. The definitions provided are from the DSHS CARE system. Add your own tips for navigating the behaviors and share with your peers.

Anger

- Do not take it personally. Most of the time, the anger is not about you. Do be aware of how you approached the individual – are they noticing your mood? Are you communicating with them what you are doing?
- Listen carefully. Allow the individual to express the anger before responding.
- Pay attention to the feelings behind the actions and words.
- Pay attention to changes in the environment, if something is making them uncomfortable (if they are in pain, do not feel good, etc.)
- Be aware that pain from a headache or possible fracture may result in behaviors. Addressing and reporting the suspected pain can help reduce behaviors that might result in a move or decrease in quality of life.
- Acknowledge the anger. Let the person know that you realize he or she is angry. For example, “Sara, it looks to me like you are really upset that someone took your favorite pen.” Find something to agree about. “Yes, you are right, these sheets are all wrinkled up.”
- Give the individual a chance to make decisions and be in control.
- Help the individual regain a sense of control. Ask if there is anything that would help him/ her feel better. Remember that sometimes it means giving some space and coming back later.
- The individual has the right to say no and tell you to leave.
- Offer alternative ways to express anger.
- Understand this might be the only way for them to communicate.
- If the individual is unable to control the anger and/or you feel fear that he or she could be a threat to you or others, get help immediately.

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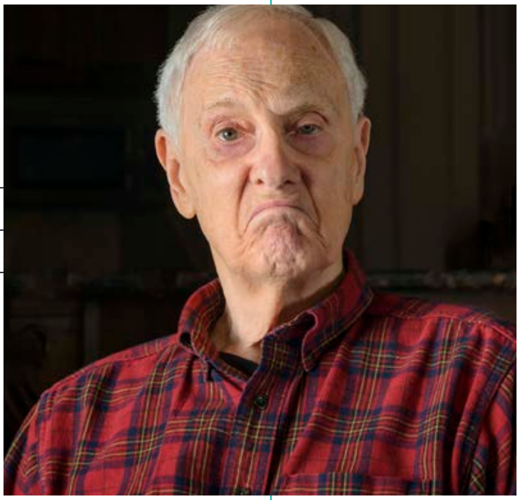
Combative During Personal Care

Hits, shoves, scratches, bites, pinches when attempting to provide care.

- Ask permission before entering personal space.
- Listen to the individual.
- People are allowed to change their mind.
- Explain what you are going to do.
- Come back later.
- Allow someone else to perform the task.
- Ask them to do all or part of the task. "Bob, here is the wash cloth, how did you do this before?



Crying and Tearfulness

Explained or unexplained crying.

- Give validation of their feelings.
- Find out why they are crying.
- Offer physical support (i.e., hug, hand holding)

Disrobes in Public

Public disrobing targets dress behavior that is contrary to local community laws, norms and individual's usual behavior. The individual is unaware that this is inappropriate. Examples of inappropriateness would include, undoing buttons on blouse so that breasts are exposed, taking off pants, etc.

- Find out why they are disrobing in public – are they too hot? Does the person need to use the bathroom?
- Do not over react. Do not giggle. Do not point. Act professionally.
- Maintain dignity of the individual. Get a blanket, redirect.

Eats Non-edible Substances/ Objects

This is eating of non-nutritive substances (plants, paper, etc).

- Find out if the individual needs something.
- Is the person hungry?
- Does the item look like a piece of food?
- Investigate why and overcome it that way.

Hallucinations and Delusions

Although hallucinations and delusions are not real, the experience and feelings are real to the person and can be frightening. While you may not be able to control the hallucination or delusion, you can use your problem solving skills to help come up with a response. In your problem solving process:

- Assess and evaluate the situation - Assess the situation and determine whether the hallucination or delusion is a problem for you or for the person with dementia. Is the hallucination or delusion upsetting to the person? Is it placing the person in danger? Is the person frightened?
- Investigate for any misperceptions of the environment that may be causing the hallucination or delusion. (i.e., are there branches scratching the window causing the individual to think someone is trying to break into their room or is the night shift coming in for safety checks and they believe someone is stealing from them?)
- Seek guidance from a supervisor. A supervisor may get medical guidance –to determine if medication is needed or might be causing the hallucination or delusion.
- Do not Argue – Unless the behavior becomes dangerous, you might not need to do anything. Do not try and convince the person that what they see, hear, smell or believe is not real if he or she is having a hallucination.
- Offer reassurance – Reassure the person with kind words and touch. For example, you might say, "I know you're worried about the gases in the vent. I will make them go away."

- Look for reasons – Try to find out what is behind the hallucination or delusion and what the situation means to the person.
- Increase lighting – Increase light to help minimize confusion of objects in the dark.
- Use distraction – When the person's emotional state is stable and is calm, turn the person's attention to other activities, such as listening to music, conversation, or drawing. Another idea is suggested that the person come with you or sit next to you to look at something or help you with something in another room.
- Maintain a familiar environment – If the person has to move, try to minimize changes in the environment.
- Keep a spare – Provide spare keys, purses, or glasses so when the person misplaces these belongings, they can be easily replaced.
- Use "Gentle Deception" – Use this technique to respond in a way that respects the person's reality.
- Assess for danger – If the person is in danger or places others in danger, assure everyone's safety. If necessary, call 911.

Once you have responded to the situation, you may need to get medical help. A doctor or other health care professionals may need to determine if medication is needed or might be causing the hallucination or delusion or whether other physical problems are causing or contributing to the behavior(s).

If the person has a history of a mental disorder, a supervisor may need to contact the person's mental health professional.

Inappropriate Toileting

Includes smearing or throwing feces, urinating in inappropriate places.

- Is the individual thinking they are doing the right thing, just not in the right place?
- Anticipate times and needs so you can assist them in maintaining their dignity so we do not overreact.
- Is the environment as user friendly as it can be?
- Do they need the door off the bathroom so they can see it?
- Can they see the toilet?
- Pay attention to non-verbal signs
- Someone opening random doors might be looking for a bathroom.
- Remember that putting clothing on backwards to prevent toileting issues is considered a restraint and is not allowed.

Injures Self

Includes both lethally motivated suicidal behaviors (intentional, self-inflicted attempt to kill oneself), and behavior inflicting intentional self-injury without suicide intent (e.g., self-mutilation). This could include head banging, self-choking, poking self in eyes. Not included in self-injury behavior is a non-intentional, accidental, unconscious self-destructive behavior that may lead to injury or premature death (e.g. chronic substance abuse, hyper-obesity, non-compliance of treatment for illness, risk-taking behaviors).

- Investigate what is causing the behavior.
- If there is a mental health diagnosis – would outpatient or inpatient help be supportive?
- Your responsibility is to protect the individuals, even from themselves.

Intimidating/Threatening

Individual attempts to force or deter someone else using threatening gestures, threatening stance with no physical contact, shouting or screaming angrily, personal insults, curses directed at someone else, using foul language in anger, kicking the wall, throwing furniture, etc. This includes explicit threats of violence against others.

- Your responsibility is to protect the person being intimidated or threatened.
- Having dementia does not give a person the right to intimidate or threaten others.
- Find a way to structure it into the care plan – for example, keep individuals separated if there is a pattern.

Mood Swings

Rapid, abrupt shift in emotions. For example: periods of tearfulness alternating with laughter with or without a reason. This includes individuals who have documented depressed or manic states.

- Look at the environment

Repetitive Anxious Complaints or Questions

Non-health related. For example, persistently seeks attention/reassurance regarding schedules, meals, laundry, clothing, relationship issues, etc.

- Look deeper at the reason – is there an unmet need?
- It might be that phase of dementia.
- Be repetitive with them.
- There might be validity to complaints and questions. Listen!
- Be patient. They honestly do not remember.

Repetitive Physical Movements and Pacing

Hand wringing, fidgeting, also includes restlessness, picking at body and clothing.

- Find something for the individual to do.
- Is it anxiety?
- What can you involve them in? (Folding napkins or setting up for the next activity? Dog walking?)
- If pacing, make the environment safe. Create rest areas to encourage rest stops when they can.
- Provide snacks and fluids on the go.

Resistive to Care with Words and Gestures

Resists taking medications, injections, ADL assistance, help with eating or treatments. The signs of resistance are limited to words and gestures and does not include when individuals have made an informed choice to not follow a course of care.

- Know the individual – how to approach and what is the best way to provide care for them.
- If one person cannot get the job done, it will not be helpful to bring 2, 3, or 4 more staff in all at once.
- Offer choices. "Would you like to take a shower or a bath?" "Would you like to take your medications before or after breakfast?"

Rummages Through or Takes Belongings of Others

Without appropriate consent. E.g. goes through someone else's drawers, looks through or takes other's mail.

- Give the individual a place to "shop".
- Provide stations for rummaging.
- Do not take things away from the individual. You can get it later.

Seeks Vulnerable Sexual Partner

Includes any instance of deliberate sexual violence such as sexual feelings directed toward children, siblings, or toward family members or others. This includes rape.

- Protect the individuals you care for.
- Be aware of each individual's level of dementia and ability to consent.

Sexual Acting Out

The individual does not intend to victimize others. This includes deliberate exhibitionism toward adult males/ females or towards children in order to elicit reactions from others. The individual is aware that the behavior is inappropriate. This does not include an individual who masturbates in private.

- See lesson 5.

Spitting

Spits inappropriately e.g. on the floor, or at others etc.

- Provide the individual with something to spit into that is appropriate.

Unrealistic Fears or Suspicions

Expresses fear of being abandoned, left alone, or being with others. There is no basis for this fear or belief. Additional symptoms to consider are: the individual is unwilling to be left alone, may follow you or other significant individuals of importance to them, unwilling to let these individuals out of their sight.

- Validate the individual's feelings.
- Get into their reality.
- Take time.
- Sit down.
- Listen.

Unsafe Smoking

Burns cigarettes down to fingertips, smoking in unauthorized areas, not using ashtrays or other containers, smoking when using oxygen. Includes instances where there is an actual, accidental fire.

- Behavior requires immediate attention.
- Has the individual been assessed for safe smoking? If not, take action.
- You have a responsibility for keeping the individual safe.
- Be familiar with resident rights.

Up at Night When Others are Sleeping and Requires Interventions

Includes being awake and calling out, but not getting up; also includes being awake and out of bed, moving around when others are sleeping, and disturbing the social environment.

- Is the behavior related to delirium?
- Is the individual sick in some way?
- Did the person work graveyard shift in their past?
- Understand the individual – patterns, norms, etc. Sometimes a pattern they have had for years might make them look different, but it might just be part of who they are.

Verbally Abusive

Threatens, screams, curses at you, family or others.

- Identify if there is a pattern.
- What lead up to the behavior?
- Take a time out, come back later.

Wanders and is Exit Seeking

Wandering is when an individual moves about with no seemingly discernible, rational purpose. A person who wanders may be oblivious to his/her physical or safety needs. Wandering behavior should be differentiated from purposeful movement (e.g., a hungry person moving about their living area in search of food). Wandering may be by walking or wheelchair. This does not include pacing back and forth.

This behavior is focused on wandering and is exit seeking or gets outside or off the property. This is different than wandering related to boredom or a need for movement.

It is most important to understand that an individual who wanders is generally expressing a need.

- Ask yourself what the person is attempting to do. The individual might be trying to go home or to work.
- Use redirection or distraction if the situation is calm.
- Was wandering a part of the individual’s history? Example: An individual who is a former police chief would go around checking doors. He might be walking the halls, opening doors, looking inside. He might not be exit seeking but might appear to be that way.
- If an individual says, “I want to go home”, use validation and redirection. Do not say, “This is your home.” Instead say, “I want to go home too, but before we go, can you help me ______ (fold clothes, have a meal, activities, etc.),” or "tell me about your home".
- Does the individual need some fresh air? Would taking scheduled walks alleviate the issue?
- What need is not being met? Are they looking for something or someone? Where are they at in their timeline? How can you help meet that need?
- Engaging in conversation may offer clues as to what he or she is needing.

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Lesson Summary

- 23 behaviors were identified and linked to higher frequency of moves with individuals living in adult family homes and assisted living facilities.
- An awareness of these behaviors can help you navigate situations with kindness and compassion with the goal of improving quality of life for the individuals you care for.

Checkpoint

Select two specific behaviors listed in this lesson and write a summary that includes the name of the behavior, a possible description of the behavior, possible triggers of the behavior, and possible actions that might help you navigate through the situation. Be prepared to present this information to the group.

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Videos

Many videos are available online through YouTube and other sources that provide information on this topic. The following videos might provide additional information.

ABC NIGHTLINE Tells America About the Virtual Dementia Tour®
https://www.youtube.com/watch?v=QEmBmokHU3Q
(6:50)
VDTSWD
Published on Apr 5, 2013
ABC News reporter Cynthia McFadden experiences the Virtual Dementia Tour and shares the story of a family facing Alzheimer's disease.

Understand Alzheimer's Disease in 3 Minutes
https://www.youtube.com/watch?v=Eq_Er-tqPsA&feature=youtu.be
(3:14)
TenderRoseHomeCare
Uploaded on Mar 2, 2010
Video describes the progression of Alzheimer's Disease—how it damages the brain and how it affects behavior—in a simple, clear way that anybody can understand. Every family caregiver should watch this to better understand what is happening with their loved one.

What is Alzheimer's disease? - Ivan Seah Yu Jun
https://www.youtube.com/watch?v=yJXTXN4xrI8
(3:49)
TED-Ed
Published on Apr 3, 2014
Alzheimer's disease is the most common cause of dementia, affecting over 40 million people worldwide. And though it was discovered over a century ago, scientists are still grappling for a cure. Ivan Seah Yu Jun describes how Alzheimer's affects the brain, shedding light on the different phases of this complicated, destructive disease.

Vascular Dementia & Artery Plaque
https://www.youtube.com/watch?v=7FfRzEF9ei0
(:42)
Alzheimer's Weekly
Published on Feb 23, 2013
Vascular dementia is often brought on by atherosclerosis. This animation from Mayo Clinic illustrates how a person develops atherosclerosis.

Living with Lewy Body Dementia - Mayo Clinic
https://www.youtube.com/watch?v=RSRbR1R4mz0
(2:57)
Mayo Clinic
Uploaded on Aug 22, 2011
The disease is the second most common form of dementia, Alzheimer's being the first. There is no cure, but experts at Mayo Clinic are researching Lewy Body disease in hopes of improving the lives of people who struggle with it.

Frontotemporal Dementia - Mayo Clinic
https://www.youtube.com/watch?v=Xm3GpyaK-EE
(3:04)
Mayo Clinic
Published on Oct 28, 2014
Frontotemporal Dementia - Mayo Clinic

Daniel My Brother (Huntington's Disease)
https://www.youtube.com/watch?v=JzAPh2v-SCQ
(2:11)
Jason Mundy
Uploaded on Feb 13, 2010
Video of my bother (Daniel Mundy) and his battle with Huntington's Disease

Parkinsonian Gait Demonstration
https://www.youtube.com/watch?v=j86omOwx0Hk
(1:13)
Belal Alsabek
Uploaded on Nov 13, 2009

Henry - Man In Nursing Home Reacts To Hearing Music From His Era
https://www.youtube.com/watch?v=fyZQf0p73QM
(6:29)
Music & Memory
Uploaded on Nov 18, 2011
http://www.MusicandMemory.org

Dementia Dog - Living Well with Dementia
https://www.youtube.com/watch?v=JsMdDkr27EY
(1:51)
Design Council
Published on Feb 20, 2015
Meet Dementia Dog, a pilot service providing assistance dogs to people with dementia, helping them lead more fulfilled, independent and stress-free lives.

How Can We Include People with Dementia in Our Community?
https://www.youtube.com/watch?v=P77EuUZyqZ0&feature=youtu.be
(2:52)
Trinity College Dublin
Published on Feb 18, 2014

The Bookcase Analogy - Dementia Friends
https://www.youtube.com/watch?v=9iOnxYbdrrE&feature=youtu.be
(5:13)
Alzheimer's Society
Published on Sep 16, 2015
Dementia Friends Champion Natalie talks through the ‘bookcase analogy’. The analogy can help you to understand the way dementia affects a person.

Gladys Wilson and Naomi Feil
https://www.youtube.com/watch?v=CrZXz10FcVM&feature=youtu.be
(5:46)
Memorybridge
Uploaded on May 26, 2009
Naomi Feil, founder of Validation Therapy, shares a breakthrough moment of communication with Gladys Wilson, a woman who was diagnosed with Alzheimer's in 2000 and is virtually non-verbal. Learn

Handout - Activity Ideas Page 1

Purpose: Have Meaningful Contact with Others

Activity	Benefits	Benefits
Reminiscing	• Can stimulate memory • Helps the person reflect on past experience and bring closure to unresolved issues	• Ask a question to get it going, such as: "Have you ever worked on a ranch?" Or "Have you ever seen a tornado?" • Use caution not to highlight what cannot be remembered.
Storytelling	• Can stimulate memory • Gives a sense of pride	• Initiate by saying "Tell me about how you …or when you…" • The facts are not important. It is really about the enjoyment of telling the story. (early phase)
Looking at photo albums or magazines	• Provides visual stimulation	• Make magazines and photo albums readily available. (all phases)
Taking a walk	• Can reduce stress and agitation • May help the person to sleep better • Stimulates senses	• Walk with the person outdoors, unless your setting has a secure outdoor space for walking. • Make sure all pathways are clear of debris or clutter. (all phases)
Brush hair, massage hands, feet or back	• Provides personal interaction	• Be attentive to personal preferences. (all phases)
Ice cream socials or other social activities	• Provides sensory stimulation • Provides a pleasurable experience	(all phases)
Feeding the birds Petting a cat or dog	• Can lower blood pressure • Promotes relaxation	• Make sure animals are calm and accustomed to being around people. (early to mid-phases)

Purpose: To Feel Productive (That He or She Has Something to Contribute)

Activity	Benefits	Benefits
Folding clothes, stirring batter, kneading dough, washing vegetables, tearing lettuce, setting the table, washing the car, raking leaves	• Helps maintain hand-eye coordination • Stimulates senses • Provides a sense of purpose • Provides opportunities to tap into past skills	• Provide activity stations where the person can initiate independent activity.

Handout - Activity Ideas Page 2

Purpose: Have Meaningful Contact with Others

Activity	Benefits	Benefits
Performing personal care (ADLs)	• Gives a sense of pride and independence • Makes the activity more meaningful • Helps the person retain skills	• Do tasks with the person, not for the person. • Praise successes. • Give limited choices to avoid confusion. • Remember that routine provides security.
Separating change or buttons into piles Matching and sorting socks	• Helps maintain fine motor skills	• Make items available and let the person initiate the activity. • It does not matter whether everything is done correctly.

Purpose: To Continue to Participate in Life-Long Routines/Patterns

Activity	Benefits	Benefits
Coffee and a newspaper	• Promotes relaxation and interaction • Provides a sense of security	• People may lose their ability to read, yet enjoy being read to.
Folding clothes	• Helps keep hand-eye coordination intact	• Set out a basket of clothes and allow the person with dementia to initiate the activity. • Prompt, or give visual cues if necessary.
Praying or reading from a spiritual text	• May provide a sense of calm	• Know and respect the person's belief system.
Happy hour with beverages and appetizers	• Provides socialization	
Game of cards, checkers, or dominos	• Provides recreation and socialization	• Rules do not matter—it is the interaction that is important.

Handout - Strategy for Approaching Behaviors

1

Stop

- Stop or pause
- Calm yourself

2

Identify

- What need or desire does the individual have that is not being met?
- What happened just before the behavior started?
- What are the physical, environmental, and emotional triggers?
- Were other people involved?
- Is this a new behavior?
- Are there any patterns that you can see?

3

Action

- Minimize or eliminate triggers
- Adapt
- Give space
- Soothe and comfort
- Reassure
- Distract or redirect
- Encourage
- Protect and support others
- Get help
- Document and report
- **Re-Evaluate**

Remain and appear calm and supportive and do not take the behaviors personally.
If you are unable to get yourself calm and focused, give yourself a time-out or ask for help.

Notes

Notes

DSHS
WASHINGTON STATE
Department of Social
and Health Services

DSHS 22-1665 (Rev. 4/25)