Dementia Care

Specialty Training

July 2007

Basic Training for Managers and Caregivers

Dementia Care

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Icons to Help Guide You Through the Materials

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MODULE 1

Introduction to Dementia

Washington State
Department of Social
& Health Services

ADSA Aging & Disability
Services Administration
www.adsa.dshs.wa.gov

What Do You Know About Dementia?

Activity

Check "True" or "False" for each of the questions below to see what you know about dementia.

True	False	
☐	☐	1. Dementia is a normal part of aging.
☐	☐	2. Delirium is another name for dementia.
☐	☐	3. People with dementia lose all ability to communicate.
☐	☐	4. A person with dementia behaves in ways that are challenging just to be difficult.
☐	☐	5. People with dementia cannot complete any Activities of Daily Living (ADL's) without assistance.
☐	☐	6. When assisting a person with dementia, it is important that every ADL be completed in a timely fashion.
☐	☐	7. Some people with dementia may experience hallucinations or delusions.
☐	☐	8. Sometimes a person with dementia will make sexual advances to strangers.
☐	☐	9. People with dementia undress or fondle themselves to embarrass others.
☐	☐	10. Certain drugs cause side effects and create symptoms that look like dementia.

Check to see how you did on pages 11 & 12.

Dementia

Module Goals:

To provide caregivers and managers:

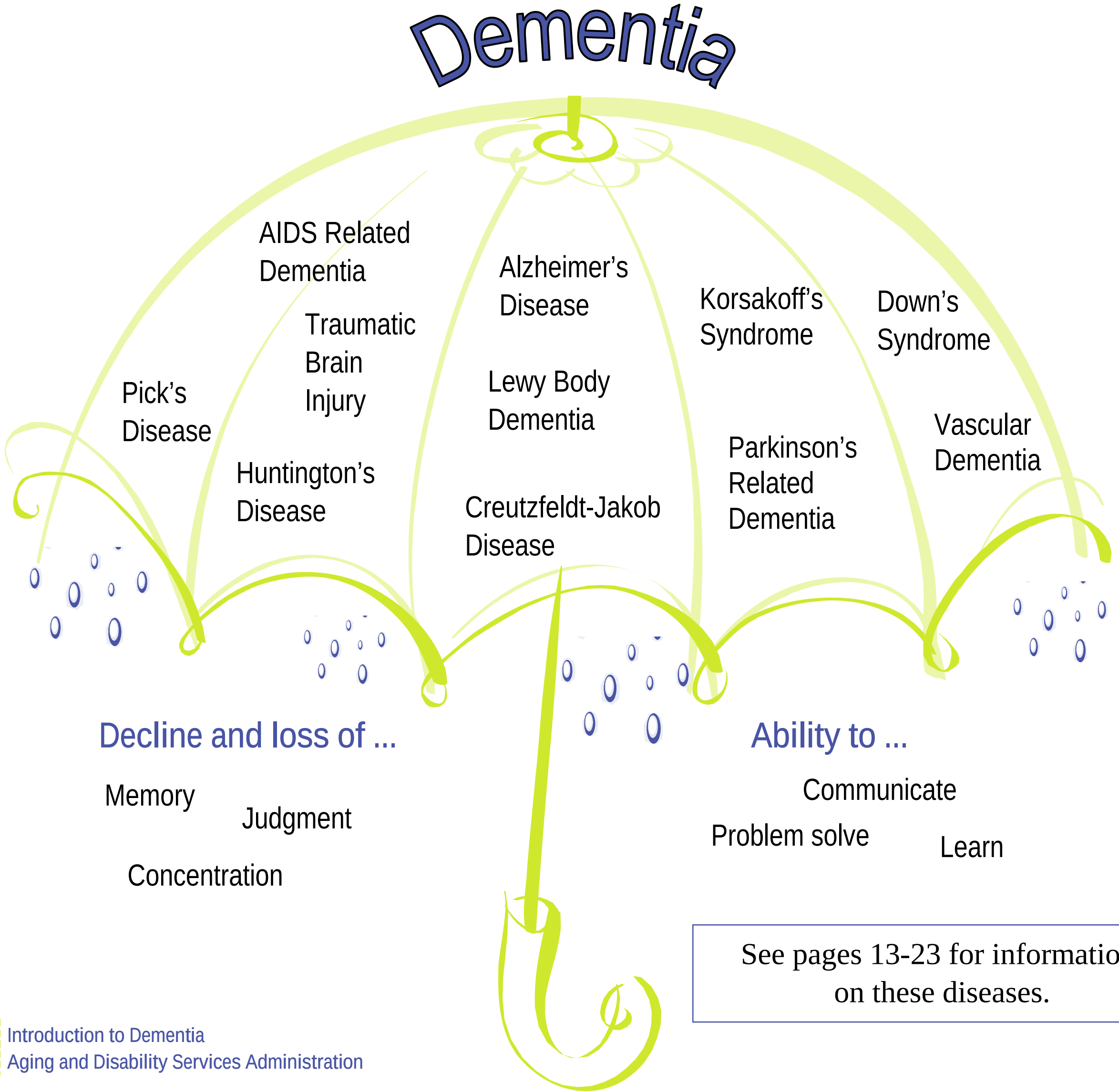
- Information, resources, and care tips to work with people with different types of dementia.
- Information regarding the differences between dementia, delirium, and depression and why it is important to know.

What is Dementia?

Dementia is a broad term used to describe symptoms that result when the brain is damaged by disease, injury, or illness. These symptoms can include a decline and loss of memory, concentration, judgment and the ability to communicate, learn, and problem solve.

Dementia is not a disease itself.

Dementia is not a disease itself or a normal part of aging. Dementia is the umbrella term that covers all of the symptoms that occur when the brain has been damaged.



See pages 13-23 for information on these diseases.

Dementia	Distinguishing Symptoms	Resources
AIDS Related Dementia	• Loss of appetite • Inappropriate emotional responses • Unsteadiness • Changes in personality	• www.thebody.com and search by dementia
Alzheimer's	• Collecting behavior • Repetition • Sundowning • Exploring/wandering	• www.alzheimers.org.uk • www.nia.nih.gov and click on Alzheimer's Disease Information • www.alz.org
Creutzfeldt-Jakob	• Minor lapses in memory • Mood changes • Feeling muddled • Jerky movements	• www.cjdfoundation.org • www.mayoclinic.com and search by Creutzfeldt-Jakob
Down's Syndrome	• Decline in physical/mental abilities • Difficulties communicating • Confusion • New onset of seizures	• www.dsscotland.org.uk and search by dementia
Huntington's	• Jaw clenching • Slurred speech • Swallowing and/or eating difficulty • Walking difficulty (stumbling/falling) • Uncontrolled muscle contractions • Hostility/irritability	• www.mayoclinic.com and search by Huntington's disease • www.hdac.org • www.about-dementia.com and click on Huntington's
Korsakoff's Syndrome	• Involuntary jerky eye movement • Drowsiness • Invent information to fill in gaps in memory	• www.alzheimers.org.uk and click on Factsheets, then Korsakoff's Syndrome
Lewy Body Dementia	• Nightmares • Abilities fluctuate daily, even hourly • Fainting/falls • Visual hallucinations	• www.helpguide.org and search by Lewy body • www.lewybodydementia.org • www.alzheimer.ca/english and click on Alzheimer's Disease, then Related Dementias

Dementia	Distinguishing Symptoms	Resources
Parkinson's	• Gait—shuffling, head down and shoulders drooped • Tremors • Excessive sweating • Muscle stiffness/rigidity • Constipation • Lack of motivation • Moodiness • Slowed thinking • Easily distracted	• www.helpguide.org and search by Parkinson's dementia • www.about-dementia.com and click on Parkinson's
Pick's	• Repetitive behavior • Repeat words others say • Poor judgment • Develop taste for sweet foods • Overeat or eat one type of food • Excessive alcohol intake-when this was not previously a problem • Lack of compassion or concern • Changes in sexual behavior	• www.helpguide.org and search by Pick's
Traumatic Brain Injury	• Difficulty with hand/eye coordination • Behavioral changes, including impaired self-control • Emotional problems, including irritability and outbursts	• www.ninds.nih.gov and click on disorders, then Traumatic Brain Injury
Vascular	• Dizziness • Weakness in arms or legs • Symptoms present in a stepwise fashion • Restlessness • Periods of acute confusion followed by periods of stability	• www.alzheimers.org.uk and click on Factsheets, then Vascular dementia • www.helpguide.org and search by Vascular Dementia

How Does Dementia Affect the Brain?

The diseases, injuries, and illnesses listed on the previous page 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. See the illustration below for an example.

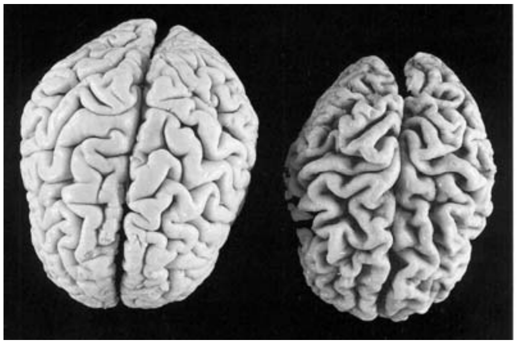


Figure 1 Normal Brain **Figure 2 Brain with Alzheimer's**

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.

There is memory loss with all types of dementia.

The illustration below shows what happens to the brain in areas that control memory.

Figure 1
Normal part of the brain that controls memory

Figure 2
The same part of the brain destroyed by dementia

Common Effects of Dementia:

People with dementia often:

- Cannot remember 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.

There are a variety of reactions you may have in dealing with the effects of dementia. A person with dementia may not be aware of his or her changed behavior and is not doing things intentionally.

If you find yourself taking it personally or having a negative emotional reaction, stop and take a deep breath. Remember, the person's brain is no longer working correctly.

Care Tips

- Never argue, shout, lecture, make fun of, or force a person with dementia to do something he or she does not want to do.
- Look for reasons to praise the person with dementia. It will help remind you of the things he or she can still do.
- Be positive. Your attitude will influence the outcome of any interaction.

Other Conditions and Dementia Symptoms

There are other physical conditions that can create symptoms similar to dementia. It is important to be aware of them and rule them out because:

- With appropriate treatment and care, some of these conditions and the dementia symptoms they are causing can be reversed.
- Some of these conditions can be life threatening (delirium and depression) and require immediate medical attention.
- People can be misdiagnosed and you want to advocate for proper treatment.

There are other physical conditions that can create symptoms similar to dementia.

For example, a person begins to show a marked increase in confusion because of a Urinary Tract Infection (UTI). If the UTI is treated, the confusion would likely go away. If it is assumed the person's confusion is from dementia, the person would not get the treatment needed.

Physical conditions that can cause or create symptoms that are similar to dementia include:

- Delirium
- Depression
- Brain tumors
- Drug reactions
- Infections (UTI, meningitis, syphilis)
- Nutritional deficiencies
- Thyroid problems

Differentiating Dementia, Depression, and Delirium

Delirium, dementia, and depression can all have similar symptoms. The following information will help you distinguish between these conditions and symptoms.

If you see any of the symptoms associated with these conditions, it is important to get the person to his or her medical professional as quickly as possible. An accurate diagnosis needs to be made and appropriate treatment prescribed.

Delirium

Family Friendly

Delirium is a condition characterized by the rapid onset of ***acute*** confusion. It is caused by a variety of physical illnesses or ***toxicity.***

Delirium can be reversed with the appropriate treatment. The type of treatment the person will receive depends on what is causing the delirium.

If you suspect the person may be experiencing delirium, **seek immediate medical attention. Death can occur if the delirium goes untreated.**

A person with an existing brain injury, such as prior strokes, head trauma or tumor, or a person experiencing ***Transient Ischemic Attacks*** **(TIAs)** is more likely to develop delirium.

What are the symptoms?

- Acute and sudden changes in memory.
- Reduced awareness of the environment or becoming very alert.
- Agitation as a result 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.

What are the causes?

- 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.

What is the progression of delirium?

- Sudden onset.
- Varies in severity, may be worse at night or when waking up.
- Usually clears up when the underlying condition is treated.

Acute *— extremely serious or severe.*

Toxicity *— the degree to which something is poisonous (for example, from getting too much of a substance).*

Transient Ischemic Attacks *— a brief episode in which the brain does not get enough blood.*

Depression

Family Friendly

Depression is a treatable illness that involves the body, mood, and thoughts. Depression is related to physical changes in the brain and connected to a chemical imbalance that can be inherited, psychological, or triggered by a stressful event or environmental conditions.

Depression is a common condition and common among people with dementia. Numerous studies in dementia estimate that 30-50% of people with dementia have depression.

Because the symptoms of depression (see below) and dementia are so similar, an older person with these symptoms should see a medical professional for an evaluation.

Without treatment, depression can be life threatening.

It is important to know if a person with dementia also is depressed because the depression can go untreated and **makes the effects of the dementia worse**. For example, depression can make it even harder for a person with dementia to remember things. He or she can also be more confused, anxious, and withdrawn.

It is important to ensure that the person sees a doctor so that appropriate treatment can be prescribed.

What are the 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.

What causes depression?

People with dementia who have depression often benefit from having the depression treated.

There is no single cause for depression. Often a combination of genetic, psychological, and environmental factors contribute to the onset of depression. Some contributing factors include:

- A family history or a genetic link to depression.
- Stressful or upsetting events, such as a disability, having to move, or the death of a loved one.
- The effects of certain illnesses or the side-effects of medication.
- Feelings of loneliness or isolation.
- Feelings of boredom or having little control over situations.
- Worries over issues such as money, relationships, or the future.
- Other psychological factors including an anxiety disorder, eating disorder, schizophrenia, or substance abuse.

Distinguishing Between Delirium, Dementia, and Depression

Delirium, dementia, and depression can all have similar characteristics or symptoms. The following information will help you distinguish between these conditions and their characteristics or symptoms.

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 prescribed.

Feature	Delirium	Dementia	Depression
Onset	• Rapid, often at night	• Chronic, generally comes on slowly • Hard to pinpoint start	• May happen with a life change or stressful event
Cause	• Usually physical illness or getting too much of a medication	• Brain cells being destroyed	• Many contributing factors
Course	• Short • Daily variations of symptoms • Worse at night when it is dark and on awakening	• Long • Symptoms progressive though they are mostly stable over time	• Persistent, symptoms fluctuate • May be worse in the morning
Duration	• Hours to weeks (less than 1 month)	• Months to years	• At least 2 weeks, can be several months or years
Person's Response	• Cannot hide symptoms	• Too much effort to hide symptoms	• Tries to hide symptoms
Orientation	• Varies in severity, generally impaired • Will misinterpret things	• May be impaired	• May experience disorientation
Memory	• Short term memory impaired	• Short and long term memory impaired	• Possible impairment
Thinking	• Disorganized, fragmented • May be slow, fast, or dream-like	• Difficulties with concepts	• Inability to concentrate, uninterested
Perception	• Distorted, especially visual (illusions, delusions)	• Lose ability to interpret senses	• Unchanged
Sleep-Wake Cycle	• Disturbed, cycle reversed (often drowsy during the day and awake at night)	• Fragmented	• Variable sleep patterns
Physical Illness	• Usually present	• Often absent	• Unexplained aches and pains

Activity

Identifying Delirium, Dementia, and Depression

For each feature, put an A or B in the correct blank area.

Feature	Dementia	Depression	Delirium	
Perceptions			Are distorted	A. Lose ability to interpret senses. B. Unchanged.
Memory	Short-term and long-term impaired			A. Impairment is possible. B. Short-term impaired.
Thinking		Inability to concentrate		A. Distorted, dreamlike. B. Difficult to think or reason.
Onset	Slow and hard to pinpoint			A. Rapid, often at night. B. May coincide with a stressful event.
Person's Response			Cannot hide symptoms	A. Tries to hide symptoms. B. Too much effort to hide symptoms.
Cause		Many contributing factors		A. Physical illness or toxicity. B. Brain cells being destroyed.
Treatment			Underlying illness needs immediate treatment	A. Medications help, but no cure. B. Treatment is effective, but can be life threatening without treatment.
Duration	Lasts months to years Rest of life			A. Hours to weeks, less than a month. B. At least two weeks, up to months or years.
Course		Fluctuate and can change daily		A. Usually progressive and long-term. B. Severity fluctuates, may be worse at night.
Physical Illness			Usually present	A. Unexplained aches and pains. B. Often absent.

Activity

True/False – What Do You Know About Dementia?

Refer back to your answers on page 1.

1. **False. Dementia is a normal part of aging.**

   Dementia is not a normal part of aging. It is the result of certain diseases, injuries or illnesses that damage the brain.

   See Module 1, pages 2-5, for more information.

2. **False. Delirium is another name for dementia.**

   Delirium is a different condition with a group of symptoms that cause TEMPORARY dementia-like symptoms. This condition happens quickly (within hours or a day) and always has an underlying physical cause. It can occur alone or with dementia.

   See Module 1, pages 7 for more information.

3. **False. People with dementia lose all ability to communicate.**

   Dementia affects each person's ability to communicate differently. Dementia often affects a person's verbal communication. The person can usually continue to communicate through body language.

   See Module 2, pages 24-27, for more information.

4. **False. A person with dementia behaves in ways that are challenging just to be difficult.**

   There are many things that can cause challenging behaviors. Often the person is trying to communicate a need but his or her ability to communicate has been affected by dementia. It is important to spend some time and figure out what the person may be trying to tell you.

   See Module 3 for more information.

5. **False. People with dementia cannot complete any ADL's without assistance.**

   Dementia affects each person's abilities differently. While some people may require some assistance with ADL's, others do not. Even though the brain is dying, many skills and abilities are still retained throughout the progression of the dementia.

   See Module 4, pages 72-74, for more information.

6. False. When assisting a person with dementia, it is important that every ADL be completed in a timely fashion.

When working with a person with dementia, flexibility on your part is more important than a set schedule. Flexibility includes allowing the person as much time as he or she needs to get things done, stopping a task or activity if the person is frustrated or it is not working for them, and figuring out a way that works better for that person.

See Module 4, pages 72-74, for more information.

7.True. Some people with dementia may experience hallucinations.

A person with dementia may sometimes experience hallucinations. He or she may see, hear, smell, taste, or feel things which are not really there. The most common hallucinations are those which involve sight or hearing.

See Module 5, pages 87-88, for more information.

8. **True. Sometimes a person with dementia will make sexual advances to strangers**.

A person with dementia often forgets social rules or etiquette and behaves inappropriately because those parts of the brain are damaged. For example, a person with dementia may make sexual advances to a stranger who resembles a spouse, lover, or companion.

See Module 6, pages 94-95, for more information.

9. False. People with dementia undress or fondle themselves to embarrass others.

Although it may feel like the person is trying to embarrass you, he or she no longer understands that this behavior is inappropriate. A person with dementia often forgets social rules and etiquette and behaves inappropriately because parts of the brain are damaged.

See Module 6, pages 94-95, for more information.

10. True. Certain drugs cause side effects and create symptoms that look like dementia.

A wide range of drugs can cause symptoms of dementia in the elderly, often mimicking the symptoms of dementia. It is important to rule out medication side effects when working with people with dementia or the elderly.

See Module 7, page 105, for more information.

AIDS Related Dementia

Further Readings Family Friendly

AIDS (Acquired Immune Deficiency Syndrome) related dementia is caused by the way the Human Immunodeficiency Virus (HIV) affects the brain or when infections take advantage of the person's weakened immune system and damage the brain.

Symptoms:

- Forgetfulness
- Confusion
- Difficulty paying attention
- Sudden changes in mood or behavior
- Slurred speech
- Clumsiness or being unsteady
- Muscle weakness
- Loss of appetite
- A lack of interest or concern
- Responses that do not seem appropriate to the situation

Progression:

- May start at any age.
- May not change for a period of time.
- May begin slowly or come on quickly.
- May get worse rapidly or continue to get worse slowly.
- Will lead to the person needing total help with care.

Diagnosis:

- A ***CT scan*** is used to find out if there is an infection in the brain.
- A ***Magnetic resonance imaging* (*MRI*)** scan is used to show if tissue in the brain is shrinking.
- A ***Spinal Tap*** is used to detect the amount of HIV infection in the fluid surrounding the brain.
- A mental status examination.

CT scan *— method for producing a three dimensional image of a part of the body using waves of energy.*

MRI *— a method for producing computer images of internal body tissues using radio waves.*

Spinal tap *— withdrawing of spinal fluid from the lower back using a hollow needle.*

Treatments may include:

- A combination of medications and other treatments to stop or slow down the ability of HIV to cross into the brain.

Resources:

www.thebody.com and search by dementia.

Care Tips

- Because the person is often young, it is important to keep the person actively involved in his or her care.
- Because there is a lot of stigma attached to this diagnosis, it is important to talk about things. Listen, try to understand, and show the person that you care.
- Do not be afraid of the person. You cannot get HIV/AIDS or dementia from touching or hugging the person.

Alzheimer's Disease (AD)

Further Readings **Family Friendly**

Lesions — a region in an organ or tissue which has suffered damage through injury, disease, or wounds.

Alzheimer's is a progressive, degenerative brain disease. ***Lesions*** clog and prevent communication between brain cells and destroy the brain from the inside.

Symptoms:

- 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
- Eating often or forgetting to eat
- Shuffle/unsteady walking
- Confusion
- Forgetting names of people or places
- Personality changes
- Mood swings

Progression:

- Begins subtly.
- Extends over a period of 8-12 years.

Diagnosing:

- A battery of tests—there is no specific test for Alzheimer's.
- Laboratory analysis or a brain scan to rule out other conditions.
- A medical history, physical exam (including a neurological exam), and a mental status exam.

Treatments:

- There is no cure for Alzheimer's disease.
- Medications to slow down symptoms caused by Alzheimer's disease.
- Therapeutic activities.
- Exercise to minimize physical decline.

Resources:

- www.alzheimers.org.uk
- www.nia.nih.gov and click on Alzheimer's Disease Information
- www.alz.org

Care Tips

- Established routines help make the day more predictable and provide a sense of comfort and security.
- Involve the person in tasks as much as possible.
- Limit choices. Having fewer options makes deciding easier. For example, provide two outfits to choose between — not a closet full of clothes.
- Reduce distractions at mealtimes or during conversations so that the person can better focus on one thing at a time.
- Take more time. Schedule extra time to complete even simple tasks so that you don't hurry the person.

Creutzfeldt-Jakob Disease (CJD)

Further Readings

Family Friendly

Creutzfeldt-Jakob disease (CJD) is a fatal disease of the brain. There are several types of CJD. With CJD, infectious proteins attack the central nervous system and invade the brain. These proteins cause brain tissue to die and become so filled with holes that the brain eventually looks similar to a sponge.

The disease itself is quite rare, but the number of cases diagnosed is increasing. Although most people develop CJD for no apparent reason, researchers have identified some causes including heredity, certain medical procedures, and exposure to contaminated medical instruments. A relatively new type of CJD is “Mad Cow Disease” caused by exposure to contaminated meat.

Symptoms:

- Memory loss
- Personality changes
- Hallucinations
- Muscle stiffness or spasms
- Clumsiness or a lack of coordination
- Mood changes
- Unsteady walking
- Slow or slurred speech
- Jerky movements
- Incontinence

Progression:

- Develops rapidly.
- Ends in death, usually within six months of the appearance of early symptoms.
- Very rarely the disease can last for more than two years.

Diagnosing:

- A neurological examination and spinal tap to rule out other forms of dementia.
- An MRI scan can be used to detect brain degeneration.
- An ***Electroencephalogram (EEG)*** can be used to detect a specific abnormality caused by CJD.
- Brain ***biopsy*** or autopsy must be performed to conclusively diagnose the disease.

EEG *— an instrument used to record brain activity.*

Biopsy *— remove sample tissue to look for the presence, cause, or extent of a disease.*

Treatments:

- There is no cure for CJD.
- Making the person as comfortable as possible.
- Medications to help relieve pain.
- Medications to help relieve involuntary muscle jerks.

Resources:

- www.cjdfoundation.org
- www.mayoclinic.com and search by Creutzfeldt-Jakob

Care Tips

- This is a disease that progresses rapidly. The goal for providing care is to keep the person comfortable. Emotional support for the person and family education may also be important.
- Hospice may be a good resource.

Down’s Syndrome

Further Readings **Family Friendly**

Down’s syndrome is caused by a chromosome abnormality, usually due to an extra copy of the 21st chromosome. For unknown reasons, people with Down’s Syndrome are four times more likely to get Alzheimer’s than other people and at an early age. What is known is that some people with an inherited extra copy of chromosome 21 develop the same lesions in the brain as people with Alzheimer’s disease.

Symptoms:

- Confusion
- Loss of memory and logical thinking
- Personality changes
- Decline in ADL skills
- Wandering
- New onset of seizures
- Disorientation
- Changes in coordination and gait
- Difficulties communicating

Progression:

- Onset is at a younger age than the general population with the first signs of dementia starting between the ages of 36 and 62.
- Gets worse over a period of about 8 years.

Diagnosing:

- Having a baseline test of cognitive function at age 30.
- A detailed medical history and mental status exam.
- A thorough physical and neurological exam.

Treatments:

- Medications that are used to treat Alzheimer’s dementia may be used to improve memory.

Resources:

www.dsscotland.org.uk and search by dementia.

Care Tips

- Activities are very important as dementia happens at a younger age. Activities should be appropriate to the person and his or her cognitive abilities. Cueing and general supportive care are important.

Huntington's Disease

Further Readings

Family Friendly

Huntington's disease is a progressive disease that involves the wasting of nerve cells in certain parts of the brain. Huntington's disease causes uncontrolled movements, a loss of intellectual functioning, and emotional problems. Every child of a parent with the disease has a 50% chance of inheriting it.

Symptoms:

- Uncontrollable facial movements
- Jaw clenching
- Abnormal body movements due to uncontrollable muscle spasms
- Loss of coordination and balance
- Slurred speech
- Difficulty swallowing and/or eating
- Difficulty walking, person may stumble or fall
- Personality changes
- Paranoia and/or hallucinations
- Behavior changes, may include being:
  - Irritable or moody
  - Restless or fidgety
  - Not wanting to be around people
- Loss of memory
- Loss of judgment

Progression

- Commonly begins between the ages of 35-50.
- Progresses without remission over a 10-20 year period.
- Usually ends in death as a result of infection, pneumonia, heart failure, choking, or aspiration.

Diagnosing:

- Genetic testing and family history.
- MRI scan of head.
- ***Positron Emission Topography*** *(PET)* scan of brain.

***PET scan** — a nuclear medicine imaging technique that produces a three-dimensional map of functional processes in the body.*

Treatments:

- There is no known way to stop the progression of the disorder.
- Medications, which vary depending on the symptoms, to minimize muscle spasms and psychiatric symptoms.

Resources:

www.mayoclinic.com and search by Huntington's disease

www.hdac.org

Care Tips

- Pay attention to the person's mood. There is a high level of depression among people with Huntington's and a greater risk of suicide.
- There is high risk of falls with Huntington's. Make sure to remove fall hazards and encourage the use of assistive devices, if needed (cane, walker, etc.).
- Monitor and provide assistance with movement if necessary.

Korsakoff's Syndrome

Further Readings

Family Friendly

Korsakoff's Syndrome is caused by a lack of thiamine (vitamin B1), which affects the brain and nervous system. There are many causes for a vitamin B1 deficiency. Excessive use of alcohol is one cause. Excessive use of alcohol blocks the body's ability to utilize thiamine. Poor eating habits also contribute to the lack of vitamin B1.

Korsakoff's differs from other dementias in that brain damage occurs in important small areas in the mid-part of the brain.

Symptoms:

- Memory loss, particularly of events right after the onset of the condition
- Difficulty in acquiring new information or learning new skills
- Indifference in some cases or talkative and repetitive behaviors in others
- Hallucinations
- Inventing events to fill in the gaps in memory
- Drowsiness and confusion
- Vision changes, including: double vision, eyelid drooping, or abnormal eye movements
- Loss of muscle coordination, unsteady, uncoordinated walking

Progression:

- Will get worse if due to alcohol and the individual continues to drink.
- May be completely halted, if due to alcohol, and the person stops drinking.
- If the progression is halted, the earlier memory loss may not be regained.

Diagnosing:

- Psychological tests of memory.
- Examination of the nervous/muscular system and reflexes.
- Nutritional assessment.
- Brain MRI.
- Korsakoff's cannot be diagnosed while the person is drinking excessive amounts of alcohol. The person must stop drinking alcohol for at least 4-5 weeks to get through withdrawal first.

Treatments:

- High doses of Vitamin B1, usually by injection.
- Hospitalization for alcohol withdrawal, if caused by alcohol.

Care Tips

- Encourage the person to eat a well balanced diet.

If caused by excessive use of alcohol:

- Encourage and support the person to quit drinking alcohol.
- Tell the appropriate person where you work if you find alcohol in the person's room.
- Set boundaries and inform the person of the consequences if he or she continues to drink alcohol.
- People with Korsakoff's may not always tell the truth and are not always reliable historians. Get more information and check the facts before acting on information.

Resources:

- www.alzheimers.org.uk click on Factsheets, then Korsakoff's Syndrome.

Lewy Body Dementia

Further Readings **Family Friendly**

Lewy Body Dementia is caused by the build up 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.

Symptoms:

Abilities fluctuating daily, even hourly, making it appear that they are getting better at times. Other symptoms:

- Visual hallucinations
- Shuffling and difficulties with balance
- Very slow movements
- Muscle stiffness
- Loss of facial expression
- Fainting and/or falls
- Nightmares
- Problems sleeping
- Spatial disorientation

Progression:

- Changes occur at about the same rate as Alzheimer's.
- Generally progresses over a 5-20 year period.

Diagnosing:

- Physical, mental status, and neurological exams, and a detailed medical history.
- A CT scan to detect degeneration in the brain.
- A proper diagnosis is very important since people with Lewy Body Dementia react badly with certain kinds of medications. Some medication may make the condition worse and may even cause death.

Treatments:

- Medications to control shakiness and stiffness.
- Medications may improve alertness, cognition, and potentially reduce hallucinations.
- There is no cure for Lewy Body Dementia.

Resources:

- www.helpguide.org and search by Lewy body
- www.lewybodydementia.org

Care Tips

- For muscle rigidity, consult with the doctor to explore the use of range of motion exercises with the person.
- Because the person's abilities fluctuate, he or she will appear better at times. When the person gets worse again, it may seem like the person is faking it or playing up his or her symptoms. Remember a full range of symptoms is part of this disease. Go with what the person tells you and what you see related to this condition.

Parkinson's Related Dementia

Further Readings

Family Friendly

Parkinson's is a disease of the central nervous system. About 20% of people with Parkinson's develop dementia. A majority of people who develop dementia will have Alzheimer's disease.

Symptoms:

- Memory problems
- Parkinson's gait—shuffling, head down, shoulders drooped, lack of arm swinging, and leaning backwards, or forwards unnaturally
- Tremors
- Rigidity or muscle stiffness
- Poor balance/high risk of falls
- Constipation
- Lack of motivation
- Moodiness and/or depression
- Slowed thinking
- Confusion and/or disorientation
- Loss of facial expression
- Easily distracted
- Excessive sweating
- Loss of bowel and/or bladder control

Progression:

- Is slow. Symptoms often begin to show about 10-15 years following the diagnosis of Parkinson's.

Diagnosing:

- Ruling out other disorders that produce similar symptoms.
- Neurological exam.
- Medical history.
- CT scan or MRI scan.

Treatments:

- There is no cure for Parkinson's disease.
- Medications tailored to the individual in selection, dosage, and time, to relieve symptoms.
- A surgically implanted device that lessens tremors.

Care Tips

- Be patient and give the person plenty of time to do ADLs. Parkinson's disease makes their muscles stiff and sore.
- There is a high risk of falls with Parkinson's. Make sure to remove fall hazards and encourage the use of assistive devices, if needed, such as a cane or walker.
- Monitor and provide assistance with movement if necessary.
- Reduce stimulation. People with Parkinson's are often sensitive to noise and light.
- Always make sure that the person gets his or her medications as close to the prescribed time as possible. To be most effective, Parkinson's medications need to be taken on time.
- Constipation is a common problem with Parkinson's. Monitor and encourage an increase in fluids, physical activity, and fiber when appropriate.

Resources:

- www.helpguide.org and search by Parkinson's dementia.
- www.aboutdementia.com and click on Parkinson's.

Pick's Disease

Further Readings

Family Friendly

Pick's disease is a rare and irreversible form of dementia. Pick's disease is characterized by shrinkage of the brain tissues and the presence of abnormal bodies called "Pick's bodies" in the nerve cells of the affected areas of the brain. Symptoms are similar to those of Alzheimer's.

Symptoms:

- Lack of insight
- Lose the ability to feel for others-may appear selfish and unfeeling and have an attitude of "I don't care"
- Habitual and repetitive behavior
- Lose inhibition-for example, may exhibit sexual behaviors in public
- Lack of spontaneous conversation
- Talks but the intent and meaning is unclear, repeat back what others say
- Abrupt mood changes
- Become outgoing when previously quiet or withdrawn
- Changes in eating habits, such as develops taste for sweets
- Overeating
- Excessive alcohol intake
- Difficulty maintaining conversation for any length of time
- Decreased interest in daily living activities

Progression:

- Decline is normally steady and relatively rapid.
- Usually begins between the ages of 40 and 60.
- Extends over a period of less than 2 years to more than 10.
- Total disability occurs early in the disease process compared to other forms of dementia.
- Death is usually caused by a secondary infection.

Diagnosing:

- Neuropsychological assessment.
- EEG.
- CT scan of head.
- Brain MRI.
- ***Cerebrospinal*** fluid exam.

Cerebrospinal — relating to the brain or spinal cord.

Treatments may include:

- There is no proven effective treatment for Pick's disease.
- Medications used to treat Alzheimer's disease generally do not work because they increase aggression.

Resources:

- www.helpguide.org and search by Pick's.

Care Tips

- Triggers for behavior may be difficult to identify with a person with Pick's disease.
- Watch for signs of possible aggressive behavior and protect yourself.
- Pay attention to changes in the person's eating habits.

Traumatic Brain Injury (TBI)

Further Readings

Family Friendly

Traumatic brain injury (TBI) is an injury to the brain caused by trauma to the head. Even a relatively mild head injury can cause permanent damage to the brain.

Symptoms:

The symptoms that the person has varies depending on the type and location of the injury to the brain.

- Memory problems
- Problems thinking and remembering information
- Behavioral problems including:
  - aggression
  - impulsivity
  - impaired self-control
- Inappropriate sexual activity
- Difficulty with hand/eye coordination
- Difficulties with language including trouble remembering words or speaking in complete sentences
- Difficulty understanding information
- Seizures
- Emotional problems including being irritable and emotional

Progression:

- Varies from complete recovery to persistent symptoms and disability. It depends on the type and location of the head trauma and the resulting damage to the brain.

Diagnosing:

- X-rays, CT scans.
- Medical and mental status examination.

Treatments:

Ongoing treatment may include a number of rehabilitation efforts including:

- Physical therapy
- Behavior modification
- Cognitive rehabilitation
- Psychotropic medications
- Family support
- Medical care
- Social services

Resources:

- www.ninds.nih.gov and click on disorders, then Traumatic Brain Injury.

Care Tips

- People with TBI may appear “normal” as the brain injury is not always apparent or visible. Gauge the person’s level of understanding as you proceed with a task.
- Do not assume the person cannot do tasks. What a person can’t do one day, he or she may be able to do another day.
- The person may do better with repetition and/or a written schedule of activities. Structure can be very comforting to a person that has had a TBI.

Vascular Dementia

Family Friendly

Further Readings

Vascular dementia is a type of dementia that occurs when the brain does not get enough oxygen and nutrients. This happens when the blood vessels that supply oxygen become diseased or blocked and interrupt the flow of blood to the brain. High blood pressure, heart problems, high cholesterol, and diabetes all can cause damage to the blood vessels.

__Vascular__ — the system of vessels for carrying blood, includes veins, arteries, and capillaries.

There are two main types of vascular dementia:

- Stroke—caused by an interruption in the supply of blood to specific parts of the brain or as the result of a series of small strokes called a transient ischemic attacks (TIAs).
- Small vessel disease—caused by damage to tiny blood vessels that lie deep in the brain. The symptoms develop more gradually and are often accompanied by walking problems.

Symptoms:

- Problems with concentration
- Memory problems, forgetfulness
- Periods of acute confusion
- Dizziness
- Laughing or crying inappropriately
- Physical weakness or paralysis
- Moving with rapid, shuffling steps
- Problems communicating, slurred speech
- Hallucinations or delusions
- Wandering and getting lost
- Physical or verbal aggression

Progression:

- Onset can be gradual or dramatic.
- May not change in severity for long periods and then take a big dip.
- Damage already done to the brain cannot be reversed but further damage can be greatly minimized with treatment.

Diagnosing:

- Medical history, symptoms, current health, and lifestyle (diet, exercise).
- Cognitive tests and brain scans.

Treatments may include:

- Medications to improve blood circulation to the brain.
- Lifestyle changes including regular exercise, healthy eating, limiting alcohol intake, and stopping smoking.
- Rehabilitative support, such as physiotherapy, OT, and speech therapy.

Resources:

- www.alzheimers.org.uk and click on Factsheets and then Vascular dementia.

Care Tips

- Symptoms often progress in a stair like fashion. Note any changes, as they may indicate that the person has experienced another small stroke.

Dementia Care

Specialty Training

MODULE 2

Communicating with People Who Have Dementia

Washington State
Department of Social
& Health Services
ADSA Aging & Disability
Services Administration
www.adsa.dshs.wa.gov

Communicating with People Who Have Dementia

Module Goals:

To provide caregivers and managers information and tools to:

- Understand the impact of dementia on communication.
- Better communicate with people who have dementia.

Communication and Dementia

Dementia affects the parts of the brain that control communication in different ways for different people. 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 can be noted in memory, ***comprehension, language skills***, and ***social communication***.

Comprehension—*the ability to understand the meaning of something.*

Language skills—*the use of words, signals, or gestures to communicate thoughts and feelings.*

Social communication—*the ability to converse in social situations.*

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

- Have difficulty finding a 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 and interrupt, ignore another speaker, not respond when spoken to, only talk about him or herself, or demand constant attention.
- Have difficulty expressing emotions appropriately.
- Experience difficulty with writing.
- Be able to read words but may not understand the meaning.

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.

Always include the person with dementia in conversations to the greatest extent possible.

Changes in Communication Ability as Dementia Progresses

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 non-verbal 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 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 ***clichés.***
- Manage to get along in most social situations.

Cliché — an overused phrase or expression.

Adapted from Arizona Long Term Care Gerontology Center, *Alzheimer's Disease: Pieces of the Puzzle,* University of Arizona, Tucson, AZ, 1990.

Middle Phase of Dementia

Memory

- May experience moderate loss of long and short-term memory.
- Cannot remember less common words or concepts and less familiar names.
- Will no longer be able to hide memory problems.
- Learning new material becomes very difficult.

Comprehension

- Will have trouble understanding day-to-day conversations.
- Will be unable to understand when people talk too fast.
- Will 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 is slower.
- Often use slang or "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 not be interested in starting a conversation.
- Ask fewer questions and seldom comment or correct themselves.
- Answers to questions are often inappropriate. May forget the question that was asked.
- Can still handle some casual social situations.

Late Phase of Dementia

Memory

- Does not know the time, place, and person.
- Fails to recognize self or family members.
- 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.

Because of all 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 get information from the person.
- Listen and interpret what the person is trying to communicate with you.

A person with dementia may have difficulty understanding what you are saying, or react or respond in ways you are not expecting.

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.

Take extra care in how you approach a person with dementia and pay special attention to what you might be communicating nonverbally.

Approaching a Person with Dementia

- 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 pick up on it. Do all that you can to be calm and relaxed.
- Always approach the person slowly from the front or side. Do not approach the person from behind.
- 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.
- Use a friendly tone of voice and facial expressions.
- Call the person by name and tell him or her what you are there for.

Non-Verbal Gestures

- Touching and holding the person's hand may help keep his or her attention.

  One word of caution about touch—do not assume that the person likes to be touched. Always 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 or impatience.
- Use hand gestures and facial expressions to be more easily understood.

Watch your body language. The person with dementia will pick up feelings of anger or impatience.

- 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.

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.

Say less when giving information to a person with dementia—he or she may only be able to process a few words at a time.

- Use a low tone (pitch) of voice. A raised voice can signal that you are upset.
- Always talk slowly and clearly.
- Say less—some people may only be able to process a few words at a time.
- 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.

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.

When asking for information from a person with dementia, allow plenty of time for him or her to think about what you have asked.

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.
- If the person has difficulty finding a word, ask him or her to explain it in a different way.

- 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.

***Open-ended questions** — questions that require a spontaneous response from an unlimited set of choices.*

Listening and Interpreting Information

- Listen for and learn to recognize the person's feelings and emotions. Use your senses, as well as your intuition, to try and understand what the person is attempting to communicate.
- Focus on the person's feelings 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.

Listen for and learn to recognize a person with dementia's feelings and emotions.

Communicating Respect

A person with dementia is sensitive to feelings and emotions. It is important to always be aware of, what you say, and how you say it. Make sure that your communication is always respectful.

- Keep the person's culture in mind and know what is respectful communication in that culture. Talk to the person's family to learn more about what is respectful.
- Always 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.

Always be aware of what you say and how you say it when communicating with a person with dementia.

Importance of Environment

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

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.
- Always check that any problems a person may be having communicating is not due to the person's impaired vision, hearing, or poorly fitting dentures. Make sure glasses, hearing aids, and dentures are all 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.

Practicing Communication Strategies

When working with people who have dementia, be prepared to be creative and draw on a variety of strategies to improve communication.

Listed below are some specific tips and strategies to help you communicate more effectively with a person with dementia. These strategies may seem simple but they become very important when you are dealing with a person with dementia.

Practice these strategies until they become second nature to you. The goal is to use these strategies without even having to think about it.

- 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.”

This last strategy has been called Gentle Deception, because it involves letting go of the “truth” or your reality in order to hear what the person with dementia is saying. The idea is to let the person say whatever he or she wants to say without trying to persuade the person that he or she is wrong, incorrect, or out of touch with reality. Instead, you agree with the person and allow the person with dementia to retain his or her sense of reality.

We will now take a closer look at each of the strategies and you will be able to practice working with each of them.

Avoid or *Reframe* Open-Ended Questions

***Reframe** — Reword or restate.*

Open-ended questions are questions that require the person responding to choose from an unlimited or unrestricted set of options and come up with a spontaneous answer. For the person with dementia, this might be difficult.

Avoid using open-ended questions when talking to a person with dementia.

As a caregiver you can 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.

Francis is helping Ruth dress today. Francis goes to the closet and opens the door, where there are many clothes to choose from.

Francis: *Ok, Ruth. I'm here to help you dress today. What would you like to wear?*

Why might the question be difficult for Ruth to answer? Use the space below to fill in your thoughts.

Reflection:

Francis meant well in giving Ruth lots of options. Unfortunately, this only confused Ruth. There was too much information to process. Ruth may be overwhelmed with the choices and may not remember that it is her closet, what is in it, or even what it means to wear clothes.

Michael, on the other hand, knows that providing too many options can be overwhelming for Ruth.

The next day, Michael is there to help Ruth dress.

Michael: *Ruth, would you like to wear this green shirt or this red one?"*

Ruth: *I like the red shirt. I like red.*

Michael: *Yes, red is a pretty color. It reminds me of Christmas. That's the shirt we will use today. That is a pretty one. There we go.*

Why is this question easier for Ruth to answer? Use the space below to fill in your thoughts.

Reflection:

Michael made the decision easier for Ruth. Ruth still got to pick her clothes out, but she was able to select one of the two choices.

More Practice:

John has Picks disease and lives at home. You are the caregiver for John today and it is time for lunch. How might you ask John what he would like for lunch without using an open-ended question? Use the space below to fill in your thoughts.

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.

If you ask questions or give directions that require a person with dementia to reason something out, think logically, or understand time, you may be asking the person to do something that is impossible for him or her to do.

Jennifer is working with Bill and comes to let Bill know that it is time for lunch

Jennifer: *Bill, the morning flew by, didn't it? Do you know what time it is?*

Why could this question be difficult for Bill? Use the space below to fill in your thoughts.

Reflection:

Bill looked confused, didn't he? Perhaps it is because Bill was overwhelmed and was trying to make sense of what Jennifer said. Jennifer meant well, yet she used concepts that for someone with dementia could be very confusing.

When Bill heard, "the morning flew by" he may have been trying to understand how the morning could fly. Adding to his confusion, Jennifer asked Bill to recall what time it is. Bill was having difficulty understanding what she was being asked and he got overwhelmed and frustrated.

Francis, on the other hand, knows that trying to reason with a person with dementia can be frustrating for the caregiver and for the person with dementia. She has learned to avoid mention of time and avoids reasoning.

Francis: Y*ou've had a busy morning, Bill. It is now time for lunch.*

Bill: *No. No. I have to eat before I go to school.*

Francis: *That's right. You must be really hungry.*

Why is this statement easier for Bill to understand? Use the space below to fill in your thoughts.

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Reflection:

Francis simplified the information by stating that it was time for lunch. Her statement did not require Bill to respond or to try and interpret the time or what happens at this time of day.

More Practice:

Melvin has Lewy Body Dementia and always 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 to Melvin without using logic?

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Ask, Rather Than Tell, the Person What to Do

Telling a person with dementia what to do can be frustrating and confusing when the person cannot remember the “right” or obvious way to do something.

“Don’t do that” sounds like a parent scolding a child and can be viewed as threatening or demeaning.

Rather than telling the person what to do, encourage the person and ask for his or her participation in the task.

Jennifer: *Bill, put your shoes on.*

Bill: *No. Leave me alone. Get out of here.*

What might be contributing to Bill’s reaction? Use the space below to fill in your thoughts.

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Reflection:

Jennifer was attempting to get Bill to complete a task. She made the assumption that Bill remembered what shoes are for, where his shoes were, and how to put them on his feet. Bill may have felt like he was being ordered around and he didn’t like that.

Michael handles this situation using the strategy of asking, rather than telling a person with dementia what to do.

Hey Bill. Would you like help with your shoes? I can help you put your shoe on. Ok? There you go.

Reflection:

Michael sensed that Bill was resisting doing the task. He was able to gently guide Bill in the task and used visual and tactile cues to help him complete it.

More Practice:

You are Sue's caregiver. You enter her room where she is seated on the bed trying to put her legs through her shirt sleeves. What might you do to help Sue with dressing? What might you say? Use the space below to fill in your thoughts.

Say Less

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

Francis: *Ok Bill, let's get you dressed for breakfast. It's okay. Afterwards, we will have a sing-a-long. Let's get you dressed. Sing-a-longs are your favorite activity. It's ok. Let's get you dressed.*

How might Bill react to this request? Use the space below to fill in your thoughts.

Reflection:

Bill looked a little scared, didn't he? Perhaps Francis forgot that too much information can be overwhelming, confusing, and misinterpreted by a person with dementia.

Francis had some knowledge about Bill's preferences and likes. She attempted to engage Bill in an activity she knew he enjoyed. Unfortunately, because of his dementia, he only heard the very first words of the first sentence. Bill heard "*let's get you.*" It is not surprising that Bill looked frightened.

Jennifer remembered that it is important to say less and keep things simple and tried a different approach.

Jennifer: *Bill, let me help you get dressed for the sing along. I'm helping you.*

Reflection:

When Jennifer approached Bill, she offered to help him and was clear with what she would be doing with him. Even if he heard only the first words, he heard "*let me help you.*" This simple change can make a difference.

More Practice:

You are trying to get residents involved in an art project. You know that Kris loves to be creative. What might you say to Kris to encourage her participation? Use the space below to fill in your thoughts.

Gentle Deception

Use Gentle Deception to see the situation from the person with dementia's point of view. This helps you to have a conversation with a person with dementia without getting into an argument. Because of the effects of dementia, he or she may seem out of touch with reality.

Trying to orient the person to reality when the person does not understand what's going on, only frustrates the person and may make the person feel defensive. Let the person with dementia say whatever he or she wants to say and go with it.

Ruth repeatedly states she wants to go home. You know that this is not a possibility as her home has been sold.

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!*

Francis: *I am sorry Ruth. You cannot go home. Your house has been sold. Your family knows you're here. This is your new home. This is where you live now.*

Ruth: *No, no. I want to go home. This is not where I live. No.*

Francis: *Ruth, you live here now. We will take real good care of you.*

What might you say to Ruth? Use the space below to fill in your thoughts.

Reflection:

Francis was trying to comfort Ruth. Unfortunately, by trying to orient her to the “reality” that her house had been sold, she overwhelmed Ruth and reinforced all of her losses.

Michael witnessed what happened with Francis and Ruth and did not want to make the same mistake. He remembered and used the concept of Gentle Deception.

Michael: *Hey, what’s happening Ruth?*

Ruth: *I want to go home. I don’t know where I am. My family is probably worried about me. Can you get me out of here? Let me go home now!*

Michael: *Why don’t you tell me about your home?*

Ruth: *I love my home. It’s beautiful.*

Michael: *I bet it is beautiful.*

Ruth: *My family is probably worried about me. I want to go home.*

Michael: *You have a lovely family. I talked to them and they know that you are here with me.*

Ruth: *They do?*

Michael: *Yes. They do. Now, why don’t you and I take a walk and go to the dining room, ok?*

Ruth: *Ok.*

Michael: *Maybe we can get you some orange juice.*

Ruth: *Then I can go home?*

Michael: *We’ll see. Let’s go get some juice, ok?*

Reflection:

As this scenario indicates, Gentle Deception can be used to screen out troubling messages. Instead of reminding Ruth of a painful reality, Michael asks questions that get Ruth talking and reminiscing about her former home. This helps to calm her down and allows him to redirect her energy. Reminding Ruth that her house had been sold would only have caused her further pain.

More Practice:

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? Use the space below to fill in your thoughts.

Pulling It All Together

These tips and strategies will help you communicate more effectively with a person who has dementia. In addition, there are some general things to always 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.

Let’s see how things work when we pull these strategies together.

Jennifer is helping Bill with his bath. She has a busy schedule and has a lot of tasks to complete before her day is complete. She enters Bill’s room.

Jennifer: *Bill, I have a lot of stuff to do today so I need to hurry and help you with your bath. I’m going to organize your clothes and take them to the bathroom. I need you to get ready for your bath. Who helped you with your bath yesterday? What did they do with your robe?*

Bill: Bill looks confused and doesn’t respond to Jennifer.

Jennifer: *Bill, I need to help. You need to cooperate with me.*

Bill: *No!*

What did Jennifer say that might have contributed to Bill’s behavior? Use the space below to fill in your thoughts.

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What did Jennifer do well in the conversation? Use the space below to fill in your thoughts.

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Reflection:

Jennifer has a schedule to keep and is feeling rushed. She needs to keep on task so that she can get all her work done. While Jennifer's concerns are realistic, she communicated a feeling of being rushed to Bill both by her words (verbally) and by her actions (non-verbally). This has caused Bill stress from the start.

Although Jennifer told Bill to get ready for his bath, he may not remember the steps he has to take to do it. Then, Jennifer asks Bill two questions about the recent past. With dementia, Bill may have lost memories of the recent past and may not remember what happened yesterday or what or where his robe is.

Not knowing what he is supposed to be doing, Bill gets confused and frustrated and becomes resistant to taking a bath.

Instead of asking Bill to rush because she is rushed, Jennifer could have stopped for a moment outside Bill's door to slow down. Instead of asking Bill so many questions, Jennifer may have simplified her directions to Bill.

Let's see how the situation may have been handled differently.

Jennifer: *Bill, I'm here to help you with your bath today, ok?*

Bill: *Ok.*

Jennifer: *I brought your robe so that you stay warm, ok?*

Bill: *Ok.*

Jennifer: *Follow me to the bathroom, ok?*

Bill: *Ok.*

Reflection:

In this conversation, Jennifer provides Bill clear information on what she is going to be doing. She does not ask him to recall information that may be difficult to remember. In addition, even though she may feel hurried, she has not verbally or non-verbally communicated this to Bill.

More Practice:

Francis approaches Ruth and attempts to engage her in conversation.

Francis: *Hi Ruth. I bet you really like reading the newspaper and keeping up with the progress in this year's elections? I know you were involved in city politics, weren't you? You probably did a lot of reading when you taught at the university. What exactly did you teach?*

Ruth: *I taught trumpets.*

Francis: *You know you can't teach trumpets. Did you mean you taught music?*

Ruth: *I taught trumpets.*

Francis: *Whatever. Anyway, who do you think is going to win the election? Do you think we'll ever have a woman president in the future?*

What did Francis say that made it difficult for Ruth to engage in the conversation? Use the space below to fill in your thoughts.

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What did the Francis do well in the conversation? Use the space below to fill in your thoughts.

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Reflection:

Francis has a good understanding of Ruth's background and work experience. While this information is important and can help direct some of Francis's interactions with Ruth, Francis has overwhelmed Ruth by asking too many questions.

In addition, her questions require Ruth to recall past information, relate it to the present, and also consider the future. Because of the affects of dementia, Ruth may be unable to process this information and become overwhelmed and frustrated.

Let's see how Francis may have approached the task differently using the strategies and tips demonstrated earlier.

Francis: *Hi Ruth. Are you enjoying reading your newspaper this morning?*

Ruth: *I like reading the paper. It keeps my mind sharp.*

Francis: *That's right. Reading is a good activity. This sure is an interesting election year, isn't it?*

Ruth: *Oh, I like reading about the election of President Kennedy.*

Francis: *That's good Ruth.*

Reflection:

Francis asked Ruth close-ended questions. She gave Ruth the opportunity to elaborate on her understanding of the election year, if she maintains any interest and/or ability. Francis does not expect Ruth's response to be coherent and logical, as she may have lost this ability. And, Francis does not correct Ruth when she refers to President Kennedy.

Dementia Care

Specialty Training

MODULE 3

Creative Approaches to Challenging Behaviors

Washington State
Department of Social
& Health Services

ADSA Aging & Disability
Services Administration
www.adsa.dshs.wa.gov

Creative Approaches to Challenging Behaviors

Module Goals:

To provide caregivers and managers with:

- A variety of tools and methods to help you explore and handle challenging behaviors.
- Creative approaches for providing care.

In your role as a caregiver, you sometimes need to deal with challenging behaviors and situations. Your role is to try and understand what is causing the behavior and handle the situation knowledgeably and respectfully.

Your role is to try and understand what is causing the challenging behavior and handle the situation knowledgeably and respectfully.

One thing to keep in mind when dealing with an individual with dementia is there may be many things going on with the person that may contribute to his or her behavior.

In order to decide how best to respond to a challenging behavior, you need to take a step back and try to figure out what the person's behavior may be telling you.

- Is there something the person needs?
- What is happening in the person's living space?
- Does the behavior put the person or anyone else at risk of harm?
- Is the person getting positive attention for the behavior?

There is no ***one size fits all*** solution when dealing with challenging behaviors with people with dementia. Different people will have different needs.

There are a number of methods and tools that have proven successful. They are presented in the rest of this section.

Exploring Challenging Behaviors

Framework for Action

Step 1: Describe and try to understand the behavior.

Step 2: Decide if there is a problem and for whom.

Step 3: Decide what action, if any, needs to be taken.

Step 4: Check if your plan worked.

The Framework for Action is a four-step method for dealing with challenging behaviors.

Step 1: Describe and try to understand the behavior

- What exactly is the person doing, when, and with whom?
- Have you seen this behavior with this person before? Are there any patterns you can see?
- Is the person trying to communicate a need or desire?
- What happened in the environment or with other people at the time of the behavior that may have triggered it?
- Have there been any changes in the person's physical health?

Step 2: Decide if there is a problem and for whom

- Is anyone in physical or other danger because of the behavior?
- Can the behavior be explained as a way a person with dementia reacts to situations?
- Who is concerned or being impacted by the behavior (family members, caregiving staff, the person with dementia, other residents)?
- Does the behavior need to change or can you help the person concerned better understand it?

Step 3: Decide what action, if any, needs to be taken

- Does anything need to be done?
- If yes, what other help do you need? What do you expect others to do?
- Is there something you expect the person with dementia to do?
- Are there any other resources you will need to carry out your plan?

Step 4: Check if your plan worked

- Did your plan of action work?
- What worked well? Is there anything that didn't work?
- Did you learn anything that might help you better understand or deal with this behavior in the future?
- Is there anything you want to do differently if the behavior happens again?

Adapted from Archibald, C. (1995) in T. Kitwood and S. Benson (Eds.). *The New Culture of Dementia Care*. London: Hawker Publications

Using the ***Framework for Action***, review Elsa's situation.

Situation: *Elsa is 80 years old and has Pick's Disease but otherwise is in good health. She moved to a boarding home two months ago. In the past two weeks, her behavior has changed.*

In the evening, she appears nervous and is constantly pacing. She shouts when the TV is turned on, calls visitors bad names, and yells at them "Get out of here!" Family members have asked you to do something about Elsa. When she yells and screams, staff responds immediately and showers her with attention.

Elsa: *Hey, get that off. Help. Help. Get that off. It's too loud.*

Jennifer: *Elsa, stop yelling. You're upsetting everyone, can't you see that. What's wrong with you? You have everything you need, so stop it!*

Elsa: *Oh, shut up! Shut up! Shut up!*

Michael: *Do you know what Jennifer? I'm afraid Elsa is going to hit someone? I think we need to take her into her room until she stops yelling.*

Jennifer: *She's just being difficult and trying to get our attention. I don't want her to get the other residents all upset.*

Michael: *I know. (*To Elsa*) Elsa, why don't we go to your room until you calm down a little. We will come back in here a little later.*

Elsa: *Where are we going? Where are you taking me? Where the hell are you taking me?*

Jennifer: *Stop Elsa. What's wrong with you?*

Reflection:

Michael and Jennifer wanted to do the right thing. They did what many people do. They tried to stop the behavior before they could understand what was going on. They were both upset and whether they knew it or not, Elsa was picking up on their discomfort.

Michael and Jennifer needed to step back and try and figure out what Elsa was trying to tell them. One method for doing this is called: ***Framework for Action.***

Framework for Action is a four-step method used for dealing with challenging behaviors and Elsa's behavior is a little challenging.

Using this method, we'll explore how Michael and Jennifer could better help Elsa. We'll start by looking at the first step where Michael and Jennifer try to understand the behavior. The focus in not on solving the behavior but rather on accurately describing the behavior to better understand it.

Elsa: *Help! Help! Somebody needs to get in here and turn this TV off. It's too loud.*

Michael: *Elsa, I'm going to turn the TV off.*

Jennifer: *It's alright Elsa. We're going to turn the TV off. It's going to be ok. There. He turned the TV off. Is that alright now? Is that better?*

Michael: *We've got to do something about Elsa's yelling. It's driving me crazy and it's really bothering the other residents. Maybe you can help me try and figure out what to do.*

Jennifer: *I know, the yelling is too much! Elsa has been yelling and screaming at other residents, but she wasn't like this when she first got here. Her behavior changed suddenly. I've noticed that Elsa starts yelling when there are a lot of people around and when there is a lot of noise.*

Michael: *Yeah, I've noticed that too. It must be kind of hard moving to a new place. I know that anytime I'm somewhere new, I hate it until I get settled in. Can you imagine what it must be like when you have dementia and you don't recognize anyone who's in your house? I think I'd be scared, too.*

Jennifer: *That's all so true. I sometimes have to remind myself of what it's like for the person with dementia. She might not recognize any of us. Remember how they always told us to rule out any medical problems? Well, maybe Elsa has a urinary tract infection or is in pain or something.*

Considering this scenario, use the Framework for Action to describe the behavior in the box provided below. You may want to reference the chart "Dealing with Challenging Behaviors" on pages 60-62.

Step 1: Describe and try to understand the behavior

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To decide if there is a problem and for whom, Jennifer and Michael decide to talk with Donna, the supervisor.

Michael: *Hi Donna. Got a minute?*

Donna: *Yeah, come on in. What's up?*

Michael: *Jennifer and I thought it'd be best if we got your advice. Elsa's been yelling and screaming at other residents and at their family members. I can't stand it when she starts screaming.*

Jennifer: *It makes me nervous because I'm afraid she's going to get physical or something.*

Michael: *Yeah, what bothers me is that I don't want people thinking that I've done something to make her yell. I think Elsa's family is embarrassed.*

Donna: *You both have good points. It can be embarrassing and scary, but does Elsa's behavior hurt anyone else?*

Jennifer: *Well, no, not really. But, I'm afraid it might bother the other residents, our reactions. I know I get all stressed out and they notice that about me.*

Donna: *Well, it's important to know that Elsa's behavior seems to bother us more than it bothers other residents. You know, we might want to have her checked to see if there's not something going on with her medical condition.*

Decide if there is a problem and if there is, for whom. Write your answer in the box below.

Step 2: Decide if there is a problem and for whom

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Reflection:

Michael and Jennifer have stepped back and really looked at Elsa's behaviors. They've been able to see that though her behavior is disturbing, it really isn't hurting anyone. They were also able to talk to their supervisor, Donna, and ask for help.

In Step 3, Donna, Michael ,and Jennifer need to decide what action, if any, needs to be taken.

Donna: *One of the first things we need to consider is whether there may be a medical reason for the new behavior. Elsa needs to be seen by the nurse to make sure she doesn't have a UTI or some other medical problem. We also need to read her records and talk to family members to see if she's had these behaviors in the past.*

Jennifer: *I talked to her son and daughter the other day and they said she wasn't normally like this. They were really worried because she seemed like a stranger.*

Michael: *Yeah, her husband said that she was so quiet and never used bad language. He can't believe some of the things that fly out of her mouth.*

Donna: *We need to consider how difficult this must be for the family. Sometimes when family members see these kinds of changes, they don't understand that it is the dementia that causes these behaviors. I'll try to gather some resource information on dementia that I can give them.*

We might also want to brainstorm some things we can do to divert or redirect Elsa's behavior. She might just need to be involved in activities or tasks. If we stop focusing on the yelling and just get her involved in something to do, it just might stop.

Jennifer: *I could try getting her to help with some of the tasks when I'm getting the table ready for dinner. We'll see how that works.*

Michael: *I'll suggest we take a walk when she starts yelling and screaming. It might help to get her away from the noise.*

Decide what action, if any, needs to be taken and write it in the box below.

Step 3: Decide what action, if any, needs to be taken

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Reflection:

Donna, Jennifer, and Michael now have a plan of action to deal with Elsa. They have some good strategies and ideas. The good thing is that if these don't work, they can always come up with new strategies.

In Step 4, Donna, Michael, and Jennifer check to see if the plan worked. The key is to focus on the strategies that work and check to see if the plan worked periodically.

Michael: *I can't believe how Elsa's behavior has changed. Once she was treated for her UTI, it was like she was a different person. Guess those infections can make a person really upset.*

Jennifer: *Yeah. Elsa seems to have taken well to being included in some of the activities. She seems to really like helping set the tables at meal time.*

Donna: *Be sure to write this stuff in Elsa's record just in case she starts yelling and screaming again. I'm sure other caregivers will find your strategies helpful.*

Michael & Jennifer: *Ok.*

In the box below, write your answer to how the plan worked.

Step 4: Check if your plan worked

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Here are some examples of the types of things you may have listed for each step in the **Framework for Action**.

Step 1: Describe and try to understand the behavior

- Elsa is yelling and screaming at other residents. Her behavior changed suddenly. She wasn't like this before. Elsa yells when there is noise and when others are around.
- Elsa is in a new living environment and might be afraid or overwhelmed since everything (housing, other residents, routine, staff) is unfamiliar. Elsa may not know where she is and thinks other people are in her home.

Step 2: Decide if there is a problem and for whom

- Elsa's behavior may be irritating or embarrassing to others, but it does not appear to be hurting anyone else.
- Elsa's family seems to be bothered by the behavior.
- Elsa may be in distress or pain.

Step 3: Decide what action, if any, needs to be taken

- Have Elsa seen by a medical professional.
- Address the issues that Elsa's family is having and educate them on typical dementia behaviors.
- Find tasks to divert Elsa's attention.

Step 4: Check if the plan worked

- Elsa had a UTI that may have been causing her behavior. Once treated, the behavior stopped.
- Elsa responded well to diversion. She seemed to enjoy new tasks.
- Elsa's yelling and screaming has stopped.
- Document the strategies that worked.

The “ABC” Technique

The “ABC” technique is another tool to help you get a better understanding of what may be causing challenging behavior. This is done by using a simple “ABC” approach.

This information will be easier to remember and think about if careful notes are documented in the person's records over a period of time.

Antecedent - *What was happening before the behavior occurred?*

- Were there things in the environment that were different (unfamiliar people, things, noises)?
- Has anything changed in the person’s schedule?
- Has the person’s physical or medical condition changed?
- Was there anything different from the normal routine?

Behavior - *What is the behavior?*

- What is the person doing?
- What things are you seeing that cause you concern?
- What are you hearing that causes you concern?
- What are your concerns about the behavior?

Consequence - *What happens in response to the behavior?*

- How did others (staff, family, other residents) respond to the behavior?
- What was the person’s reaction to this response?

Adapted from L. Gwyther’s adaptation of: Mace, N. Journal of Gerontological Nursing, v.II, #10, 1986.

Situation: *Phil is a 63 year old male and has Alzheimer’s Disease. He was diagnosed when he was 58 and is currently living in a boarding home. He has been in the home for 6 months.*

When he first got to the boarding home, he was able to understand directions and communicate his needs. In the last 3 months, he seems to be more confused and is having difficulty following directions. He gets frustrated and angry.

Yesterday when he was being bathed, he bit a caregiver. Later in the day, he pushed another caregiver into a wall. The caregivers are scared and concerned that he might hurt them.

Jennifer: *I'm not going to help Phil with his bath today. Did you hear that he bit Carmelita yesterday while she was helping him with his bath?*

Michael: *Ouch. Really?*

Jennifer: *Yep. She said it really hurt and she cried like a baby. I would have too… I might have bitten back. Michael, you're big and strong, you deal with Phil.*

Michael: *I may be bigger and stronger than you, but I'm not dumber. I'm not going to help him. It looks to me that he doesn't need a bath today, what do you think?*

Jennifer: *I'm ok with that. I'm off the next two days and so I won't have to deal with it. And I'm keeping my distance from Phil today.*

Michael: *Yeah, me too!*

Reflection:

Michael and Jennifer are wise to be concerned about safety, but ignoring Phil's needs or refusing to work with Phil is not acceptable. Phil's behavior is challenging and can be intimidating and threatening, yet it is important to remember that Phil's behavior is a product of his dementia. There are strategies for problem solving Phil's situation and finding ways to work with him effectively.

Lets consider the "ABC" technique to better understand what might be causing a behavior.

The "ABC" approach starts with 'A' for antecedent. What was happening before the behavior started?

'B' is for behavior. What is the behavior?

'C' is for consequence. What happens in response to the behavior?

Jennifer: *Donna heard that we are afraid to bathe Phil or to do any work with him. She suggested we use the "ABC" technique and try and figure out what might be happening with Phil.*

Michael: *Darn, Donna hears everything, doesn't she? "ABC" technique, huh. Guess we need to do what she suggested otherwise she'll hear that we didn't do it.*

Don't we start by trying to figure out what was happening just before Phil started biting and pushing the care staff?

Jennifer: *Yeah. That's right. I think we have to think about what was different in Phil's routine or if there was something going on that was upsetting him.*

Carmelita told me that on the day he bit her that she had been having a bad day. She had a new resident to deal with and she was way behind schedule. She needed Phil to cooperate with her but the more she asked him to do things, the more challenging he became.

Michael: *I hear you. I have a busy schedule too and when Phil doesn't get things done quickly enough, it throws me off schedule. I try to be patient but sometimes I just blurt out what I want him to do. You know, Phil has trouble when I ask him to do too many things at once.*

Antecedent

Reflection:

Both Jennifer and Michael are reflecting on what was happening right before Phil became combative. They are doing a good job. Not only are they considering what was going on in Phil's environment, but they are considering what was happening with them as well.

Behavior

Next they will look specifically at what Phil's behavior was.

Michael: *Steve said Phil seemed really calm right before he pushed him into the wall. It was like he just exploded. One minute he was fine and the next, he was off like a rocket. If he keeps up this type of behavior, he might hurt someone or get himself hurt.*

Jennifer: *Interesting. Same thing happened to me. Phil was calm and then he suddenly exploded. Yet, when I think about it, he seemed overwhelmed with the directions I was giving him.*

Carmelita told me that right before he bit her, he seemed different, like he was embarrassed that she had to help him and he didn't want her helping him take off his pajamas or bathing him.

Michael: *Yeah? Maybe that's it.*

Jennifer: *This is new for him. When he first got here, he could bath without help. Donna also mentioned that we might want to think about how someone with dementia might be feeling embarrassed because they need help. Donna's so smart!*

Consequence

Reflection:

Jennifer and Michael are doing a good job in identifying the specific behavior. They are reflecting on the actual behavior and not focused on trying to find a solution. Once they are clear with the specific behaviors, they can focus on what happens in response to the behavior. For help with this, Jennifer and Michael went to talk with Donna, their supervisor.

Donna: *So, Michael, Jennifer, how is it going with Phil?*

Michael: *Phil seems to get a kick out of the fact that the staff are afraid of him, like he gets the sense that he's in control. Don't you get that sense Donna?*

Donna: *It may appear that he feels in control, but it is important to remember that someone with dementia is losing many things and often feels overwhelmed and out of control. It is really important to observe Phil and if he is being physically intimidating, it is ok to set limits.*

Jennifer: *What do you mean set limits? If he has dementia he won't understand, will he?*

Donna: *Well, that depends. Some people with dementia know what is and is not acceptable. It's worth trying out, isn't it? We also need to see how other staff are responding to Phil. Is he getting a lot of attention or is he being left alone? These are all important things to look at when working with Phil.*

Once we have a good sense of the ABC's of Phil's behaviors, we can figure out what to do.

Reflection:

The “ABC” technique is a good method for helping identify what might be triggering behaviors and determining what is best when working with a particular person. When we have a better understanding of what might be happening before the behavior occurs (antecedent), and what happens in response to the behavior (consequence), we will then have more insight in helping us deal with the behavior.

Listed below are some examples of the observations Michael and Jennifer may have made using the “ABC” technique.

Antecedent - *What was happening before the behavior occurs?*

- Carmelita was having a bad day and was behind schedule.
- There was a new resident in the boarding home.
- Phil is having more difficulty understanding directions.
- The caregivers are frustrated and Phil might sense their frustration.

Behavior - *What is the behavior?*

- Phil becomes angry and appears frustrated.
- Phil bit the caregiver.
- Phil pushed a caregiver into a wall.

Consequence - *What happens in response to the behavior?*

- Caregivers respond in fear.
- Phil does not have to do the task and is no longer overwhelmed or embarrassed.

Now that you have a better picture of what is happening with Phil, what are some things you might try when helping Phil? Use the space below to fill in your thoughts.

Managing Challenging Behaviors

A third approach to help manage challenging behaviors is called **Managing Challenging Behaviors**. It has six steps.

1. Describe the behavior.

The more clearly the behavior is described the easier it is to decide which behavior you will target. Don't try and resolve everything at once. **Begin with one behavior at a time**.

2. Gather information about the behavior.

How often and when does the behavior occur? Where does it happen most? Who is involved and affected by the behavior? Is the person expressing feelings such as anger, frustration, fear? What is the staffs' response? Did it work?

Depending on the situation, talk with the person, other staff, family members, or the person's health care provider and make sure to read the person's chart or records.

3. Identify what happens before and after the behavior.

There are usually several things involved in the behavior. Learning as much as you can about the person and his or her behavior gives you the best chance of figuring out how to deal with it. The answer to what happened before and after the behavior will help you determine if something is "triggering" the behavior.

The more you learn about a behavior, the easier it is to work with it.

4. Set realistic goals and make plans.

Think of several alternative solutions or actions that are realistic based on the situation and resources needed. Choose one solution or action to try and make a plan.

Your plan should include what has to be done, by whom, what you expect to happen (your goal), and how you will determine whether your plan is or isn't working. Involve the person as much as possible.

5. Reward staff and the person for achieving goals.

Changing behavior can be hard work, no matter how small the change needed. It is important to acknowledge and reward each step towards a change.

Both the person and staff should be rewarded. What the reward should be depends on each individual such as verbal praise, a favorite activity, or a small break. Any reward should be given as soon as possible after each positive change.

6. Continually evaluate and modify plans.

Be flexible when carrying out your plan. Frequently take a step back and evaluate how your plan is working. Then make any needed changes.

Teri, Linda and Rebecca Logsdon. "Assessment and Management of Behavioral Disturbances in Alzheimer's Disease," Frontiers in Medicine, 1990, Vol. 16, No. 5, pp.36-42.

Situation:

Mary has dementia with Lewy bodies. She has been at the boarding home for three years. Though her dementia has progressed, she has never really presented any behavioral challenges.

The past two nights as Michael and Jennifer are helping her prepare for bed, she has become resistive. She claims that there is a snake in her bed and that

Jennifer: *Hey Michael, I need your help getting Mary ready for bed tonight. The past two nights she's been really awful. Every time I try to get her ready for bed, she starts screaming that there is a snake in her bed. I keep telling her that there are no snakes in the building. She just gets madder and madder.*

Michael: *Well, I don't know if I can help, but I will see what I can do.*

Reflection:

Jennifer and Michael will use the **Managing Challenging Behaviors** approach to deal with Mary's behavior. This is a six step process. In Step 1, Jennifer and Michael attempt to identify Mary's behavior. Because there are several behaviors occurring, they start by focusing on one behavior at a time.

Step 1: Describe the behavior.

Jennifer: *Mary, we're here to get you ready for bed. Are you tired? Let's get your nightshirt on.*

Mary: *Don't make me do it. I don't want to get in that bed. There is a snake in that bed. Why do you want to put me in a bed with a snake?*

Michael: *Mary, there is no snake in your bed. Can't you see there's no snake? How do you think a snake would have gotten in here?*

Mary: *Stop! They are trying to kill me. Help me! Help me! Help!*

Jennifer: *We need to get her to stop screaming. She's going to scare all the other residents.*

Michael: *Maybe we need to step out and see if we can figure out what to do. Maybe Donna has some ideas.*

Jennifer: *Ok. Mary, we'll be back in a little bit.*

Reflection:

Identifying and focusing on only one behavior can be difficult. Jennifer and Michael need some help to gather information on Mary's behavior. They have decided to go to their supervisor for help with Step 2, gathering more information about the challenging behavior.

Step 2: Gather information about the behavior.

Donna: *Hi. So what's going on? I heard Mary yelling quite a bit. Are you having trouble?*

Jennifer: *Yeah. She doesn't want to go to bed. She's yelling and screaming that there is a snake in her bed and now she says that we're trying to kill her.*

Michael: *She's never like this. It seems to happen only at bedtime. She really seems scared, as if we are trying to hurt her.*

Donna: *Wow, that's quite the allegation. So let's take a minute to figure this out. First let's start by talking about one behavior at a time. What should we start with?*

Michael: *That's easy. We want her to stop yelling.*

Jennifer: *And, we want her to go to bed.*

Donna: *Ok. So again, let's focus on one behavior at a time. We want to get her to stop yelling, right? So first we'll focus on why she is yelling.*

Step 3: Describe what happens before and after the behavior.

Reflection:

In Step 3, Donna helps Jennifer and Michael focus specifically on what was happening right before and after the behavior. By doing this, they can begin to identify what may be triggering Mary's reaction.

Jennifer: *I think she's yelling because she's mad. And, she's mad because she has to go to bed.*

Michael: *Yeah. I don't think she likes us helping her.*

Donna: *Ok. Those things may all be true, but what happens right before she starts yelling?*

Jennifer: *Well, she never used to yell before. Something's different.*

Michael: *Something's different alright. Now she thinks there's a snake in her bed.*

Donna: *Ok. So, there is something else going on here, right? She's saying there's a snake in her bed.*

Jennifer: *Yes, and she won't stop because she really believes this.*

Donna: *So, this is all really good information. Did you know that Mary has dementia with Lewy Bodies? People with this kind of dementia sometimes have hallucinations and see things that aren't really there.*

Michael: *Wow. So, is she really seeing a snake?*

Jennifer: *Of course not, Michael! What do you think?*

Donna: *Now wait a minute. For Mary, those snakes are real. We may not be seeing what she sees but in her mind, that snake is in her bed. And if there is a snake in her bed, what does she do? She screams and yells. So really the challenge isn't her yelling and screaming, but rather it is to get rid of the snake in her bed.*

Step 4: Set realistic goals and make plans.

Reflection:

Donna, Jennifer, and Michael have done a good job on focusing in on one particular behavior. By doing this, they have information that will help with Step 4 of this process, which is setting realistic goals and making plans for dealing with the behavior.

Jennifer: *So, are we supposed to lie and say there is a snake to get her to stop yelling?*

Donna: *We don't call it lying, remember? We are trying to see things from Mary's perspective and enter her reality. We call it Gentle Deception. We've talked about this before, remember? We'll agree with Mary and then just do whatever we need to do to get rid of the snake.*

Michael: *Ok. C'mon Jennifer. I'd like to give it a try.*

Jennifer: *Sure, Michael. You're good at pretending.*

Mary: *Yes.*

Michael: *Hey, Mary. We are going to get you ready for bed now, ok?*

Mary: *There's a snake in that bed. Someone put it there. Help!*

Michael: *Mary, you know what? I'm going to take care of that snake for you. I'm not too afraid of snakes. I'm going to take that trashcan and catch the snake inside.* (Michael takes the trashcan and grabs at the bed). *There we go, and I'm going to take the snake and I'm going to drive it far away in my car. Ok.*

Mary: *You'd do that?*

Michael: *Of course.*

Mary: *Thank you.*

Jennifer: *Okay, Mary, here's your nightshirt. Let's get ready for bed.*

Reflection:

Donna knew that Mary truly believed she was seeing a snake in her bed. Rather than trying to convince her that it was not true, Donna set a realistic goal of entering into Mary's reality. Fortunately, it worked. It's important to have several alternative solutions or actions ready in the event one doesn't work.

Michael: *Hey, Donna. That was really great. It really worked.*

Jennifer: *Yep, Gentle Deception. I'll take some pretending lessons from Michael.*

Reflection:

At first, Jennifer and Michael made a common mistake. They tried to convince Mary that she was making things up. Instead of calming Mary, this got her more upset and her behavior escalated.

They were smart to ask Donna to help them deal with the behavior so that it didn't get worse. Donna was able to help them see the importance of using the **Managing Challenging Behaviors** approach. She helped them understand that when they are working with someone who has dementia, the person's sense of reality is important.

Step 5: Reward staff and the person for achieving the goal.

Donna: *I appreciate that you came to me to help problem solve instead of pushing Mary, which would only have made her more upset. And you know, what worked tonight might not always work. Remember, you should always evaluate to see if what you are doing is working and if it is not, be flexible and try something different. This was a tough one guys and you both did a great job!*

Jennifer: *Thanks!*

Michael: *Gosh, I like Donna.* Jennifer nods in agreement.

Step 6: Continually evaluate and modify plans.

Reflection:

Donna rewarded Jennifer and Michael by praising them for their efforts in achieving their goal, which is Step 5 of this process. And, she reminded them that they will need to be flexible and evaluate their efforts on a continuous basis, which is Step 6.

Managing Challenging Behaviors

Listed below are some notes regarding problem solving Mary's behavior using the Managing Challenging Behaviors approach.

1. Identify the challenging behavior.

Mary is yelling "there's a snake in my bed" when caregivers come to prepare her for bed.

2. Gather information about the challenging behavior.

This is a new behavior for Mary. Mary has dementia with Lewy bodies. With this type of dementia, visual hallucinations are common. Mary is only exhibiting this behavior at bed time. She appears frightened and has recently become distrustful of staff.

3. Identify what happens before and after the challenging behavior (the antecedent and the consequence).

Mary was alone in her room. The environment was quiet. Jennifer and Michael do not see anything new or changed in Mary's room.

In the past two nights, Jennifer left Mary alone and did not prepare her for bed, as she did not know how to deal with her behavior. Jennifer's attempts to convince Mary that there was not a snake in her bed did not work. In fact, Mary appeared to get angrier and said "they are trying to kill me".

4. Set realistic goals and make plans.

Jennifer and Michael's goal is to reduce Mary's fear and get her safely in bed. Donna helps Michael and Jennifer realize that for Mary the snake is real. Because Mary believes there is a snake in her bed, she is afraid to go to bed. Together, they decide to try and enter Mary's reality. They make a plan for "getting rid of the snake".

5. Reward staff and the person for achieving goals.

Jennifer and Michael received praise from their supervisor for their good work problem solving and dealing with Mary's behavior. Donna also positively reinforced and recognized Jennifer and Michael for seeking help when they did not know what to do.

Mary is rewarded by being able to go to bed calmly and without fear.

6. Continually evaluate and modify plans.

Donna reminds Michael and Jennifer that though this approach worked with Mary this time, it may not always work in the future. They will need to evaluate the situation again and be flexible in trying new approaches if the hallucinations return.

Signs of Difficulty

Challenging Behavior	Possible Causes	Care Tips
Crying, tearfulness	• Pain/discomfort. • Depression.	• Look for signs of pain/discomfort. • Talk to the person about how he or she is feeling.
Easily upset/troubled	• A reaction to changes in the environment. • A reaction to feeling threatened or overwhelmed. • Feeling rushed, out of control, or overwhelmed.	• Avoid changes and surprises. People with dementia do better with a regular routine. • Explore reasons for the behavior. • Provide frequent reassurance. • Don't take it personally. • Slow down and reduce stimulation. • Simplify or break a task into small steps.
Overly concerned with health/body functions Repeats complaints or questions Constant movement or pacing Fears/suspicions that have no cause	• The dementia or a medical condition (UTI, medication that doesn't mix well or should not be taken together). • Feeling insecure or unsafe. • Feeling lost. • The person is searching for something (memory, person they were, usefulness). • Needs to go to the bathroom. • Hunger or thirst.	• Talk to your supervisor or the person's doctor about concerns related to a medical problem. • React calmly to the person's feelings. • Reassure the person that he or she is safe. • Encourage the person to take a walk or provide another activity. • Provide familiar items. • Check to see whether the person needs to go to the bathroom. • Offer a snack or beverage.

Inappropriate/Unsafe Behavior

Challenging Behavior	Possible Causes	Care Tips
Hurts self Eats things and food that should not be eaten (dirt, dog food, paper)	• Mental health issues. • Confusion about what things can and can’t be eaten. • Confusion about what meal time is.	• Ensure the person’s safety. • Report it to the appropriate staff. • Lock up potentially dangerous items. • Seek treatment for mental health issues. • Record and document incidents.
Takes off clothes in public Uses the bathroom in inappropriate places Inappropriate sexual acting out	• Clothes are uncomfortable or the person is too hot or cold. • A symptom of the specific type of dementia the person has.	• Try to figure out if the person is communicating a need. • Remind and tell the person what is appropriate. • Offer privacy by taking the person to a private place. • Provide visual and tactile cues to redirect or prompt appropriate behavior.
Hiding items Hoarding/collecting items Rummage/takes belongings	• A need to keep busy and complete tasks.	• Provide items to hide and rummage.
Up at night/requires help and attention Wander/exit seeking Wanders/not exit seeking Left home and gotten lost	• Sleeping too much during the daytime. • A need for more physical exercise. • Looking for familiar items or places. • Trying to find a way to get home. • Medical concerns.	• Get the person a snack and then encourage them to go back to bed. • If there has been a change in sleep patterns, check for changes related to medical concerns. • Make sure the person is busy during the day. • If exit seeking, figure out what the person is searching for and create a plan to assure his or her safety.

Behaviors that Look Like Psychiatric Symptoms

Challenging Behavior	Possible Causes	Care Tips
Delusions Hallucinations Manic symptoms Mood swings	• Medical problems. • A symptom of the specific type of dementia the person has.	• Do not try and talk the person out of the hallucination. It will further upset the person. • Connect, don’t correct.

Physically Agitated/Aggressive

Challenging Behavior	Possible Causes	Care Tips
Assaultive Breaks, throws items Intimidating/threatening Seeks sexual partner who can't protect themselves	• Pain. • A reaction to a perceived threat. • A reaction to a new situation. • Trying to communicate a need or emotion. • Feeling rushed or out of control. • Experiencing too much stimulation. • Caregiver may be in the wrong place at the wrong time.	• Ensure the safety of everyone involved. • Look for signs of pain or discomfort. • Set limits. Abuse is not acceptable. Although this may not change the behavior, a person with dementia sometimes understands what is and is not acceptable. • Look for things that trigger the behaviors. • Acknowledge/validate feelings as they occur.
Aggressive and resistive to personal care	• Frustration. • Embarrassment. • Too many cues or directions too quickly. • Trying to maintain some sense of personal control. • May not see the need to do it.	• Explore how to make interaction pleasant to avoid resistance. • Break tasks into small steps. • Slow down. • Negotiate to do the task at another time. • Get help from your supervisor.

Verbally Agitated/Aggressive

Challenging Behavior	Possible Causes	Care Tips
Inappropriate verbal noises Refusing to go along with care Yelling/screaming	• Trying to communicate a need or an emotion. • Pain. • Trying to maintain a sense of control. • Too many cues or directions too quickly. • UTI.	• Try to figure out what the person is trying to communicate. • Look for any signs of pain/discomfort. • Provide comfort to the person and talk in a calm and reassuring way. • Slow down. Give simple directions.
Accuses others of stealing Uses foul language Verbally abusive	• A symptom of the specific type of dementia a person has. • Frustration. • Misjudging or misinterpreting the situation. • Feeling overwhelmed, fearful, or unsafe.	• Distract the person with an activity or task. • Do not deny or confront the problem. It will only escalate the situation. • Talk to the person about what he or she is feeling.

Different Ways to Look at Dementia Caregiving

Further Readings

Activity Based Alzheimer Care

Activity Based Alzheimer's Care suggests that activities are the foundation of care. Every event, encounter, or exchange is an activity, be it a bath, meal, song, or smile. An activity is defined as an interaction between the individual and the environment.

Activity Philosophy: The activities that make up a person's daily experience should reflect, as much as possible, the individual's preferred lifestyle while enabling a sense of usefulness, pleasure, success, and as normal a level of functioning as possible.

Activities are meaningful when they reflect these components. Activities are appropriate when they are meaningful and when they respect the person's age, beliefs, culture, values, and life experiences.

Activities should enable a sense of usefulness, pleasure, success, and as normal a level of functioning as possible.

Activity Based Assessment: A thorough Activity Based Alzheimer's Care assessment should include:

- Medical information.
- Background information/family history.
- Social/cultural information.
- Occupational background.
- Interests/abilities.
- Current abilities regarding cognition, motor status, sensory status, and social abilities.
- Needs—both physical and social.
- Strengths—both physical and social.

Activity Based Program Design

Programs should have a flexible structure and be responsive and adaptive to change and need.

Programs should be strength-based on the person's abilities, interests, and strengths, rather than his or her problems, weaknesses, or losses.

Adapted from Activity Based Alzheimer's Care: Building a Therapeutic Program.. Alzheimer's Association.

Further Readings

In **GENTLECARE,** people, programs, and physical space are used to create a “prosthetic” environment that supports the person with dementia to live and function as independently as possible throughout the course of the disease.

> **PROSTHESIS** - (pros-thee’-sis) a device or artificial structure either external or implanted that substitutes for or supplements a missing or defective part.

The goal of the “prosthetic” environment is for people, programs, and physical space to work in harmony to produce a support or prosthesis to compensate for deficits due to dementia.

In much the same way that a person who sustains a spinal cord injury is prescribed a wheel chair to compensate for the paralysis and be more independent, a person with dementia can be set up in an environment that supports the person’s ability to manage his or her needs.

Support the person with dementia to live and function as independently as possible throughout the course of the disease.

Key Components to GENTLECARE

There are three key components to **GENTLECARE**: people, programs, and physical space.

People

People are the essential therapeutic agents in dementia care. People form a vital support system that must be maintained throughout the disease process. All people the person has contact with affect the health of the person with dementia.

The beliefs, attitudes, and language of these people shape the life of the person with dementia. Patience, respect, and good humor positively affect the person with dementia.

Programs

Programs consist of activities throughout course of the entire day of a person with dementia. Rather than adopt a rigid system of activities driven by artificial wake-up, sleep, and meal times, GENTLECARE carefully uses **all** activity in the life of the person to enhance and ensure a meaningful life.

Programs for persons with dementia are most effective when they are an integral part of the daily living process, rather than “add-ons” or “take-outs” to the life process.

Adapted from Jones, Moyra. Gentlecare: Changing the Experience of Alzheimer’s Disease in a Positive Way, Moyra Jones Resources, Burnaby, B.C., Canada, 1996. Reprinted by permission.

Programs which focus on and support self-care, communication, intimacy, relaxation, stress reduction, competency, and former life roles often have magical results in the care of persons with dementia.

All programs should avoid challenges and be designed to support and celebrate the existing strengths of the person.

Physical Space

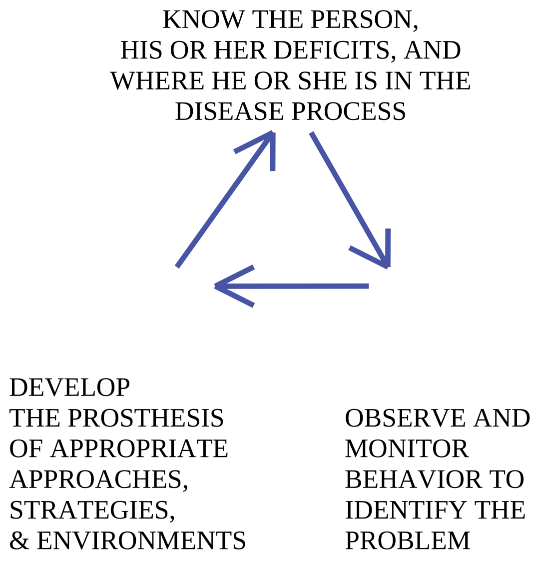
The physical environment of the person with dementia needs to be simple, normalized, and therapeutic.

Many design features can enhance the person’s function and quality of life, including:

- Secure perimeters.
- Indoor and outdoor walking loops.
- Appropriate way-finding cues and signage.
- Multiple small social and dining areas.
- Reduction of glare, noise, and confusion.
- “Family cluster” arrangements.

A simplified graphic display of the approach is shown below.

THE GENTLECARE APPROACH



KNOW THE PERSON,
HIS OR HER DEFICITS, AND
WHERE HE OR SHE IS IN THE
DISEASE PROCESS

OBSERVE AND
MONITOR
BEHAVIOR TO
IDENTIFY THE
PROBLEM

DEVELOP
THE PROSTHESIS
OF APPROPRIATE
APPROACHES,
STRATEGIES,
& ENVIRONMENTS

GENTLECARE in Practice

The following are three examples that demonstrate how creativity that can be used in the practice of GENTLECARE. These examples show how people, programs, and physical space can be used to assist a person with dementia to enjoy a comfortable life, avoiding confrontation and crisis.

1. A maintenance worker on a GENTLECARE unit does *not* merely walk on the unit and hang a picture. Instead, as a member of the GENTLECARE team, he is aware that he will be working in the person's "home."

   He will talk with the person with dementia, identify his project, ask the person's opinion, attempt to involve him or her in the task as much as possible, and thank him or her for their contribution to the work, thereby greatly enhancing self-esteem.

2. The practice of using public address systems to call people to telephones and make announcements is not viewed favorably in GENTLECARE. Such systems are frightening, disorienting, intrusive, and confusing for people struggling with cognitive impairment.

   A GENTLECARE environment would be designed to eliminate this stress from the lives of people who reside in facilities by replacing sound systems with personal pagers or written messages.

3. The practice of getting people up and dressed at the convenience of caregivers is most unsettling to people with dementia. GENTLECARE advocates adapt the morning wake-up routine to when the person wakes up naturally.

   This approach advocates for not rushing the person and allowing him or her to enjoy the beginning of the day and prepare for the coming day's activities.

Validation Therapy

Further Readings

Validation Therapy is based on our understanding that after a certain point in dementia the person’s sense of “present time” no longer functions.

Therefore, to communicate with people with dementia and meet their needs, caregivers have to relate to where the person with dementia is, rather than try to reorient the person to the present.

The use of Validation Therapy reduces anxiety in many people with dementia by making them feel safe and less confused.

For example, a person with dementia calls out for her mother who died decades earlier. The caregiver does **not** disagree with or correct her. Rather, staff mimic her feelings with sympathetic facial expressions and ask questions, such as “Do you miss your mother?” “What would you like to tell her?” to get her talking about her feelings and concerns and bring a level of comfort.

Validation therapy also helps to decrease unwanted behaviors, such as biting, stripping, episodes of incontinence, crying, swearing, yelling, and pacing.

Close eye contact, a clear, low tone of voice, and gentle touch, also are key to reaching people with severe cognitive loss.

Keys to Using Validation Therapy

- Be non-judgmental, accept, and respect the wisdom of the person.
- Help the person be at peace.
- Acknowledge and validate feelings.
- Listen with empathy.
- Do not treat the person as a child.
- Do not punish, threaten, or patronize. Do not shut off the person's feelings.
- Tune into the person, listen to verbal clues, and observe non-verbal clues.
- Put the person’s feelings into words to affirm them.
- Do not expect all people with dementia to act alike. Respect the unique differences.

Adapted from Feil, Naomi, ACSW. Validation The Feil Method, Edward Feil, Cleveland, Ohio, 1991

The Wellness Approach

Further Readings

The Wellness Approach focuses on the capabilities a person still has instead on what is missing or lost. Realistically, focusing on the positive helps the person with dementia reach his or her highest level of functioning.

The Wellness Approach is partly an attitude and partly a matter of techniques, such as:

- Identifying, emphasizing, and building on remaining abilities.
- Respectfully praising even small successes in an adult way.
- Encouraging independence instead of taking over for the person.
- Respecting the person's dignity, privacy, and individuality at all times.

The overall goal of care is to make the person's life as positive and fulfilling as possible through meaningful, satisfying relationships and activities provided in a nurturing and caring way.

Make the person's life as positive and fulfilling as possible through meaningful, satisfying relationships and activities provided in a nurturing and caring way.

Three keys to successful care

Key 1: Build trust and a sense of competence in the person.

Key 2: Search for, and build on, the person's remaining capacities.

- **Emotional capacity** – The ability to experience feelings, although the expression of these emotions may not be understood.
- **Awareness of environment** – Awareness and responsiveness to the environment, even if not fully comprehended by a person with dementia.
- **Social capacities** – The ability to respond to and show concern for others.
- **Ability to communicate** – A person with dementia may still be able to communicate with words, and usually remain able to communicate emotions nonverbally.
- **Ability to make logical connections** – A person with dementia may still be able to make some logical connections. What may seem irrational to us may be logically connected to an impaired person's perceptions.

Key 3: Look for the meaning and purpose behind behavior.

Family members can serve as a vital link to the individual’s past and personality.

Make sure to:

- Pay attention to the environment and the person, including his or her reactions to different situations, people, and surroundings. Notice things that upset or calm the person.
- Learn about the individual’s interests and background, how to predict when he or she will become upset and how to help if this happens.

  Family members can serve as a vital link to the individual’s past and personality.
- Listen to the person’s emotional communication, rather than just his or her words.
- Remain calm and reassuring in the face of difficult situations.

Adapted from *Alzheimer’s Disease: Pieces of the Puzzle*, University of Arizona, Arizona Long Term Care Gerontology Center, 1990.

Further Readings

The Best Friends Approach encourages caregivers to know each person with dementia as an individual and to treat him or her as they would their best friend.

Best Friends Assessment
The Best Friends approach to conducting an assessment involves striving to achieve the following goals:

- To understand the state of the person's cognitive abilities.

  It is important to consider the person's memory, judgment, speech, initiative, and problem solving. Finally, the assessment should look at the whole picture and ask whether the person's cognitive abilities are poor, fair, good, or excellent.

Know each person with dementia as an individual and treat him or her as you would your best friend.

- To understand the current state of the person's physical health, including vision, hearing, and mobility.

  The assessment looks at the person's physical strengths and weaknesses and how his or her overall physical health will affect the care plan.

- To reduce excess disabilities.

  Treatable medical problems should be treated. Untreated medical problems can make the symptoms of dementia worse.

- To understand the ***premorbid*** and ***postmorbid*** personality.

  This helps us understand what changes have occurred. If you perceive a change is negative, set goals to work on making positive changes in this area.

Premorbid *— Before the disease*.

Postmorbid *— After the disease.*

- To be able to list three things which the person particularly enjoys or responds to.

  This is a starting point for looking at the person's overall care needs and potential activities.

- To understand who this person is—his or her values, beliefs, and traditions.

  Think of one or two phrases that describe the person before the illness. This helps refocus your efforts on the person and his or her values, concerns, and achievements.

Best Friends Philosophy

Best Friends advocates that the following elements of friendship be considered when caring for a person with dementia:

- Friends know each other’s history and personality.

  A Best Friend becomes the person’s memory, is sensitive to the person’s traditions, and learns the person’s personality, moods, and problem solving style.

- Friends do things together.

  A Best Friend involves the person in daily activities and chores, ties activities to the person’s past and interests, encourages the person to enjoy the simpler things in life, and remembers to celebrate special occasions.

- Friends communicate.

  A Best Friend listens, speaks, and asks questions skillfully, using body language, and gently encourages participation in conversations.

- Friends build self-esteem.

  A Best Friend gives compliments often, carefully asks for advice or opinions, offers congratulations, and always offers encouragement.

- Friends laugh often.

  A Best Friend tells jokes and funny stories, takes advantage of spontaneous fun, and uses self-deprecating humor often.

- Friends are equals.

  A Best Friend does not talk down to the person, always works to protect the dignity of the person, and recognizes that learning is a two-way street.

- Friends work at the relationship.

  A Best Friend is not overly sensitive, does more than 50% of the work, builds a trusting relationship, and shows affection often.

Adapted from Bell & Troxel (1997). *The Best Friends Approach to Alzheimer’s Care*. Maryland: Health Professionals Press, Inc.

Dementia Care

Specialty Training

MODULE 4

Helping With ADLs

Washington State
Department of Social
& Health Services

ADSA Aging & Disability
Services Administration
www.adsa.dshs.wa.gov

Helping with Activities of Daily Living (ADLs)

Module Goals:

To provide caregivers and managers with information and tips on:

- The importance of activities and ways to make them more meaningful for a person with dementia.
- Ways to more effectively assist a person with dementia with ADLs.
- Ideas and tips for involving people with dementia in activities.

Creating Meaningful Dementia Care Activities

Recent studies on dementia care suggest that activities are the foundation of good dementia care. Activities are important because they help a person with dementia:

- Experience a sense of independence and control.
- Have meaningful contact with other people.
- Continue to participate in life-long patterns or routines.
- Stay active and have something to do.
- Feel productive—that he or she can still contribute.

The art of dementia care activities is not in what is done, but in all of the interactions that go into the process of doing it. 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 his or her self-esteem.
- Stimulate his or her physical senses.

> *The art of dementia care activities is not in what is done, but in all of the interactions that go into the process of doing it.*

In order to plan meaningful, individualized activities with these goals in mind, you will need to know a lot about the person's background, interests, and what he or she enjoys.

Spend time talking to the person and getting to know him or her as an individual. You will want to learn about the person's:

- 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 such things as always starting the morning with a cup of coffee and the newspaper, taking a walk after dinner, or an evening prayer.

Continuing with past routines provides a sense of comfort and security for people with dementia.

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 him or her continue them.

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

Self directed and staff directed activities

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

Some people may have difficulty initiating activities due to the effects 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 that are directed by staff. Staff directed activities should include both tasks that the person does in the normal course of a day and activities that are special for that person

For ideas and suggestions on activities to do with a person with dementia, see pages 84-86.

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.

ADLs as Meaningful Activities

Most people with dementia retain some ability to perform Activities of Daily Living (ADLs) as the dementia progresses. Because ADLs have been so much a part of a person’s life, he or she retains 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.

Never underestimate the importance of keeping the person actively involved in ADLs for as long as possible.

As a person’s dementia progresses, he or she 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”.

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

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 a number of 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.

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.

Assisting with Bathing

Family Friendly

Bathing involves multiple stressors for a person with dementia.

Things to Keep in Mind:

- Bathing involves multiple stressors for a person with dementia. Because of dementia, the person is less able to deal with stress.
- 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 he or she is 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.
- Lighting is important. Lights shining off of 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.

Care Tips

Before the Bath:

- Get to know and incorporate the person's past personal routines and preferences for bathing.
- 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.

Care Tips

During the Bath:

- Give simple directions, one step at a time.
- Encourage the person to do as much as he or she is able to do.
- Concentrate 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 preserve the person's dignity at all times when bathing.
- Allow adequate time for bathing and do not rush.
- 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.

Assisting with Dressing

Family Friendly

Getting dressed can be a very complex and overwhelming task for many people with dementia.

Things to Keep in Mind:

- 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 he or she is too hot or too cold. Keep an eye out for signs of discomfort.

Care Tips

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.
- 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 isn't harmful, the same or mismatched clothes is better than a confrontation.

While Dressing:

- Preserve the person's dignity at all times while dressing. This might include things like shutting the door, closing the drapes, or looking away when he or she is 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 a little later.

Dementia Scenario 1— Responding to Challenging Behaviors

Activity

Mr. Winsky 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.

Research:

Review the information on Lewy Body Dementia on page 19 and “Assisting with Bathing” on pages 75-76.

Using this information and the skills covered in Module 2—*Communication With People Who Have Dementia* and Module 3—*Creative Approaches to Challenging Behaviors*:

Problem Solve:

Describe three ways you could help Mr. Winsky to work through his resistance and make the experience less stressful.

Demonstrate:

How you would try to get Mr. Winsky’s cooperation to take a bath.

Dementia Scenario 2—Supporting the Person with Dementia’s Strengths Using Caregiving Techniques

Activity

Ms. Swenson has Huntington’s Disease. You are there to help her get dressed this morning. Although she is normally able to participate in some dressing tasks, muscle spasms have kept her awake much of the night. She is tired and restless this morning when you arrive.

Research:

Read the information on Huntington’s Disease on page 17 and “Assisting with Dressing” on page 77.

Using this information and the skills covered in Module 2—*Communication With People Who Have Dementia* and Module 3—*Creative Approaches to Challenging Behaviors*:

Problem Solve:

Describe three things you could do to encourage and support Ms. Swenson’s strengths this morning.

Demonstrate:

How you would support Ms. Swenson’s strengths while assisting her to dress.

Assisting with Eating

Family Friendly

Things to Keep in Mind

A person with dementia may:

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

Care Tips

- 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 so she or he can follow your lead.
- As the person loses the ability to use silverware, provide finger foods as much as possible.
- 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.

Common Eating Problems

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.
- Lack of exercise.
- Damage to the brain—the person may no longer recognize food.
- Difficulties with chewing or swallowing.
- Constipation.

Care Tips

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.

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 that he or she has already eaten.

Ways to deal with overeating:

Care Tips

- 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.
- Ill-fitting dentures make chewing difficult.

Ways to deal with chewing and swallowing problems:

Care Tips

- 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.

Assisting with Personal Hygiene- Oral Care

Family Friendly

Things to Keep in Mind

- 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 his or her cheek or jaw.
  - Moaning or shouting.
  - Rolling his or her head or nodding.
  - Flinching when washing his or her 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 his or her 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:

Care Tips

  - 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 his or her 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 his or her gums.
- Check how easily the person can grip the toothbrush. Adapted grips for toothbrushes are available, if needed.
- Make sure the person does one step to the best of his or her 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 his or her teeth, help the person feel involved by putting your hand over his or her hand and guiding 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.

Dementia Scenario 3— Best Practices when Caring For and Interacting with a Person with Dementia

Activity

Mr. Johnson has Alzheimer's and has lived at your facility for almost a year. It is lunch time and you are there to help him eat. You have noticed that Mr. Johnson is not eating well and has lost some weight.

Research:

Read the information on Alzheimer's on page 14 and "Assisting with Eating" on pages 79 - 80. Using this information and the skills covered in Module 2—*Communication With People Who Have Dementia* and Module 3—*Creative Approaches to Challenging Behaviors*:

Problem Solve:

Describe three ways you could help to ensure Mr. Johnson gets proper nutrition.

Demonstrate:

How you would encourage Mr. Johnson to eat.
Using this information and the skills covered in Module 2—*Communication With People Who Have Dementia* and Module 3—*Creative Approaches to Challenging Behaviors*:

Dementia Scenario 4—Helping with Activities of Daily Living

Activity

Ms. Pauley has Parkinson's related Dementia. You are there to help her brush her teeth in preparation for bed. This evening, her hand tremors are worse and she is having difficulty brushing her teeth.

Research:

Read the information on Parkinson's related Dementia on page 20 and "Assisting with Personal Hygiene-Oral Care on page 81.

Using this information and the skills covered in Module 2—*Communication With People Who Have Dementia* and Module 3—*Creative Approaches to Challenging Behaviors*:

Problem Solve:

Describe three ways you can help to ensure Ms. Pauley gets good mouth care.

Demonstrate:

How you would assist Ms. Pauley to brush her teeth.

Assisting with Toileting

Family Friendly

Things to Keep in Mind:

- 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 he or she gets to the toilet.
  - Find the toilet.
  - Recognize the toilet.
  - Use the toilet properly.
  - Recognize when the bladder is completely emptied.

Care Tips

Make sure the bathroom is clearly marked—put a sign 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 fasteners.
- A commode may help if the distance to the bathroom is too far.
- If the person is having trouble urinating, try giving him or her a drink of water or run water while the person is on the toilet.
- If the person is restless, try giving him or her 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

Care Tips

- Observe the person’s toileting patterns. Cue the person to use the toilet at regular times that follow his or her pattern.
- Watch for non-verbal cues, such as pulling on clothes, agitation, or a flushed face.
- Try toileting before and after meals and before bed.
- Respect the person’s privacy and dignity at all times.
- Incontinence can be embarrassing and humiliating. Be sensitive to these feelings and treat the person with empathy and understanding.
- Accidents are bound to happen. Treat the situation in a matter-of-fact manner. Never scold or humiliate the person.

Incontinence is the most common reason families give for the decision to move their loved one into a residential facility.

Activity Ideas for People With Dementia

Resources Family Friendly

Purpose: Have Meaningful Contact with Others

Activity	Benefits	Care Tips
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?”
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.
Looking at photo albums or magazines	• Provides visual stimulation	• Make magazines and photo albums readily available.
Taking a walk	• Can reduce stress and agitation • May help the person to sleep better • Stimulates senses	• Always walk with the person outdoors, unless your facility has a secure outdoor space for walking. • Make sure all pathways are clear of debris or clutter.
Brush hair Massage hands, feet or back	• Provides personal interaction	• Be attentive to personal preferences.
Ice cream socials or other social activities	• Provides sensory stimulation • Provides a pleasurable experience	
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.

Purpose: To Experience a Sense of Independence and Control

Activity	Benefits	Care Tips
Performing personal care (ADLs)	• Gives a sense of pride and independence • Makes the activity more meaningful • Helps the person retain skills	• Always do tasks with the person, not for the person. • Praise all 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	Care Tips
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.

Purpose: To Stay Active and Have Something to Do

Activity	Benefits	Care Tips
Singing songs Listening to music Playing an instrument	• Can help express emotions • May decrease agitation	• Always be mindful of the person’s abilities and interests.
Playing word games Completing puzzles	• Stimulates cognitive functioning	
Tossing a ball	• Promotes interaction • Helps eye-hand coordination	
Dancing	• Stimulates body movement • Can improve range of motion	
Sculpt with clay Painting Flower arranging Working with wood	• Provides sensory stimulation • Provides outlet for creativity	• Recognize that every activity can be used to incorporate creative expression in the person’s life.

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

Activity	Benefits	Care Tips
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.

Dementia Care

Specialty Training

MODULE 5

Hallucinations and Delusions

Washington State
Department of Social
& Health Services

ADSA Aging & Disability
Services Administration
www.adsa.dshs.wa.gov

Hallucinations and Delusions
With Dementia

Module Goals:

To provide caregivers and managers information and tools to:

- Differentiate between hallucinations and delusions.
- Identify appropriate intervention strategies for dealing with hallucinations and delusions.

Hallucinations

Some people with dementia may experience ***hallucinations***. A person with dementia may see, hear, smell, taste, or feel things which are not really there. Hallucinations seem very real to the person with dementia and can cause him or her extreme anxiety or even panic.

***Hallucination** — a false perception of objects or events involving the senses that can only be verified by the person experiencing them.*

Visual Hallucinations

Visual hallucinations are the most common type of hallucination in dementia. People with Lewy body dementia are more likely to have persistent visual hallucinations.

***Visual hallucinations** — when a person sees a person or object that isn't there.*

Visual hallucinations can start when a person misinterprets what he or she is seeing. For example, a person may think he or she 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 aren't there - sometimes involving complicated scenes or bizarre 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.

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.
- Changes that are occurring in the brain as the dementia progresses.

It is important to rule out physical causes of visual hallucinations.

Auditory Hallucinations

***Auditory hallucinations** — when a person hears voices or noises that don't exist.*

There are several indications you may see that a person with dementia is experiencing an ***auditory hallucination***. He or she 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 do this and are not having an auditory hallucination).

Possible causes of auditory hallucinations are identical to those for visual hallucinations and also include hearing loss or a hearing aid not working correctly. As with hallucinations, it is important to rule out physical causes and have the person's hearing and hearing aid (if he or she has one) checked.

Reaction of the person with dementia to hallucinations

A person with dementia who is experiencing hallucinations may have a variety of different reactions to them. The person may:

- Become suspicious.
- Realize that his or her imagination is playing tricks and pay no attention to the hallucination.
- Find it difficult to decide whether or not the hallucination is real.
- Become convinced that what he or she is hearing or seeing is real.
- Get frightened.

Delusions

***Delusion** — a fixed false idea, sometimes based on a misinterpretation of a situation.*

Delusions are common with dementia. A person with dementia that is having delusions may sometimes become overly suspicious and develop distorted ideas about what is actually happening.

Reaction of the person with dementia to delusions

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. For example, 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.

Other causes of delusion-like behavior

There are times when things that appear to be delusions have other explanations. Always rule out, as much as possible, any other explanations for what the person may be experiencing.

The problems with memory that occur with dementia can lead the person to be suspicious, paranoid, and have false ideas.

Always rule out any other explanation for the behavior if you suspect the person is experiencing delusions.

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 he or she has 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).
- Create a false idea to make sense of the present reality (say they lost their leg in WWII to explain a leg that was recently amputated).
- State that family has abandoned them (because they don't recall recent family visits).

As another example, Mr. Smith is adamant that his caregiver tried to rip off his clothes today and wanted to hurt him. In reality, his caregiver was assisting him with a bath. His account is confused although parts of what he is saying are real. Because of his confusion from the dementia, Mr. Smith misinterpreted what was happening.

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."

Finally, rule out any physical causes such as illness or medication side effects.

Distinguishing Hallucinations and Delusions

Understanding the difference between hallucinations and delusions is important because it will help you better understand what is happening with that person. Having this information will help you in your problem solving process.

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.

Activity

Distinguishing Hallucinations and Delusions

Read each situation below. Decide whether it is a hallucination or delusion. Place an “X” in the appropriate column. There may be multiple answers.

Situation	Hallucination	Delusion
Rose is convinced that her murder is being planned by the other residents.		
Bill smells poisonous gases coming from the heater vents.		
Michael tells other residents that he going to dinner with the Governor.		
Ruth claims that she speaks with her dead husband.		
John sees his wife’s face in the mirror when she is not around.		

Responding to the Person’s 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 or not 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?

Get medical guidance – Ask a physician or other medical personnel to determine if medication is needed or might be causing the hallucination or delusion.

Don’t Argue – Unless the behavior becomes dangerous, you might not need to do anything. Don’t 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. Don't worry. 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 – Turn the person's attention to other activities, such as listening to music, conversation, or drawing. Or, suggest that the person come with you or sit next to you in another room.

Maintain a familiar environment – If the person has to move, try and 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.

Always 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, contact the person's mental health professional.

For additional review on how to respond to a person with dementia's hallucinations and delusions, go to Module 3, *Creative Approaches to Challenging Behaviors* pages 56 - 59, and review the scenario.

Activity

Responding to Hallucinations and Delusions

Using what you have learned about hallucinations and delusions with dementia, practice identifying appropriate responses you might use with each situation below.

Responding to Delusions

Delusion	Your Response
"People are stealing my things."	
"I am in danger."	
"I need to get home to my children."	
"Somebody stole my purse."	
"I am the supreme being."	

Responding to Hallucinations

Hallucination	Your Response
"My caregiver is really a vampire. I saw her teeth"	
"My roommate has a gun."	
"I see the devil at the door."	
"There are worms in my soup."	
"My wife's boyfriend is in the bath room."	

Dementia Care

Specialty Training

MODULE 6

Sexuality and Dementia

Washington State
Department of Social
& Health Services

ADSA Aging & Disability
Services Administration
www.adsa.dshs.wa.gov

SEXUALITY AND DEMENTIA

Module Goals:

To provide caregivers and managers with information on:

- Understanding sexuality and intimacy.
- Dementia’s effects on sexuality.
- Differentiating between sexual and sexualized behaviors.
- How to effectively deal with these behaviors.

Sexuality and Intimacy

Sexuality is a central and natural part of who we are throughout our lifetime. It encompasses sex, gender identities, roles, sexual orientation, eroticism, pleasure, intimacy, and reproduction.

Intimacy involves caring touch, empathic understanding, comfort and a feeling of safety in relationship. All human beings are sexual beings and have a need for intimacy.

Physical closeness and companionship are important to most people—including older adults. However, as people age, they often worry about their sexuality. Some may feel that at a certain age sex is no longer appropriate—that sex is for the young. This belief is a bias often found throughout our society.

This bias makes it essential for you to get accurate information about the normal changes of aging and the many options for supporting sexuality. It is much easier than it was a generation ago.

More information is available on the Internet, in books, and from the medical community. More middle-aged and older adults feel freer to discuss sexuality with their friends and learn from and support each other.

For more information on sexuality and aging, visit: [http://www.sexhealth.org/sexaging/index.shtml.](http://www.sexhealth.org/sexaging/index.shtml)

Sexuality — *the feeling of sexual desire and its expression through sexual activity.*

Intimacy— *the giving and receiving of love and affection.*

Sexuality and Dementia

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. However, 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

It is important to remember that any strange or uncharacteristic 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.

Sexualized behavior – *behaviors that appear sexual in nature, however when examined closely reflect a need for touch, intimacy, or something else.*

Inappropriate 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*****.**

Staff Attitudes Towards Sexuality and Dementia

Care of people with dementia calls for a high degree of technical and interpersonal skill, particularly in the area of sexuality in dementia.

When caring for a person with dementia, you need to look at and resolve any misconceptions or biases you may have in the area of sexuality.

To handle situations that can arise, you will need to look at and resolve any misconceptions or biases you may have. You may also have to work through any embarrassment or shyness you have about dealing with this subject.

You may also have to grapple with difficult concepts and dynamics that are complex and hard to understand. These include:

Consent—what constitutes consent and for how long does a person with dementia maintain the ability to consent?

Decision Making Capacity—Is the person with dementia able to make decisions in his or her best interest?

Duress—Is the person acting out of duress. Those closest to the person with dementia will want reassurance that the family member or friend is not being intimidated or manipulated to act in a way that he or she is not comfortable with?

Your guiding principle should be ***"do no harm***". If neither party is being harmed and his or her 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.

Client Rights and Seeing Beyond Dementia

The key to approaching sexual behaviors is the same as the approach to all other care—consider the person and his or her 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 he or she wishes, 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.

Dementia Considerations

Caregivers need to remember the capacity of a person with dementia can waiver from one minute to the next.

Caregivers have to 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.

Sexuality is a basic need that people with dementia should be able to express without fear or disapproval.

Caregivers should also become familiar with their facility's policy around sexual behaviors. Talk with your supervisor even if it is not a concern with current residents. You need to be prepared and know what is expected of you in these situations before something happens.

Other things you can do

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.

Sexuality, Dementia, and Client Rights

General Definitions and Considerations	Dementia Considerations and Rights	Care Tips
Sexuality • Is central throughout life. • Encompasses many dimensions including gender, sexual orientation, eroticism, and reproduction. • Is influenced and influences self image, values, and relationships. • Is generally guided by social norms of what is and is not acceptable. • Is learned and can change over time.	**Sexuality** • People with Dementia are sexual beings. • Learned sexual behaviors may be forgotten. • Dementia may effect what the person considers appropriate or inappropriate.	• Help the person find appropriate ways to express their sexuality. For example, encourage safe and gentle touch. • Never shame the person. • If the person confuses the meaning of touch, gently remind them that you are providing care.
Intimacy • Giving and receiving affection is a basic need. • Involves personal sharing on a physical, emotional, intellectual, and spiritual level. • May be sexual or not.	**Intimacy** • Giving and receiving affection is still a basic need for the person with dementia. • Memory loss may impair the person's ability to recognize spouse/partner • Touching during care tasks may feel like intimate touch and the person with dementia might confuse the touch as being sexual.	• Increase touch and intimacy by holding hands, sharing hugs, or touching the person as you speak with them. Always make sure to ask before you touch the person.
Client Rights Right to be: • Who they are sexually (gender, sexual orientation). • Sexually active. • Free from acting under duress. Right to: • Privacy. • Choose and reject partners. • Engage in behaviors different from past behaviors (gender, sexual orientation).	**Client Rights** • Your guiding principle should be *"do no harm"*. • Consent may waiver from minute to minute. • Consider the person's decision-making capacity.	• Assess and make sure no one is being harmed. • Be familiar with your facility's policy around sexual behavior. • Look at and resolve any misconceptions or biases you may have.

Working With Sexualized Behavior

Although sexualized behaviors can be embarrassing, it is important to remember that dementia affects the person's understanding of social situations and therefore his or her ability to behave as might be expected.

Even though some people with dementia display sexualized behaviors, it is fairly 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 inappropriate 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 and 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 – Speak to family and your supervisor about understanding and dealing with potentially embarrassing situations.

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

If sexualized behaviors do happen, remain calm and do not communicate anger, shame, or distress to the person with dementia.

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

Dementia and Sexualized Behaviors

Sexualized Behavior	Dementia Considerations	Care Tips
Bold Behavior • Flirtation. • Inappropriate sexual advances towards others (both male/female).	• 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 and fasteners.	• Expressing a need to go to the bathroom. • May be bored. • May be frustrated. • Clothing may be restraining and painful.	• 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.	• Don’t 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 other residents.	• May be confused. • Advances may be directed toward someone that resembles a spouse, lover, or companion.	• Do not judge the person. • Re-direct any inappropriate behaviors. • Set limits if behaviors are sexually inappropriate. People with dementia understand limits. • View all behaviors as a way that the person is trying to communicate a need. • Always consider client rights.

Remember, the need for intimacy and closeness is a very important and natural part of people’s lives—including people with dementia. Find ways to include touch in your everyday caregiving routines so a person with dementia continues to get some physical contact.

Situation:

Linda is 77 years old and has Vascular Dementia. She recently moved into the boarding home because her husband could no longer provide the care she needed. Linda does not recognize her husband and has recently shown interest in Tom, a male resident at the boarding home. Earlier today a staff member found the two cuddling and kissing in Linda's bed. News of this was getting around.

Jennifer: *Michael, did you hear that Krista busted Linda and Tom making out in bed? Crazy, huh?*

Michael: *I don't even want to hear that stuff. That's just not right. Linda is probably not even aware of what is going on. She is so cute and sweet. I think Tom took advantage of her. I think Tom should be moved out of here if he's going to do that kind of stuff. I don't want to have anything to do with him".*

Jennifer: *Yeah. I feel sorry for Linda. I'm going to make sure to check on her and make sure everything's ok. I also feel sorry for her husband. He's the innocent one here. Poor guy! I think Tom needs to be moved out of here.*

Reflection:

Jennifer and Michael are having a reaction to what they think are inappropriate sexual behaviors. These behaviors are not uncommon and sexual behavior can take many forms. What sometimes appears to be a sexual behavior is actually the person with dementia communicating a need for intimacy.

Jennifer and Michael did what many people do. Their biases influenced their response and they formed judgments before they actually understood what was happening.

Their answer to the behavior was to have Tom moved out of the boarding home.

Let's consider a five-step intervention that Michael and Jennifer could have taken before reacting the way they did.

Step 1: Describe the behavior one behavior at a time.

In Step 1, they will describe the behavior one behavior at a time.

Jennifer: *The new resident, Linda, seems a little lost here, doesn't she?*

Michael: *Yeah. When I've seen her she seems to be lost and looking for attention. She seems to really like Tom and he seems to like her attention.*

Reflection:

Step 2: Gather information about the behavior.

In Step 2, they gather information about the behaviors.

Jennifer: *I talked to the other staff and they noticed that Linda and Tom have been spending a lot of time together. Some of the other girls were making such a big deal of it. They really only sit and hold hands and kiss every once in awhile.*

Michael: *Yeah. I noticed it too. It's kind of weird but when Linda's husband's here, she doesn't even seem to notice him. He knows what's going on with her and Tom. I wonder what he thinks about it?*

Step 3:
Identify what happened before and after the behavior.

In Step 3, they will identify what happened before and after the behavior.

Jennifer: *Some of the staff are making a big deal of it. Krista was saying all kinds of things. She was even calling them perverts and saying they are sick. She was trying to get the other staff to keep them apart and Linda was getting really angry.*

Michael: *Krista talked to me, too. She said that she thought Tom should be moved out of here because he's dangerous and that he's taking advantage of Linda.*

Jennifer: *You don't think that's true, do you?*

Michael: *No.*

Jennifer: *Well I talked to her husband about it. He told me that Linda always had close male friends but that this time she has gone too far. He told me that he felt Linda was cheating on him and that he couldn't stand to see her touching and kissing another man.*

Michael: *That's really sad, huh? Maybe the dementia support group could help him understand dementia. Maybe Krista should go too.*

Step 4:
Set realistic goals and make a plan.

In Step 4, they will set realistic goals and make a plan.

Jennifer: *Maybe we should talk to Donna about Krista. Donna is a good supervisor. She won't tell Krista that we talked to her. Donna might be able to send Krista to get some training or something.*

Michael: *What if Krista still thinks that Tom is weird and has to sent away?*

Jennifer: *I'm sure Krista's not that dumb. But, if she acts like that, I'm sure Donna can handle her.*

Step 5:
Reward staff and the person for achieving the goal.

Once they have achieved their goal, they can feel good about their success, which is Step 5.

Jennifer: *Wow, Krista sure has changed her attitude. I'm glad. I think Donna talked to her and from what I hear, she reminded her about Linda's and Tom's rights.*

Michael: *Yeah, I think it also helped that we had the workshop on dementia and sexualized behavior.*

I never realized it before, but when a person has dementia, they can sometimes forget that they're married. It's different, but they might even like the same sex when they never had before.

Jennifer: *Yeah, and I didn't think about how some behaviors look sexual but they are really not.*

Michael: *Talking about that sex stuff made me uncomfortable. I don't want anyone thinking that I don't know a lot about sex, because I do, you know.*

Jennifer: *Whatever. Like you said Michael, it's not always about sex!*

Reflection:

This process helped both Michael and Jennifer address a behavior without interjecting their biases and beliefs.

It helped that Donna offered a workshop on dementia and sexualized behavior to help them talk about and understand these behaviors. Attitudes and beliefs are difficult to change. But, if the person with dementia and his or her need for care is always considered and kept a priority, any behavior can be dealt with effectively.

Activity

Sexualized Behaviors and Dementia

Scenario

Thomas is 54 and has early onset Alzheimer's. He is single and has lived in the boarding home for one year. He has always related well to all residents. Recently, staff has noticed that he is constantly following Debbie, a 63 year old woman with advanced stage Alzheimer's, and is constantly asking her to kiss him and fondle his genitals.

Using a step-by-step problem solving method, how might you deal with this situation? Use the space below to fill in your thoughts.

____

____

____

____

Reflection:

To effectively problem solve and address this situation, you will need to determine:

- Debbie is not being subjected to undue duress.
- If Thomas maintains the ability to understand his behaviors.
- If Thomas's behavior is an expression of a need for touch and intimacy.
- That Debbie and Thomas are both safe.

Sexual Aggression and Excessive Interest in Sex

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, 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. 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 too persistent.

Balancing Needs and Protection

There can be times when a person with dementia can be open to physical or emotional abuse in a relationship. Caregivers 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 assured, those involved in the support and care of him or her will need to determine a number of things. Is the person with dementia:

- Comfortable with the relationship?
- Able to avoid exploitation?
- Capable of saying no?
- Being treated with respect, dignity, and the right to 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.

One last caution. It is important to recognize that if the behavior of a person with dementia is not consistent with prior beliefs and values, he or she is still entitled to sexual expression. The person’s rights must always be considered when determining the need for protection.

Talking with Families About Sexual Situations

Although it is critical that caregivers 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.

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

Talking about sexuality can be uncomfortable or cause great anxiety for many people —including caregivers and family members. If a caregiver and their supervisor decide to talk with family, they 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 actually 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 diseases. Families may need support and assistance in assuring the health and safety of their family member.

The risk of sexually transmitted diseases (STDs) doesn't diminish with age. Managers should create a policy, if one doesn't exist, for addressing the risk of STDs. STDs, including HIV, are a potential danger to anyone sexually active—including people with dementia.

Resources

Video Resource: *Freedom of Sexual Expression* – Terra Nova Films. Available through the Central Washington Alzheimer's Association at 1-800-848-7097.

Perspectives—Panel of experts

- Linda Ronco—Complaint Specialist, ADSA Residential Care Services
- Patricia Hunter—Director of Programs and Policy, Western and Central Washington Alzheimer's Association
- Louise Ryan—State Ombudsman, Washington State Long Term Care Ombudsman
- Lillian Hruska—Memory Care Director, Garden Courte Alzheimer's Care
- Dick Lundgren—Family member

Dementia Care

Specialty Training

MODULE 7

Medications and Dementia

Washington State
Department of Social
& Health Services

ADSA Aging & Disability
Services Administration
www.adsa.dshs.wa.gov

Medications and Dementia

Module Goals:

To provide managers basic information regarding medication(s):

- Prescribed to treat dementia.
- Side-effects.
- That can cause dementia-like symptoms.

Introduction

A licensed medical care practitioner may order certain medications if a person is experiencing symptoms of dementia such as memory loss, agitation, depression, anxiety, hostility, delusions, or hallucinations.

These medications will not "cure" dementia, but temporarily slow the progression of memory loss and help lessen the impact of some of the symptoms.

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 a 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.
- Always be aware of each medication's side effects or possible ***adverse*** reactions. 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.

Only a licensed health care practitioner can determine and prescribe what medication to use, how often, and in what dosage.

Adverse *— creating unfavorable, harmful, or undesirable results.*

Common Medications for General Health Problems

There are many prescription and non-prescription medications (OTC medications, vitamins, food supplements, and herbal remedies) given to the elderly for common health problems.

Medications are commonly prescribed for diagnoses such as high blood pressure, heart disease, mental disorders, diabetes, pain, or seizures.

Older adults are especially sensitive to medications. When prescribing any medication, a licensed medical practitioner and the person with dementia (or his or her decision maker), must weigh whether the benefits of the drug outweigh its possible side effects.

A good rule of thumb for medications prescribed to older people is to start low and go slow. This means to start with as low a dose as possible, increase the dose slowly, and add new medications one at a time.

A person with dementia who is taking any drug must be monitored closely.

A person with dementia who is taking any drug must be monitored closely by staff and his or her medical practitioner to ensure that the drug is working as prescribed and not causing adverse reactions or side effects.

Some people with dementia may not be able to communicate that they are experiencing side effects or having difficulty with medication.

It is important to stay alert to any physical or behavioral signs that the person is uncomfortable or in pain. Signs of discomfort may include grimacing or other facial expressions that reflect a resistance to taking the medication.

Medication Side Effects

All medications can cause side effects. Non prescription 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. Symptoms of side effects may also be mistaken for a new illness or the progression of dementia.

Common side effects include:

- Bleeding
- Nausea
- Constipation
- Fatigue
- Weight gain
- Anxiety
- Confusion
- Dry mouth
- Changes in balance - resulting in falls or fear of falling
- Disorientation

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 can be made 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 assess.
- Side effects can be lessened to reduce discomfort by working with the person's medical practitioner.

A complete list of all prescription and non-prescription medications must be reviewed by the person's licensed medical practitioner and pharmacist at least once a year, or more often if needed.

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.

Report any side effects or adverse reactions to a drug to the appropriate person where you work.

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.

Drugs Used with People Who Have Dementia

General Dementia Medications

General dementia medications improve or maintain memory or cognitive function. These drugs increase the levels of a chemical in the brain that helps restore communication between brain cells.

It is helpful to know some of the common medications prescribed for people with dementia. Which medication is prescribed depends on what symptoms, conditions, disorders, or diseases the person is experiencing.

General dementia medications improve memory or intellectual function.

Common medications used to improve memory or cognitive function include:

- Aricept (Donepezil)
- Namenda (Memantine)
- Cognex (Tacrine)
- Exelon (Rivastigmine)
- Razadyne/Razadyne Extended Release (Galantamine)

Medical research continues to increase the number of drugs available. It is important to stay current with new drugs that come on the market, and changes to recommended usage of current medications.

Most of the major Alzheimer's websites will have current information on new drugs and dementia. For example, visit www.alzinfo.org and click on "Drugs and Treatment".

See page 111 for more information on current drugs used to treat dementia and their side effects.

Antidepressants

Depression is very common among people with dementia.

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.

It is important to discuss with a doctor alternatives to medications before starting treatment with antipsychotic medications. See Module 5 for more information on alternatives.

Antipsychotic medications must always be used cautiously due to the side effects.

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.

Antipsychotic medications must NEVER be used as a chemical restraint.

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 FDA has issued a warning. For more information, see the Washington Department of Health and Social Services *2006 Fact Sheet: Treating Dementia* on page 111.

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.

Extrapyramidal Side Effects

Extrapyramidal side effects (EPS) are side effects caused by the effect of the medication on the central nervous system. Different types of EPS and their symptoms are described in the following section.

Dystonia

Neurological — dealing with the brain.

Dystonia is a ***neurological*** disorder that causes involuntary muscle spasms and twisting of the limbs.

What you may see:

- Strange facial expressions, facial grimaces, distortions, as well as spasms of the muscles of the lips, tongue, face, throat, or the tongue sticking out or curling.
- Difficulty with speech and swallowing.
- The eyes may involuntarily roll up in the head.
- Spasms of the larynx (also called the "voice box").

  Laryngeal spasms are life threatening. When spasms occur, the air can be shut off to the lungs making it impossible for the person to breathe.

  Call 911 immediately!

Dyskinesia

Dyskinesia is an impairment of control over ordinary muscle movement.

What you may see:

- Sudden involuntary muscle movements or tics.
- Rhythmic movements of the limbs and trunk.

Tardive Dyskinesia

Tardive Dyskinesia is involuntary movements of the tongue and facial muscles. This condition is the result of taking anti-psychotic medication for many months or years and is irreversible. The medication is usually stopped unless the drug is vital to the person with the mental disorder.

What you may see:

- Jerks or tics of the mouth, tongue, face, arms, or legs.

Parkinsonism

Parkinsonism is a nervous disorder marked by symptoms of trembling limbs and muscular rigidity that resemble Parkinson's disease. This disorder may be caused by the frequent use of some drugs or by exposure to certain chemicals.

What you may see:

- Muscular rigidity
- Slow movements
- Stooping posture
- Shuffling gait
- Tremors
- Falls
- Mask-like expression
- Difficulty swallowing, choking, drooling
- A significant lack of interests, drive, or motivation

Akathisia

Akathisia is uncontrollable limb and body movements, usually caused by drugs, especially some anti-psychotic drugs. Symptoms may be difficult to see.

What you may see:

- A feeling of restlessness – an urge to move or an inability to sit still - often accompanied by anxiety or agitation.
- Unprovoked violent behavior.

Medications to Treat Dementia and Their Side Effects

Resources

Trade (Common) Name	Generic Name	Possible Side Effects
Aricept	Donepezil	Cramps, diarrhea, insomnia, nausea, or vomiting
Namenda	Memantine	Constipation, cough, dizziness, headache, or hypertension
Cognex	Tacrine	Abdominal pain with cramps, anorexia, diarrhea, dizziness, drug-induced Hepatitis, Dyskinesia, headache, nausea, and vomiting
Exelon	Rivastigmine	Abdominal pain with cramps, anorexia, constipation, depression, diarrhea, disorder of the digestive system, dizziness, fatigue, intestinal gas, hallucinations, headache, impaired cognition, nausea, and vomiting
Razadyne	Galantamine	Anorexia, diarrhea, nausea, vomiting, or weight loss

For more information, see: http://www.alzinfo.org/alzheimers-treatment-drug.asp and click on drugs and treatment.

2006 Fact Sheet:

Treating Dementia

THE BACKGROUND: Atypical antipsychotic drugs

A class of drugs known as atypical antipsychotics has been commonly used in recent years to soothe agitation, delusions and aggression in people with dementia-related behaviors, including those present in Alzheimer's disease. The atypical antipsychotics succeeded a first generation of antipsychotic medications (the so-called "typical" antipsychotics). The latter were very successful in the treatment of schizophrenia, but they sometimes involved side effects that the atypicals were expected to avoid.

Several recent studies have now raised questions about that. In their wake, Washington State's evidence-based reviews of this research and other scientific findings are establishing guidelines that physicians and pharmacists can use to provide more coherent use of these medications and to avoid their use or over-use in situations that are not justified. The scientific data was provided to the state by the Oregon Health Sciences University (OHSU) Evidence Based Practice Center, and clinical criteria drawn from that research was the product of a Mental Health Drug Work group (MHDW) convened by Washington State Medicaid's Chief Medical Officer two years ago. The group includes clinicians and a broad range of medical professionals. Drugs involved in the workgroup's review were aripiprazole, clozapine, olanzapine, quetiapine and risperidone.

MORTALITY RISK

Of particular concern in any medication is the estimation of the mortality risk and whether use of the drug is of greater danger to the patient than taking no drug at all. The MHDW concluded that there is sufficient evidence to show that the atypical antipsychotics do pose a significant risk for death in the treatment of dementia-related behaviors. The guidelines below represent the workgroup's consensus recommendations for minimizing this risk to patients.

GUIDELINES FOR PRESCRIBERS

After review and study of the supporting literature from OHSU, the workgroup concluded that the five atypical antipsychotic medications should receive a "C" grade under the Health and Recovery Services Administration's four-point Hayes scale. The following guidelines are intended for use by providers prescribing these medications for patients:

1. **New starts over age 60 should not exceed one-and-a-half times these study doses:**

a.	**Olanzepine 15 mg (x 1.5 =)**	**22.5 mg**
b.	**Risperidone 2 mg (x 1.5 =)**	**3.0 mg**
c.	**Quetiapine 200 mg (x 1.5 =)**	**300 mg**
d.	**Ziprasidone 160 mg (x 1.5 =)**	**240 mg**
e.	**Aripiprazole 15 mg (x 1.5 =)**	**22.5 mg**

2. **Providers should consider carefully and review the use of these drugs for new or existing clients, with only a dementia diagnosis and polypharmacy doses (i.e., more than one atypical antipsychotic prescription) for more than two months.**

3. **Existing clients with evidence of poor adherence or polyprescribing may also require review.**

Before exceeding these criteria, providers should investigate the possibility of less risk and less cost in alternate therapy.

FOR MORE INFORMATION, CONTACT:
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Dementia Care

Specialty Training

MODULE 8

Setting the Tone

Washington State
Department of Social
& Health Services
ADSA Aging & Disability
Services Administration
www.adsa.dshs.wa.gov

Setting the Tone:

Working with Families and Friends

Module Goals:

To provide managers information and strategies for:

- Getting to know and understand more about the importance and make-up of a person with dementia's family unit.
- Interacting with and supporting a person with dementia's family and friends.
- Supporting the well-being of caregiver staff.
- Promoting self care.

The Importance of Setting the Tone

You set the tone and create an environment that makes it safe and encourages families to play an essential role in the care of the person with dementia. Ultimately, a good working relationship between you, family members, and other staff assures the best quality care for a person with dementia.

Considerable advance planning and attention is necessary to assure that:

- Staff is well prepared for interacting with the person with dementia's family and friends.
- Time is taken to develop and nurture this relationship and create a partnership in providing care.
- Staff needs are also clearly recognized and addressed.

A good working relationship between you, family members, and other staff assures the best quality care for a person with dementia.

Understanding the Family Unit

There may be many people that contribute to the support of a person with dementia. It is important to think beyond what was the traditional family unit where a person with dementia was cared for by a spouse of many years or an adult child.

Other common family units can include:

- Stepchildren of a remarried father or mother
- A newly married spouse
- An unmarried partner
- Elderly siblings
- Nieces and nephews
- A same-sex partner
- Close friends
- Grown grandchildren
- Cherished pets

In this course, when reference is made to the person with dementia's family, all of these family units are included and more.

Getting to know the person's 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 the person with stimulation, affection, and fun.

Staff need to be encouraged to get to know the person's family. Family are also an important source of information that will help caregivers provide individualized and quality care for their loved one.

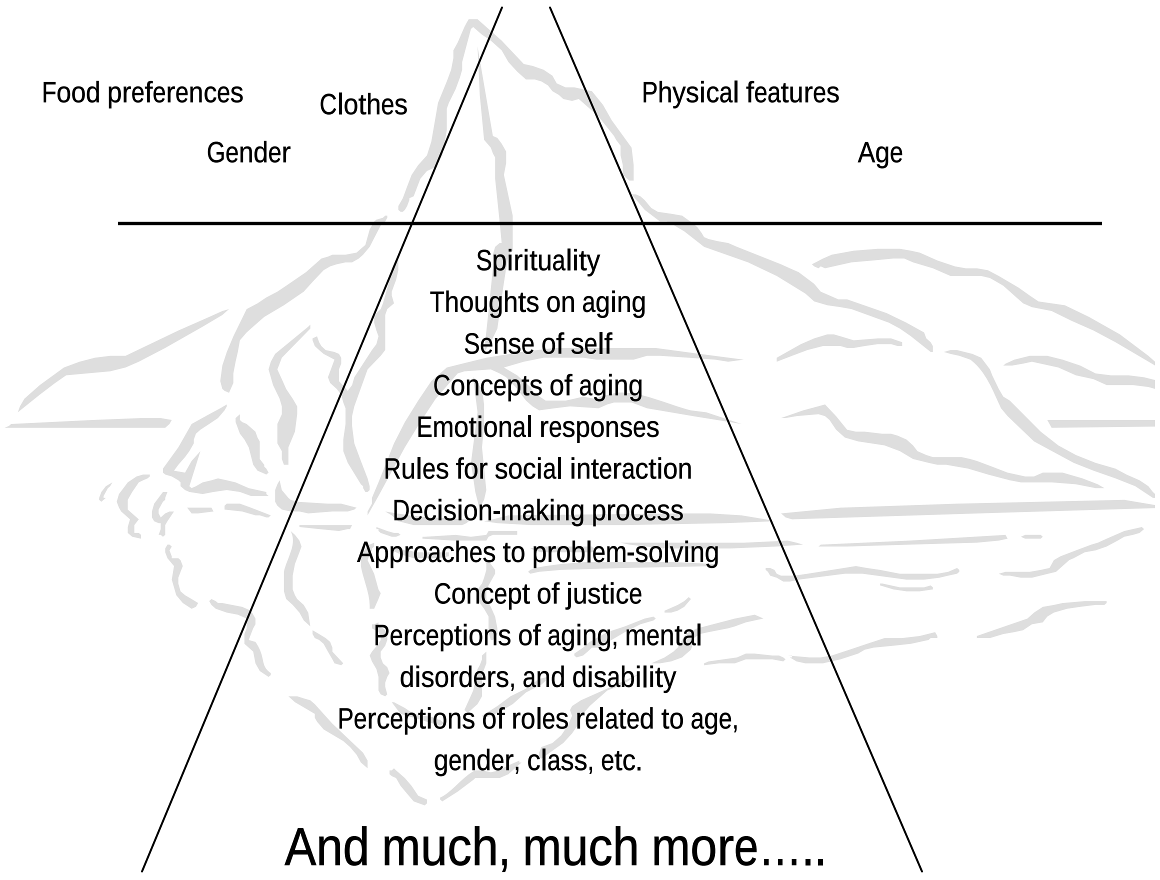
***Facets** – one of the many parts or features of something.*

The following illustration of an "Iceberg" represents different ***facets*** 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.

Take some time to get to know the whole person.

The tip of the iceberg does not represent the entire person. There is much more below the surface. Take some time to get to know the whole person.

The Iceberg

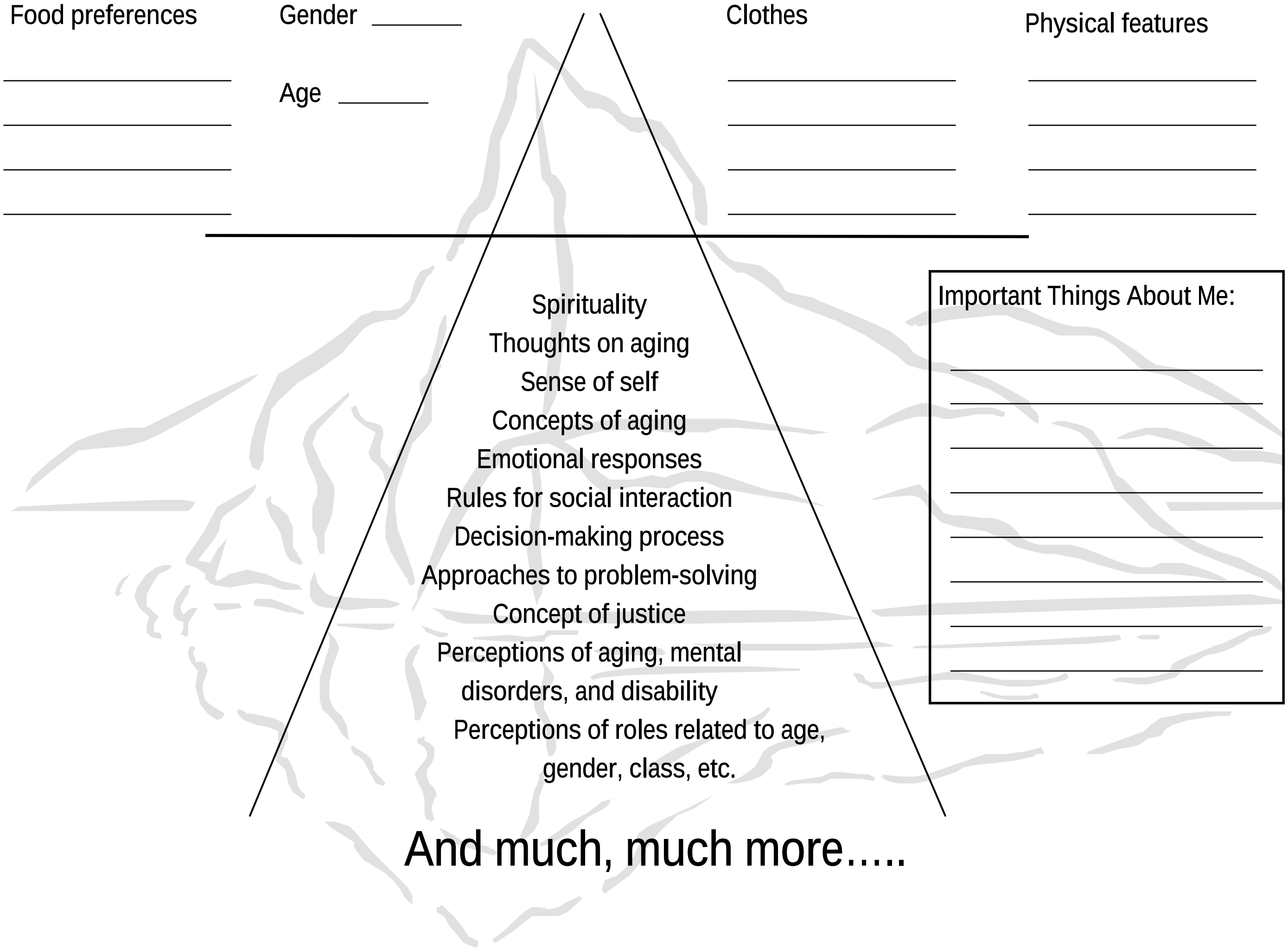


Getting to Know You

Activity

Take a few minutes and consider the things you would like others to know about you. Fill in the blanks and box below.

The Iceberg



Food preferences

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Gender ________

Age ________

Clothes

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Physical features

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Spirituality
Thoughts on aging
Sense of self
Concepts of aging
Emotional responses
Rules for social interaction
Decision-making process
Approaches to problem-solving
Concept of justice
Perceptions of aging, mental disorders, and disability
Perceptions of roles related to age, gender, class, etc.

Important Things About Me:

____

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And much, much more.....

Considerations for Dealing with Family Members and Friends

When a loved one has dementia, the whole family experiences dramatic changes. The family may go through an extremely difficult time and may look to staff for support.

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

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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.
- **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 react with denial, withdrawal, anger or other behaviors that are not helpful to staff or the person with dementia. These families need time, understanding, and support. Staff need patience with, and acceptance of, those who are having difficulty.
- **Information about the disease, support services available, and the facility's services** – Families need to know about the disease process, information about the availability of support groups or counseling, and how to plan ahead. They need to know what they can and cannot expect from your facility and staff.

When dealing 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. Encourage staff to not take sides but to 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 be experiencing, 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, always 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

Managers should encourage and support caregiving staff to do the following.

- Welcome family members and friends when they approach you. Be friendly and open. If staff are rushed, remind them to give a quick greeting and tell family that he or she has to do something.
- Involve the family in care planning. Although this may be time consuming, it will help prevent problems.
- 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, staff should respect it and try to follow their lead.
- Listen. Sometimes, families just need to talk with someone. Encourage staff to ask family members how they are doing and show interest in what they have to say. Staff do not need to provide all of 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 staff created the situations you face. Remind staff to give themselves 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 doesn't 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.

Be gentle with yourself and with family members.

Neither they, nor you, created the situations you face.

What caregivers can share with families

- Fun things they 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 they see in the person.
- Relationships the person has developed.

What caregivers can 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

Clear communication is essential to building trust between families and caregivers. Making sure your policies and procedures are clear and well documented are important ways that managers can help avoid confusion and build this trust.

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Having family-related policies and procedures that include:

- An admission policy.
- Procedures for obtaining a person's history.
- Procedures for giving family information about the facility and the care practices.
- Policy that outlines the family's role in care planning.
- Policy that determines how frequently families will be informed about the person with dementia's status.

  This is especially important when the person with dementia first arrives at the facility. Managers should work with staff to plan when and how each issue will be discussed with the family and which issues can be covered gradually over the first weeks rather than immediately.
- Discharge planning policy and procedures.
- What the facility expects from the family.

Internal policies are also needed that include:

- How staff should respond to distressed family members.
- What direct care staff should do if a family member's behaviors interfere with care or distresses the staff.
- How staff should handle certain challenging behaviors such as sexualized behaviors or aggression.

Encouraging Self Care for Caregivers

The rewards of caregiving can be felt by caregivers over the course of time. Caregiving can build self-esteem and a sense of self-worth.

You can increase staff confidence and feelings of empowerment by making sure each individual knows he or she is doing a good job and is making a positive difference in someone's life. Staff require and deserve respect for what they do.

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The task of giving individualized, affectionate care to people with dementia can place heavy psychological, emotional, and physical demands on staff. Caregivers can experience demands that are too great or difficult to handle. They 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 what to do with constant and repetitive questions.

It is important that you recognize when caregivers are feeling stressed, frustrated, overwhelmed, fearful, or reluctant to communicate their needs. Caregivers should be encouraged to use strategies for:

- Recognizing the warning signs of frustration.
- Finding ways to reduce stress.
- Communicate his or her needs.
- Asking for help.

Information on strategies to help with self care and the caregiver can be found in the *Revised Fundamentals of Caregiving, Edition 2*, Module 11.

Creating a Safe Environment and Promoting Self Care

As a manager, you need to remain aware of your own reactions and responses towards your staff. If a caregiver makes a mistake or has difficulty dealing with a situation, use that experience as an opportunity to teach rather than criticize. Caregivers need to know that they can always come to you when they are experiencing challenges that they do not feel equipped to handle

Staff need extra support when the demands of caregiving is draining. As a manager you can't take **all** of the responsibility for the well-being of your caregiving staff. The following are things you can do to assure caregivers are well supported.

- Help caregivers learn ways to rethink their situations to reduce frustration and develop effective adaptive responses.
- Remind caregivers that although they cannot control how others are behaving in difficult circumstances, they can control how they respond to the situation.
- Offer special training and support to caregiving staff. Identify and contact any training or support organizations that might be helpful in your area. Make a list of what is available for your caregivers.

Special training and support can make a great difference for caregiving staff.

Self Care for Managers

As a manager, you also need to ask for and accept help. Discuss your needs and concerns with colleagues and friends who might be willing to help and listen. Remember, you have the right to ask for help and express your needs.

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Requests may also be placed by phone at (360) 570-3062 .

You must be approved by DSHS to offer this training. To learn more about becoming a community or facility training or to inquire about additional CDs or DVDs, visit: www.adsa.dshs.wa.gov/Professional/#training or call 360-725-2548.

The Dementia Care Specialty Training curriculum is a basic training for managers and caregivers. This training was developed to meet Washington State's dementia training requirement, established to recognize that people with dementia have special care needs.

Participants who successfully complete this training will learn basic skills needed to provide care to people with dementia.

Washington State
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