ALZHEIMER'S DISEASE & EMERGENCY PLANNING CHALLENGES FOR STATE AND LOCAL HEALTH PROFESSIONALS AND COMMUNITY PARTNERS

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Rangaraj Gopalraj, M.D., Ph.D.
Assistant Professor, Family & Geriatric Medicine
Associate Appointment, Palliative Medicine
University of Louisville

Betty Shiels, PhD-C, LCSW
Director, KY Emergency Preparedness for Aging & LTC Program
Kent School of Social Work, University of Louisville

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LEARNING OBJECTIVES

- What is Alzheimer's Disease?
- How big a public health problem is this?
- How does it affect the older adult and their caregivers?
- What are the implications for emergency preparedness?
- What can we do about it?

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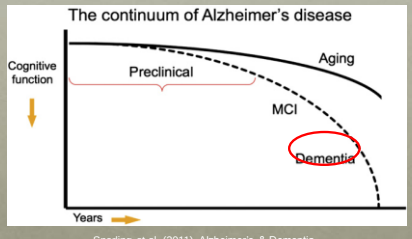
PROGRESSION OF MEMORY CHANGES



Sperling et al, (2011). Alzheimer's & Dementia

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CAUSES OF DEMENTIA (TYPES)

- Dementia is a group of brain disorders that results in the loss of intellectual and social skills severe enough to interfere with day-to-day life
- There are many causes of dementia
- Most common causes:
  - Alzheimer's disease 50-80%
  - Vascular disease 10-20%
  - Dementia with Lewy bodies 5-10%
  - Frontotemporal dementia 12-25%

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ALZHEIMER'S DISEASE

Dr. Alois Alzheimer

Auguste D.

http://www.alz.org/brain/01.asp

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ALZHEIMER'S DISEASE

- Age usually >65 in sporadic cases (Late Onset AD).
  - 11% of older persons may have Alzheimer's Disease
  - 60-70% of persons living in nursing facilities may have Alzheimer's
- F>M
- Mean duration ~8 yrs. Range 2-20 yrs.
- Early Onset AD in 50s is extremely rare
- Genetic mutations in Amyloid Precursor Peptide
- Increased risk associated with ApoE e4 allele

http://www.alz.org/research/science/alzheimers_brain_tour.asp

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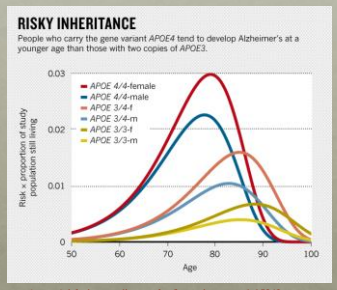
APOE AND ALZHEIMERS



http://www.nature.com/news/alzheimer-s-disease-the-forgetting-gene-1.15342
J. Raber et al. Neurobiol. Aging 25, 641–650 (2004) 7

THE ALZHEIMER'S BRAIN

http://www.nature.com/news/alzheimer-s-disease-the-forgetting-gene-1.15342
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DIAGNOSTIC FEATURES

- Memory impairment
- One or more of the following:
  - Aphasia—(problems with communication)
  - Apraxia--(problems with movements despite intact motor function)
  - Agnosia--(problems recognizing faces/objects despite intact sensation)
  - Disturbance in executive functioning (planning, problem solving, anticipating outcomes)
- Represent a decline from prior levels of function
- Interfere with social/occupational functioning
- Slowly progressive
- No other etiology per neuro exam, labs, imaging

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ALTERNATIVE GUIDELINES

- Memory criteria reflects an "Alzheimerization" of dementia
- AD presents with early, severe memory impairment, other dementias may not
- Alternative is impairment in multiple domains that impact daily function

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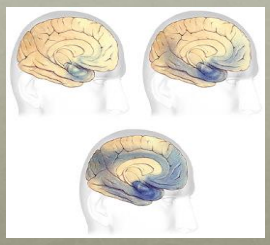
STAGES

- 1. Decline in memory
  - personality change
  - executive impairment
- 2. Cortical phase
  - Aphasia
  - Apraxia
  - Agnosia
- 3. Physical decline
  - Incontinence
  - Gait d/o
  - Dysphagia
  - Mute



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ALZHEIMER'S IS GROWING!

- Today, 5.3 million Americans are living with Alzheimer's disease, more than 95% of them are over the age of 65. By 2050, up to 16 million will have the disease.
- Within the next 10 years, 19 states will see a 40 percent or greater growth in the number of people with Alzheimer's.

EVERY 67 SECONDS someone in the United States develops the disease.

http://www.alz.org/facts/downloads/ff_infographic_2015.pdf
http://www.alz.org/facts/downloads/facts_figures_2015.pdf

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MORE WOMEN ARE AFFECTED

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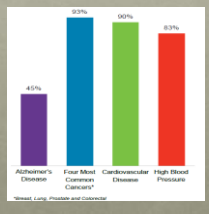
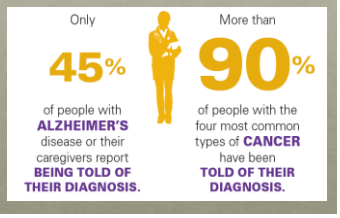
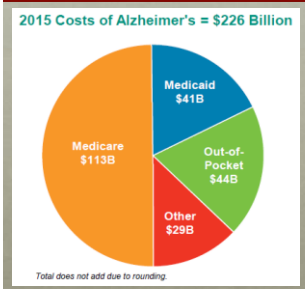
POOR AWARENESS!

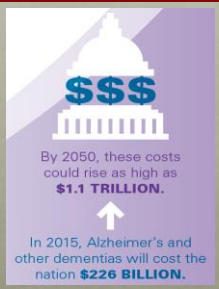
- Only about half have ever been diagnosed.
- Among individuals diagnosed with the disease, only 33% are aware they have it.





ALZHEIMER'S CARE IS EXPENSIVE





Average per-person Medicare spending is three times higher for those with Alzheimer's compared to all other seniors [15]

ALZHEIMER'S KILLS

- 6th leading cause of death in the United States.
- Deaths from Alzheimer's increased 71% from 2000 to 2013, while deaths from other major diseases (including heart disease, stroke, breast and prostate cancer, and HIV/AIDS) decreased.
- In 2013, over 84,000 Americans officially died *from* Alzheimer's; in 2015, an estimated 700,000 people will die *with* Alzheimer's – meaning they will die after having developed the disease.
- Alzheimer's is the only cause of death among the top 10 in America that cannot be prevented, cured, or even slowed.

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TOLL ON CAREGIVERS

- In 2014, 15.7 million family and friends provided 17.9 billion hours of unpaid care to those with Alzheimer's and other dementias – care valued at $217.7 billion.
- 34% of Alzheimer's caregivers are over 65 years old
- 60% of Alzheimer's and dementia caregivers rate the emotional stress of caregiving as high or very high; about 40 percent suffer from depression.
- Three-quarters of Alzheimer's and dementia caregivers report that caregiving made their health worse.

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IMPACT ON FAMILY CAREGIVER

- The number with Alzheimer's disease and other dementias in the USA in 2013 is predicted to more than double by 2050 (13.8 million)
- Caring for someone with Alzheimer's can lead to deterioration in caregivers' physical health, psychological well-being and social relations
- Two-fifths of baby boomer caregivers in our study reported having high blood pressure or arthritis
- Caregivers of persons with dementia experience greater burden and strain from dementia caregiving compared to those of people without dementia

Age and Ageing 2015; 44: 300–306

CAREGIVER ROLE IN BPSD

- Research has demonstrated that a reduction in neuropsychiatric symptoms decreases patient injuries, hospitalization rates, and caregiver burden.
- Group education programs and interactive coaching tailored to the unique needs of the caregiver is effective at decreasing BPSD.
- Short-term outcomes of such a program include increased caregiver knowledge, improved caregiver perceived self-efficacy, and positive attitudes regarding non-pharmacological therapy.
- Non-pharmacological therapy, including music, exercise, aromatherapy, and massage, is safe and effective.

Worldviews on Evidence-Based Nursing, 2015; 12:2, 108–115.

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Table 3. **Summary of Findings on Potential Risk Factors and Interventions for Cognitive Decline**

Direction of Association and Factors	Quality of Evidence
Increased risk	
Apolipoprotein E ε4 genotype	Low
Low plasma selenium level	Low
Depressive disorder	Low
Diabetes mellitus	Low
The metabolic syndrome	Low
Current tobacco use	Low
Decreased risk	
Cognitive training*	High
Vegetable intake	Low
Mediterranean diet	Low
ω-3 Fatty acids*	Low
Physical activity*	Low
NonCognitive, nonphysical leisure activities	Low
No association	
Vitamin C, vitamin E, and β-carotene*	High
Conjugated equine estrogen*	High
HMG-CoA reductase inhibitors (statins)*	Moderate
Ginkgo	Moderate
Dehydroepiandrosterone*	Moderate
Cholinesterase inhibitors*	Moderate
Multivitamin*	Moderate
Vitamins B_6 and B_{12} and folic acid*	Moderate
NSAIDs*†	Low
Alcohol intake	Low
Antihypertensives*	Low
Homocysteine	Low
Hypercholesterolemia	Low
Anxiety disorders	Low
Hypertension	Low
Obesity	Low
Early childhood factors	Low
Higher levels of education	Low
Social network or social support	Low
Inadequate evidence to assess association	
Folate levels	–
Tai ji quan	–
High caloric intake	–
Ginkgo biloba*	–
Memantine	–
Sleep apnea	–
Resiliency	–
Occupational level	–
Traumatic brain injury	–
Toxic environmental exposures	–
Agent Orange exposure or the Gulf War	–
Head size	–
Genetic factors other than apolipoprotein E genotype	–

HMG-CoA = 3-hydroxy-3-methylglutaryl coenzyme A; NSAID = nonsteroidal anti-inflammatory drug.
* Data from both observational studies and randomized, controlled trials.
† Not associated with decreased risk, but some evidence suggests that they may be associated with increased risk.

Summary of Findings on Potential Risk Factors and Interventions for Cognitive Decline.

Plassman B L et al. Ann Intern Med 2010;153:182-193

Annals of Internal Medicine

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RISK AND PROTECTIVE FACTORS

- Plassman et al, 2010 – NIH Conference
- Observational studies
  - Increased risk associated with depression, diabetes, smoking, ApoE e4
  - Decreased risk associated with Mediterranean diet, vegetable intake, physical activity, cognitive engagement
- RCT's
  - Physical activity, cognitive training/engagement
  - ACTIVE study (Ball et al, 2002; JAMA 288(18):2271-2281)

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RISK FACTORS AND WHAT THEY SUGGEST

- Observational studies
  - Increased risk associated with depression, diabetes, smoking,
  - Alzheimer's co-morbidity: depression, anxiety, delusions, hallucinations, agitation and aggression
  - Memory Issues
  - Confusion
  - Impaired Functioning– ADLs related to lower mobility, urinary incontinence; Steadiness on feet; Vision impairment
  - Inability to meet basic needs
  - Inability to communicate basic needs

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ALZHEIMER'S AND SHELTERING-IN-PLACE

- Many older persons prefer to shelter-in-place during disasters
- Isolated seniors with Alzheimer's are likely to be among that group
- Louisville experience
- They may require family or first responders to check on them
- May have heightened needs for food, water, medications
- Not able to understand public communication so they may not have any idea what has happened
- Connect to service providers as soon as possible—
  - Area Agencies on Aging, Home Health providers, Meals on Wheels, Neighbors

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PLANNING FOR PERSONS WITH ALZHEIMER'S

- Establish emergency plans for Individuals and Family Members
- Include functioning and memory issues on the plan, if possible
- Be sure to include contact information for caregivers, service providers, family members and health care providers
- Update medication list on plan as often as possible
- Be sure to include all assistive devices on the list, including eyeglasses, hearing aids, walkers, etc.
- Put plan in plastic sleeve on refrigerator door or other easy access if evacuation is necessary
- First responders—don't forget to bring meds, plan, assistive devices if evacuating person

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PLANNING FOR PERSONS WITH ALZHEIMER'S

- Enroll in the Medic Alert System, and
- the Alzheimer's Association Safe Return Program for 24-hour nationwide response for wandering and medical emergencies

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EMERGENCY GO-KIT

- The kit might contain:
  - warm clothing
  - sturdy shoes
  - spare eyeglasses
  - hearing aid batteries
  - incontinence undergarments, wipes, and lotions
  - pillow, toy, or something the person can hold onto
  - medications
  - water

http://www.nia.nih.gov/alzheimers/publication/alzheimers-disease-and-disaster-preparedness

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EMERGENCY GO-KIT

- The kit might also contain:
  - favorite snacks and high-nutrient drinks
  - zip-lock bags to hold medications and documents
  - copies of legal, medical, insurance, and Social Security information
  - physician's name, address, and phone number
  - recent photos of the person with Alzheimer's

http://www.nia.nih.gov/alzheimers/publication/alzheimers-disease-and-disaster-preparedness

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PLANNING FOR PERSONS WITH ALZHEIMER'S

- Develop a Buddy Plan
  - Establish at least one person living in proximity as a Buddy
  - The Buddy will check on the person regularly and agrees to check on the person with Alzheimer's in the event of a disaster
  - The Buddy is aware of the emergency plan for the person
  - Have a Buddy Agreement signed and in place
  - Family members can communicate with the Buddy in a disaster

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EMERGENCY SHELTERING AND PERSONS WITH ALZHEIMER'S

- It is estimated that over 50% of persons evacuating to emergency shelters are over 60 years old.
- An estimated 11% of older persons have Alzheimer's Disease plus an additional percentage with related dementias
- In an 80-bed emergency shelter, approximately 4+ persons may have Alzheimer's
- In a 200-bed shelter, approximately 10+ persons may have Alzheimer's

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EMERGENCY SHELTERING AND PERSONS WITH ALZHEIMER'S

- Keep in mind two-thirds (67%) of persons with Alzheimer's are not aware of their diagnosis
- They may not present as confused initially
- Assessment may be difficult as they may be so adaptive
- Once assessed in the shelter, try to connect with a caregiver, family member or service provider
- In the absence of a caregiver, try to connect a volunteer, etc. to monitor the person on a regular basis
- Family caregivers may be more stressed to manage the person in the shelter and may need support

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EMERGENCY SHELTERING AND PERSONS WITH ALZHEIMER'S

The person with Alzheimer's might present in a shelter as:

- Very anxious
- Behaving erratically
- Withdrawn
- Or, highly adaptive

Shelter staff can manage effectively by:

- Remaining calm and supportive
- Set an even tone of voice to reassure
- Be sensitive to his or her emotions.
- Stay close, offer your hand, lower yourself to their eye level
- Do not leave him or her alone

http://www.nia.nih.gov/alzheimers/publication/alzheimers-disease-and-disaster-preparedness

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EMERGENCY SHELTERING AND PERSONS WITH ALZHEIMER'S

To lessen potential for chaos or crisis in the shelter

- Make sure obstacles, wiring, barriers are managed as falls risk is very high

- Select a separate room or space for persons with Alzheimer's to allow for:
  - Persons with Alzheimer's benefit from a regular sleep schedule so lighting needs to be adjusted at bedtime
  - Lots of noise or loud noises can exacerbate behavioral symptoms
  - Routine is very beneficial to persons with Alzheimer's: eating schedules, toileting schedules, sleep schedules
  - Security is very important for shelter operators to avoid Golden Alerts
  - Persons with Alzheimer's may wander off if exits are not monitored

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EMERGENCY SHELTERING AND PERSONS WITH ALZHEIMER'S

- Ideally, shelters may assign one-to-one volunteers to the persons with Alzheimer's
- Train shelter intake / assessment staff and teams about the Alzheimer's Association Safe Return Program to connect evacuee with family
- Create a shelter toolkit for Persons with Alzheimer's
  - Games
  - Playing cards

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RESOURCES AND PARTNERS

- Local Alzheimer's Association
- Groups of Alzheimer's caregiver alumnae
- Area Agencies on Aging
- Nursing students
- CNA faculty at community colleges
- Churches
- Retired social workers, nurses, CNAs
- Geriatricians

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RESOURCES AND PARTNERS

- Alzheimer's Disease and Disaster Preparedness; http://www.nia.nih.gov/alzheimers/publication/alzheimers-disease-and-disaster-preparedness
- Alzheimer's Association, Disaster Preparednesshttp://www.alz.org/national/documents/topicsheet_disasterprep.pdf
- Alzheimer's and Dementia Caregiver Center https://www.alz.org/care/alzheimers-dementia-disaster-preparedness.asp
- Prepares for a Disaster—For Seniors By Seniors http://www.redcross.org/images/MEDIA_CustomProductCatalog/m16740732_sdarc_senior_disaster_booklet.pdf

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SUMMARY

- Alzheimers is one form of dementia
- Can be due to abnormal proteins or energy metabolism
- It takes a toll on caregivers
- It can affect how patients respond to emergencies
- Awareness and preparation will aid in response

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QUESTIONS?

We welcome all questions---

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CONTACT INFORMATION

Betty Shiels, PHD-C
OVAR/GEC
University of Louisville
Kent School of Social Work
(502) 852-8003
betty.shiels@louisville.edu

Raj Gopalraj, M.D., Ph.D
University of Louisville
Dept. for Family and
Geriatric Medicine
rangaraj.gopalraj@louisville.edu

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