THE 36-HOUR DAY
HOW WE CARE

Peter V. Rabins
Department of Psychiatry
Johns Hopkins School of Medicine
Dementia Syndrome
(Neurocognitive Disorder)

• Declines in 2 or more cognitive capacities resulting in functional decline

• Normal level of consciousness and alertness

• Onset in adulthood
PREVALENCE OF DEMENTIA BY AGE

AGE

PREVALENCE (%)

60  65  70  75  80  85  90
INCIDENCE OF DEMENTIA

AGE

PER YEAR

0 1 2 4 8 16 32

PERCENTAGE

±13% ±34%
<table>
<thead>
<tr>
<th>Behavior</th>
<th>No. of Families Responding</th>
<th>Families Reporting Occurrence, No. (%)</th>
<th>Families Reporting Behavior to Be a Problem, No. (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Memory disturbance</td>
<td>55</td>
<td>55(100)</td>
<td>51(93)</td>
</tr>
<tr>
<td>Catastrophic reactions</td>
<td>52</td>
<td>45(87)</td>
<td>40(89)</td>
</tr>
<tr>
<td>Demanding/critical behavior</td>
<td>52</td>
<td>37(71)</td>
<td>27(73)</td>
</tr>
<tr>
<td>Night waking</td>
<td>54</td>
<td>37(69)</td>
<td>22(59)</td>
</tr>
<tr>
<td>Hiding things</td>
<td>51</td>
<td>35(69)</td>
<td>25(71)</td>
</tr>
<tr>
<td>Communication difficulties</td>
<td>50</td>
<td>34(68)</td>
<td>25(74)</td>
</tr>
<tr>
<td>Suspiciousness</td>
<td>52</td>
<td>33(63)</td>
<td>26(79)</td>
</tr>
<tr>
<td>Making accusations</td>
<td>53</td>
<td>32(60)</td>
<td>26(82)</td>
</tr>
<tr>
<td>Meals</td>
<td>55</td>
<td>33(60)</td>
<td>18(55)</td>
</tr>
<tr>
<td>Daytime wandering</td>
<td>51</td>
<td>30(59)</td>
<td>21(70)</td>
</tr>
</tbody>
</table>

**“Don’t know” answers excluded.**
### TABLE 1.—BEHAVIOR PROBLEMS OF PATIENTS CITED BY FAMILIES

<table>
<thead>
<tr>
<th>Behavior</th>
<th>No. of Families Responding</th>
<th>Families Reporting Occurrence, No. (%)</th>
<th>Families Reporting Behavior to Be a Problem, No. (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bathing</td>
<td>51</td>
<td>27(53)</td>
<td>20(74)</td>
</tr>
<tr>
<td>Hallucinations</td>
<td>49</td>
<td>24(49)</td>
<td>16(42)</td>
</tr>
<tr>
<td>Delusions</td>
<td>49</td>
<td>23(47)</td>
<td>19(83)</td>
</tr>
<tr>
<td>Physical violence</td>
<td>51</td>
<td>24(47)</td>
<td>22(94)</td>
</tr>
<tr>
<td>Incontinence</td>
<td>53</td>
<td>21(40)</td>
<td>18(86)</td>
</tr>
<tr>
<td>Cooking</td>
<td>54</td>
<td>18(33)</td>
<td>8(44)</td>
</tr>
<tr>
<td>Hitting</td>
<td>50</td>
<td>16(32)</td>
<td>13(81)</td>
</tr>
<tr>
<td>Driving</td>
<td>55</td>
<td>11(20)</td>
<td>8(73)</td>
</tr>
<tr>
<td>Smoking</td>
<td>53</td>
<td>6(11)</td>
<td>4(67)</td>
</tr>
<tr>
<td>Inappropriate sexual behavior</td>
<td>51</td>
<td>1(2)</td>
<td>0(0)</td>
</tr>
</tbody>
</table>

**“Don’t know” answers excluded.**
Frequency of NPI Disturbance by Cache County Study

- Agitation: with dementia (35) vs. no dementia (5)
- Disinhibition: with dementia (15) vs. no dementia (10)
- Abnormal Motor Behavior: with dementia (25) vs. no dementia (0)

Lyketsos (2000)
Frequency of NPI Disturbance by Cache County Study

- Delusions
  - With dementia: 20
  - No dementia: 5

- Hallucinations
  - With dementia: 15
  - No dementia: 10

Lyketsos (2000)
COMMON CAUSES OF DEMENTIA

- Alzheimer disease 66%
- Vascular dementia 15-20%
- Dementia with Lewy bodies 8-15%
- Fronto-temporal dementia 5%
Diagnostic Features of Alzheimer Disease

• Slowly progressive dementia

• No other etiology identified: non-contributory neurological examination, laboratory evaluation and brain imaging

• Decline in memory plus either:
  - aphasia
  - apraxia
  - agnosia
  -(dysexecutive function )
3 ‘Stages’ of Alzheimer Disease

1. Decline in memory
   - personality change
   - executive function impairment

2. Cortical phase
   - aphasia
   - apraxia
   - agnosia

3. Physical Decline
   - incontinence
   - gait disorder
   - swallowing/feeding
   - muteness
<table>
<thead>
<tr>
<th></th>
<th>Impairment in</th>
</tr>
</thead>
<tbody>
<tr>
<td>AMNESIA</td>
<td>memory</td>
</tr>
<tr>
<td>APHASIA</td>
<td>language</td>
</tr>
<tr>
<td>APRAXIA</td>
<td>doing</td>
</tr>
<tr>
<td>AGNOSIA</td>
<td>recognition/perception</td>
</tr>
</tbody>
</table>

After McHugh and Folstein
4. Diagnosis

you are required to place a big times your writing

8.10.82
<table>
<thead>
<tr>
<th>THE 4 A’s OF ALZHEIMER DISEASE</th>
<th>IMPAIRMENT IN</th>
</tr>
</thead>
<tbody>
<tr>
<td>AMNESIA</td>
<td>memory</td>
</tr>
<tr>
<td>APHASIA</td>
<td>language</td>
</tr>
<tr>
<td>APRAXIA</td>
<td>doing</td>
</tr>
<tr>
<td>AGNOSIA</td>
<td>recognition/perception</td>
</tr>
</tbody>
</table>

After McHugh and Folstein
“Honey, am I home?”
## THE PATIENT’S EXPERIENCE: AMNESIA

<table>
<thead>
<tr>
<th>Intact Awareness</th>
<th>Lack of Awareness</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Fearfulness</td>
<td>• Anger at attempts by others to limit</td>
</tr>
<tr>
<td>• Distress over Failure</td>
<td>• Unconcern</td>
</tr>
<tr>
<td>• Avoid failure: Lessen involvement</td>
<td></td>
</tr>
</tbody>
</table>
THE PATIENT’S EXPERIENCE: APHASIA

Intact Awareness
• Frustration directed towards self → anger, depression, withdrawal

Lack of Awareness
• Anger at others for lack of comprehension
• Inability to ask questions, express emotions verbally, express pain verbally
THE PATIENT’S EXPERIENCE:
AGNOSIA

Lack of Awareness

• Constant unfamiliarity
  ?wandering
  ?suspiciousness
  ?resistance to invasion of privacy
TREATMENT: PHARMACOLOGIC AND NON-PHARMACOLOGIC
How long to Continue Anti-dementia Drugs?  
Howard NEJM 2012

Figure 3. Mean Scores on the Standardized Mini–Mental State Examination (SMMSE) and the Bristol Activities of Daily Living Scale (BADLS), According to Visit Week and Treatment Group.

Scores on the SMMSE range from 0 to 30, with higher scores indicating better cognitive function; scores on the BADLS range from 0 to 60, with higher scores indicating greater impairment. Shown are raw estimates of the mean score at each visit. I bars denote the standard error.
Risperidone: Psychosis and Aggressive Behavior in Dementia

Behave-AD Psychosis Score: Mean Change from Baseline

- Placebo
- RIS .5 mg
- RIS 1 mg
- RIS 2 mg

Weeks

Mean Change

Endpoint
Deaths Based on Total Drug and Placebo Exposures Pooled by Drug

Non-pharmacological Approaches

• Identify precipitants and avoid/minimize
• Establish realistic expectations
  - avoid over/under expectations
  - avoid over/under stimulations
• Simplify environment
• Structure/schedule day
• Talk through
• Repetition
• Encourage remaining abilities
Meta-Analysis of Nonpharmacological Interventions for Neuropsychiatric Symptoms of Dementia

Henry Brodaty, D.Sc.
Caroline Arasaratnam, B.Psych. (Hons)

Objective: Behavioral and psychological symptoms are common in dementia, and they are especially stressful for family caregivers. Nonpharmacological (or psychosocial) interventions have been shown to be effective in managing behavioral and psychological symptoms, but mainly in institutional settings. The authors reviewed the effectiveness of community-based interventions.

Results: Nonpharmacological interventions were effective in reducing behavioral and psychological symptoms, with an overall effect size of 0.34 (95% CI = 0.20–0.48; z = 4.87; p < 0.01), as well as in ameliorating caregiver reactions to these behaviors, with an overall effect size of 0.15 (95% CI = 0.04–0.26; z = 2.76; p = 0.006).
## Brodaty Meta-analysis of Caregiver Interventions

1. **Skills training for caregivers**
   - Managing behavioral and psychological symptoms of dementia
   - Communicating better with care recipient
   - Using role play, videos modeling behavior management strategies, cognitive-behavioral interventions, vignettes, live interviews
   - Enhancing care recipients quality of life, e.g., improving daily activities, increasing pleasant events

2. **Education for caregivers**
   - Psychoeducation
   - Improving home care
   - Tailored advice and recommendations
   - Problem-solving methods
   - Improving support network
   - Computer-mediated automated interactive voice response
   - Planning: emergencies, legal, financial
3. **Activity planning and environmental redesign**
   - Planning activities with caregiver for care recipient
   - Modifying care recipient’s physical and social environment

4. **Enhancing support for caregivers**
   - Social support
   - Web or telephone support
   - Strategies on how to access support
   - Family counseling

5. **Self-care techniques for caregivers**
   - Health management
   - Stress management
   - Coping with change as a result of caregiving
   - Music therapy
   - Counseling

6. **Miscellaneous**
   - Collaborative care with a health professional or care manager
   - Exercise for care recipient
The 36-Hour Day
A Family Guide to Caring for Persons with Alzheimer Disease, Related Dementing Illnesses, and Memory Loss in Later Life

NANCY L. MACE, M.A.
PETER V. RABINS, M.D., M.P.H.

PRACTICAL DEMENTIA CARE

PETER V. RABINS
CONSTANTINE G. LYKETSOS
CYNTHIA D. STEELE

“The best guide of its kind.”
—CHICAGO SUN TIMES

A JOHNS HOPKINS PRESS HEALTH BOOK
An Approach: The 4 Ds

- **DESCRIBE**  Be specific
- **DECODE**  Consider possible causes, common and uncommon
- **DEVISE**  Base on ‘decode’  Use common sense
- **DETERMINE**  Be as specific as possible
DESCRIBE

- What
- Where
- When
- Why
- Who
Decode

- Cognitive
- Psychiatric
- Medical
- Environmental
- Caregiver
AN APPROACH: The 4Ds

<table>
<thead>
<tr>
<th>PROBLEM</th>
<th>DESCRIBE (Identification)</th>
<th>DECODE (Evaluation)</th>
<th>DEVISE (Intervention)</th>
<th>DETERMINE (Monitoring)</th>
</tr>
</thead>
<tbody>
<tr>
<td>FALL</td>
<td>Where, Circumstance,</td>
<td>Apraxic, Weakness,</td>
<td>Identify risk factors,</td>
<td>Count</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Imbalance, Vision,</td>
<td>intervene accordingly</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Environ</td>
<td></td>
<td></td>
</tr>
<tr>
<td>PRESSURE ULCER</td>
<td>Regular eval</td>
<td>Staging</td>
<td>Medical tx, Devices,</td>
<td>Regular comment;</td>
</tr>
<tr>
<td></td>
<td>Early recog</td>
<td></td>
<td>Turning reg</td>
<td>Consult</td>
</tr>
<tr>
<td>WT LOSS</td>
<td>Regular wt</td>
<td>Nutrition consult</td>
<td>Feeding; Supplements;</td>
<td>Weekly</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Tube; Meds</td>
<td></td>
</tr>
<tr>
<td>AGGRESSION</td>
<td>Describe behavior</td>
<td>Identify precipitants</td>
<td>Environment; Meds;</td>
<td>Change tx if no better;</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Consult</td>
<td>Monitor side effects</td>
</tr>
</tbody>
</table>
END OF LIFE CARE OF DEMENTIA
<table>
<thead>
<tr>
<th>Type of Treatment</th>
<th>Faced with Decision</th>
<th>Only Decided For</th>
<th>Ever Decided Against</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>N (%)</td>
<td></td>
<td>%</td>
</tr>
<tr>
<td>Hospital admission</td>
<td>38 (52.8)</td>
<td>13.1</td>
<td>86.8</td>
</tr>
<tr>
<td>Blood test/ diagnostic test</td>
<td>29 (40.3)</td>
<td>44.84</td>
<td>55.2</td>
</tr>
<tr>
<td>Feeding tube</td>
<td>25 (34.7)</td>
<td>8.0</td>
<td>92.0</td>
</tr>
<tr>
<td>X-ray</td>
<td>21 (29.2)</td>
<td>66.7</td>
<td>33.3</td>
</tr>
<tr>
<td>Infection treatment</td>
<td>25 (34.7)</td>
<td>64.0</td>
<td>36.0</td>
</tr>
<tr>
<td>Respirator/ ventilator</td>
<td>17 (23.6)</td>
<td>23.5</td>
<td>76.5</td>
</tr>
<tr>
<td>Resuscitate</td>
<td>14 (19.4)</td>
<td>--</td>
<td>100</td>
</tr>
<tr>
<td>Surgery</td>
<td>4 (5.6)</td>
<td>--</td>
<td>100.0</td>
</tr>
</tbody>
</table>
### Difficulty with Decision

<table>
<thead>
<tr>
<th>Decision</th>
<th>To Treat</th>
<th>Decision</th>
<th>To Limit</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not Difficult</td>
<td>87.7 %</td>
<td>Not Difficult</td>
<td>55.2 %</td>
</tr>
<tr>
<td>Any Difficulty</td>
<td>12.3 %</td>
<td>Any Difficulty</td>
<td>44.8 %</td>
</tr>
</tbody>
</table>

### Satisfaction with Decision

<table>
<thead>
<tr>
<th>Decision</th>
<th>To Treat</th>
<th>Decision</th>
<th>To Limit</th>
</tr>
</thead>
<tbody>
<tr>
<td>Somewhat Satisfied</td>
<td>28.8 %</td>
<td>Somewhat Satisfied</td>
<td>80.6 %</td>
</tr>
<tr>
<td>Very Satisfied</td>
<td>71.2 %</td>
<td>Very Satisfied</td>
<td>19.4 %</td>
</tr>
</tbody>
</table>
GENETICS
GENETIC ISSUES

• Abnormalities in 3 genes are known to cause AD
  • APP gene on chromosome 21
  • PS-1 gene on chromosome 14
  • PS-2 gene on chromosome 1

• Account for fewer than 2% of cases of AD
• Function of these genes unknown
• Between 30-60% of AD is under genetic influence

• APOE gene linkage well established
  - APOE $E4$ gene increases risk
  - APOE $E2$ gene may decrease risk
  - These genes are “normal”
  - APO genes carry cholesterol
Genetics Continued: ~20 Recently Discovered Genes (2013)

- Clusterin
- CLU
- BIN1
- PICALM
- CR1 (complement receptor 1)
- MS4A
- CD2AP
- EPHA1
- ABCA7
- HLA-DRB5
- PTK2B
- SLC4A4
- DSG2
- INPP5D
- MEF2C
- NME8
- ZCWPW1
- CELF1
- FERMT2
- CASS4

- PLUS 13 OTHERS THAT MAY CONTRIBUTE

- Need to be replicated
- May account for 15% of cases
The 3 new pathways leading to Alzheimer’s disease
Morgan Neuropath and Appl Neurobiol 2011; 37:353-7

3 Implicated Pathways

- **Immune System Function**
  - CLU
  - CR1
  - ABCA7
  - MS4A
  - CD33
  - EPHA1

- **Cholesterol Metabolism**
  - APOE
  - CLU
  - ABCA7

- **Synaptic Dysfunction/Cell Membrane Processes**
  - PICALM
  - BIN1
  - CD33
  - CD2AP
  - EPHA1

![Diagram of the pathways](image)
BETTER DRUG THERAPIES
Potential Strategies for Bio-remediation

- **ANTI-AMYLOID**
  - Remove bad amyloid
  - Lower production of bad amyloid
  - Increase production of good amyloid

- **OTHER**
  - Immune enhancers
  - Stem cell transplants
  - Other memory enhancer drugs
  - Deep brain stimulation
PREVENTION

• “Primary”- Anti-amyloid

• Secondary-Prevent morbidity

• Tertiary-Maximize treatment (Quality of Life)
Presence of neuropsychiatric symptoms is associated with more rapid progression in an incidence cohort in Cache County

### Table 1
Multivariate Cox regression model

<table>
<thead>
<tr>
<th>Variable</th>
<th>B</th>
<th>SE</th>
<th>Wald</th>
<th>df</th>
<th>Significance</th>
<th>Exp (B)</th>
<th>Lower</th>
<th>Upper</th>
</tr>
</thead>
<tbody>
<tr>
<td>NPI*</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>All domains 1–3</td>
<td>0.10</td>
<td>0.35</td>
<td>0.08</td>
<td>1</td>
<td>0.779</td>
<td>1.10</td>
<td>0.56</td>
<td>2.17</td>
</tr>
<tr>
<td>At least one domain 4+</td>
<td>0.91</td>
<td>0.31</td>
<td>8.70</td>
<td>1</td>
<td>0.003</td>
<td>2.48</td>
<td>1.36</td>
<td>4.54</td>
</tr>
<tr>
<td>AD onset age</td>
<td>-1.09</td>
<td>0.32</td>
<td>11.67</td>
<td>1</td>
<td>0.001</td>
<td>0.34</td>
<td>0.18</td>
<td>0.63</td>
</tr>
<tr>
<td>AD onset age²</td>
<td>0.01</td>
<td>0.002</td>
<td>12.38</td>
<td>1</td>
<td>&lt;0.001</td>
<td>1.01</td>
<td>1.003</td>
<td>1.011</td>
</tr>
<tr>
<td>Female</td>
<td>0.64</td>
<td>0.32</td>
<td>4.05</td>
<td>1</td>
<td>0.044</td>
<td>1.90</td>
<td>1.02</td>
<td>3.56</td>
</tr>
<tr>
<td>Education—less than high school</td>
<td>0.55</td>
<td>0.34</td>
<td>2.63</td>
<td>1</td>
<td>0.105</td>
<td>1.73</td>
<td>0.89</td>
<td>3.35</td>
</tr>
</tbody>
</table>

*Reference category is NPI total score = 0.
†Reference category is greater than or equal to high school.

(Rabins, 2013)
Presence of agitation is associated with more rapid progression in an incidence cohort in Cache County.
Barnes and Yafee 2011: Attributable Risks for AD

<table>
<thead>
<tr>
<th></th>
<th>Population prevalence</th>
<th>Relative risk (95% CI)</th>
<th>PAR (confidence range)</th>
<th>Number of cases attributable (thousands; confidence range)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>USA</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Diabetes mellitus</td>
<td>8.7%</td>
<td>1.39 (1.17-1.66)</td>
<td>3.3% (1.5-5.4)</td>
<td>174 (77-288)</td>
</tr>
<tr>
<td>Midlife hypertension</td>
<td>14.3%</td>
<td>1.61 (1.16-2.24)</td>
<td>8.0% (2.2-15.1)</td>
<td>425 (119-798)</td>
</tr>
<tr>
<td>Midlife obesity</td>
<td>13.1%</td>
<td>1.60 (1.34-1.92)</td>
<td>7.3% (4.3-10.8)</td>
<td>386 (226-570)</td>
</tr>
<tr>
<td>Depression</td>
<td>19.2%</td>
<td>1.90 (1.55-2.33)</td>
<td>14.7% (9.6-20.3)</td>
<td>781 (506-1078)</td>
</tr>
<tr>
<td>Physical inactivity</td>
<td>32.5%</td>
<td>1.82 (1.19-2.78)</td>
<td>21.0% (5.8-36.6)</td>
<td>1115 (308-1942)</td>
</tr>
<tr>
<td>Smoking</td>
<td>20.6%</td>
<td>1.59 (1.15-2.20)</td>
<td>10.8% (3.0-19.8)</td>
<td>574 (159-1050)</td>
</tr>
<tr>
<td>Low education</td>
<td>13.3%</td>
<td>1.59 (1.35-1.86)</td>
<td>7.3% (4.4-10.3)</td>
<td>386 (236-544)</td>
</tr>
<tr>
<td>Combined (maximum)</td>
<td>..</td>
<td>..</td>
<td>54.1%</td>
<td>2866951*</td>
</tr>
</tbody>
</table>

PAR=population attributable risk. *Absolute number.
Self-reported exercise is associated with longer time to dementia.

Cox proportional hazards regression.
Does the Treatment of Dementia Improve Quality of Life?

- Modest evidence that psychosocial interventions improve HRQOL

- No evidence that environmental design improves HRQOL

- No evidence that pharmacotherapy improves HRQOL