



Alzheimer's Disease A Public Health Response

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Guest Speakers

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- Anne Decker

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Definition of Dementia

- Progressive mental decline with many causes
- Neurodegenerative disease: progressive destruction of cortical nerve cells
- 70% due to Alzheimer's disease
- Not normal aging
- Curable causes of dementia are uncommon

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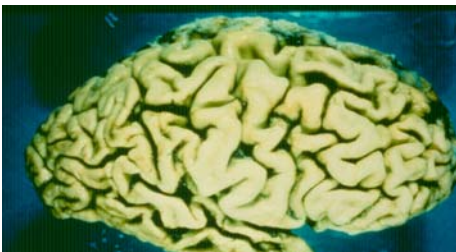
Normal Brain



Normal Brain. Note vessels seen in the normal sulci on the surface of the cerebral cortex—smart outer layer

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Brain Showing Moderate Alzheimer's Disease



Brain from moderate Alzheimer's patient: note vessel are deep in the shrunken sulci of the atrophied cortex due to neuronal destruction.

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Presentation of Different Dementias

- Alzheimer's Disease: memory, word finding, getting lost driving
- Frontotemporal: inappropriate behavior, problems with judgment; subtypes with Parkinsonism, ALS or primary aphasia
- Lewy Body Dementia: hallucinations, Parkinsonism, fluctuating course
- Vascular or Multiple Infarcts: strokes

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Current Estimates of Alzheimer's Disease Prevalence

- Worldwide:
 - 26 million (2007)
- US:
 - 5 million (2007)
- NYS:
 - 330,000 (2000)

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Alzheimer's Disease Epidemic

- Disproportionately affects older Americans
 - 25% of people aged 75+
 - 50% of people aged 85+
- Estimated medical cost to US society is enormous.
- Changing population demographics
- Worldwide disease prevalence will quadruple by 2050 unless a disease modifying therapy is found (1 in 85 people)

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Non-modifiable Risk Factors for Alzheimer's Disease

- Aging
- Female Gender
- Environmental
- Genetics
- Mild Cognitive Impairment (MCI)

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Mild Cognitive Impairment (MCI)

- Amnestic (memory) form most common
- Trouble with recent memory
- No decline in any activities of daily life
- Test of recent memory mildly abnormal
- Majority develop Alzheimer's disease
- Under intense study for tests for early diagnosis of Alzheimer's disease

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Genetics

- Primary family member has Alzheimer's disease: 30% lifetime risk
- Dominant gene: 50% risk of Alzheimer's disease
 - 1-3% of general population
- APOE4 genotype: increased risk
- Down's Syndrome – high risk

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Risk Factors: Treatable/Preventable

- Diabetes
- Hypertension
- Metabolic Syndrome
- Arteriosclerosis
- Head Injury

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Clinical Course

Early Stage: 5 or more years

- Recent memory loss
- Difficulty finding words
- Spatial Confusion
 - Getting lost driving
 - Trouble finding things

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Clinical Course

Moderate stage: 2 or 3 years

- Increased trouble with finding their way
- Wandering (Safe Return bracelet is advised)
- Increased memory and executive problems
- Language and reading trouble
- May become psychotic

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Clinical Course

Severe Stage: 1 or 2 years

- Loss of language and ability to walk
- Become totally dependent
- Later develop swallowing problems
- Aspiration leads to pneumonia
- Stop eating

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Public Health Challenges

Detection:

- Who has or will develop Alzheimer's disease?
- How many cases are there really?
- Who will identify the estimated 330,000 cases in NY and those at risk?
- Lack of specific simple detection test
- Co-morbidities (caregiver, patient)

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Public Health Challenges

Primary care providers see most cases

- Lack the tools and support to identify and treat patients with Alzheimer's disease over the course of the illness
- Not prepared to introduce new medications yet to be discovered

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Clinical Diagnosis

Based primarily on evaluation of activities of daily living by informant (usually spouse)

Physician tools include conversation, memory testing, and spatial testing

- Draw-a-Clock
- Naming objects in 1 minute
- Mini-mental Status Examination (MMSE)
 - Insensitive to early diagnosis
 - Does not measure behavioral symptoms

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Clinical Diagnosis

When to refer to a specialist (Neurologist, Geriatrician, Psychiatrist):

- Unsure of diagnosis
- Unusual presentation of dementia
- Management of psychosis
- Additional neurological problems
- Imaging needed

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Current Medical Management

- Treat co-morbidities
- Introduce symptomatic treatment: cholinesterase inhibitors and memantine
- Non-pharmacological therapeutic approaches
- Treat depression: often seen early in the disease and may even herald it
- Care for the caregiver

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Current Medical Management

- Use antipsychotics if absolutely necessary
- Drugs for Parkinsonism: occurs in about 25% of moderate stage cases
- Use hospice for terminal severe stage

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Potential Improvements for Diagnosis

- Quantitative MRI
- PET Scanning using molecular markers to detect disease specific brain changes
- Other biomarkers: blood, urine and spinal fluid biochemical and genetic tests.
- Some combination of methods

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Promise of Disease Modifying Therapy in the Near Future

- Therapies directed to the molecular abnormalities of Alzheimer's disease
- Clinical trials
- Potential therapies are already in early trials
- Improved diagnostic methods will lead to:
 - Faster drug testing, requiring fewer subjects
 - Earlier drug approval

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The Lasting Benefits of Counseling and Support for Alzheimer's Disease Caregivers

Mary Mittelman, DrPH

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Definition of "Caregiver"

- Anyone who provides assistance to someone else who is in some degree incapacitated and needs help
- Family members and friends are the primary source of care for 75% of impaired older adults living in the community

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Profile of Alzheimer's Disease Caregivers

- 70% of Alzheimer's disease patients are cared for at home
- 4-5 million family members provide informal care to people with dementia
 - 50% are 50+ years old
 - 59% female (primarily spouses, daughters and daughters-in-law)
 - 50% employed full time

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Challenges Faced by Alzheimer's Disease Caregivers

- Alzheimer's disease typically lasts for 5-15 years
- Increasing cognitive and functional impairments lead to complete dependence
- Disease symptoms change over time
 - Early: Memory problems
 - Middle: Troublesome behaviors
 - Late: Activities of daily living

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NYU Spouse Caregiver Intervention Study 1987-2007

A Randomized Controlled Trial to Test the Efficacy of Counseling and Support for Family Caregivers

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NYU Caregiver Intervention Study Design

- Comprehensive baseline interview
- Random assignment to treatment or control group
- Regular comprehensive follow-up interviews
- All participating caregivers receive services routinely available at the NYU Aging and Dementia Research Center

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Study Subjects

- 406 spouse-caregivers of people with Alzheimer's disease
- Living with the person with Alzheimer's disease
- At least 1 close relative in the area

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Treatment Schedule

Within a fixed period of time:

- An individual counseling session
- 4 family counseling sessions
- A second individual counseling session

Over the entire course of the disease:

- Participation in a support group
- Telephone consultation for caregiver or family member as needed

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Outcomes of NYU Intervention

- Psychosocial intervention improves caregiver satisfaction with social network
 - Number of close friends and relatives
 - Satisfaction with emotional support
 - Satisfaction with assistance
- The effects of the intervention on satisfaction with support begin within 4 months of enrollment and continue for at least 5 years

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Outcomes of NYU Intervention

- Psychosocial intervention reduces caregiver symptoms of depression
 - Change is gradual, and isn't statistically significant until 8 months after enrollment in intervention
 - Effects continue for more than 3 years

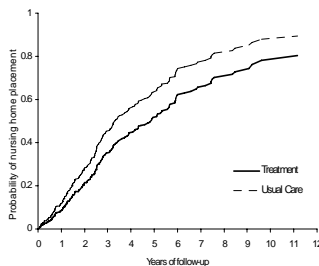
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Outcomes of NYU Intervention

- Psychosocial intervention reduces caregiver reaction to troublesome patient behaviors
 - Change gets greater as time goes on
 - Effects lasts more than 4 years
- Psychosocial intervention reduces effect of caregiving on physical health of caregivers
 - Effects lasts more than 2 years

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Outcomes of NYU Caregiver Study



Psychosocial intervention delays nursing home placement an average of 557 days

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Conclusions

- Widespread availability of counseling and support could have a major impact on the well-being of family caregivers and on persons with Alzheimer's disease
- Comprehensive care for people with dementia should include more than prescriptions for medication

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Pilot Study Replicating NYU Caregiver Intervention among in Spanish Latino Caregivers

Carolyn Rosenthal Gelman, PhD
NYU School of Social Work

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Preliminary Findings

- Little information about Alzheimer's disease in NYC Latino community
- Very difficult to enroll Latino caregivers
- Outcomes: Latino Caregivers
 - Lack knowledge/access to services
 - Require significant case management/ad hoc counseling
 - Experience marked psychosocial stressors and significant levels of anxiety and depression

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Next Steps: Community Studies to Demonstrate Feasibility and Effectiveness

Proposed Multi-site Replication of the NYU Caregiver Intervention in Community Settings - The North East Collaboration

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Planned Intervention

- **Assessment in order to tailor intervention**
 - **Identified family caregiver**
 - **Person with dementia**
- **Interventions**
 - **Counseling sessions and ad hoc counseling**
 - **Arrange for respite for primary caregiver during counseling sessions**
 - **Caregiver support groups**
 - **Information and referral**

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Community Barriers

- **Physicians' reluctance to diagnose**
- **Patients and families unaware of basis for diagnosis**
- **Lack of awareness of services**
- **Lack of funding for counseling and support services**

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Planned Strategies to Overcome Barriers

- **Physician Education**
- **Community leader education**
- **Partnership with community service providers**
- **Board of advisors including all stakeholders**

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Goals for the Future

- **If community studies demonstrate effectiveness, results will lead to:**
 - **More widespread availability of counseling and support for family caregivers**
 - **New and better interventions to help family caregivers**
 - **Adaptation of these interventions for caregivers of people with other diseases**

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Public Health Response

- **Advocate for increased:**
 - **Public awareness and community education about Alzheimer's disease**
 - **Resources for counseling & support for patients and their caregivers**
 - **Education and training for primary care providers on early detection and comprehensive, integrated care**
 - **Within medical schools**
 - **Within established medical community**

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Public Health Response

- Advocate for increased:
 - Reimbursement to providers for time spent screening and caring for Alzheimer's patients and caregivers
- Encourage providers in public health and primary care to practice positive bedside manners with patients and their families

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Resources

- NYS Department of Health
www.health.state.ny.us
- Alzheimer's Association (includes Safe Return Program)
www.alz.org
- The Alzheimer's Disease Education and Referral Center (ADEAR)
www.nia.nih.gov/Alzheimer's/
- Family Caregivers Alliance
www.caregiver.org/caregiver/jsp/home.jsp

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