



Family Caregiver Education Series

## Living with Dementia: Dementia Basics

September 8, 2022

10:00 – 11:30 a.m.

**Debbie Emerson, M.S.**, Community Health Educator  
CARES® Dementia Specialist

**Gia Barsell**, Manager of Dementia Services  
PAC Independent Trainer & Advanced Consultant

## Upcoming Webinars

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- ***Exploring End-of-Life Legal and Financial Issues***

**Presenter:** Julie Fiedler, RN, JD, Horizon Elder Law

Thursday, October 13, 2022

10:00 – 11:30 a.m.; Q and A 11:30 a.m. – noon

- **Medicare: An Overview and Update**

**Presenter:** Jenny Pardini, Alameda County HICAP  
(Health Insurance Counseling and Advocacy Program)

Thursday, November 10, 2022

10:00 – 11:30 a.m.; Q and A 11:30 a.m. – noon

*Register for webinars at [www.HopeHospice.com](http://www.HopeHospice.com)*



## Archived Dementia Webinars

[www.HopeHospice.com/family-past](http://www.HopeHospice.com/family-past)

- Dementia or “Normal” Aging? How to Tell the Difference  
-August 2022
- Self-Care for the Caregiver  
-June 2022
- Dementia: Next Steps After a New Diagnosis  
-April 2022
- Managing Daily Care  
-March 2022
- Understanding Behavior as Communication  
-December 2021



## Agenda

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- Dementia Defined
- Underlying Causes
- Stages of Dementia
- Brain Abilities/Changes
- Risk Reduction Strategies



## Dementia Defined

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### Dementia is NOT . . .

- a normal part of the aging process.
- only about a loss of memory.
- always permanent.
- the same as Alzheimer's disease.
- a stand-alone diagnosis.



## Dementia Defined

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### Dementia IS . . .

A group of **symptoms** involving a decline in:

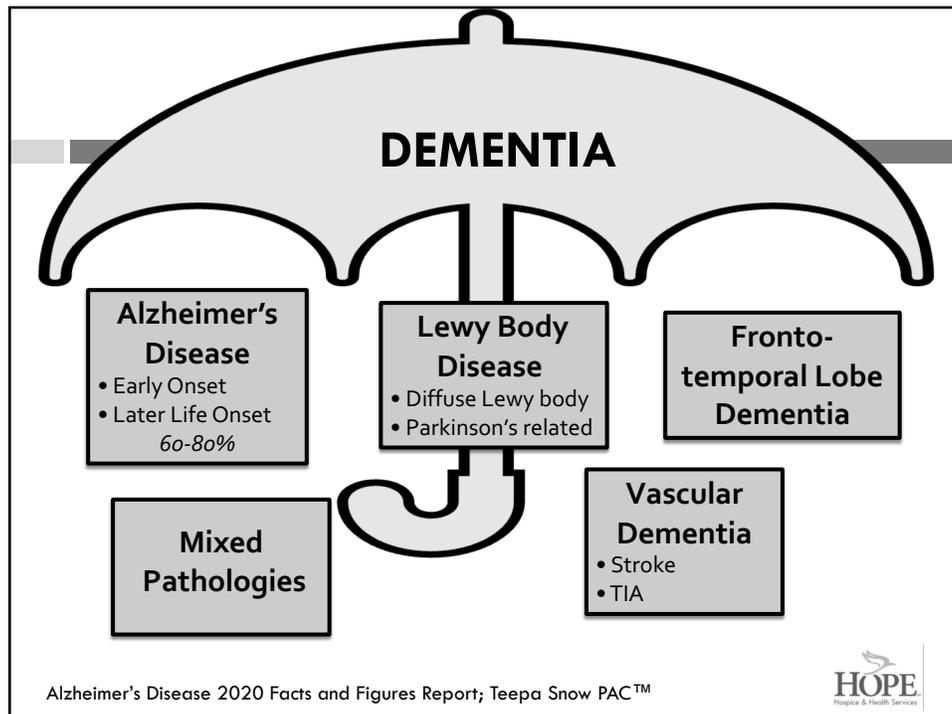
- cognitive functioning and
- behavioral abilities

*. . . that affect one's daily life*



## What does it mean to “have dementia?”

- Exhibits life-altering symptoms that reflect a change from the person’s typical behavior
  - memory issues
  - difficulty speaking and understanding
  - confusion
  - difficulty with problem-solving, decision-making
  - problems with focus, staying on-task
  - personality changes
  - agitation, aggression, disorientation, paranoia
  - social withdrawal/isolation
- Diagnosed with an underlying condition that is causing these symptoms



## Leading Causes of Dementia

- Alzheimer's disease
  - 60-80%
  - Cognitive decline includes loss of memory, language problems, issues with time, place, situations
  - Can last a few years to up to 20 years
  - Early onset cases – prior to 65; 5-6% of cases
  - Diagnosed by brain scans, cognitive and behavioral exams
- Vascular dementia
  - 5-10%
  - Stroke, TIA – restrict blood flow to brain
  - Damage dependent on what areas of brain impacted
  - Symptoms may appear suddenly
  - Progression is less predictable than other causes



## Leading Causes of Dementia

- Lewy Body Disease (Lewy Body Dementia)
  - Symptoms similar to Alzheimer's
  - Characterized by visual hallucinations
  - Parkinson's-related dementia
    - Characterized by motor impairments caused by Lewy bodies (abnormal proteins)
    - 50-80% experience dementia after about 10 years
- Frontotemporal Lobe Dementia
  - Symptoms usually appear between ages 40-65
  - May be misdiagnosed as psychological disorder
  - Drastic personality changes; speech, reasoning, social judgment



## Leading Causes of Dementia

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- Mixed Pathologies
  - AKA mixed dementias
  - Simultaneously have more than one underlying condition
  - Most common: Alzheimer's and vascular dementia
  - Symptoms vary depending on brain region impacted
  - 50% of Alzheimer's patients had evidence of co-existing condition



## Dementia or something else?

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- Pseudo-dementias; delirium:
  - Reactions to medications
  - Infections
  - Metabolic imbalance (ex. dehydration; low-blood sugar)
  - Vitamin or mineral deficiency (ex. B vitamins; sodium; potassium)
- Vision or hearing loss
- Emotional distress
- Chronic pain



## Evaluating Symptoms

- Thorough medical exam: Medical and medication history
- Assessment of functioning and behavioral changes
  - Impaired memory or thinking skills
  - Changes in personality, mood
  - Interview with family member
- Medical tests
  - Blood
  - Brain imaging
- Cognitive test(s) to evaluate memory, judgment, ability to understand visual information:
  - General Practitioner Assessment of Cognition (GPAoC)
  - Mini-cog
  - Montreal Cognitive Assessment (MoCA)



## Stages of Dementia

- Standard dementia scales focus on abilities lost
- Alzheimer's Association Stages
  - Three-stage functional model
  - Early, middle, late
- Global Deterioration Scale (GDS)
  - Seven-stage medical model (1-7)
  - Hospice is stage 7
- Allen Cognitive Levels
  - Six-level model  
(ACL 6 – normal cognitive abilities; ACL 1 – needs 24/7 care)
  - Focus on losses and remaining abilities



## Stages of Dementia

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### Early-Stage (Mild)

- Usually functions independently
- Memory lapses; word retrieval issues
- May have trouble at work or with planning/organizing
- Symptoms not widely apparent, but family may notice changes
- Important to get legal and financial matters in place



## Stages of Dementia

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### Middle-Stage (Moderate) (longest stage – 8-20 years)

- Greater difficulty communicating verbally
- Increased forgetfulness and confusion
- May become easily frustrated or angry
- May behave in ways that are out of character; loss of social filter
- Requires more cuing and prompting
- May get lost or wander



## Stages of Dementia

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### **Late-Stage (Advanced)** (several weeks to several years)

- Loses ability to respond to environment
- Great difficulty in communicating
- Primarily communicates through behaviors
- Changes in physical abilities: walking, sitting, swallowing; fall risk
- Usually requires 24/7 care



## Stages of Dementia

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### **End-stage**

- Chair and/or bed bound
- Reliance on facial expressions and tone of voice
- Difficulty with chewing and swallowing
- Repetitive behaviors
- Requires 24/7 care



## Teepa Snow's Gems™ Levels

- Focus on what remains possible
- Six GEMS levels: sapphire, diamond, emerald, amber, ruby, pearl
- Key Points:
  - Abilities are ever-changing
  - Levels may fluctuate daily
  - May display behaviors from more than one level
  - Focus on the positive

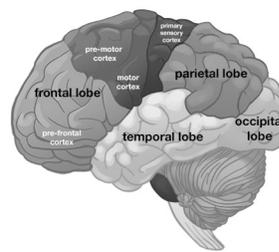


View *Teepa Snow's Gems™ Levels* (October 21, 2020)  
at [www.hopehospice.com/family-past-webinars/](http://www.hopehospice.com/family-past-webinars/)



## Brain Abilities Impacted

- Memory
- Language
- Vision
- Perception
- Motor Skills
- Reasoning
- Judgment
- Abstract Thinking
- Attention

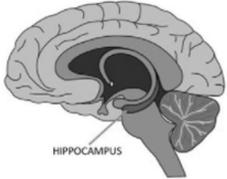


**KEY ABILITIES IMPAIRED BY DEMENTIA**

<p style="text-align: center;"><b>MOTOR SKILLS</b></p> <p><b><u>FINE</u></b></p> <ul style="list-style-type: none"> <li>• Dexterity: using utensils, writing, dressing</li> <li>• Chewing and swallowing</li> </ul> <p><b><u>GROSS (LARGE)</u></b></p> <ul style="list-style-type: none"> <li>• Balance, coordination</li> <li>• Gait</li> </ul>	<p style="text-align: center;"><b>ABSTRACT THINKING</b></p> <ul style="list-style-type: none"> <li>• Higher level thinking skills</li> <li>• Understanding connection between ideas, concepts, etc.</li> <li>• Concepts of time, money, symbols</li> <li>• Understanding sarcasm, figures of speech</li> </ul>
<p style="text-align: center;"><b>REASONING/JUDGMENT</b></p> <ul style="list-style-type: none"> <li>• Understanding cause &amp; effect</li> <li>• Problem-solving</li> <li>• Drawing conclusions; decision-making</li> <li>• Understanding another's perspective</li> <li>• Social filter</li> <li>• Impulse control</li> </ul>	<p style="text-align: center;"><b>ATTENTION</b></p> <ul style="list-style-type: none"> <li>• Ability to focus</li> <li>• Task completion</li> <li>• Multi-tasking</li> <li>• Awareness of environment</li> </ul>



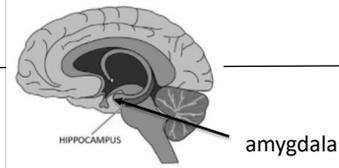
## Memory Center



- Hippocampus
- Tends to be hit first and hardest by dementia
- Difficulty forming new memories; long-term last to go
- Factual memories fade; emotional memories more resistant to deterioration
- Confabulation
- Concepts of time, space, directionality impacted



## Emotional Center

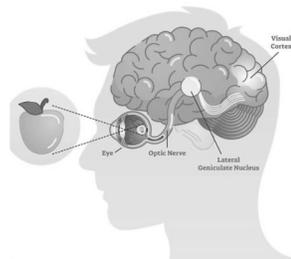


- Emotions remain intact
- Responds/reacts to emotions of others
- May not understand or remember your words, but emotions will linger
- Survival response: fight, flight, or fright
- Unable to control – emotional center may no longer be “connected” to executive functioning



## Vision

- Retina (eye) and occipital lobes (visual cortex)
- Age-related conditions
- Change in visual field:
  - Peripheral vision
  - Depth perception
  - Motion detection
- Awareness of environment diminishes



## Perception

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- Interpreting sensations (ex. sight, sound, smell)
- Interpretation involves higher level thinking:
  - Expectations
  - Experience
- Distortions:
  - Inability to differentiate between stimuli.
  - May be mistakenly diagnosed as hallucinations or delusions.



## Language: LEFT Hemisphere

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### LOST

- Vocabulary, comprehension, speech
- In early dementia – unable to comprehend approx. 1/4 words
- Tend to lose nouns first; disorganized
- May revert to native language
- Rely more on non-verbal communication
- Social isolation



## Language: RIGHT Hemisphere

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### RETAINED

- Social chit-chat
- Rhythm
- Music, poetry, prayer
- Forbidden words



## Risk Reduction Strategies

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- What's good for the heart is good for the brain:
  - Eat a balanced diet/maintain healthy weight (MIND Diet)
  - Keep blood pressure within normal range
  - Get regular exercise – at least 150 minutes/week
  - Do not smoke
  - Consume alcoholic beverages in moderation
- Establish healthy sleep habits
- Get your vaccines
- Manage stress
- Stay socially connected
- Engage in activities that challenge your brain



## New Treatment

- Aducanumab (Aduhelm™)
- Infusion therapy to treat mild stage of Alzheimer's or MCI
  - May reduce beta amyloid plaques
  - Not a cure; may slow cognitive and functional decline
  - No evidence that it will restore lost memories or functions
  - Requires thorough medical evaluation and diagnosis (Amyloid PET scan; CSF analysis)
- Controversies
  - Narrow focus on amyloid hypothesis
  - Inconclusive clinical trials/accelerated approval

*See online resource list for info about other meds*



## Thank you!

- Please complete our online evaluation – will appear on the screen when you leave webinar.
- Webinar materials posted:  
[www.HopeHospice.com/family-past](http://www.HopeHospice.com/family-past)
- [debbiee@hopehospice.com](mailto:debbiee@hopehospice.com)  
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