

Penn

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Penn Memory Center welcomes you to

Caring for the Caregiver:

people caring for som

Questions? Contact:

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Materials Needed

- A notebook for reflective journaling and taking notes;
- A folder or binder to print class Word documents and homework.

This class will be optimal if you view the recorded lectures in a quiet room, free of distractions.

Key goals: Caregivers will...

- Gain a better understanding of dementia and the different causes;
- Improve understanding of their individual needs;
- Learn how to harness inner resources and strength;
- Learn to enhance self-care while caring for someone with dementia;
- Learn practical skills for managing behaviors and communicating with someone with dementia;
- Begin or continue planning for the future.

Session by Session Overview

Class 1: Introduction and overview of memory loss, dementia and caregiver burden

Class 2: Identifying, examining and challenging unhelpful thoughts

Class 3: Self care for caregivers

Class 4: Behavior management

Class 5: Engaging in enjoyable activities

Class 6: Planning for the future

The Penn Memory Center (PMC)

- 1 of 30 National Institute on Aging Alzheimer's Disease Research Centers (ADRCs)
- Expert evaluation and diagnosis of neurodegenerative disorders
- Extensive research opportunities
- Multidisciplinary patient/family care
- Social work services to support families through education, programming and emotional/mental health care
- Comprehensive neuropsychological testing
- For more information: www.pennmemorycenter.org

A photograph showing a group of people, primarily women, sitting on blue mats on a wooden floor in a room with large windows and dark curtains. They appear to be participating in a program, possibly a meditation or support group. The image is partially obscured by a white curved shape on the right side of the slide.

“Caring Difference” Programs

- Caring for the Caregiver classes
- Caregiver support groups
- Grief/loss support groups
- Coaching and psychotherapy
- Empowering Caregivers lecture series
- Memory Cafes
- Time Out Respite Program
- Creative expression Through Music
- And more...



What does it mean to be a caregiver?

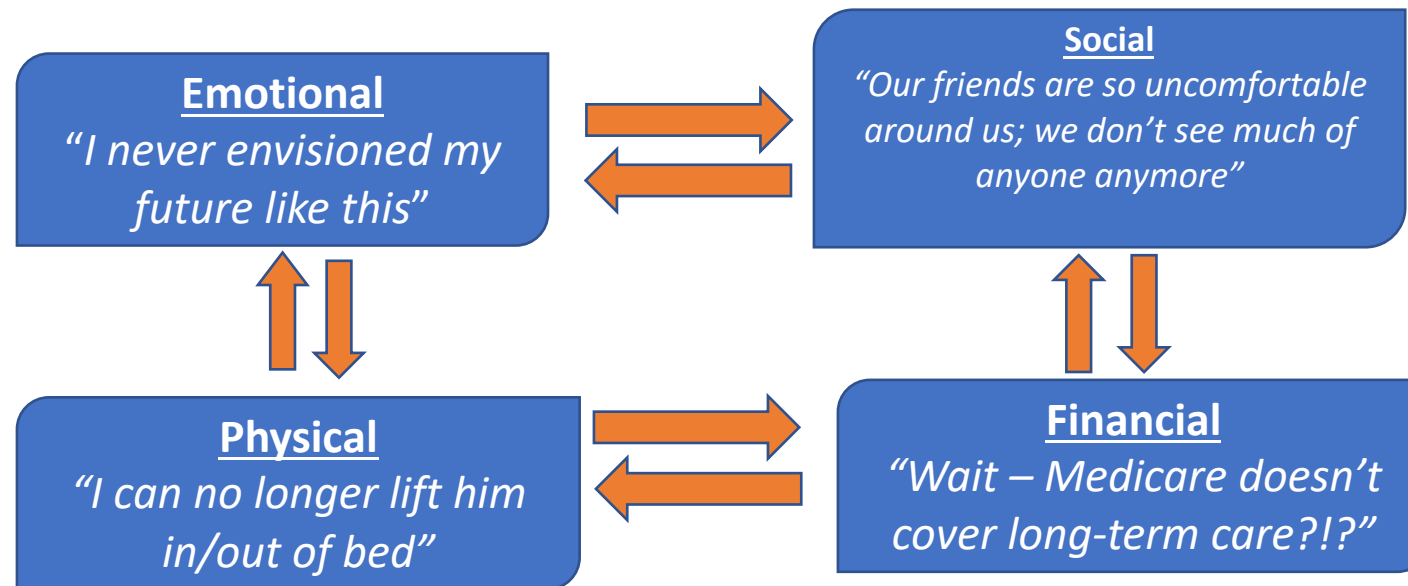
- Extraordinary care, exceeding “usual” family relationships;
- Involves significant expenditures of time, energy and money over long periods of time;
- Involves tasks that can be unpleasant, uncomfortable, psychologically stressful and physically exhausting.

Alz Assoc 2020 Facts & Figures - Caregivers

- 83% of help provided to older adults in the US comes from unpaid family caregivers; 48% are dementia caregivers
- Family caregivers provided ~18.5 billion hours of care valued at \$233.9 billion
- 2/3 are women
- 1/3 are 65+ years old
- Duration can be 10+ years
- ¼ are sandwich generation (caring for both parent and child under 18)


Caregiver burden

Interplay between the emotional, social, physical and financial stressors related to caring for someone with dementia.



Caregiving and Ambiguous Loss

- Many caregivers report that the main problem is not the illness, but the ambiguity/uncertainty it causes;
- Sadness experienced for caring for someone who is *here* (physically) but *not here* (emotionally, psychologically);
- ADRD causes unpredictable memory loss that comes and goes (roller coaster of absence and presence) which causes stress;
- Living losses have no closure/ceremony like finite losses (death)
- Ambiguous feelings can arise for caregivers, rendering them depressed and feeling immobilized leading to feelings of isolation, anxiety, sadness, guilt, shame.



Self-care and stress reduction

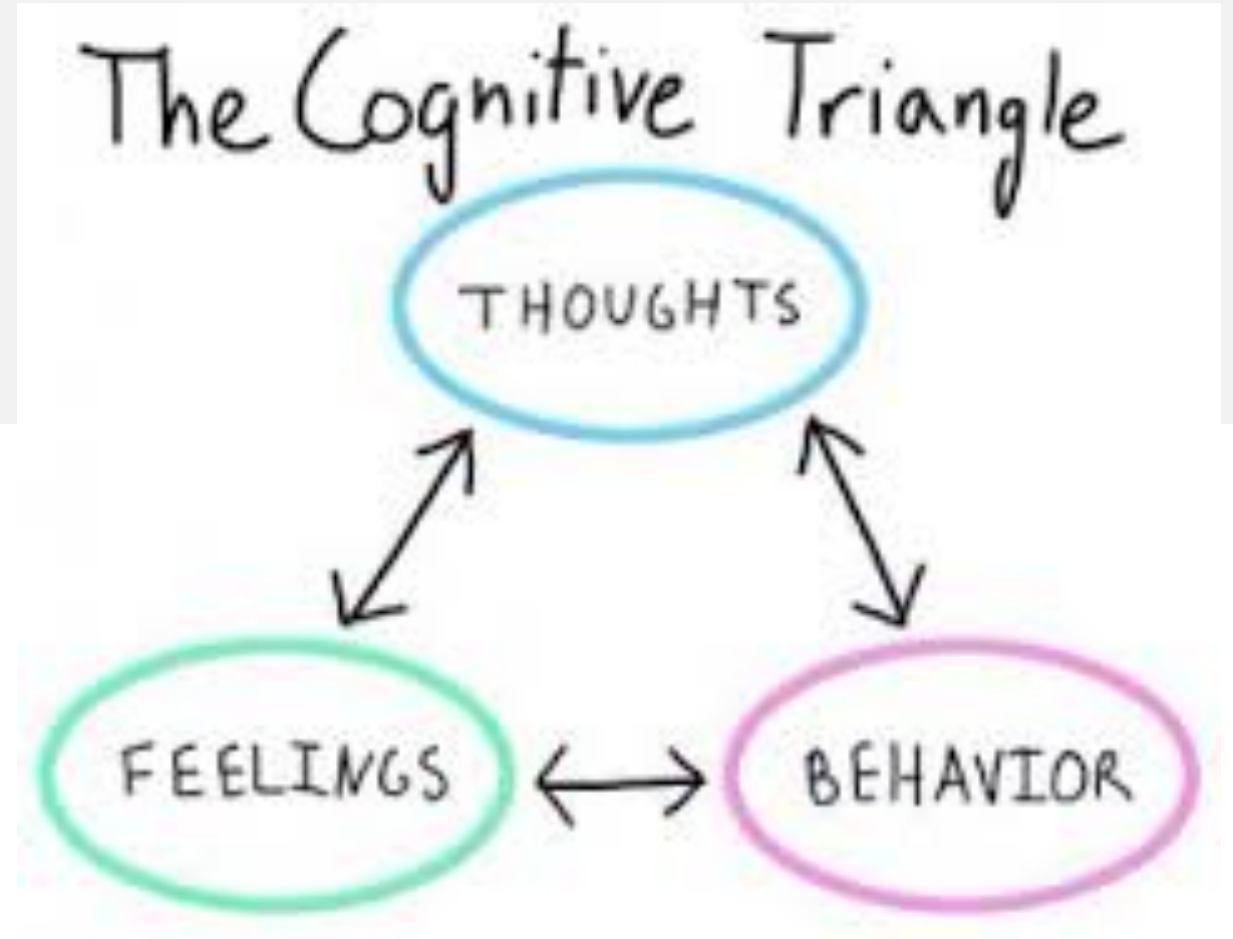
- Identify positive aspects of caregiving
- Understand impact of thoughts on mood and behavior
- Understand, manage, and challenge cognitive distortions
- Learn how to express and accept negative moods
- Move from anger to empathy
- Identify pleasant events
- Improve communication with loved one
- Learn relaxation skills
- Identify support and ask for help



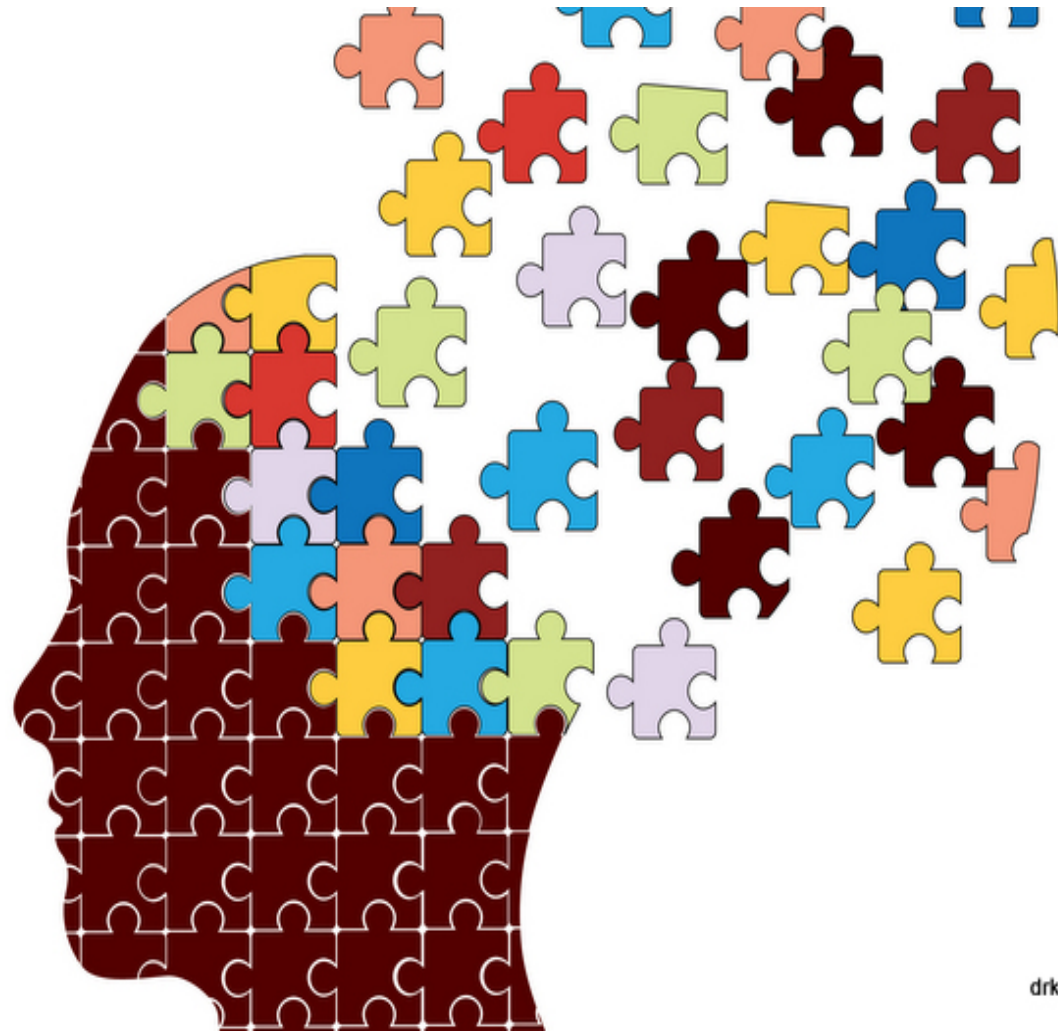


Key Concepts

- Cognitive Behavioral Therapy
- Stress reduction through mindful responsiveness
- Support from group of people going through a similar experience



Basic Overview of Memory Changes/Loss



Age-Related Memory Loss:

Typical changes include:

- Making a bad decision once in a while;
- Missing an occasional monthly payment;
- Forgetting which day it is and remembering later;
- Sometimes forgetting which word to use;
- Losing things from time to time

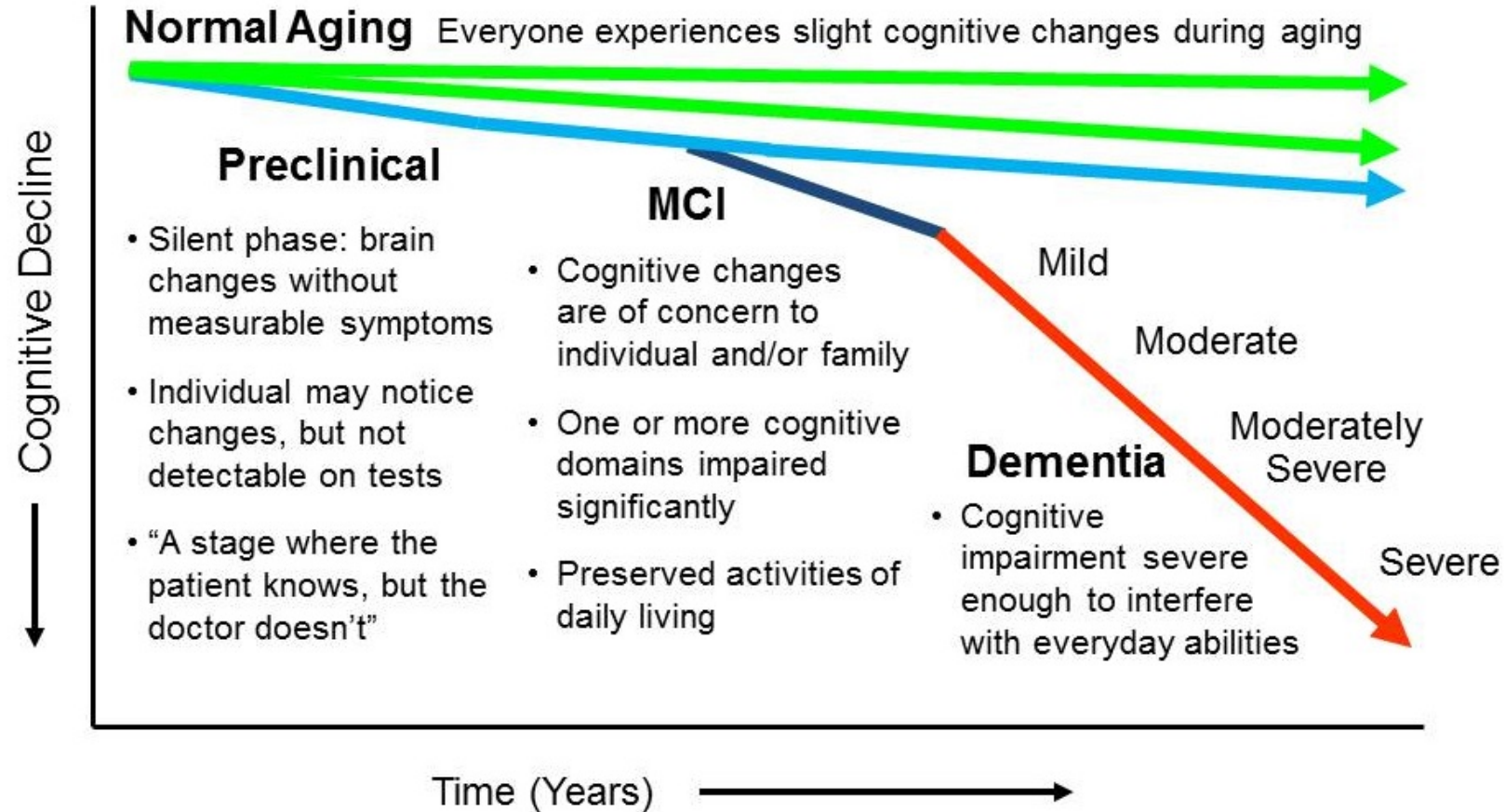
Problematic Changes:

- **Changes indicating need for a doctor's visit –**
 - Consistent poor judgment and decision making
 - Loss of ability to manage money
 - Inability to keep track of the date or the season
 - Difficulty having a conversation
 - Misplacing things and loss of the ability to retrace steps to find them
 - Trouble with visual and spatial relationships
 - Challenges in planning or solving problems

What is dementia?



Normal Aging vs. MCI vs. Dementia





Types of Dementia (*a non-exhaustive list*)

- Alzheimer's disease (most common)
- Vascular dementia
- Frontal temporal dementia
- Dementia with Lewy Bodies
- Parkinson's Disease Dementia
- Reversible causes
 - Depression, anxiety
 - Vitamin B deficiency
 - Hypothyroidism
 - Alcohol/drug abuse
 - Tumors, infections

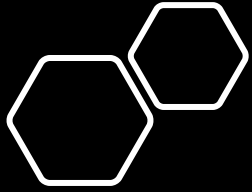
The Diagnostic Process at the PMC

- Separate report from patient and “informant”
- Bedside neurological exam
- Mini battery of neuropsychological testing
- Blood work (rule out infection, VitB deficiency, thyroid issues, etc.)
- MRI (check for hippocampal volume, check for general atrophy, check for vascular disease/stroke, rule out tumors or infections)
- Sometimes:
 - PET scan: FTG or Amyloid
 - Lumbar puncture: disease biomarkers
 - Extended neuropsych testing

Still, the only way to give someone a 100% accurate dx is through autopsy.



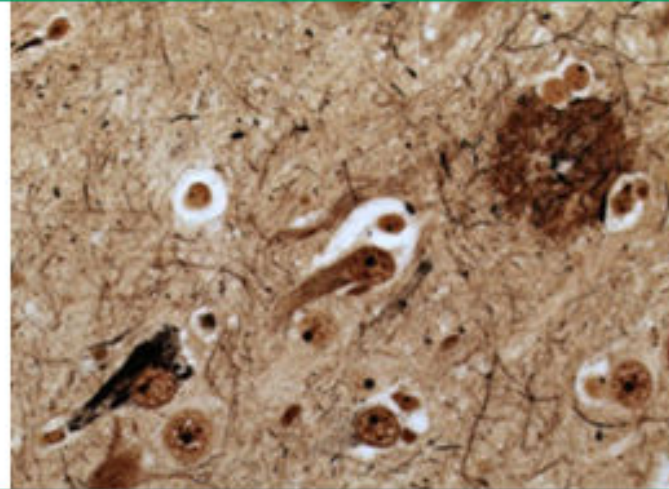
At a certain point, diagnostic specificity becomes less important than supporting patients and caregivers in symptom management and care planning.



Alzheimer's disease

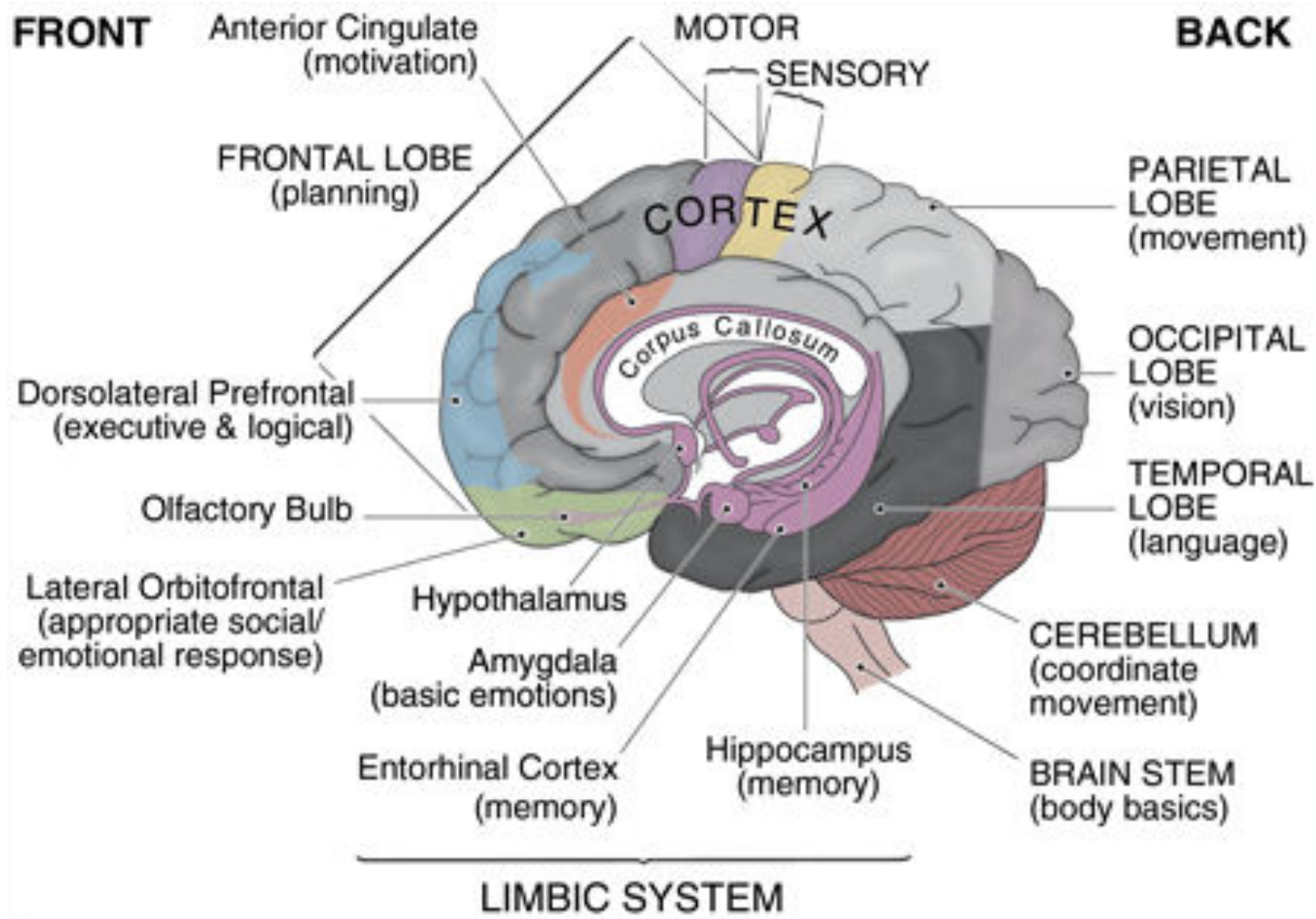
- Is a brain disorder
- Is a progressive disease
- Has no cure

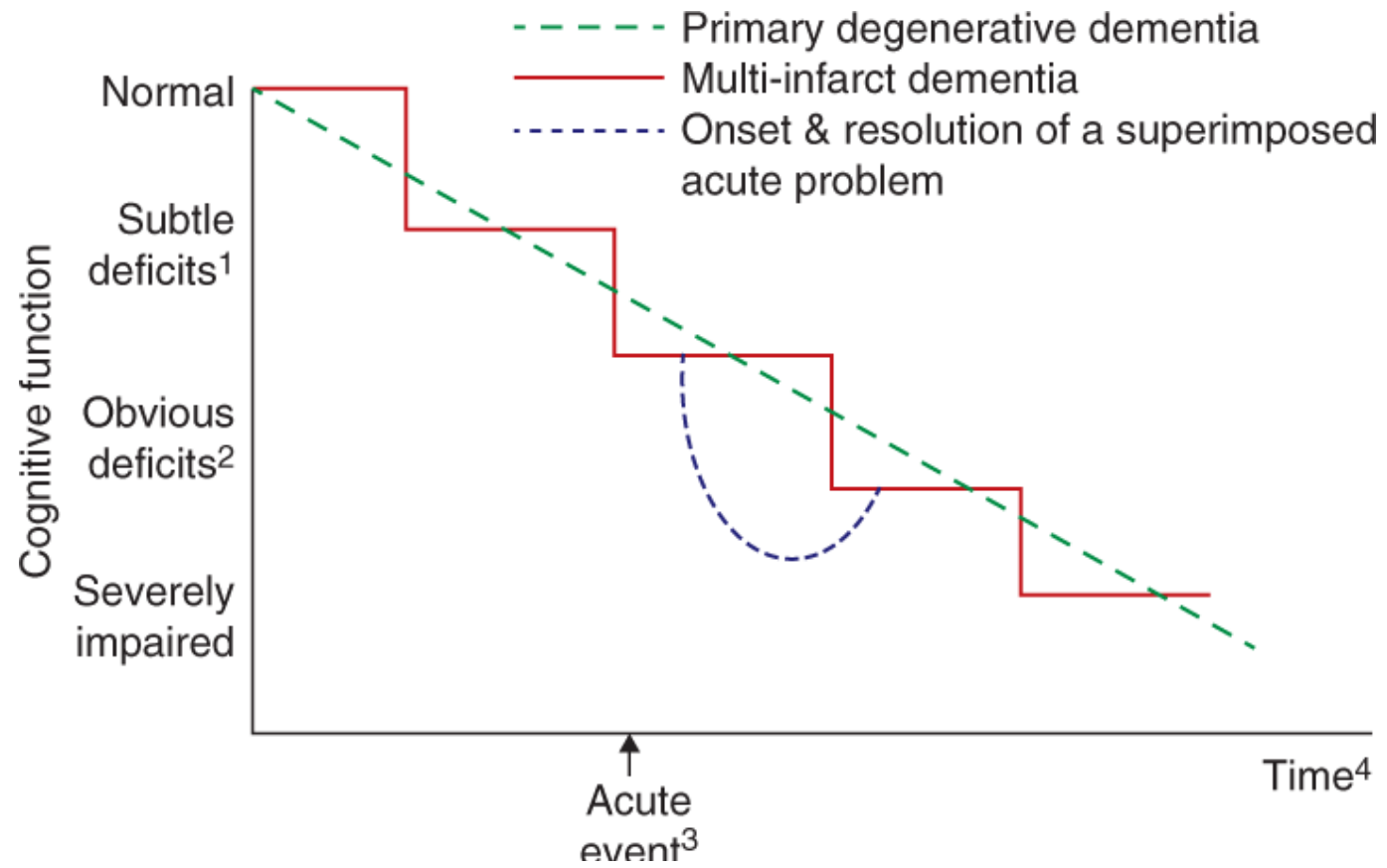
Photomicrograph of human brain with Alzheimer disease



Photomicrograph of human brain with Alzheimer disease following Bielschowsky stain. The stain highlights an extracellular neuritic plaque (upper right) and an intraneuronal neurofibrillary tangle (lower left).

UpToDate®





How Does Progression Differ?

Stages of Alzheimer's disease - Early

In the early stages, many people may:

- Become more forgetful
- Be confused about decisions, handling money and directions
- Seem more tired
- Seem “different” from usual, and make odd judgments and social mistakes
- Repeat things
- Be confused about times and places

Stages of Alzheimer's disease - Middle

In the middle stages, many people may:

- Wander or pace
- Have difficulty recognizing friends and family
- Become impatient, restless, irritable and emotional
- Be unable to learn new things
- Have trouble organizing and expressing thoughts
- Become suspicious of others or see and hear things that are not there
- Have trouble dressing appropriately
- Resist being helped and be more aggressive toward others

Stages of Alzheimer's disease - Late

- **In the later stages, any people may:**
 - Be unable to perform most activities of daily living
 - Lose control over bladder and bowel functions
 - Be unable to communicate or follow directions
 - Seem to live in a “fantasy world” (talking to people and about things that are not real)
 - Become irritated easily
 - Be unable to walk or sit alone
 - Spend much more time sleeping
 - Appear withdrawn from the world around him or her

2020 Facts & Figures - AD

- Only cause of death in the top 10 in America that cannot be prevented or cured
- Almost 2/3 of Americans with AD are women
- 1 in 3 seniors dies of Alzheimer's or another dementia
- It's the 6th leading cause of death in the US
- Only 45% of people with AD are told of their diagnosis compared to 90% of people with cancer
- In 2018 caregivers of people with ADRD provided 1.4 billion hours of unpaid care valued at \$232.1 billion
- By 2050 the cost of caring for dementia could reach \$1.1 Trillion.
- Every 65 seconds someone in the US develops the disease

Alzheimer's Association 2019 Facts & Figures www.alz.org/facts

Treatments:

- Currently approved:
 - Aricept, Namenda, Exelon patch
- Experimental Clinical Trials:
 - Researchers looking for more effective treatments, cure, and prevention
- Meanwhile:
 - Non-pharmacological behavior modification
 - Caregiver training and support

Mindfulness

“The awareness that emerges when you are paying attention, on purpose, to the present moment, without judgment.” (Jon Kabat-Zinn)

“Your mind is like a kindergarten class, and meditating is like trying to get your thoughts to take a nap. If one wakes up, tell them gently to go back to sleep. If your mind thinks, ‘but you have a to-do list!’ just say, ‘shhhh.’ (Cup of Jo)

Relaxation Exercise: The Signal Breath

- The signal breath is a simple stress management technique that can help you cope better when stressful caregiving situations arise. It is very powerful because you can use it **anywhere, at any time, during any situation.**

Mood- Monitoring: Becoming Aware of Your Moods

Checking in with Yourself:

As we begin to learn new skills to improve your mood, it's important to check in with yourself. For our purposes, "checking in" means asking yourself, "how do I feel right now?" or "how am I feeling today?" If you're not sure how you're feeling, can you identify any feelings in your body? As you check in regularly, you'll be able to identify the various mood changes you experience throughout a day, week, or month.



Mood-Monitoring:

Monitoring your mood, by keeping a daily record of your feelings, will help you understand yourself better. The daily record will allow you to identify whether your mood follows a particular pattern. For example, some people feel great on Friday after work, and feel worse on Sunday evening. The daily record will help you figure out whether there are certain times when you feel better or worse than others.

Activity: Practice Recording Your Daily Mood

Using the 10 point scale, give your mood an average rating for the day where 1 is very sad, 5 is “so-so,” and 10 is very happy.

Rate your mood now: _____

Now, please briefly give two major reasons explaining your feelings for that particular mood. Try to be as specific as possible.

1. _____

2. _____

Homework



1. Complete Mood Tracker – record daily mood
2. Practice your signal breath and rate stress level before and after your practice.

Both trackers are in the folder on the website. If you need help accessing them, email me at felicia.greenfield@pennmedicine.upenn.edu