The Facts about Dementia and Other Related Conditions

FACILITATOR GUIDE

Developed by:

University of Wisconsin Oshkosh
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Learning Points

Let’s review the main learning points.

- Understand the changes that occur in the brain with dementia
- Recognize the stages and symptoms of dementia
- Apply knowledge of dementia to residents’ care

Caring for Residents with Cognitive Disorders

Caring for residents with dementia and other cognitive disorders can be especially challenging because you can’t actually see the effects of the disease. Residents with dementia don’t automatically lose their hair, have trouble breathing, break out in a rash, lose weight, or run a fever.

In fact, dementia may only become obvious because of a change in a person’s behavior, and many of us believe that others have the ability to control their own behavior.

Only when we learn the effects of dementia on the brain can we begin to understand that behavior can’t be controlled when dementia is the culprit. Let’s start out by defining dementia.

What is Dementia?

The term "dementia" describes a group of symptoms that are caused by changes in brain function. People with dementia lose their abilities at different rates. Dementia symptoms may include:

- asking the same questions repeatedly
- becoming lost in familiar places
- being unable to follow directions
becoming disoriented about time, people, and places  
ignoring personal safety, hygiene, and nutrition

Dementia is caused by many conditions. Some conditions that cause dementia can be reversed, and others cannot. The two most common forms of dementia in older people are Alzheimer's disease and multi-infarct dementia (sometimes called vascular dementia). These types of dementia are irreversible, which means they cannot be cured.

Alzheimer’s Disease

Dementia is a brain disorder that seriously affects a person’s ability to carry out daily activities. The most common form of dementia among older people is Alzheimer’s disease (AD), which initially involves the parts of the brain that control thought, memory, and language. Although scientists are learning more every day, they still do not know what causes AD, and there is no cure.

Scientists also have found other brain changes in people with AD. Nerve cells die in areas of the brain that are vital to memory and other mental abilities, and connections between nerve cells are disrupted. There also are lower levels of some of the chemicals in the brain that carry messages back and forth between nerve cells. AD may impair thinking and memory by disrupting these messages.

Scientists think that up to 4.5 million Americans suffer from AD. The disease usually begins after age 60, and risk goes up with age. While younger people also may get AD, it is much less common. About 5 percent of men and women ages 65 to 74 have AD, and nearly half of those age 85 and older may have the disease. It is important to note, however, that AD is not a normal part of aging. Not every elderly person will have dementia or AD.

AD is a slow disease, starting with mild memory problems and ending with severe brain damage. The course of the disease and how fast changes occur vary from person to person. On average, AD patients live from eight to 10 years after they are diagnosed, although the disease can last for as many as 20 years.
Let’s take a look at some images that show the effects of Alzheimer’s disease on the brain.

Alzheimer’s changes the whole brain

Alzheimer’s disease leads to nerve cell death and tissue loss throughout the brain. Over time, the brain shrinks dramatically, affecting nearly all of its functions.

These images show:
- A brain without the disease (upper left)
- A brain with advanced Alzheimer’s (upper right)
- How the two brains compare (bottom)

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More brain changes

Here is another view of how massive cell loss changes the whole brain in advanced Alzheimer's disease. This slide shows a crosswise "slice" through the middle of the brain between the ears.

In the Alzheimer brain:

The cortex shrivels up, damaging areas involved in thinking, planning and remembering.

Shrinkage is especially severe in the hippocampus, an area of the cortex that plays a key role in formation of new memories.

Ventricles (fluid-filled spaces within the brain) grow larger.

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Under the microscope

Scientists can also see the terrible effects of Alzheimer's disease when they look at brain tissue under the microscope:

Alzheimer tissue has many fewer nerve cells and synapses than a healthy brain.

**Plaques**, abnormal clusters of protein fragments, build up between nerve cells.

**Dead and dying nerve cells contain tangles**, which are made up of twisted strands of another type of protein.

Scientists are not absolutely sure what causes cell death and tissue loss in the Alzheimer brain, but plaques and tangles are prime suspects.

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Brain Activity

A PET¹ scan shows brain activity.

Brain activity is indicated in the scan in yellow and red.

The healthy brain on the left shows a normal level of activity.

The brain of a person with AD on the right shows a much lower level of brain activity.

¹ Positron Emission Tomography
**Types of Dementia**

[Review the general types of mental decline. Point out that there are several types of dementia, and this material summarizes information about the most common types. Note that this is not a comprehensive list of all forms of dementia. Refer participants to the website listed on page 11 for more information.]

Dementia is a general term for a group of brain disorders. Alzheimer’s disease is the most common type of dementia, accounting for 50 to 70 percent of cases. Below are some general facts about Alzheimer’s and some of the other forms of dementia.

All types of dementia involve mental decline that:
- changed from a higher level (for example, the person didn’t always have a poor memory)
- is severe enough to interfere with usual activities in daily life
- affects more than one of the following four core mental abilities:
  - recent memory (the ability to learn and recall new information)
  - language (the ability to write or speak or to understand written or spoken words)
  - visuospatial function (the ability to understand and use symbols, maps, etc., and the brain’s ability to translate visual signals into a correct impression of where objects are in space)
  - executive function (the ability to plan, reason, solve problems and focus on a task)

**Alzheimer’s disease**

Although symptoms can vary widely, the first problem many people with Alzheimer’s notice is forgetfulness severe enough to affect their work, lifelong hobbies or social life. Other symptoms include confusion, trouble with organizing and expressing thoughts, misplacing things, getting lost in familiar places, and changes in personality and behavior.

These symptoms result from damage to the brain’s nerve cells. The disease gradually gets worse as more cells are damaged and destroyed. Scientists do not yet know why brain cells malfunction and die, but two
prime suspects are abnormal microscopic structures called plaques and tangles.

**Mild cognitive impairment (MCI)**
In MCI, a person has problems with memory or one of the other core functions affected by dementia. These problems are severe enough to be noticeable to other people and to show up on tests of mental function, but they are not serious enough to interfere with daily life. When symptoms do not disrupt daily activities, a person does not meet criteria for being diagnosed with dementia. The best-studied type of MCI involves a memory problem.

**Vascular dementia (VaD)**
Many experts consider vascular dementia to be the second most common type following Alzheimer’s disease. It occurs when clots block blood flow to parts of the brain, depriving nerve cells of food and oxygen. If it develops soon after a single major stroke blocks a large blood vessel, it is sometimes called “post-stroke dementia.”

**Mixed dementia**
In mixed dementia, Alzheimer’s disease and vascular dementia occur at the same time. Many experts suspect that mixed dementia develops more often than previously realized and may become increasingly common as people age. This is based on autopsies showing that the brains of up to 45 percent of people with dementia have signs of both Alzheimer’s and vascular disease.

**Dementia with Lewy bodies (DLB)**
With DLB, abnormal deposits of a protein called alphasynuclein form inside the brain’s nerve cells. These deposits are called “Lewy bodies” after the scientist who first described them. Lewy bodies have been found in several brain disorders, including dementia with Lewy bodies, Parkinson’s disease and some cases of Alzheimer’s.

**Parkinson’s disease (PD)**
Parkinson’s is another disease involving Lewy bodies. The cells that are damaged and destroyed are chiefly in a brain area important in controlling movement. Symptoms include tremors and shakiness; stiffness; difficulty with walking, muscle control, and balance; lack of facial expression; and
impaired speech. Many individuals with Parkinson’s develop dementia in later stages of the disease.

For more information on these and other types of dementia, go to the Alzheimer’s Association website at www.alz.org.

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Understanding the Stages and Symptoms of Dementia

Dementia, including Alzheimer’s disease, develops slowly and causes changes in the brain long before there are obvious changes in a person's memory, thinking, use of words or behavior. The stages and common changes that a person may experience are outlined below.

[Mention a few items from each list. Ask participants which of these changes they have observed.]

Common Changes in Mild Dementia

- Loses spark or zest for life - does not start activities without encouragement
- Loses recent memory without a change in appearance or in casual conversation
- Loses judgment about money
- Has difficulty with new learning and making new memories
- Has trouble finding words - may substitute or make up words that sound like or mean something similar to the forgotten word
- May stop talking to avoid making mistakes
- Has a shorter attention span and less motivation to stay with an activity
- Easily loses way going to familiar places
- Resists change or new things
- Has trouble organizing and thinking logically
- Asks repetitive questions
- Withdraws, loses interest, is irritable, not as sensitive to others’ feelings, uncharacteristically angry when frustrated or tired
- Won't make decisions. For example, when asked what she wants to eat says, "I'll have what she is having."
- Takes longer to do routine chores and becomes upset if rushed or if something unexpected happens
- Forgets to pay, pays too much, or forgets how to pay - may hand the checkout person a wallet instead of the correct amount of money
- Forgets to eat, eats only one kind of food, or eats constantly
- Loses or misplaces things by hiding them in odd places or forgets where things go, such as putting clothes in the dishwasher
- Constantly checks, searches or hoards things of no value

**Common Changes in Moderate Dementia**

- Changes in behavior, concern for appearance, hygiene, and sleep become more noticeable
- Mixes up identity of people, such as thinking a son is a brother or that a wife is a stranger
- Poor judgment creates safety issues when left alone - may wander and risk exposure, poisoning, falls, self-neglect or exploitation
- Has trouble recognizing familiar people and own objects; may take things that belong to others
- Continuously repeats stories, favorite words, statements, or motions like tearing tissues
- Has restless, repetitive movements in late afternoon or evening, such as pacing, trying doorknobs, fingerling draperies
- Cannot organize thoughts or follow logical explanations
- Has trouble following written notes or completing tasks
- May become sloppy or forget manners
- Makes up stories to fill in gaps in memory. For example, "Mama will come for me when she gets off work."
- May be able to read but cannot formulate the correct response to a written request
- May accuse, threaten, curse, fidget or behave inappropriately, such as kicking, hitting, biting, screaming or grabbing
- May see, hear, smell, or taste things that are not there
- May accuse spouse of an affair or family members of stealing
- Naps frequently or awakens at night believing it is time to go to work
- Has more difficulty positioning the body to use the toilet or sit in a chair
- May think mirror image is following him or television story is happening to her
- Needs help finding the toilet, using the shower, remembering to drink, and dressing appropriately for the weather or the occasion
- Exhibits inappropriate sexual behavior, such as mistaking another individual for a spouse. Forgets what is private behavior and may disrobe or masturbate in public

Common Changes in Severe Dementia

- Doesn't recognize self or close family
- Speaks in gibberish, is mute, or is difficult to understand
- May refuse to eat, chokes, or forgets to swallow
- May repetitively cry out, pat or touch everything
- Loses control of bowel and bladder
- Loses weight and skin becomes thin and tears easily
- May look uncomfortable or cry out when transferred or touched
- Forgets how to walk or is too unsteady or weak to stand alone
- May have seizures, frequent infections, falls
- May groan, scream or mumble loudly
- Sleeps more
- Needs total assistance for all activities of daily living
Other Conditions that Affect Behavior

Dementia-like symptoms may also appear due to reversible conditions such as a high fever, dehydration, vitamin deficiency and poor nutrition, bad reactions to medicines, problems with the thyroid gland, or a minor head injury.

Medical conditions like these can be serious and should be treated by a doctor as soon as possible.

In addition to dementia, which affects behavior and disturbs memory, delirium and depression are two other disorders that may also affect behavior.

Delirium

Delirium affects awareness and usually causes abrupt changes in behavior rather than the slower changes seen in dementia. Delirium may be caused by infection, medication or other illnesses. Because direct caregivers spend large amounts of time with residents, they are good resources for detecting delirium.

Some medical experts report that the most common cause of delirium in residents is urinary tract infection. Other causes include respiratory infections, electrolyte imbalance, congestive heart failure, and drug interactions.

Symptoms may include:

- Reduced awareness of surroundings
- Can’t maintain focus or attention
- Disoriented
- Hallucinations (seeing or hearing persons or things no one else can see/hear)
- Symptoms come on quickly
Depression

Depression affects mood with symptoms of sadness and loss of interest. The symptoms must last for at least two weeks. At least five of the following symptoms must be present to diagnose depression:

- Tearful or sad feelings
- Weight change (usually loss of weight)
- Trouble sleeping
- Psychomotor (bodily movements triggered by the brain) agitation or retardation
- Fatigue or loss of energy
- Feelings of worthlessness or guilt
- Inability to concentrate
- Difficulty making decisions

If you notice any of these symptoms, notify your supervisor or charge nurse. Someone who is qualified to diagnose delirium or depression will then make the appropriate treatment decision. Both delirium and depression can be treated successfully, so early detection is important.

Activity: Recognizing the Symptoms of Dementia

Let’s take the information we’ve covered and apply it to some specific situations. Please meet three elders residing in residential care facilities.

[Give participants several minutes to read the scenarios and jot down their thoughts. Participants have space in their guides for writing. Ask the group for responses individually. Record responses on a flip chart. If you have a larger audience, consider breaking the group into smaller teams. Ask them to appoint a recorder and a reporter. Have each group report out on their observations and suggestions. Document responses on a flip chart. At the end of the exercise, give participants an opportunity to copy new ideas into their own training materials.]
Mrs. Lara Jacobs

Mrs. Jacobs has lived in the same neighborhood all her life. She was an active and outgoing community member. Mrs. Jacobs raised three children and never missed a school activity. She was very involved in her church and served as the part-time secretary for 20 years. Her husband passed away several years ago, and she has been living on her own since then.

One year ago, when Mrs. Jacobs turned 85, her children convinced her to move to Oak Grove CBRF because they felt she could no longer safely live alone. Mrs. Jacobs looked forward to the move because she knew three of the other residents there. The old friends formed a card club and enjoyed playing on Tuesday and Thursday afternoons. They often discussed current events and shared the latest photos of their grandchildren.

Lately, one of the caregivers named Chaz has noticed some changes in Mrs. Jacobs’ behavior. She no longer seems interested in talking about her family or events in the community. Mrs. Jacobs carries on conversations on her own about things that happened in her past, especially during the years when she was a young mother. She often tells Chaz, “Lisa’s second birthday is tomorrow. I have to bake her cake.”

Last week, Chaz found a confused Mrs. Jacobs wandering the halls in search of the card game. After showing her the way, he stayed on to observe for awhile. Chaz noticed that Mrs. Jacobs seemed to get the rules confused and couldn’t recognize the cards. At one point, she threw her glass of water at one of her friends and accused her of cheating.
Review the lists of common changes in mild, moderate and severe dementia. Which of the changes seem to fit Mrs. Jacobs’ behavior?

________________________________________________________

________________________________________________________

What should Chaz do after noticing the changes in Mrs. Jacobs’ behavior?

________________________________________________________

[Suggested responses: report the changes in behavior to a supervisor for potential treatment or change in medication; ask Mrs. Jacobs’ friends for their observations; identify and/or share approaches with other staff that might help Mrs. Jacobs; remember that the changes in behavior are due to dementia.]
Mr. Joseph Lewis

Mr. Joseph Lewis spent his career in the Air Force and lived all around the world. When he retired, he and his wife moved to northern Wisconsin. From the day he moved to the community, Mr. Lewis has insisted that everyone he meets call him Joe. Joe’s wife passed away about four years ago.

When Joe was 74, he slid on his wet driveway and broke his arm. He decided to sell his home and move to Leisure Living Community Based Residential Facility (CBRF). Joe said it was the best decision he’s made since he married his wife because there is always someone around to talk to. Joe is an early riser. When he moved to Leisure Living, he would spend his days reading the newspaper, either in the neighborhood park or at the bakery down the street. He ate in the dining room each evening and greeted everyone as they came through the door.

Lately, one of the resident assistants, Mai, has noticed some changes in Joe’s schedule and behavior. Joe has stopped taking his daily walks after losing his way home. The newspaper sits on the table unopened. Instead of coming to the dining room for dinner, Joe stays in his apartment to eat. Mai has noticed that his clothes are looser than when she met him. When Joe leaves his apartment, he no longer greets his friends with a smile. One of the other residents mentioned that Joe became angry with her when she stopped to speak to him.
Review the list of common changes in mild, moderate and severe dementia. Which of the changes seem to fit Joe’s behavior?

________________________________________________________

________________________________________________________

What should Mai do after noticing the changes in Joe’s behavior?

________________________________________________________

________________________________________________________

[Suggested responses: report the changes in behavior to a supervisor for possible screening for depression, potential treatment, or change in medication; identify and/or share approaches with other staff who have also worked closely with Joe; remember that the changes in behavior are due to dementia or other conditions beyond the resident’s control.]
Miss Isabel Johns

Miss Isabel Johns is the youngest of three sisters. The sisters have been close their whole lives. Miss Johns is the only sister who never married. Unlike her sisters, who started families early, Miss Johns attended college and became a teacher.

Miss Johns moved to Caring Hearts Nursing Home because her needs could no longer be met at the community based residential facility (CBRF) where she had been living. Miss Johns became ill with pneumonia and never fully recovered. She became too weak to stand on her own and almost fell when she tried to get out of bed.

Janelle is a CNA assigned to Miss Johns’ wing. The two sisters tell Janelle that they are grateful to her for taking such good care of their little sister.

In the short time that Miss Johns has been at the nursing home, her needs have steadily increased. She is on a special diet because she is prone to choking. Under the guidance of the floor nurse, Janelle is responsible for keeping Miss Johns clean and comfortable. Yesterday, when Janelle came in to check on Miss Johns, her sisters were very upset. They told Janelle that they felt their sister was no longer being cared for properly. Just a few months ago, she seemed relatively healthy to them. Now she sleeps most of the day and seems confused when she’s awake. She cries and moans, even when she’s sleeping. Her sisters wonder why she isn’t getting the help she needs to feel better.
Review the lists of common changes in mild, moderate and severe dementia. Which of the changes seem to fit Miss Johns’ condition?

________________________________________________________

________________________________________________________

What should Janelle do after noticing the changes in Miss Johns’ behavior?

________________________________________________________

[Suggested responses: report the changes in behavior and the concerns of the family to a supervisor for tests for physical causes of the decline, potential treatment or change in medication; ask the sisters for ideas on how to soothe Miss Johns; identify and share those approaches with other staff; remember that the changes in behavior are due to dementia or other conditions beyond the resident’s control.]
Wrap Up

Dementia is caused by significant changes in the brain that cannot be reversed. As dementia progresses, changes in behavior will occur. Understanding why these changes happen will help you address challenges in a professional manner. Always remember that the changes aren’t something that residents can control, and the behaviors are not purposefully directed at you.

Learning Points

Let’s review the main learning points:

- Understand the changes that occur in the brain with dementia
- Recognize the stages and symptoms of dementia
- Apply knowledge of dementia to residents’ care

NOTE: This material was developed by the Wisconsin Department of Health Services-Division of Quality Assurance and the University of Wisconsin-Oshkosh Center for Career Development and Employability Training (CCDET) as part of the federal Caregiver Abuse and Neglect Prevention Project.

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Training Materials Checklist

For this training, you will need:

- Laptop computer (recommended)
- MS PowerPoint (*PPT Viewer 2007 can be downloaded for free at Microsoft.com*)
- LCD Projector (recommended)
- Screen for viewing the PPT (recommended)
- Flip chart and markers
- Printed Participant Guides
- Pens or pencils
- Evaluation (optional)
- Certificate of completion (optional)

Note: It is strongly recommended that the PPT be viewed using an LCD projector. If that option is not available, the PPT may be downloaded and printed as a handout.