

# COPING WITH DEMENTIA

Signs/Symptoms, Treatment, Prevention,  
Caregiver Support

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# DEFINING DEMENTIA

- Umbrella term
  - Diseases and conditions that develop when nerve cells in the brain die or no longer function normally
- Causes changes in memory, behavior and ability to think clearly
- With Alzheimer's disease, eventually basic body functions are impaired such as walking & swallowing

# 2013 FACTS & FIGURES

- ◉ Alzheimer's Disease is the 6<sup>th</sup> leading cause of death in the US
- ◉ More than 5.2 million are living with the disease
  - Someone develops Alzheimer's every 68 seconds
- ◉ This year, ~450,000 will die with AD
- ◉ Since 2000, deaths from AD have risen 68%, while deaths from other major diseases have decreased
- ◉ 1 in 3 seniors dies with Alzheimer's or another dementia

- Nearly 15% of caregivers are long-distance
- Out of pocket expenses for long-distance caregivers is nearly twice as much as local caregivers
- In 2012, caregivers provided over 17 billion hours of unpaid care valued at more than \$216 billion
- There are more than 15 million caregivers
- In 2013, AD will cost the nation \$203 billion and expected to rise to \$1.2 trillion by 2050

# DSM-IV CRITERIA

- Symptoms must include decline in memory and in at least one of the following cognitive abilities:
  - Ability to speak coherently or understand spoken or written language
  - Ability to recognize or identify objects
  - Ability to perform motor activities, assuming intact motor abilities and sensory function and comprehensive of the task
  - Ability to think abstractly, make sound judgments and plan and carry out complex tasks
- The decline in cognitive abilities must be severe enough to interfere with daily life

- Physician diagnosis is essential
- Of 39 articles describing 5,620 people with dementia like symptoms reported that 9% had potentially reversible dementia.
  - Common: depression, delirium, medication side effects, thyroid problems, vitamin deficiencies, excessive use of alcohol

# COMMON TYPES

## Types

- *Alzheimer's disease*
- Brain abnormalities:
  - Deposits of protein fragment beta-amyloid (plaques) and twisted strands of the protein tau (tangles)
  - Nerve cell damage and death

## Characteristics

- Most common; 60-80%
- Difficulty remembering names and recent events; apathy and depression. Later impaired judgment, confusion, behavior changes, difficulty speaking, swallowing walking
- 2011 recommendation to be considered a disease that begins well before the development of symptoms

## Type

- ◉ *Vascular Dementia*
- ◉ Brain injuries such as microscopic bleeding and vessel blockage
  - Location determines thinking and physical functioning affected

## Characteristic

- ◉ Multi-infarct or post-stroke dementia
- ◉ Impaired judgment or ability to make plans
- ◉ May be present with signs of AD
- ◉ Mixed dementia



## Type

- ◉ *Dementia with Lewy Bodies (DLB)*
- ◉ Abnormal aggregations (or clumps) of the protein alpha-synuclein. If develop in the cortex, dementia can result. Also aggregate in the brains of people with Parkinson's but the aggregates may appear in a different pattern

## Characteristics

- ◉ These alone can cause dementia or in conjunction with those with AD or vascular dementia
- ◉ Initial or early symptoms such as sleep disturbances, well-formed visual hallucinations, muscle rigidity or other parkinsonian movement features

## Type

- ◉ *Frontotemporal lobar degeneration (FTLD)*
- ◉ Nerve cells in the front and side regions of the brain especially affected

## Characteristics

- ◉ Changes in personality and behavior and difficulty with language
- ◉ Generally develop symptoms at a younger age (~60) and survive fewer years than those with Alzheimers

# 2011 CRITERIA FOR ALZHEIMER'S

- Three stages
- Pre-clinical
  - Before symptoms are present
  - Measurable changes in brain, cerebrospinal fluid and/or blood markers that may indicate earliest signs of the disease
  - Additional research needed on these markers
- MCI due to Alzheimer's
  - Mild but measurable changes to thinking abilities are noticeable
  - Do not affect ability to carry out everyday activities
  - Estimates that 10-25% of people age 65 or older have MCI
  - Nearly 50% of all people who visit a doctor about MCI symptoms develop dementia in 3-4 years

- Dementia due to Alzheimer's disease
  - Obvious symptoms such as memory, thinking and behavior changes that impair ability to function in daily life

# BIOMARKER TESTS

- 1) Biomarkers showing the level of beta-amyloid accumulation in the brain
  - 2) Biomarkers showing that neurons in the brain are injured or actually degenerating
- Many researchers believe that future treatments to slow or stop progression will be most effective when administered during the preclinical and MCI stages
  - Further research is needed to validate the markers and which tests or combination of tests is most effective

# RISK FACTORS

- Advancing age, but AD is not a typical part of aging
- Family History
  - 1<sup>st</sup> degree relative
  - Increased risk is not entirely explained by whether the individual has inherited the apolipoprotein E- $\epsilon$ 4 gene
- APOE-  $\epsilon$ 4 gene
  - Carries the blueprint for a protein that carries cholesterol in the bloodstream
  - Everyone inherits one form  $\epsilon$ 2,  $\epsilon$ 3 ,  $\epsilon$ 4 from each parent;  $\epsilon$ 4 increases risk and at a younger age
  - Estimate 40-65% of those with AD have one or two copies of the  $\epsilon$ 4 gene

## ○ MCI

- MCI does not always lead to dementia

## ○ Cardiovascular Disease Risk Factors

- Health of the brain related to the health of the heart and blood vessels
  - Smoking, obesity, diabetes, cholesterol, hypertension

## ○ Education

- More education seems to help build a “cognitive reserve” to help compensate for changes in the brain
- May have more connections between neurons
- Or may have to do with lower SES groups being at higher risk for disease and less access to medical care

## ○ Social and Cognitive Engagement

## ⦿ Traumatic Brain Injury

- Disruption of brain function caused by a blow or jolt to the head or a penetration by a foreign object
- Over half are caused by car accidents
- Moderate TBI Doubles the risk; Severe 4.5 times the risk
- Boxers, football players, combat veterans



# PREVENTION

- Physical Activity
- Heart-healthy diet
  - Low in saturated fats and rich in vegetables and vegetable based oils
- To a lesser extent: social interaction and continued cognitive engagement

# TREATMENT

## ⦿ Pharmacologic

- Aimed at slowing or stopping brain cell death and malfunction are being studied worldwide

## ⦿ 5 drugs approved by the US Food & Drug Administration

- Temporarily improve symptoms by increasing the amount of neurotransmitters in the brain
- Effectiveness varies; 6-12 months for about ½ of those who take them

Drug name	Brand name	Approved For	FDA Approved
1. donepezil	Aricept	All stages	1996
2. galantamine	Razadyne	Mild to moderate	2001
3. memantine	Namenda	Moderate to severe	2003
4. rivastigmine	Exelon	Mild to moderate	2000
5. tacrine	Cognex	Mild to moderate	1993

## ⦿ Non-pharmacologic Therapy

- Approaches such as cognitive training and behavioral interventions
- ⦿ Aim to reduce behavioral symptoms such as depression, apathy, wandering, sleep disturbances, agitation and aggression
- ⦿ Few studies providing evidence of effectiveness; trial by trial basis

# ACTIVE MANAGEMENT

- ◉ Appropriate use of available treatment options
- ◉ Effective management of coexisting conditions
- ◉ Coordination of care among physicians, health care professionals and caregivers
- ◉ Participation in activities and/or adult day care programs
- ◉ Taking part in support groups and supportive services

# CAREGIVER CHARACTERISTICS

- Caregiving: attending to another individual's health needs. Often including one or more activities of daily living
- Unpaid caregivers provided an estimated 17.5 billion hours of unpaid care, valued at \$216 billion
  - approximately half of the net value of Wal-Mart sales in 2011 and more than 8 times the total sales of McDonald's in 2011
- *Using several sources such as the 2010 Behavior Risk Factor Surveillance System (BRFSS) survey (CT, NH, NJ, NY, TN), the Aging, Demographics, and Memory Study (ADAMS)-national sub-sample of Health and Retirement Survey, the National Alliance for Caregiving (NCA/AARP); the following characteristics were compiled*

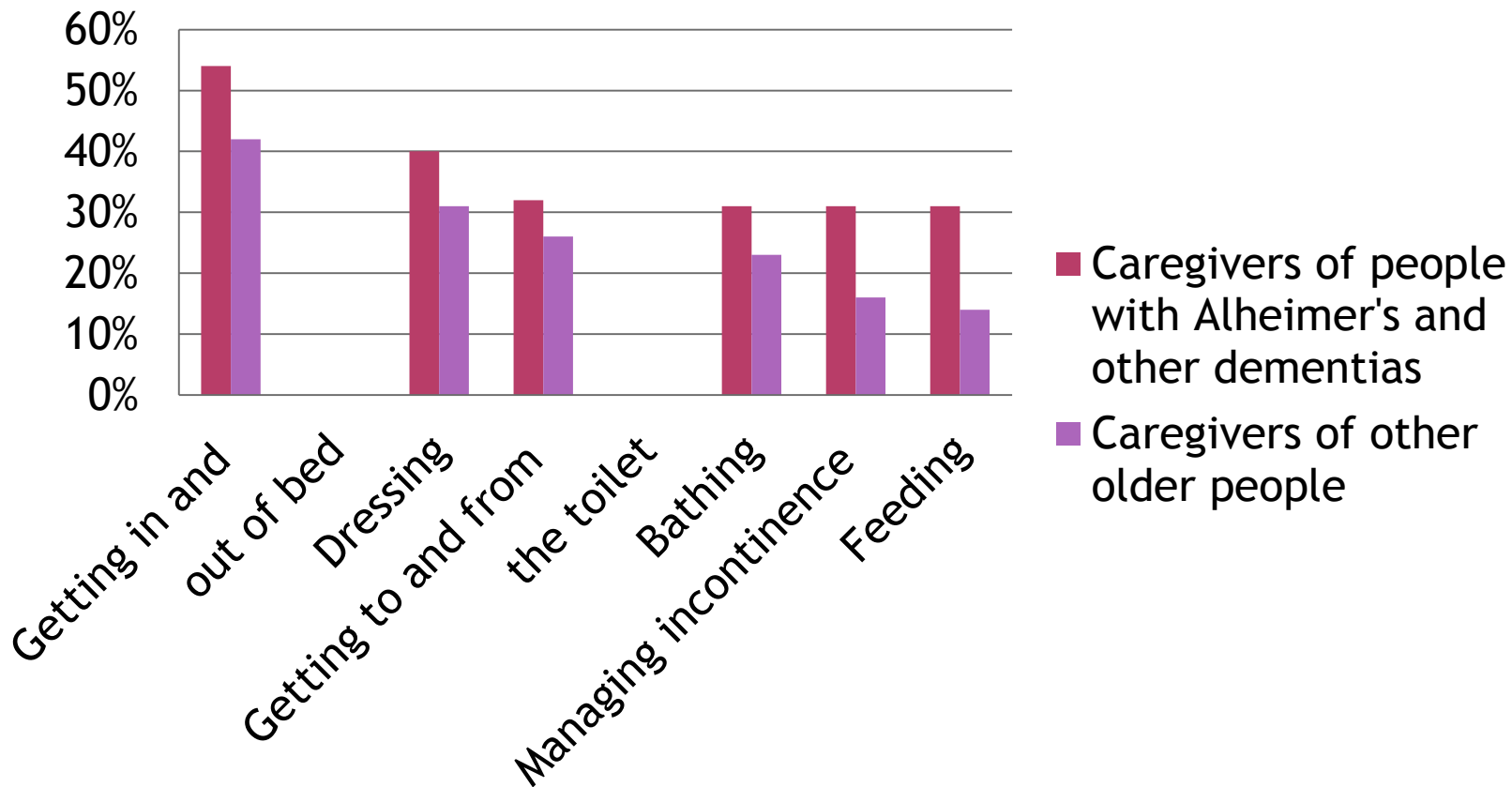
- 62% of caregivers were women
- 23% 65 years or older
- 50% had some college education or beyond
- 59% currently employed, a student or homemaker
- 70% married or in long-term relationship
- Greater proportion white/Caucasian
- Almost half took care of parents
- 30% had children under 18 living with them
- Hispanic and African-American caregivers spend more time (30 hrs/wk vs 20 white, 16 Asian)
- Hispanic (45%) and African-American caregivers (57%) are more likely to experience high burden from caregiving than whites and Asian-Americans

# CAREGIVING TASKS

- ◉ Dementia caregivers tend to provide more extensive assistance than those caring for people with other diseases
- ◉ 2/3 advocate for their care recipient with government agencies and service providers and nearly half arrange and supervise paid caregivers from community agencies
- ◉ Usually manage symptoms other caregivers do not face such as neuropsychiatric symptoms and severe behavioral problems



# Proportion of Caregivers of People with Alzheimer's and Other Dementias vs. Caregivers of Other Older people who provide Help with Specific Activities of Daily Living, US, 2009

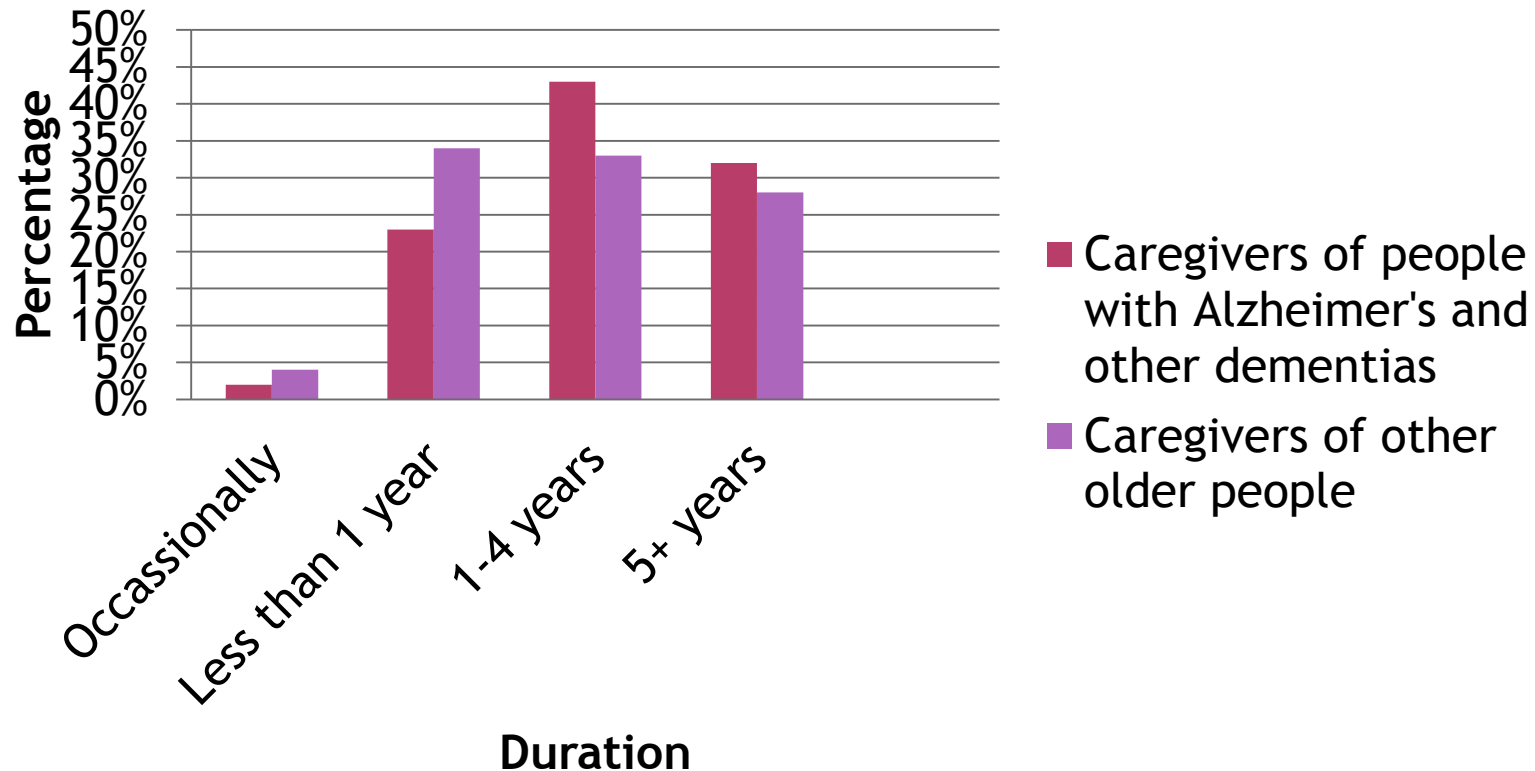


Data from the National Alliance for Caregiving and AARP

- When person is moved to assisted living or nursing home, care often changes to providing emotional support such as visiting, interacting with facility staff and advocating for appropriate care
  - Some studies suggest that distress remains unchanged or even increases after a relative is admitted to a residential care facility while others have found a significant decrease
  - The relationship seems to make the difference
  - Husbands, wives and daughters were significantly more likely to indicate persistent burden up to 12 months following placement and husbands more likely to indicate persistent depression up to a year following

# DURATION OF CAREGIVING

**Proportion of Alzheimer's and Dementia vs. Caregivers of Other Older People by Duration of Caregiving, US, 2009**



Data from the National Alliance for Caregiving and AARP

# CAREGIVER HEALTH

- Family caregivers' can experience increased emotional stress, depression, impaired immune system response, health impairments, lost wages due to disruptions in employment, and depleted income and finances
- The intimacy and history of experiences and memories between the caregiver and recipient are threatened
- 61% of respondents in 2009 NAC/AARP survey rated the emotional stress of caregiving as high or very high
- Most family caregivers report “a good amount” to “a great deal” of strain concerning financial issues (56%) and family relationships (53%)

- In the ADAMs sample, 44% of caregivers of people with dementia indicated depressive symptoms
- Caregivers most likely to indicate stress were women, older, residing with care recipient, white or Hispanic, and believed there was no choice in taking on the role of caregiver
- Stress over behavioral issues increases the chance that the care recipient will be placed in a nursing home
- 71% agree that there is no “right or wrong” when deciding to place their loved one in a nursing home but experience guilt, emotional upheaval and difficulties adapting to the transition
- Demands increase as end-of-life approaches

# PHYSICAL HEALTH

- ◉ 43% reported that the physical impact of caregiving was high to very high
- ◉ Concerned about general health
- ◉ Chronic stress related to elevated biomarkers of CVD and impaired kidney function
- ◉ More health care costs and emergency department visits especially if care recipient was depressed, had low functional status or had behavioral disturbances
- ◉ Higher rates of stress can be related to higher mortality
- ◉ *Stress influenced by dementia severity, perception of challenge, social support, caregiver personality*

# EMPLOYMENT

- ◉ 60% report being employed full or part-time
- ◉ Often have to make major changes to work schedules
- ◉ 20% had to take a leave of absence
- ◉ 23% take less demanding job or go to part-time
- ◉ Work performance can suffer

# CAREGIVER SUPPORT

- Interventions aimed to lessen negative aspects of caregiving with the goal of improving health outcomes
  - Enhance caregiver strategies to manage dementia-related symptoms
  - Bolster resources through enhanced social support
  - Provide relief/respite form daily care demands
- Result: decreased stress and delayed nursing home admission



# CHARACTERISTICS OF EFFECTIVE CAREGIVER INTERVENTIONS

- ◉ Long term
- ◉ Whole family issue
- ◉ Training in management of behavior problems
- ◉ Multidimensional interventions
  - Individual consultation
  - Family sessions and support
  - Ongoing assistance with management as disease progresses

Ex: New York University Caregiver Intervention;  
Resources for Enhancing Alzheimer's Caregiver  
Health (REACH) II programs

# TYPE AND FOCUS OF CAREGIVER INTERVENTIONS

Type of Intervention	Description
Psychoeducational	Structured programs providing info about the disease, resources, services, skills etc. Led by professionals with specialized training
Supportive	Building support among participants; exchange ideas and strategies. Professionally or peer led
Psychotherapy	Relationship between caregiver and trained therapy professional
Multicomponent	Combinations of the above. Led by skilled professionals

- Less consistent demonstrated benefits:
  - Support groups
  - Respite services such as adult day care
  - Pharmacological therapies
  
- More research needed to determine efficacy of support programs among different caregiver groups across diverse clinical, racial, ethnic, SES, and geographical contexts

# LONG-DISTANCE CAREGIVERS

- New area of study
- Estimated 2.3 M long distance caregivers; at least one hour or more away
- Most are secondary caregivers; 1 in 5 are primary caregivers
- Cost- higher out of pocket expenses
- Greater challenges assessing the recipients condition and needs
- Higher levels of distress and family discord over role
- More difficulty communicating with health care providers

# RESOURCES

## Caregivers

- [http://www.alz.org/national/documents/lib\\_best\\_care.pdf](http://www.alz.org/national/documents/lib_best_care.pdf)
- <http://www.alz.org/care/>
- <http://www.payingforseniorcare.com/alzheimers/financial-assistance.html>

## Research

- <http://www.nia.nih.gov/alzheimers/alzheimers-disease-research-centers>
- [http://www.alz.org/professionals\\_and\\_researchers\\_14899.asp](http://www.alz.org/professionals_and_researchers_14899.asp)

# ONE WOMAN'S STORY

[http://www.cbsnews.com/8301-3445\\_162-6600364/jans-story-love-and-early-onset-alzheimers/](http://www.cbsnews.com/8301-3445_162-6600364/jans-story-love-and-early-onset-alzheimers/)