

# Dementia and Alzheimer's Disease: The Basics



## PARTICIPANT GUIDE

Developed by:

**UW Oshkosh**

Center for Community Development, Engagement and Training (CCDET)

**Wisconsin Department of Health Services**

Division of Quality Assurance

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## Learning Points

Let's review the main learning points.

- Understand the basics about dementia and Alzheimer's disease
- Recognize the stages and symptoms of dementia
- Apply knowledge of dementia to residents' care

## Caring for Residents with Cognitive Disorders

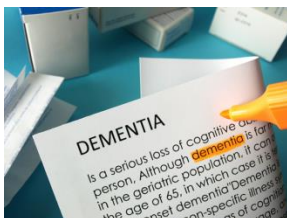


Caring for residents with dementia and other cognitive disorders can be especially challenging because you can't actually see the effects of the disease. Residents with dementia don't automatically lose their hair, have trouble breathing, break out in a rash, lose weight, or run a fever.

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 cause. Let's start out by defining dementia.

## Activity: Thinking about Dementia



The term "dementia" can bring about uncomfortable feelings. For others, confusion about the definition or condition exists. Some may wonder if they will get the disease. When you think of the term "dementia," what word or words come to mind? This course will address many of those questions and more.

# What is Dementia?

Dementia is not a stand-alone disease. It's a general term that describes a group of symptoms such as loss of:

- Memory
- Language skills
- Visual perception
- Problem solving
- Self-management
- Focus and attention

**IMPORTANT NOTE:** More than one symptom severe enough to interfere with daily life must be indicated to lead to a diagnosis of dementia.

Some people with dementia are unable to control their emotions, and their personalities may change. Dementia ranges in severity from the mildest stage, when it is just beginning to affect a person's functioning, to the most severe stage, when the person must depend completely on others for basic activities of daily living.

Signs and symptoms of dementia result when once-healthy neurons (nerve cells) in the brain stop working, lose connections with other brain cells, and die. While everyone loses some neurons as they age, people with dementia experience far greater loss. While dementia is more common as people grow older (up to half of all people age 85 or older may have some form of dementia), it is **not** a normal part of aging. Many people live into their 90s and beyond without any signs of dementia.

Several conditions can cause dementia. Some can be reversed when the underlying condition is treated, while others cannot. The two most common forms of irreversible dementia are Alzheimer's disease and vascular dementia (also called multi-infarct dementia).

## Alzheimer's Disease (AD)

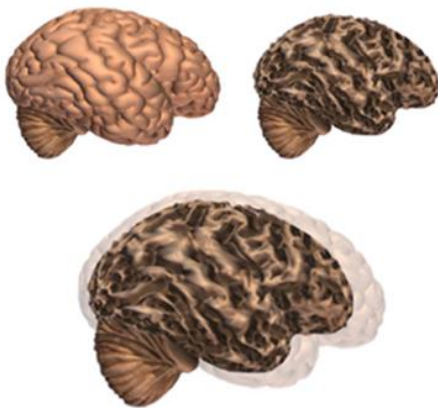
The most common type of dementia is AD. Although symptoms can vary widely, the first problem many people with AD notice is forgetfulness severe enough to affect their work, lifelong hobbies or social life. Other symptoms include confusion, trouble with organizing and expressing thoughts, misplacing things, 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.

- 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
- While younger people may experience early-onset dementia, it is much less common
- 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
- **AD is *not* a normal part of aging. Not every elderly person will have dementia or AD**

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



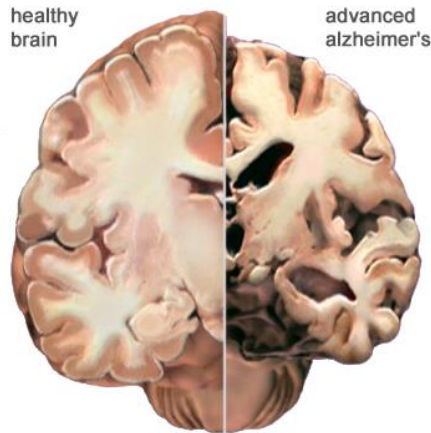
Alzheimer's disease leads to nerve cell death and tissue loss throughout the brain. Over time, the brain shrinks dramatically, affecting nearly all of its functions. These images show:

**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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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:

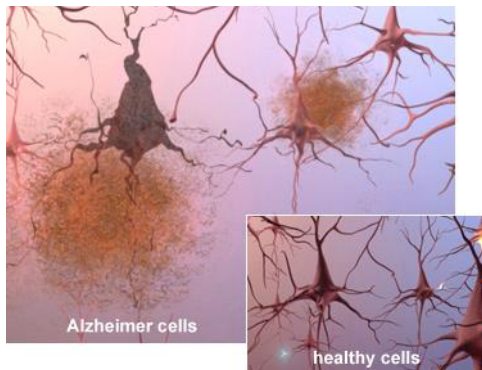
The **cortex shrivels up**, damaging areas involved in thinking, planning and remembering.

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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## Alzheimer's Disease: A Video Tour of the Brain



1. What is Alzheimer's Disease

This video examines the progression of Alzheimer's throughout the course of the disease. It provides an excellent explanation of the sequence of symptoms, based on the affected area of the brain.

[www.aboutalz.org](http://www.aboutalz.org)

## Other Types of Dementia

### Mild cognitive impairment (MCI)

With 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

Vascular dementia is the second most common type of dementia. It's caused by injuries to blood vessels, such as strokes, that supply blood to the brain. Conditions such as hypertension (which is also called high blood pressure), diabetes and high cholesterol increase the risk of strokes. Changes in thinking skills can occur suddenly following strokes that block major brain blood vessels.

Symptoms:

- Confusion
- Disorientation
- Trouble speaking or understanding speech
- Memory loss (may or may not be present, depending on the part of the brain where blood flow is reduced)

## Dementia with Lewy bodies (DLB)

DLB is the third most common type of dementia. Lewy bodies are abnormal groups of protein that develop inside nerve cells. Lewy bodies are named for the neurologist who first discovered them while working with Dr. Alzheimer in the early 1900's. Lewy bodies are also found in other brain disorders, including Alzheimer's and Parkinsonian dementia. The brains of many people with Lewy Body dementia and Parkinsonian dementia also have plaques and tangles — hallmark brain changes linked to Alzheimer's disease.

Symptoms:

- Changes in thinking and reasoning
- Confusion and alertness that varies significantly from one time of day to another or from one day to the next
- Parkinsonian-type symptoms, such as a hunched posture, balance problems and rigid muscles
- Visual hallucinations
- Delusions
- Dream, sleep disorders
- Memory loss that may be significant but less prominent than in Alzheimer's

## Frontotemporal dementia (FTD)

FTD accounts for up to 10% of all dementias. Decline in some people is rapid but others show minimal change. In those younger than age 65, FTD may account for 20% - 50 % of dementia cases. Symptoms: FTD includes a range of specific disorders with different core symptoms. See the chart below.



**FTD movement disorders** affect certain involuntary, automatic muscle functions

- Shakiness, lack of coordination, muscle rigidity/spasms
- Walking, balancing, frequent falls, muscle stiffness

**Primary progressive aphasia** affects language skills early and later affects behavior

- Words convey less meaning, using general terms (like "girl" instead of "daughter")
- Word comprehension diminishes; can't find a word
- Reading and writing skills diminish

**Behavioral variant FTD** greatly affects personality and behavior

- Begins with subtle changes that can be mistaken for depression
- As it progresses, people may lose inhibitions and the ability to show restraint in personal relations and social settings

## 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.

## Behavioral Symptoms of Dementia

Different types of dementia have different behavioral symptoms. Not everyone will experience all of the symptoms listed below or in any particular order. In other words:

“When you have met one person with dementia...  
you have met **ONE** person with dementia.”

Any “symptom” must represent a decline from a previously higher level of functioning

### Common Changes in Mild Dementia

- ☐ Forget details of recent events
- ☐ Show less ability to concentrate or stay on task
- ☐ Lose interest in hobbies and activities that were formerly enjoyable
- ☐ Have increased difficulty adapting to change or trying new things
- ☐ Show a decline in judgment or decision-making skills
- ☐ Grasp complex ideas more slowly and take longer with routine jobs
- ☐ Misplace items; believe others are responsible for taking lost items
- ☐ Become less aware of socially appropriate norms

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## Common Changes in Moderate Dementia

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- ☐ Focus more often on events from long ago
- ☐ Become confused regarding time and place
- ☐ Become lost if away from familiar surroundings
- ☐ Forget names of family or friends, or confuse one family member with another
- ☐ Forget to turn off the stove or complete another formerly familiar task
- ☐ Wander, perhaps at night, sometimes becoming lost
- ☐ Dress inappropriately, for example going outdoors in nightwear
- ☐ See or hear things that are not there
- ☐ Repeat the same story over and over
- ☐ Neglect personal hygiene or eating
- ☐ Lose the ability to “filter” emotional responses

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## Common Changes in Severe Dementia

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- ☐ Become unable to remember events for even a few minutes; for instance, forgetting a recent meal
- ☐ Lose the ability to understand or use speech
- ☐ Become incontinent
- ☐ No longer recognize friends, family or their own reflection in a mirror
- ☐ Need help with eating, bathing, toileting and dressing
- ☐ Unable to recognize everyday objects
- ☐ Seem disturbed, restless especially at night; mixing up days and nights
- ☐ Become aggressive, especially when feeling threatened or closed in
- ☐ Have difficulty walking, eventually using a wheelchair
- ☐ Lose the ability to control movements
- ☐ Become immobile in the final weeks or months

## **Activity: Recognizing Behavioral 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.

## 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 families.

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 a while. 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?

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

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## 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, a residential care apartment complex (RCAC). 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?

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

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## 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 because she can no longer bathe or dress independently. 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 doesn't seem to recognize them at all and refuses to speak to them. 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?

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

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## Other Conditions that Affect Behavior

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Dementia-like symptoms may also appear due to reversible conditions such as a high fever, dehydration, vitamin deficiency and poor nutrition, reactions to medications, 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

## Managing Behavioral Symptoms



Changes in behavior that occur with Alzheimer's and other degenerative dementias sometimes produce the most challenging and worrisome parts of the disease. A person may become more irritable than normal, or suffer from anxiety and depression.

As the disease progresses, the person may express agitation, become aggressive, experience hallucinations and restlessness, or become prone to wandering. Sexual and other social inhibitions can disappear, resulting in inappropriate behavior. Although some medications may lessen these symptoms, they are not likely to get better or disappear. Deterioration of the brain is the cause of the behaviors and there is currently no cure.

Person-centered approaches that focus on the individual can help calm residents in distress. Can you think of some approaches can help calm a resident in distress?

# Risk Factors

## Age



The greatest risk factor for Alzheimer's disease is advanced age. Most people with Alzheimer's disease are diagnosed at age 65 or older. People younger than 65 can also develop the disease (early-onset dementia), although this is uncommon. While age is the greatest risk factor, Alzheimer's is not a normal part of aging and advanced age alone is not sufficient to cause the disease.

## Family History and Genetics



Research shows that a person with a parent, brother or sister with Alzheimer's disease is more likely to develop the disease than those who do not have a first-degree relative with Alzheimer's. The risk increases if more than one family member has the illness.

Latinos and African-Americans are at higher risk for developing the disease. The reason for these differences is not well understood, but researchers believe that higher rates of vascular disease in these groups may also put them at greater risk for developing Alzheimer's disease.

Many people with Down syndrome develop early-onset Alzheimer's disease, with signs of dementia by the time they reach middle age.

## Lifestyle Risk Factors:

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**Alcohol Abuse** – Most studies suggest that drinking large amounts of alcohol increases the risk of dementia. Alcoholism is associated with extensive cognitive problems, including alcoholic dementia. [National Institute on Alcohol Abuse and Alcoholism (<http://www.niaaa.nih.gov>)]



**Smoking** – Smokers are prone to diseases that slow or stop blood from getting to the brain. Did you know that within just 20 minutes after quitting, a person's heart rate and blood pressure drop? And within 3 months of quitting, circulation improves. [American Cancer Society ([www.cancer.org](http://www.cancer.org))]



**Diabetes** – People with poorly controlled diabetes are at risk for stroke and cardiovascular disease, which in turn increases the risk for vascular dementia. Eating well-balanced meals and regular physical activity are important keys to managing diabetes and, later in life, reducing the risk of dementia. [American Diabetes Association® ([www.diabetes.org](http://www.diabetes.org))]



**Head Injuries** – There appears to be a strong link between serious head injury and future risk of dementia. Groups that experience repeated head injuries, such as boxers, football players and combat veterans, are most vulnerable. Another study found that this risk is further increased if the head injury resulted in loss of consciousness.



**Heart Disease** – Some of the strongest evidence links brain health to heart health. The risk of developing Alzheimer's or vascular dementia appears to be increased by many of the same conditions that damage the heart and blood vessels. These include heart disease, atherosclerosis, obesity, stroke, high blood pressure and high cholesterol. Remember: What's good for your heart ♥ is also good for your brain!

## Wisconsin Facts and Figures<sup>1</sup>



- Between 2015 and 2040, Wisconsin's population age 65 and older will grow by 640,000 people, an increase of 72%
- In 2015, an estimated 115,000 Wisconsin citizens had Alzheimer's disease or another dementia. By 2040, that number is estimated to rise to 242,000.
- The population is rapidly aging in rural areas, and is most pronounced in the northern half of the state
- Of Wisconsin's 72 counties, 18 are projected to have at least 33% of their total population age 65 and older by 2040, with three estimated to reach 40%
- In 2015 2,066 people died in Wisconsin from Alzheimer's disease, the 6th leading cause of death

## Wrap Up

As dementia progresses, changes in behavior often 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 basics about dementia and Alzheimer's disease
- Recognize the stages and symptoms of dementia
- Apply knowledge of dementia to residents' care

This material was developed by University of Wisconsin Oshkosh – Center for Community Development, Engagement and Training (CCDET) in collaboration with Wisconsin Department of Health Services-Division of Quality Assurance.

<sup>1</sup> Alzheimer's Association 2018 ALZHEIMER'S DISEASE FACTS AND FIGURES; [www.alz.org](http://www.alz.org)