

Family Caregiver Education Series



**Living with Dementia:
New Diagnosis and Next Steps**
April 13, 2023 • 10:00 a.m.

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

Gia Barsell, Manager of Dementia Services and Education
PAC™ Advanced Dementia Trainer and Consultant



Upcoming Events

Hike for Hope & BBQ
Saturday, May 6, 2023
Del Valle Park, Livermore



Hospice and Palliative Care (webinar)
Thursday, May 11, 2023
10:00 – 11:30 a.m.
Presenter: Debbie Emerson

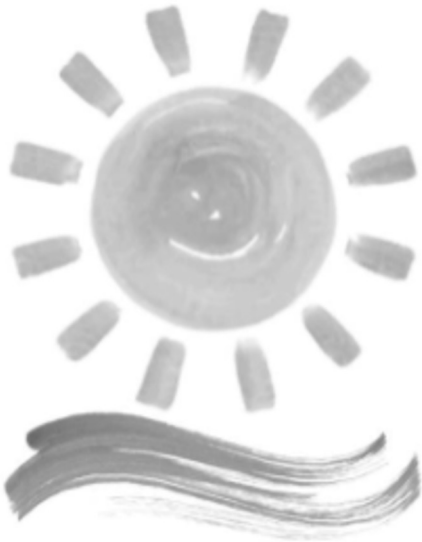
www.HopeHospice.com



Archived Webinars

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

- **Managing Daily Care**
February 2023
- **Understanding Behavior as Communication**
December 2022
- **Dementia Basics**
September 2022
- **Dementia or "Normal" Aging?
How to Tell the Difference**
August 2022
- **Self-care for the Caregiver**
June 2022



Living WELL with Dementia

A diagnosis of dementia does not mean that your life is over, nor does it define who you are. It means, however, that there will be challenges and obstacles ahead, not only for you, but for your family and friends.

Thinking about those challenges now will help prepare all involved for what the future may hold.





Agenda

- Dementia Review
- Importance of Early Diagnosis
- Handling Emotions
- Treatments
- Planning for the Future
- Strategies for Living Well
- Q and A

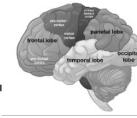


Definitions

- ❑ **Typical age-related changes** refers to the brain and body slowing down, but intelligence remains stable. May be less flexible; some memory issues.
- ❑ **Mild Cognitive Impairment (MCI)** may be the precursor to dementia.
- ❑ **Dementia-like symptoms** (delirium, pseudo-dementias) may be caused by conditions that are treatable such as infections, medication side-effects, vitamin deficiencies, dehydration, stress, vision/hearing loss, etc.
- ❑ **Dementia** is defined as a group of symptoms (a syndrome) characterized by a decline in cognitive functioning and behavioral abilities that impact one's daily life. Dementia is not a specific disease.
 - Caused by underlying conditions such as Alzheimer's disease, vascular events (stroke, TIAs), Parkinson's disease, Fronto-temporal dementia, traumatic brain injury, etc.
 - Progressive and chronic.



Causes



Underlying Diseases

- Alzheimer's disease (60-80%)
- Vascular (major stroke; TIAs)
- Parkinson's/Lewy Body Dementia
- Fronto-temporal dementia
- Traumatic brain injury (TBI)
- Primary Progressive Aphasia

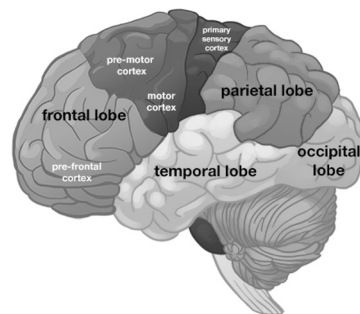
Pseudo-dementias (usually reversible)

- Medications
- Infections
- Vitamin deficiencies
- Metabolic disorders
- Dehydration
- Stress/emotional trauma
- Vision/hearing loss



How Dementia Affects the Brain

- Memory
- Communication/Language
- Vision
- Perception
- Motor Skills
- Reasoning/Decision-making
- Judgment
- Abstract thinking
- Changes in mood and/or personality



Specialists



- Neuropsychologist – PhD, PsyD
- Neurologist - MD
- Geriatric Psychiatrist – MD
- Geriatrician - MD



Evaluating Symptoms

- Thorough medical exam
 - Medical history
 - Family health history
 - Physical exam
 - Medication review
 - Alcohol and recreational drug intake
- Assessment of functioning and behavioral changes
 - Impaired memory or thinking skills
 - Changes in personality, mood
 - Interview with family member



Evaluating Symptoms (cont.)

- Neurological exams (reflexes, reaction time)
- Medical tests
 - Blood; urinalysis
 - Brain imaging – MRI, CT
 - Possibly: Amyloid PET Scan or cerebro-spinal fluid (CSF) analysis
- Cognitive test(s) to evaluate memory, judgment, ability to understand visual information
 - General Practitioner Assessment of Cognition (GPAoC)
 - Mini-cog
 - Montreal Cognitive Assessment (MCoA)
- Important to do a complete evaluation

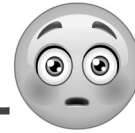


Importance of Early Diagnosis

- Assume control of the situation
- Opportunity to educate self and others
- Access to relevant information, resources, support
- Get a head start on forming care team
- Take advantage of early treatment to slow progression
- Opportunity to get legal and financial affairs in order
- Enables a longer and more independent life



Identifying Emotions



GOAL: Labeling feelings about a dementia diagnosis can help you to understand and process your emotions.

- | | |
|-------------------------------------|---|
| <input type="checkbox"/> Grief/Loss | <input type="checkbox"/> Isolation |
| <input type="checkbox"/> Despair | <input type="checkbox"/> Sadness |
| <input type="checkbox"/> Denial | <input type="checkbox"/> Depression/anxiety |
| <input type="checkbox"/> Anger | <input type="checkbox"/> Relief |
| <input type="checkbox"/> Fear | <input type="checkbox"/> Hope |
| <input type="checkbox"/> Resentment | |

Source: [Alz.org/justdiagnosed](https://www.alz.org/justdiagnosed)



Handling Emotions



GOAL: Live a positive and fulfilling life.

- Develop a strong support system
 - Share feelings with those you trust – openly and honestly
 - Connect with others who are living with dementia; join a support group
 - Talk with a therapist, counselor, or clergy member
- Take time to grieve and mourn
- Keep doing what you love for as long as you can
- Maintain your independence
- Use humor to help cope with frustration
- Remember: Dementia is NOT your identity



Sharing Your Diagnosis



Who do you tell?

- People you know well and trust; loved ones.
- People to whom you are responsible.
- People from whom you may need assistance.
- People who "need to know."
- Anyone you want!

Source: Taking Action Workbook
(Alzheimer's Association)

When do you tell them?

- When it feels like the right time.
- When it helps to explain what is going on with you.
- When planning or making decisions about your future.
- When you need help from someone.
- When you want to educate them about your condition.




Forming Your Care Team

- Family members
- Close friends
- Neighbors
- Medical professionals
- In-home caregivers
- Community groups and resources
- Anyone you want



Source: Alz.org, *Building a Care Team*







www.alz.org

FDA-Approved Treatments

- Cognitive (memory and thinking)
 - Cholinesterase Inhibitors
 - Aricept (Donepezil): all stages
 - Exelon (Rivastigmine): mild-moderate
 - Razadyne (Galantamine): mild-moderate
 - Glutamate Regulators
 - Namenda (Memantine): moderate-severe
 - May improve memory and awareness
- Behavioral & Psychological
(ex., sleep disturbances; agitation; hallucinations and delusions)





www.alz.org

New Treatments

Aducanumab (Aduhelm)
Lecanemab (Leqembi)

- Recently approved (accelerated)
- Treat MCI or early-stage Alzheimer's
- Evaluation and diagnosis required
- Infusion therapy (IV)
- May delay (not cure) clinical decline
- Do not restore lost memories or functions
- May not be covered by insurance
- Controversies





Clinical Trials

- ❑ A type of research that tests new drugs, medical devices, surgical procedures, or behavior and lifestyle changes
- ❑ **Trial Match®**
Alzheimer's Association
- ❑ National Institutes of Health
clinicaltrials.gov



OTC Supplements

- ❑ Not FDA-approved
- ❑ Limited research on efficacy, safety, tolerability
- ❑ Are not intended for those with dementia
- ❑ Can have serious interactions with prescribed medications
- ❑ Always consult a physician before taking
- ❑ **Prevagen**
 - Vitamin D3 and apoaequorin (jelly fish)
 - Claims not supported by scientific evidence
- ❑ **Neuriva Plus**
 - Phosphatidylserine and coffee cherry extract
 - Claims not supported by scientific evidence



Dietary Supplements



- ❑ Currently, no scientific evidence to support claims of memory enhancement
- ❑ Remember, always check with physician before taking supplements
- ❑ **Omega-3 Fatty Acids**
 - Benefit heart health; may reduce inflammation
 - Support and protect nerve membranes
 - Found in fatty fish; flax seeds; nuts
 - Mediterranean, MIND, and DASH diets
- ❑ **Vitamins**
 - B-complex vitamins (especially B-12)
 - Vitamin D-3 - bone health
- ❑ **Ginkgo Biloba**



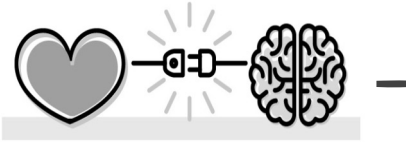
Non-Pharmacological Interventions



- ❑ **Person-Centered Care** (Teepa Snow)
 - Remember that persons with dementia communicate through their behaviors
 - Always respond to feelings, not words
 - Look for reasons behind the behavior
 - Engage in meaningful activities
 - Focus on person rather than the task
- ❑ **Music Therapy**
 - Enhances memory and cognitive functioning
 - Always retain ability to respond to music
- ❑ **Environmental Modifications**



Taking Charge



- ❑ What's good for the heart is good for the brain
 - Exercise
 - Monitor blood pressure
 - Consume a healthy diet (Mediterranean, DASH, MIND)
 - Reduce stress
- ❑ Limit alcohol; no recreational drugs
- ❑ Get adequate sleep (aim for 7-9 hours)
- ❑ Preventative medicine: Regular check-ups and vaccines
- ❑ Maintain social life, connections; avoid isolation
- ❑ Build up cognitive reserve (exercise your brain)



The MIND Diet

Mediterranean-DASH Intervention
for Neurodegenerative Delay

WHAT TO EAT

- Berries
- Olive oil
- Fish
- Poultry
- Dark, leafy greens
- Veggies
- Nuts
- Whole grains
- Beans
- Red wine

WHAT TO LIMIT

- Sweets
- Fried foods
- Butter
- Cheese
- Red meat

Getting Your Affairs in Order



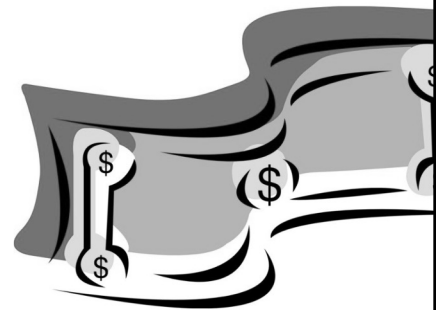
- Start discussions early with loved ones
- Create documents that communicate wishes
 - Healthcare; End of life (Advance directive; POLST)
 - Financial management (Power(s) of Attorney; Living Trust; Will)
- Review plans regularly and update documents as needed
- Put all important papers in one place
- Make copies of healthcare directives for all medical files
- Give permission in advance for doctor(s) or lawyer to talk directly with care partners
- Plan ahead for funeral and burial arrangements

Source: NIH/NIA *Legal and Financial Planning for People with Dementia*



Financial Planning: Future Care Costs

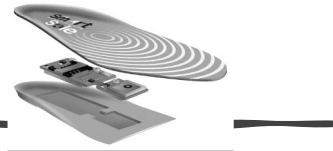
- Meet with financial planner if finances are complex
- Choose a trusted family member or friend to help manage finances
- Consider type(s) of care that may be needed:
 - In-home
 - Residential (facility): Assisted Living, Memory Care, SNF
- Paying for care
 - Long-term care insurance
 - Personal savings and assets
 - Retirement benefits
 - Government programs (Medi-Cal or Medicaid; Veterans benefits)



Source: Taking Action Workbook (Alzheimer's Association)



Personal Safety



- ❑ **Carry identification**
 - Bracelets, necklaces
 - Smart watch/GPS tracking watch
 - GPS Smart Sole Tracking Solution™
 - 24/7 Wandering Support/Medic Alert® (Alzheimer's Association)
- ❑ **Home safety**
 - Appliances with automatic shut-offs
 - Adequate lighting; night lights
 - Secure firearms and hazardous materials
- ❑ **Minimize falls**
 - Include balance exercises in daily routine
 - Remove clutter and tripping hazards in the home; install grab bars
 - Wear proper fitting shoes



Is it safe to drive?

Warning signs that driving may no longer be safe:

- ❑ Incorrect signaling
- ❑ Confusing the brake and gas pedals
- ❑ Driving at inappropriate speeds
- ❑ Frequently hitting curbs; new dents or scratches
- ❑ Getting lost going to familiar places
- ❑ Driving on the wrong side of the road
- ❑ Failing to stop at red lights or stop signs
- ❑ Sudden lane changes
- ❑ Other health issues/changes (vision, hearing, mobility)



Sources: Taking Action Workbook (Alzheimer's Association); NIH/NIA

Driving Evaluations



- American Occupational Therapy Association – Driver Rehabilitation Provider Data Base
- Driver Cognitive Assessment Center, Pleasanton
- Stanford ValleyCare, Pleasanton
- John Muir Health System
- CA DMV – Potentially Unsafe Driver
- Handicapped Placard and Plates - DMV



Links can be found on Online Resource List



Managing Daily Life



- Establish a familiar routine
- Keep clocks and calendars around the house; try a digital clock
- Use a white board to post appointments, daily activities, reminders
- Attempt just one task or activity at a time
- Perform difficult tasks when you feel you are at your best
- Take a break if you're feeling stressed or overwhelmed
- Be aware that you have more than one chance to solve most problems
- Keep familiar items (ex., glasses, purse, phone, keys) in the same place
- Make an easy-to-access reminder book
- Use a medication reminder system

Source: Taking Action Workbook (Alzheimer's Association)



Living Well with Dementia



- Accept changes in abilities
- Recognize the triggers that cause you anxiety, worry, or stress
- Accept your feelings – work through the bad ones to get to the good ones
- Be patient with yourself
- Rely on your sources of strength
- Ask others for help when needed
- Enjoy time with friends and family
- Stay active
- Continue to educate yourself and share what you learn with others

Source: Taking Action Workbook (Alzheimer's Association)

