



Family Caregiver Education Series

Living with Dementia: Dementia Basics

September 14, 2023 • 10:00 a.m.



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Upcoming Webinars



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

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

Thursday, October 12, 2023

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 9, 2023

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

Register for webinars at www.HopeHospice.com



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Archived Dementia Webinars



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

- ❖ *Dementia or "Normal" Aging?
How to Tell the Difference*
August 2023
- ❖ *Self-Care for the Caregiver*
June 2023
- ❖ *Next Steps After a New
Dementia Diagnosis*
April 2023
- ❖ *Managing Daily Care*
March 2023
- ❖ *Understanding Behavior as
Communication*
December 2022



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Session Agenda



- ❖ Dementia Defined
- ❖ Underlying Causes
- ❖ Brain Abilities/Changes
- ❖ Stages of Dementia
- ❖ Q and A



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Dementia Defined



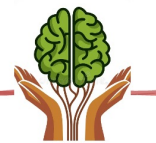
Dementia is NOT . . .

- ❖ 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



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Dementia Defined



Dementia IS . . .

A group of symptoms involving a decline in:

- ❖ cognitive functioning and
- ❖ behavioral abilities

. . . that affect one's daily life and independence.



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What does it mean to “have dementia?”

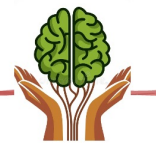


1. Exhibits life-altering symptoms that reflect a change from the person’s typical behavior, such as:
 - Memory issues
 - Difficulty speaking and understanding
 - Confusion
 - Difficulty with problem-solving, decision-making
 - Problems with focus, staying on task
 - Personality changes
 - Agitation, aggression, disorientation, paranoia
 - Social withdrawal/isolation
2. Diagnosed with an underlying condition that is causing these symptoms



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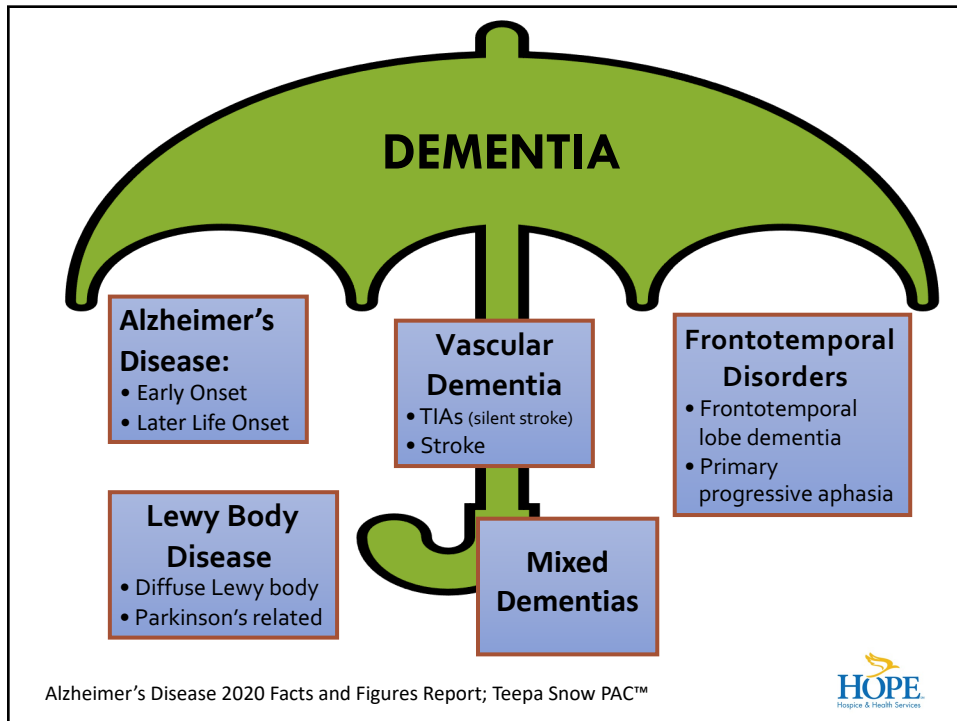
Dementia or something else?



- ❖ 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



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Alzheimer's Disease

- ❖ 60-80% of dementia cases
- ❖ Cognitive decline includes loss of memory, language problems, confusion with time, place, situations
- ❖ Can last from few years to 20 years
- ❖ Early onset cases occur prior to age 65; make up 5-6% of cases
- ❖ Diagnosed by brain scans or blood analysis; beta amyloid
- ❖ Cognitive and behavioral assessments essential

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Vascular Dementia

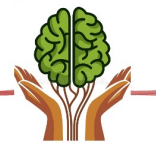


- ❖ 5-10% of cases
- ❖ Stroke, TIA (multi-infarct) – restrict blood flow to brain causing cell damage/death
- ❖ Damage depends on what area of brain deprived of oxygen
- ❖ Not all strokes cause dementia
- ❖ Symptoms may appear suddenly
- ❖ Diagnosed by brain scans (CT, MRI, PET)
- ❖ Progression is less predictable than other causes



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Lewy Body Disease

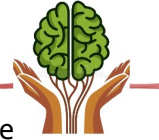


- ❖ Lewy body dementia
 - Abnormal proteins in brain
 - Symptoms similar to Alzheimer's
 - Characterized by visual hallucinations
- ❖ Parkinson's-related dementia
 - Characterized by motor impairments caused by Lewy bodies
 - 50-80% experience dementia after about 10 years



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Frontotemporal Disorders



- ❖ Affects the frontal and temporal lobes of the brain
 - Frontotemporal lobe dementia
 - Primary progressive aphasia
- ❖ Symptoms usually appear between ages 40-65
- ❖ May be misdiagnosed as psychological disorder
- ❖ Drastic personality changes
- ❖ Affects speech, reasoning, social judgment
- ❖ Genetic component



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Mixed Pathologies

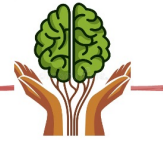


- ❖ Aka mixed dementias
- ❖ Simultaneously have more than one underlying condition that leads to dementia
- ❖ Most common: Alzheimer's and vascular dementia
- ❖ Symptoms vary depending on brain region impacted
- ❖ 50% of Alzheimer's patients had evidence of co-existing condition



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Other Dementias

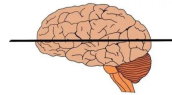


- ❖ Huntington’s Disease (genetic)
- ❖ Creutzfeldt-Jakob disease (brain infection)
- ❖ Traumatic brain injury (TBI)
- ❖ Normal pressure hydrocephalus (excess fluid in brain)
- ❖ Alcohol-induced dementia (toxicity caused by long-term abuse)
- ❖ Down Syndrome dementia
- ❖ HIV-related dementia



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Comparison of loss of brain volume (horizontal cross section)



front



Healthy brain



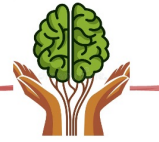
Mild cognitive difficulties



Severe Alzheimer's disease

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Four Truths About All Dementias



- ❖ At least two parts of the brain are dying
- ❖ Progressive: symptoms keep changing (worsening) as the brain deteriorates
- ❖ Chronic: not curable or fixable
- ❖ Terminal: results in death



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Evaluating Symptoms

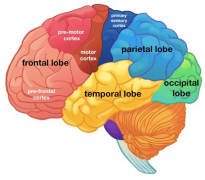


- ❖ Thorough medical exam
- ❖ Assessment of functioning and behavioral changes
 - Impaired memory or thinking skills
 - Changes in personality, mood
 - Interview with family member or close friend
- ❖ Medical tests
 - Blood
 - Brain imaging (CT, PET, MRI)
- ❖ Cognitive test(s) to evaluate memory, judgment,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




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Brain Functions Impacted



- ❖ Memory
- ❖ Language (speaking and understanding)
- ❖ Vision
- ❖ Perception
- ❖ Motor Skills (large and fine)
- ❖ Reasoning
- ❖ Judgment
- ❖ Abstract Thinking
- ❖ Attention



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KEY ABILITIES IMPAIRED BY DEMENTIA

MOTOR SKILLS

FINE

- Dexterity: using utensils, writing, dressing
- Chewing and swallowing

GROSS (LARGE)

- Balance, coordination
- Gait (style of walking)

ABSTRACT THINKING


- Higher level thinking skills
- Understanding connection between ideas, concepts, etc.
- Concepts of time, money, symbols
- Understanding sarcasm, figures of speech

REASONING/JUDGMENT

- Understanding cause & effect
- Problem-solving
- Drawing conclusions; decision-making
- Understanding another's perspective
- Social filter
- Impulse control

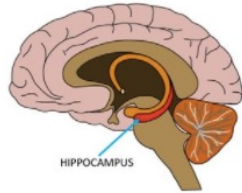
ATTENTION

- Ability to focus
- Task completion
- Multi-tasking
- Awareness of environment



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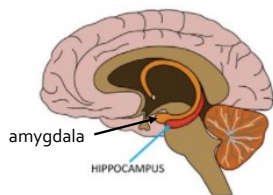
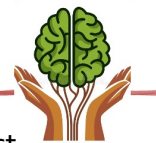
Memory Center



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

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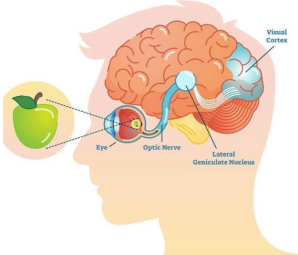
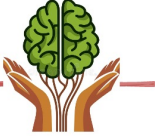
Emotional Center




- ❖ 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

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Vision

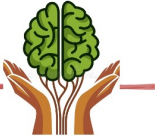



- ❖ Retina (eye) and occipital lobes (visual cortex)
- ❖ Age-related conditions
 - Macular degeneration
 - Cataracts
 - Glaucoma
- ❖ Change in visual field:
 - Peripheral vision
 - Depth perception
 - Motion detection
- ❖ Awareness of environment diminishes




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Perception




- ❖ Sensation: *taking in physical stimuli from the environment* (light, sound, pressure, chemical matter)
- ❖ Perception: *interpreting sensations*
- ❖ Interpretation involves higher-level thinking
 - expectations
 - experience
- ❖ Distortions in perception
 - inability to differentiate between stimuli
 - may be mistakenly diagnosed as hallucinations or delusions



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Language:

LEFT Hemisphere



LOST ABILITIES


- ❖ Vocabulary, comprehension, speech
- ❖ In early dementia, unable to comprehend about 1/4 words
- ❖ Tend to lose nouns first
- ❖ Disorganized speech
- ❖ May revert to native language
- ❖ Rely more on non-verbal communication
- ❖ Social connections



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Language:

RIGHT Hemisphere



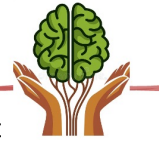
RETAINED

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



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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



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Stages of Dementia



Early Stage (Mild)

(about 2 years)

- ❖ 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



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Stages of Dementia



Middle Stage (Moderate)

(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



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Stages of Dementia



Late Stage (Advanced)

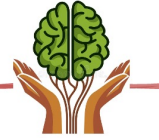
(several weeks-several years)

- ❖ 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



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Stages of Dementia



End Stage (Severe)

(can be as long as 6-7 years)

- ❖ Chair and/or bed bound
- ❖ Relies on facial expressions and tone of voice to understand others
- ❖ Difficulty with chewing and swallowing
- ❖ Repetitive behaviors more pronounced
- ❖ Requires 24/7 care



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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
 - Care partners focus on the positive

*More information on Resource List and website;
new GEMS class in January 2024*



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2024 Family Caregiver Education Series

- ❖ Teepa Snow's GEMS™ Stage Model
- ❖ Can Dementia Be Prevented? Risk Reduction
- ❖ Caregiving: A Family Matter
- ❖ Travel Tips for the Dementia Care Partner
- ❖ Managing Behavioral Symptoms of Dementia
- ❖ Taboo Topics (Sex, Lies, and Toileting)
- ❖ Bathing Challenges

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Thank you!



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Webinar slides and materials posted:

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