

# Severe Alzheimer's Disease: The Forgotten Ones

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# Overview

- Prevalence and stages of Alzheimer's disease
- Clinical features of severe Alzheimer's disease
- The medical management of severe Alzheimer's disease
- End of life decisions
- Palliative care and death

While the focus of this presentation is on severe Alzheimer's disease, the content is relevant to the severe stage of all forms of dementia

# Should we be Having this Discussion?

- Frank discussions about the course of severe medical conditions are appreciated by patients and their families
- Avoidance leads to fear and anxiety
- In Alzheimer's disease these discussions must take place early to enable patients to assert control of their lives
- It is important to remember that not all patients with AD live to the severe stage!

# Prevalence and Stages of Alzheimer's Disease

# Neuropathological Changes Characteristic of AD

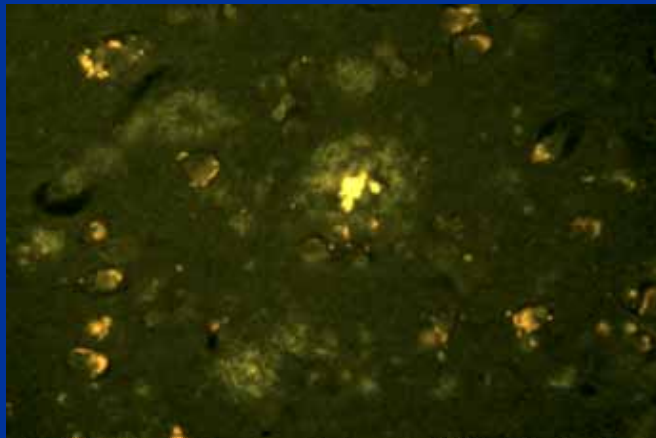
Normal



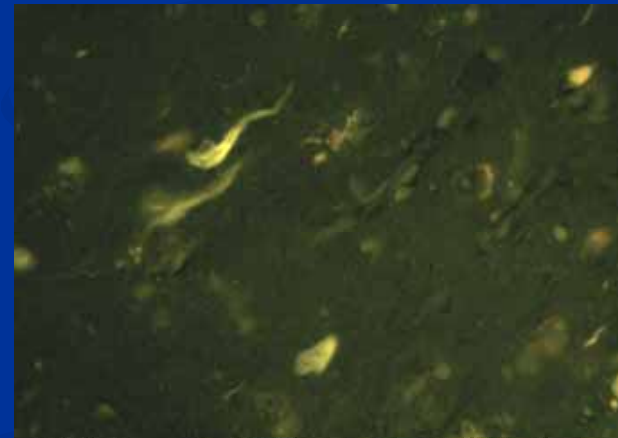
AD



AP



NFT

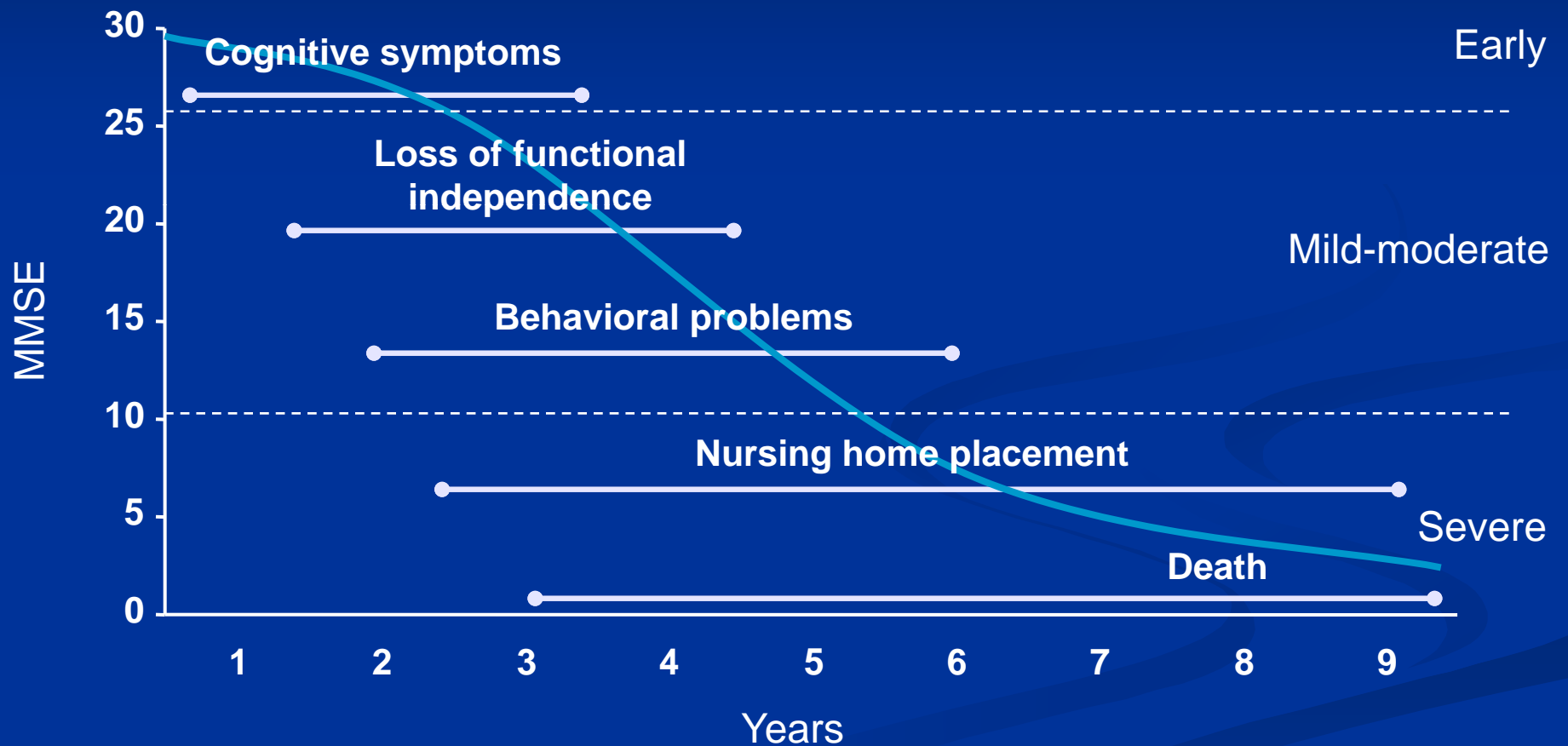


AP = amyloid plaques  
NFT = neurofibrillary tangles

# Progression of AD

- AD is a progressive disease
- For some patients, AD progresses rapidly over 2–3 years
- For most patients, the decline in function is gradual
  - over about 7 years
- Mild, moderate, and severe stages are defined

# Natural History of AD



# Staging Scales / Time in AD

| Clinical<br><i>Diagnosis</i> | Incipient<br><i>or ? AD</i> | Mild | Mod | Mod-Sev | Severe |    |
|------------------------------|-----------------------------|------|-----|---------|--------|----|
| <i>CDR Stage</i>             | 0.5                         | 1    | 2   | 3       | 4, 5   |    |
| GDS & FAST                   | 3                           | 4    | 5   | 6       | 7      |    |
| MMSE                         | 29                          | 26   | 19  | 12      | 5      | 0  |
| Years                        | 0                           | 7    | 9   | 10.5    | 13     | 19 |

*Modified from Reisberg et al ADAD 1994*

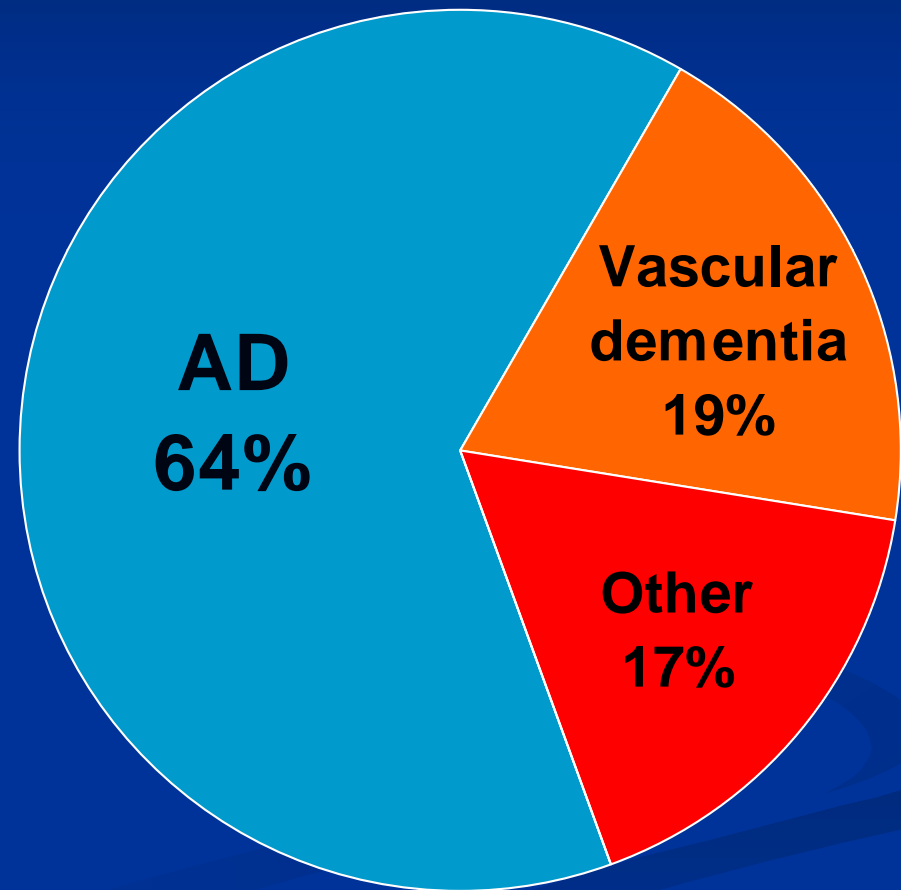
# Staging Alzheimer's Disease

- Mild
  - Patients have mild memory problems and are able to live independently with minimal assistance
- Moderate
  - Increasing difficulties with memory, language, and reasoning. Progressive loss of instrumental activities of daily living ( e.g. paying bills, preparing meals, using the telephone) and are usually unable to live safely at home without the support of a full time caregiver
- Severe
  - Severe impairments in memory, ability to communicate and reason. Challenging behaviours frequently emerge. Patients become completely dependent in their basic activities of daily living (e.g. feeding, toileting, dressing) and require long term care

# Prevalence of Alzheimer's Disease (AD)

## Estimates of AD in Canada show:

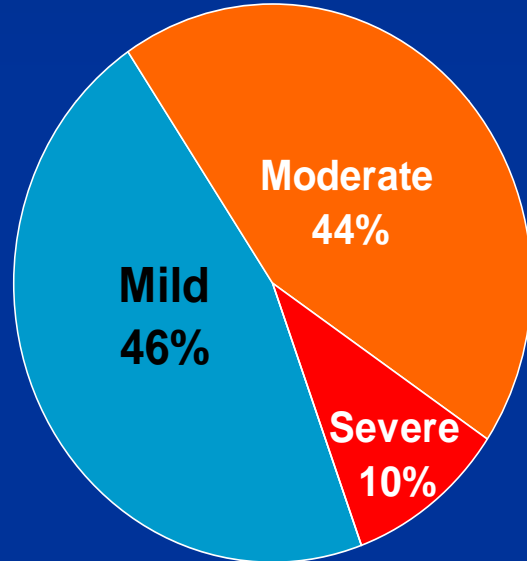
- 364,000 current cases
- 109,000 new cases each year



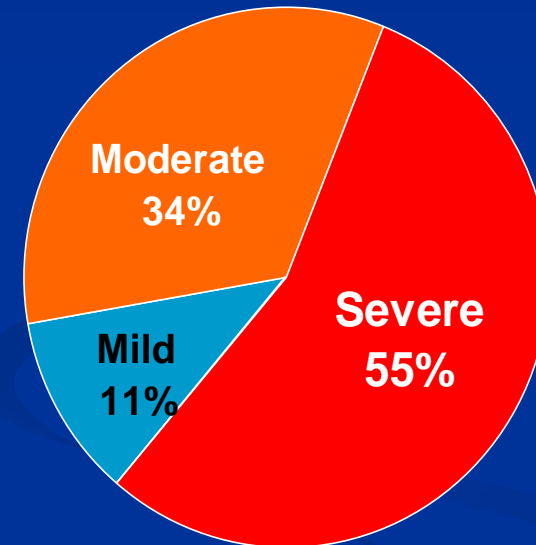
CSHA Working Group, *CMAJ*, 1994.  
CSHA Working Group, *Neurology*, 2000.

# Distribution of AD in Different Settings

AD in the Community



AD within Institutions



- Time to placement in long-term care is dependent on many factors, including, but not limited to, the stage of the disease.

CSHA Working Group, *CMAJ*, 1994.  
CSHA Working Group, *Can J Aging*, 1994.

# Clinical features of Severe Alzheimer's Disease

# Clinical Features of Severe AD

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## IMPAIRMENT IN:

### Cognition

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- Language (loss of fluency, mutism)
- Memory (episodic, semantic, implicit)
- Executive function
- Praxis
- Visuospatial

### Function

- Basic ADLs
  - Dressing
  - Grooming
  - Bathing
  - Eating
  - Continence
  - Walking
  - Motor slowing

Adapted from Boller F et al. *Eur J Neurol*, 2002

Adapted from Reisberg B et al. *Psychopharmacol Bull*, 1988

# Clinical Features of Severe AD

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## IMPAIRMENT IN: Behavior

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- Psychomotor disorders (pacing, agitation)
- Psychiatric disorders (misidentifications, hallucinations, delusions, depression, anxiety)
- Psychobehavioural disorders (aggressiveness, inappropriate shouting, incontinence)

**Behavioural problems in AD contribute to an increase in caregiver burden**

# Coroner's Inquest

- “Violent incidents in nursing homes are on the rise across Ontario. In 2004, violent residents attacked other residents 864 times in the province's long-term care homes, and attacked staff 264 times...”
- “There are 10 times as many attacks today as there were five years ago. The Ontario Nurses Association said there had been 11 homicides in Ontario nursing homes since 1999, and 3,000 reported attacks.”

CBC, Apr. 18, 2005

# Case Vignette: Resistance to Care

- Mr. D. is a 71 y/o male
- 4 yr Hx of AD
- Cared for at home by his wife who promised she would never place him in nursing home
- Patient recently became incontinent of bowel and bladder
- Patient hit, bit and kicked wife when she tried to render hygienic care

# Case Vignette: Resistance to Care

- Wife brought patient to emerg because she couldn't manage him anymore was scared he would injure her
- No NH beds available
- Patient admitted to medicine where he continued to be aggressive with care and wandered
- Meds: Olanzapine 10mg BID, Risperidone 3mg BID, Valproic Acid 250mg TID, Ativan 1mg PRN

# Case Vignette: Resistance to Care

- Rx Olanzapine 10mg BID, Risperidone 3mg BID, Valproic Acid 250mg TID, Ativan 1mg PRN
- Patient continues to wander
- Physician orders physical restraints
- After 2 weeks...

# Case Vignette: Resistance to Care



# Questions

- What do you think precipitated this patient's behaviour?
- How would you have managed this patient's care?
- What do you think about the patient's pharmacological treatment?
- How do you feel about the use of restraints in this patient?





# Caregiver “burden”

- The amount of time that caregivers spend providing support is substantial, and increases as the disease worsens

**Number of hours per week associated with care of elderly patients with increasing levels of dementia**

| Mild | Moderate | Severe |
|------|----------|--------|
| 13.1 | 22.0     | 46.1   |

# The Medical Management of Severe Alzheimer's Disease

# Issues in the Management of Severe AD

## Medical

- Patients unable to report and describe their symptoms
- Patients at risk for falls, infections, and delirium
- Behavioural problems frequently lead to polypharmacy
- Dementia drugs should not be automatically discontinued
- Minimize medications and procedures in palliative stage

# Issues in the Management of Severe AD

## *Psychosocial*

- Provide structured recreational activities that suite the individual's needs
- Patients are not invisible
- Caregiver support and education
- Respite care
- Assist with long-term care
- Respect advanced directives

# Treatment Strategies in Severe AD

- Two main neurotransmitters have been studied

## Acetylcholine

- Levels of acetylcholine are abnormally low
- The basis for the use of Aricept (Donepezil)

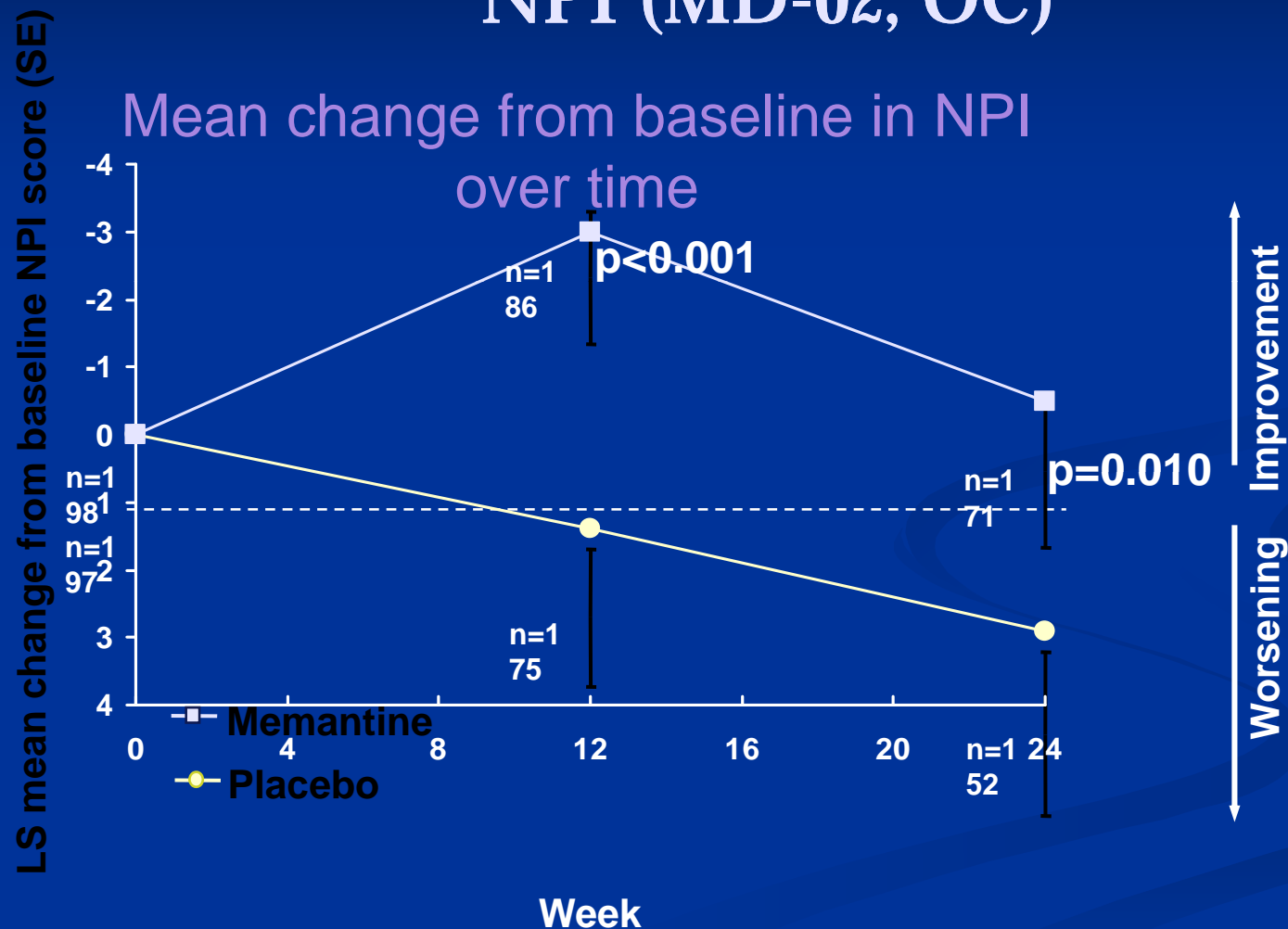
## Glutamate

- Levels of the excitatory neurotransmitter, glutamate, are elevated
- The basis for the use of Ebixa (Memantine)

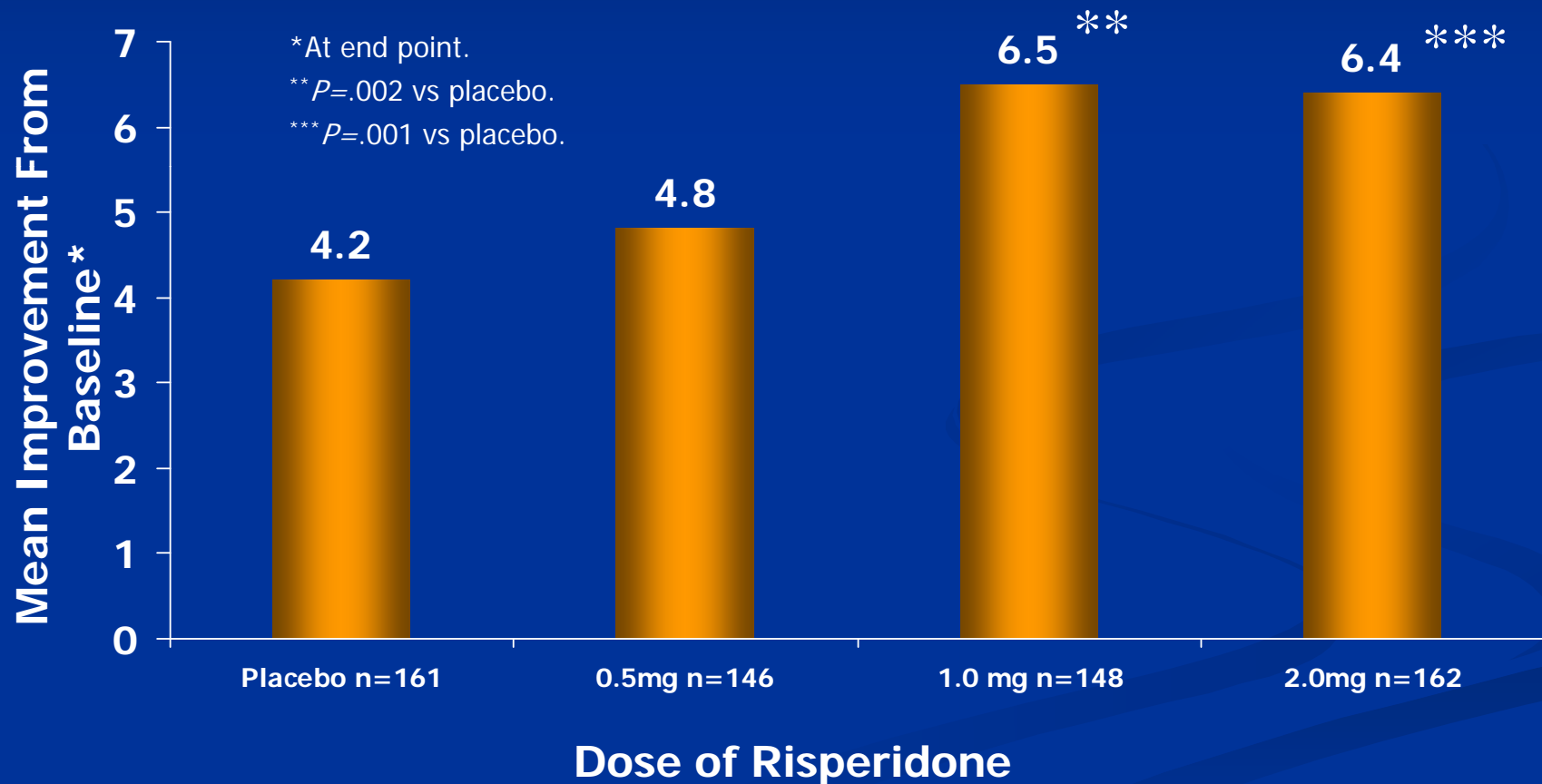
# Treatments Approved for Severe AD

- Ebixa (Memantine) and Aricept (Donepezil) have been approved by Health Canada for moderate-to-severe AD
- Both drugs can be prescribed alone or in combination
- Both treatments offer modest symptomatic benefit in the domains of cognition, function and behaviour
- These benefits are difficult to measure in severe disease

# Behavioural Improvements with Ebixa in Patients Taking Aricept NPI (MD-02, OC)



# Risperidone for the Treatment of Aggression and Agitation in Severe AD



# Neuroleptics in New Admissions to NH: A retrospective Cohort Study

- 19,780 newly admitted patients, >66 y/o with no treatment in previous year and no history of major psychosis
- 17% received neuroleptics with 100 days and 24% within one year
- Almost 10% received an initial dose that exceeded recommended thresholds
- Only 14% had prior contact with a geriatrician

# End of Life Decisions

# Severe Alzheimer's Disease: Loss of Capacity

- During the severe stage of AD critical health care decisions are made
- Loss of cognitive abilities leads to the legal incapacity to make such decisions
- Patients with AD can assert control when they appoint powers of attorney and prepare advanced directives
- Individuals must appoint powers of attorney and prepare advanced directives in the early stages of AD (while they are still capable)

# Planning for Long Term Care

- Almost all persons with AD will require long term care
- No one likes to plan for LTC
- Placing a family member in long term care is fraught with guilt and broken promises
- Wait times in many facilities is 3 or more years
- Crisis admissions – least desirable facilities

# Alzheimer's Disease: Palliative Stage

- Individuals are unable to express or comprehend language (including pain)
- Misidentifications – inability to recognize family and self
- Sleep structure can be severely impaired
- Mobility is impaired or lost
- Patients are at a high risk for falls and bed sores.
- Nutrition is difficult to maintain
- Behaviours such as purposeless pacing, physical aggression, resistance to hygienic care and screaming

# End of Life Decisions

- *Prolonging life or prolonging suffering and death?*
  - Cardiopulmonary resuscitation
  - Transfers to acute care
  - Treatment of life-threatening conditions
  - Refusal to eat/tube-feeding
  - The use of restraints

# Palliative Care and Death

# Palliative Care

- Affirm life and regard dying as a normal process
- Provide relief from pain and other distressing symptoms
- Integrate the psychological and spiritual aspects of patient care
- Offer a support system to help patients live as actively as possible until death
- Offer a support system to help the family cope during the patient's illness and in their own bereavement

[http://www.ncpc.org.uk/palliative\\_care.html](http://www.ncpc.org.uk/palliative_care.html)

# Death

- Alzheimer's disease is the 4<sup>th</sup> leading and fastest growing cause of death in seniors
- Causes: infections and falls
- Patients go through a 'palliative' stage
- We cannot prevent death but we can reduce suffering and maintain dignity
- Patients often die before reaching the severe stage
- Discussions about end of life decisions must take place early in the course of AD

# Philosophy of Hospice Care

“You matter because you are you. You matter to the last moment of your life and we will do all we can not only to help you die peacefully but to live until you die.”

# Summary

- Alzheimer's disease is the fastest growing cause of death in the elderly
- End of life issues need to be addressed in the early stages of AD
- To maintain autonomy and dignity patients should have an advanced care plan in place
- Palliative and hospice care should become a part of dementia care