Forget What You Think You Know about Dementia

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Welcome!

(I’m so happy to be here!)

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Exercise:
Consumer Description

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Learning Objectives

1. Define *dementia* and distinguish between dementia, Alzheimer's disease, and mild cognitive impairment (MCI).
2. Understand the connection between Down syndrome and dementia.
3. Become familiar with how dementia can affect a person's ability to communicate.
4. Recognize that people with dementia are still capable of meaningful interaction.
5. Identify ways of supporting and facilitating the communication efforts of people with dementia.

"I am hungry for the life that is being taken away from me. I am a human being. I still exist. I have a family. I hunger for friendship, happiness, and the touch of a loved hand. What I ask for is that what is left of my life shall have some meaning. Give me something to die for! Help me to be strong and free until my self no longer exists."

- James Thomas,

who lived with Alzheimer's for eight years before he died at age 70

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Exercise:
Sense of Taste

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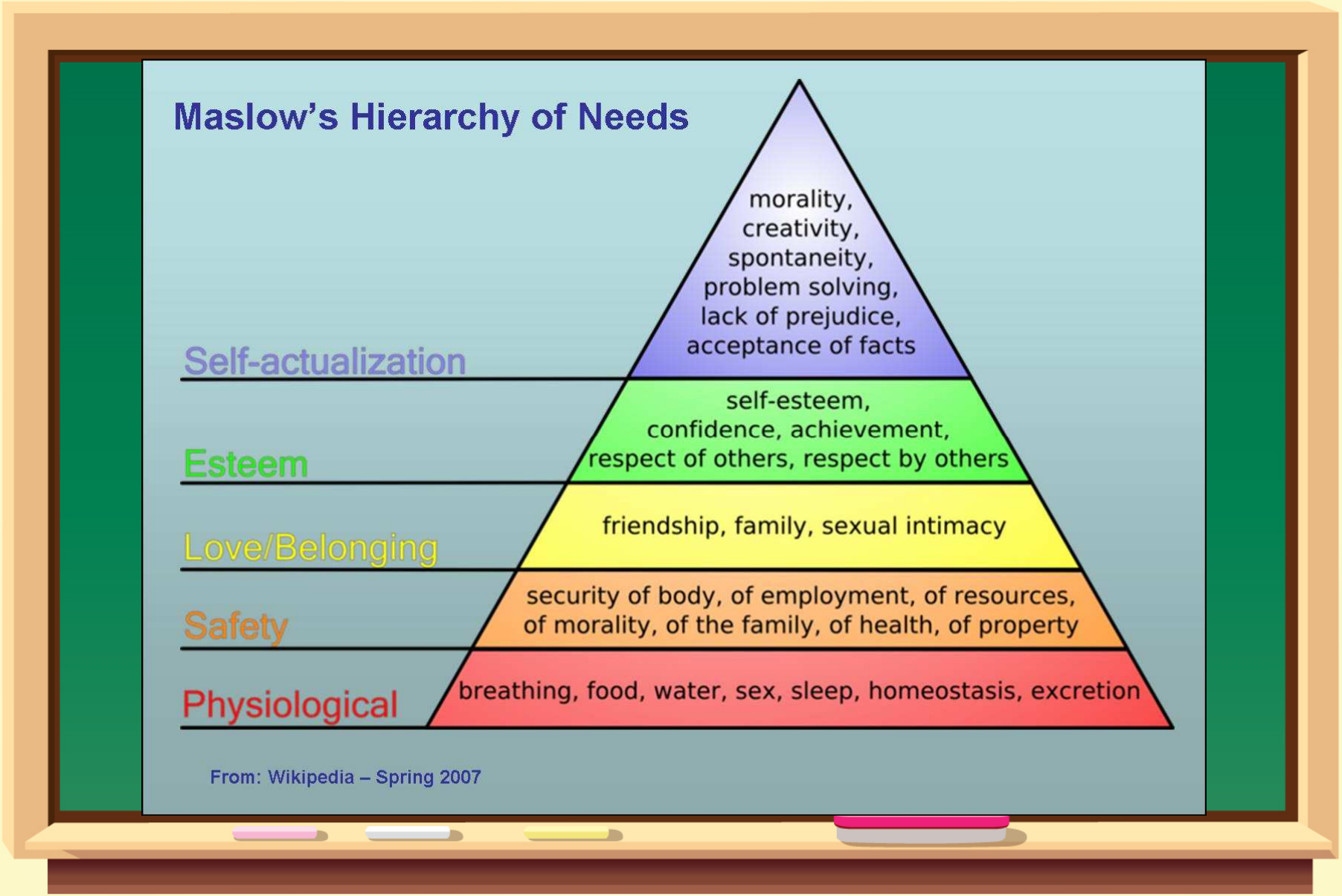

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Dementia Symptoms

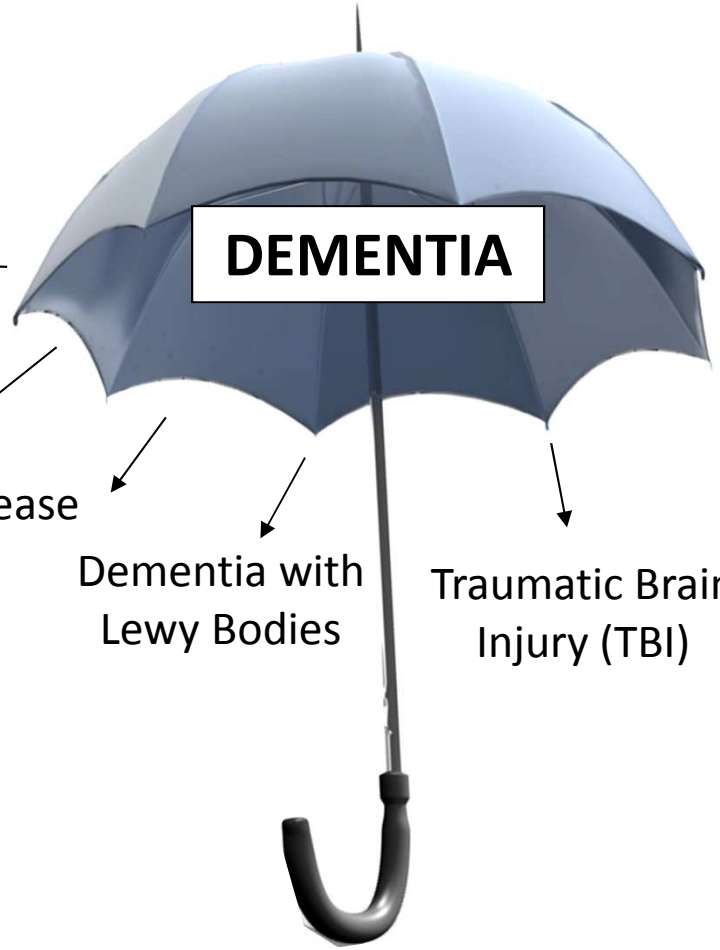
Dementia is a set of symptoms, which include difficulty:

- Recalling recent events.
- Recognizing familiar people and places.
- Finding the right words to express thoughts or name objects.
- Planning and carrying out tasks, such as balancing a checkbook, following a recipe, or writing a letter.
- Exercising judgment, such as knowing what to do in an emergency.
- Controlling moods or behaviors. Depression is common, and agitation or aggression may occur.
- Keeping up personal care such as grooming or bathing.

Dementia Symptoms *(continued)*

- Symptoms of dementia vary depending on the cause and the area of the brain that is affected.
- Memory loss is usually the earliest and most noticeable symptom.

The Dementia Umbrella



Alzheimer's disease

Vascular dementia

Parkinson's disease

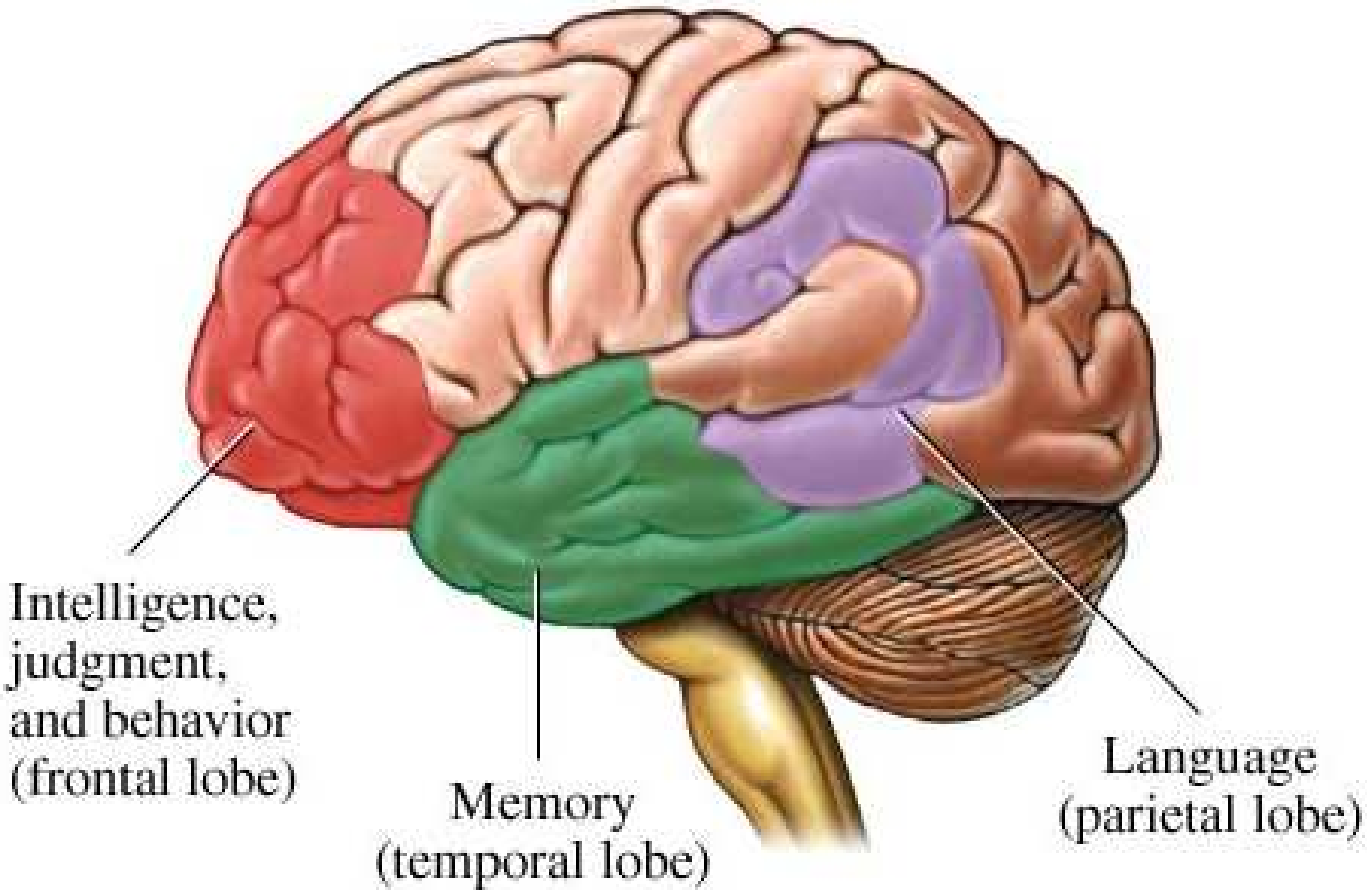
Dementia with Lewy Bodies

Traumatic Brain Injury (TBI)

Pick's disease and other frontotemporal dementias

Huntington's Disease
Creutzfeldt-Jakob Disease
Normal Pressure Hydrocephalus
Wernicke-Korsakoff Syndrome

Areas of the Brain Most Often Affected By Dementia



"Nurse, get on the internet, go to SURGERY.COM, scroll down and click on the 'Are you totally lost?' icon."

What is Alzheimer’s Disease?

- Alzheimer’s disease is not a normal part of aging.
- Alzheimer's disease is a progressive, degenerative disease of the brain, which causes thinking and memory to become seriously impaired.
- Alzheimer’s disease is the most common form of dementia and it accounts for about 70% of all cases of dementia in older adults.

Alzheimer's Disease (AD) and Down Syndrome

- People with Down syndrome have a greatly increased risk of early-onset Alzheimer's disease (AD)
  - Signs and symptoms may begin around age 50.
- Having Down syndrome increases the risk of developing AD, but not all people with Down syndrome develop AD.
- Those who have AD also have a higher rate of seizures.

Link Between Down Syndrome and AD

- Down syndrome occurs when an individual has a full or partial third copy of chromosome 21. (Typically, people have just two copies of each chromosome.)
- Chromosome 21 carries a gene that produces one of the key proteins involved with changes in the brain caused by Alzheimer's.
- Scientists have located several genes on chromosome 21 that are involved in the aging process and that contribute to the increased risk of Alzheimer's disease.

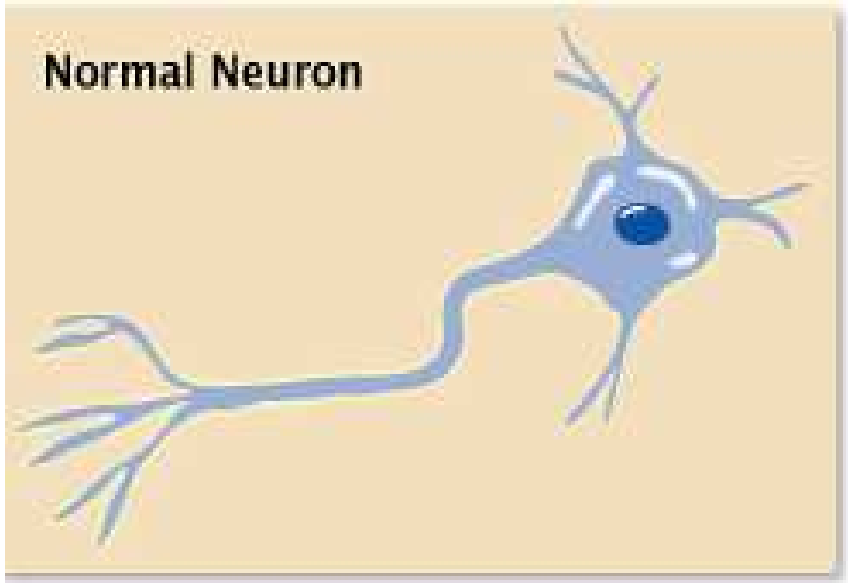
Alzheimer's Pathology

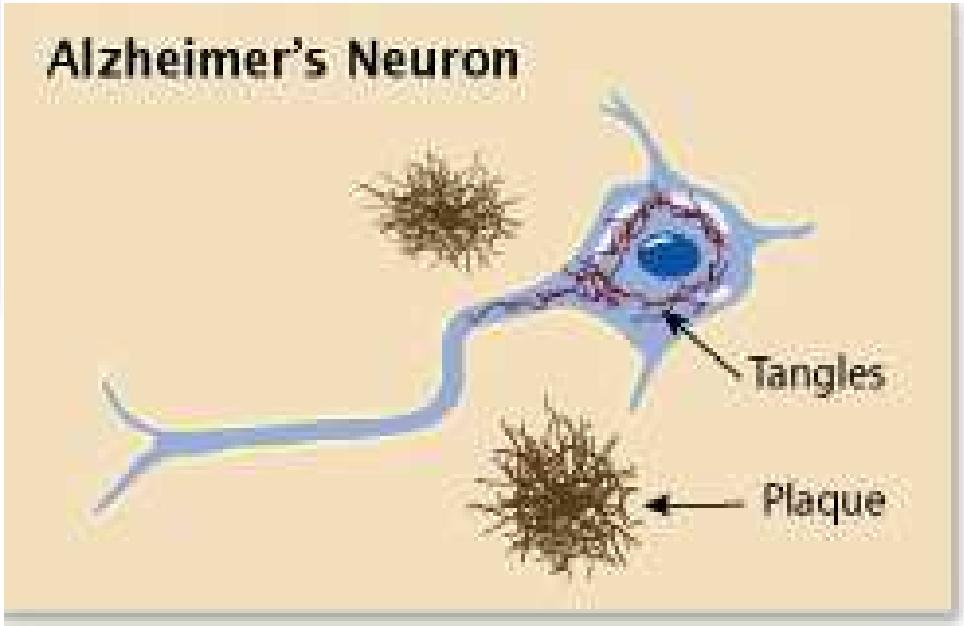
Alzheimer's disease is associated with two abnormal changes in the brain:

1. **Amyloid plaques** — Sticky plaques made of a protein called beta amyloid ("BAY-tuh AM-uh-loyd") clog the pathways between nerve cells, so messages cannot get through.

2. **Neurofibrillary tangles** — Tangles, which are twisted strands of a different kind of protein called tau ("tao"-rhymes with "cow"), disrupt and eventually destroy brain cells.

Protein Plaques and Tangles

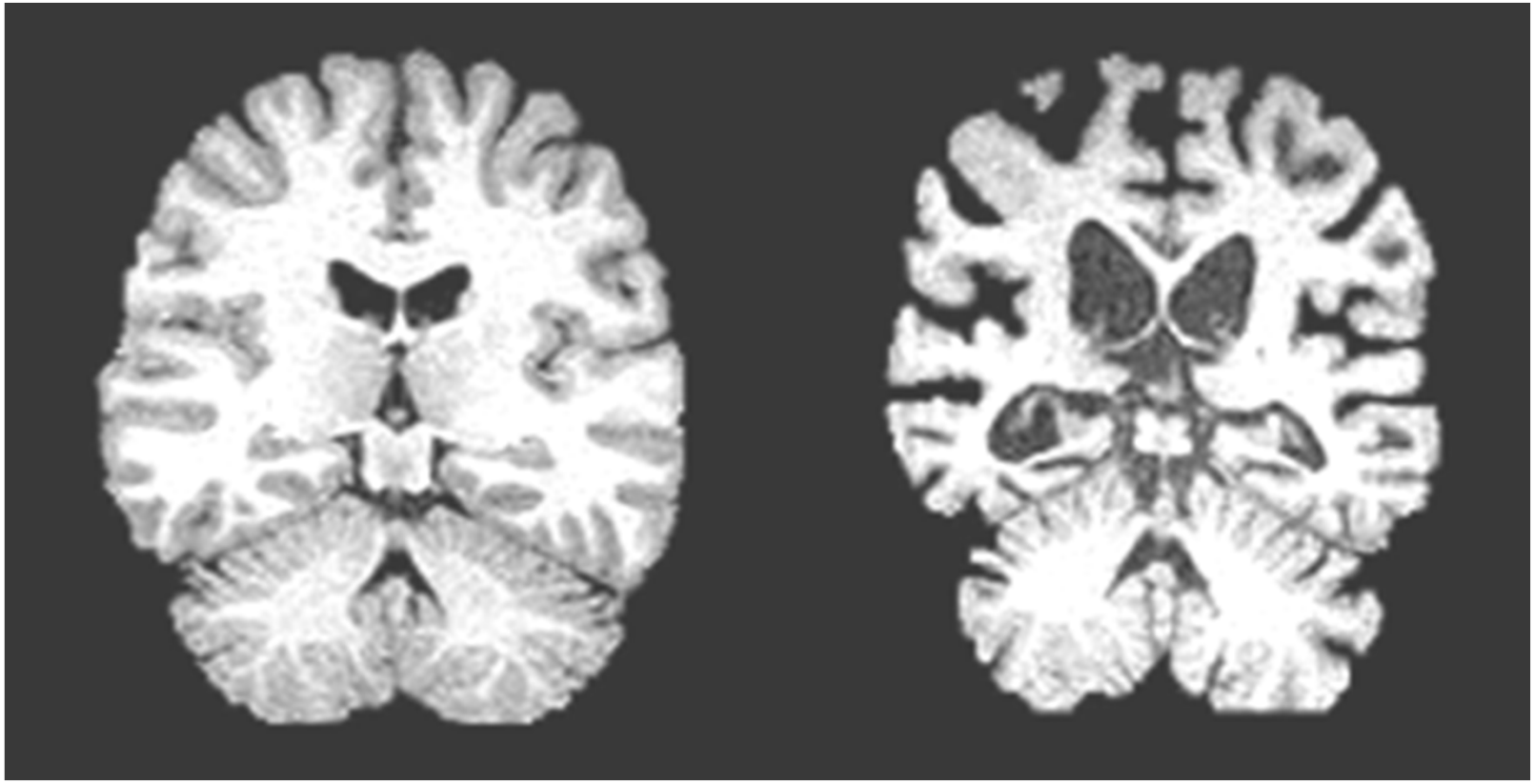




Alzheimer's and Brain Loss

Healthy Brain

Brain Affected by Alzheimer's Disease



What is Mild Cognitive Impairment (MCI)?

- As a result of the changes in the brain, people with Alzheimer's disease or other forms of dementia may:
  - Ask the same questions repeatedly
  - Be unable to follow directions
  - Get disoriented about time, people, and places
  - Experience frustration, sadness, or agitation when others don't understand what they are trying to communicate

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Dementia and Communication Challenges

- As a result of the changes in the brain, people with Alzheimer's disease or other forms of dementia may:
  - Ask the same questions repeatedly
  - Be unable to follow directions
  - Get disoriented about time, people, and places
  - Experience frustration, sadness, or agitation when others don't understand what they are trying to communicate

What We Can Do

1. Remember that a person's perception is his or her reality.
2. Encourage routines.
3. Practice patience.
4. Validate the person's feelings. Remember #1!
5. Be kind. Kindness builds trust, and trust is everything.
6. Try not to say "no." Find ways to get to "yes."

What We Can Do

7. We cannot change what is happening inside the brain of a person with dementia, but we CAN change the way we respond and react to that person.
8. WE set the tone for communication with people living with dementia.
9. People with dementia CAN communicate meaningfully!

Focus on the Person, Not the Disease

- Recognize that challenging behaviors are expressions of unmet human needs
- Get to know the person, including his or her:
  - Life story
  - Career and hobbies
  - Family
  - Religion and culture
  - Accomplishments
  - Hopes and fears
  - Likes and dislikes
- Talk to the person about topics he or she cares about - *other than care*.

Focus on the Person, Not the Disease

- Try not to view or interpret the person's behavior through the lens of dementia (malignant social psychology).
- Instead, think about what the person may be trying to communicate through his or her actions.
- Be thoughtful about the language you use. Your words reflect your beliefs.

Practice Patience and Empathy

- Give the person time to collect his or her thoughts and respond.
- Match your pace of speech and movement to the person's pace.
- Put yourself in the person's shoes and imagine what they might be thinking or feeling.
- Reassure the person, and validate his or her feelings rather than quizzing the person or attempting to reorient him/her to reality.

Exercise:
Objects and Instructions

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General Communication Strategies: NONVERBAL

- Put yourself at the person's eye level.
- Maintain eye contact and a cheerful facial expression.
- Give the person your undivided attention and concentrate fully when they are speaking.
- Use gentle touch if it seems appropriate.
- Use gestures such as pointing or motioning to accompany words.

General Communication Strategies: VERBAL

- Speak in the same natural tone of voice you would use when speaking to a good friend.
- Use the person's preferred name in conversation.
- Show you are interested in what a resident has to say with audible sounds and by asking questions.
- Share details about your own life.

General Communication Strategies: VERBAL *(continued)*

- Give genuine compliments.
- Laugh with the person.
- Avoid slang. ("*Jump* in the shower.")
- Try to avoid long, complicated sentences.
- Break long instructions into a series of shorter ones (verbal cueing).

What Do Your Words Say About You?

- ***Alzheimer's patient*** OR ***person living with Alzheimer's***
- ***Problem behaviors*** *OR* ***expressions of unmet needs***
- ***Wandering*** OR ***exploring*** OR ***walking***
- ***Diaper*** OR ***continence product*** OR ***Depend/Attend***
- ***Unit*** *OR* ***neighborhood*** OR ***program***

"I'm going to order a broiled skinless chicken breast, but I want you to bring me lasagna and garlic bread by mistake."

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Service Planning Exercise: Morning Routines

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Focus on the Person's Strengths and Remaining Abilities

- Take time to talk with the person, get to know him/her a bit, and build trust. (You will get more accurate information and save time in the long run!)
- Consider the person's living situation (living alone, with family, neighbors nearby, etc.) and how that effects the assessment and service plan.
- Remember that people with dementia can often accurately express their preferences, even if they have significant memory loss in other areas.

Focus on the Person's Strengths and Remaining Abilities

- Enter as much DETAIL as possible in narrative fields. The more detail that is included, the more person-centered the care can be.
- Make your assessments conversational. Many people with dementia don't have opportunities for good conversation, and you can make the assessment process a social opportunity!
- Model person-centered communication for family members and friends who are present and encourage those who are already connecting in person-centered ways.

Q and A
And
Troubleshooting

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Final Thoughts and Questions

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Thank you for the great work you do for Oregonians!

YOU ROCK!

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