Speaker’s Task Force on Alzheimer’s and Dementia

Testimony of
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Alzheimer’s Association, Southeastern Wisconsin Chapter
September 16, 2015
Typical changes

Typical age-related changes involve:

- Making a bad decision once in a while
- Missing an occasional monthly payment
- Forgetting which day it is and remembering later
- Sometimes forgetting which word to use
- Losing things from time to time
Problematic changes

Consistent poor judgment and decision making

Loss of an ability to manage money

Inability to keep track of the date or the season

Difficulty having a conversation

Misplacing things and loss of the ability to retrace steps to find them

Trouble with visual and spatial relationships

Challenges in planning or solving problems
What is dementia?

- Loss of cognitive functioning serious enough to interfere with daily functioning
- Causes changes in:
  - memory
  - language
  - thought
  - navigation
  - behavior
  - personality / mood
Understanding dementia

Dementia

- Reversible dementias
- Frontotemporal dementia
- Vascular dementia
- Lewy body disease
- Alzheimer's disease
Reversible causes of dementia

D - Depression, delirium
E - Emotional disorders
M - Metabolic disorders (e.g., hypothyroidism)
E - Eye and ear impairments
N - Nutritional (e.g., B12 deficiency)
T - Tumors
I - Infections
A - Alcohol, drugs, medication interactions
Irreversible types of dementia

- Alzheimer’s disease: the most common type
- Over 70% of people with dementia have Alzheimer’s disease

Causes of Dementia in People Aged 71+ Adams:

- 70% Alzheimer’s
- 17% Vascular Dementia
- 13% Other Dementia

Created from data from Plassman et al. ²
What is Alzheimer's disease?

Alzheimer’s disease:

- is a brain disorder
- is a progressive disease
- is the most common form of dementia
- has no cure
- is eventually fatal
There are 100 billion nerve cells, or neurons, creating a branching network.

Signals traveling through the neuron forest form memories, thoughts and feelings.

Alzheimer’s destroys neurons.
Neurons affected by Alzheimer's

dead cells full of tangles
Sparse, damaged cells
amyloid plaques
withered branches
Healthy vs. Alzheimer brain

- Cortex shrivels, especially near hippocampus
- Ventricles enlarge

Alzheimer's Association
How the brain works

◆ There are 100 billion nerve cells, or neurons, creating a branching network.

◆ Signals traveling through the neuron forest form memories, thoughts and feelings.

◆ Alzheimer’s destroys neurons.
Neurons affected by Alzheimer's:

- Dead cells full of tangles
- Sparse, damaged cells
- Amyloid plaques
- Withered branches
Healthy vs. Alzheimer brain

ventricles enlarge

cortex shrivels, especially near hippocampus
The primary risk factor is age
The incidence is higher in women
Down syndrome is correlated with AD
Family history can increase risk
There are two categories of genes
Faces of Dementia in Wisconsin: An Emerging Portrait
What if, all of a sudden.....

All 105,000 people in Green Bay had Dementia?
And What if…..

In 25 years, everyone in Superior, Wisconsin Rapids, and River Falls did too?
If the rate of dementia does not change…

119,900 estimated persons with dementia in 2010

68% increase

201,600 with dementia in 2035

...due to older population growth alone
But why the increase in dementia in particular?

- Increasing survival into very old age
  - Prevalence after age 85 rises to 48%
- Other killer diseases being reined in
  - Cancer
  - Heart disease
- Increasing diagnosis
- Growing racial and ethnic diversity
Percent of People Age 65+ With Cognitive Impairment

- White: 8.8%
- Latino/Hispanic: 17.5%
- African American: 23.9%
And, by and large, most of these folks are just “out there…”

Individuals 65+ with Dementia by Setting  
(n=120,000)

- Community: 90%  
- Skilled Nursing Facilities: 10%
What Would We Do If.....

We knew that almost 20% of the people in our Community Long Term Care Programs had dementia?
They do.

- Legacy Waivers: 25.5%
- Family Care: 19.5%
- PACE/Partnership: 24.9%
- IRIS (Self-Direction): 6.0%
Community Programs

• Over 9000 of the 50,000+ enrolled in LTC have dementia – 18.5%

• That will grow by 68% in the next 25 years as well....
## Skilled Nursing Facilities

Dementia Among Skilled Nursing Facility Residents

<table>
<thead>
<tr>
<th></th>
<th>Number</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Residents with a dementia diagnosis</td>
<td>12,961</td>
<td>45.5%</td>
</tr>
<tr>
<td>No dementia diagnosis</td>
<td>15,553</td>
<td>54.5%</td>
</tr>
<tr>
<td>Total Residents</td>
<td>28,514</td>
<td>100.0%</td>
</tr>
</tbody>
</table>

Source: Minimum Data Set, 12/31/12
What would we do if...

We knew that the entire population of Kenosha had dementia?
And over 50% were undiagnosed?
And 2/3 received no help from friends or family?
And 30% lived alone?
## Confusion or Memory Loss

<table>
<thead>
<tr>
<th>Have you experienced confusion or memory loss that's happening more often or getting worse?</th>
<th>Number Saying &quot;Yes&quot;</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>438</td>
<td>9.7%</td>
</tr>
<tr>
<td>Besides yourself, is at least one other adult in your household experiencing confusion or memory loss that's happening more often or getting worse?</td>
<td>275</td>
<td>9.1%</td>
</tr>
</tbody>
</table>

**Note:** These questions reference the "past 12 months"
## Does person get assistance from family or friends due to confusion or memory loss?

<table>
<thead>
<tr>
<th></th>
<th>Number</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Always</td>
<td>37</td>
<td>6.3%</td>
</tr>
<tr>
<td>Usually</td>
<td>18</td>
<td>3.1%</td>
</tr>
<tr>
<td>Sometimes</td>
<td>87</td>
<td>14.8%</td>
</tr>
<tr>
<td>Rarely</td>
<td>75</td>
<td>12.8%</td>
</tr>
<tr>
<td>Never</td>
<td>365</td>
<td>62.1%</td>
</tr>
<tr>
<td>Don’t know/not sure/refused</td>
<td>4</td>
<td>0.7%</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>586</td>
<td>99.7%</td>
</tr>
</tbody>
</table>
Help from Family/Friends?

- Never: 62%
- Sometimes: 15%
- Rarely: 13%
- Always/Usually: 9%
- Don't know: 1%
<table>
<thead>
<tr>
<th>Interaction with Health Professionals</th>
<th>Number saying &quot;Yes&quot;</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Have you discussed the memory loss with a health care professional?</td>
<td>163</td>
<td>27.9%</td>
</tr>
<tr>
<td>Of those who HAVE discussed...</td>
<td></td>
<td></td>
</tr>
<tr>
<td>A health care professional has diagnosed Alzheimer's Disease</td>
<td>13</td>
<td>8.0%</td>
</tr>
<tr>
<td>A health care professional has diagnosed dementia, but not AD</td>
<td>11</td>
<td>6.7%</td>
</tr>
<tr>
<td>No diagnosis has been given</td>
<td>135</td>
<td>82.8%</td>
</tr>
</tbody>
</table>
Bottom Lines

• 120,000 people growing to 202,000 by 2035
• 80% live at home, only 21% are in “the system” – 84,000 are not
• Over 50% are undiagnosed or misdiagnosed, and less than 30% have talked to the doc.
• Over 60% never get help, 30% live alone
• Should it be a surprise we only learn about many of these folks through crisis?
Alzheimer’s and Dementia Caregiving Issues

- Information and support needs change throughout disease course
- Local resources are often limited
- Accessing them may be complicated
- In-home care can be all-consuming
- Distance and transportation issues
Who are the Caregivers

- Non-paid children of senior adults
- Spouses of seniors
- Other family members
- Friends and neighbors of seniors
- They are your employees, patients and customers
Caregiver Facts

- Majority of caregivers in the U.S. are 35-64 years old.
- 60% of caregivers are working, majority full-time.
- Average caregiver: 18 years assisting an aging parent.
- 40% of caregivers are men, average age is 47.
- 15% of caregivers – person they support lives more than one hour away.
Caregiving and Work

• 60% of employed caregivers made some adjustment to their work as a result

• 9% left the workplace

• 13% reduced to part-time (cost to business: $3.3 billion)
Caregiver statistics

Figure 7: 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, United States, 2009

Percentage
- Caregivers of people with Alzheimer’s and other dementias
- Caregivers of other older people

Activities: Getting in and out of bed, Dressing, Getting to and from the toilet, Bathing, Managing incontinence and diapers, Feeding

- Getting in and out of bed: 54% (Alzheimer’s) vs. 42% (other older people)
- Dressing: 40% (Alzheimer’s) vs. 31% (other older people)
- Getting to and from the toilet: 32% (Alzheimer’s) vs. 26% (other older people)
- Bathing: 31% (Alzheimer’s) vs. 23% (other older people)
- Managing incontinence and diapers: 31% (Alzheimer’s) vs. 16% (other older people)
- Feeding: 31% (Alzheimer’s) vs. 14% (other older people)
OVER 15 MILLION AMERICANS PROVIDE UNPAID CARE FOR A PERSON WITH ALZHEIMER’S OR OTHER DEMENTIAS.

Eighty percent of care provided at home is delivered by family caregivers.

Caregiver statistics

**Figure 9:** Proportion of Alzheimer’s and Dementia Caregivers Who Report High or Very High Emotional and Physical Stress Due to Caregiving

<table>
<thead>
<tr>
<th>Stress</th>
<th>Percentage</th>
<th>High to very high</th>
<th>Not high to somewhat high</th>
</tr>
</thead>
<tbody>
<tr>
<td>Emotional stress of caregiving</td>
<td>61%</td>
<td>39%</td>
<td></td>
</tr>
<tr>
<td>Physical stress of caregiving</td>
<td>43%</td>
<td>57%</td>
<td></td>
</tr>
</tbody>
</table>
Importance of Caregiver and Patient Education

• Caregiver intervention can be just as effective as medication in treating dementia

• Evidence-based studies demonstrate the benefits of caregiver education and outcomes through programming

  — Arch Intern Med. 2011 Feb 28; 171(4):353-9. Translation of a dementia caregiver support program in a health care system – Reach VA. “From baseline to 6 months, caregivers reported significantly decreased burden, depression, impact of depression on daily life, caregiving frustrations, and number of troubling dementia-related behaviors.”
We Enhance Care and Support

24/7 HELPLINE
Information & Referral
Care Consultation

1.800.272.3900
We Enhance Care and Support

Support Groups

Connect to our online community

Find information and support and connect with others similar to you on: alz connected
Caregivers for Alzheimer’s and Dementia Face Special Challenges

You are not alone. Whether you need information about early-stage caregiving, middle-stage caregiving, or late-stage caregiving, the Alzheimer’s Association is here to help.

Are you a working caregiver?
Consumer
Educational Programs
Professional Education Programs

Individual online training in dementia care, as well as certification of knowledge by the Alzheimer’s Association.

- Foundations of Dementia Care
  - 12 Modules
- Dementia Care: Best Practices
  - One-Day Workshop
- Dementia Specialist: Best Practices
  - Two-Day Workshop
- 1-2 hour In-services
Continuum of Alzheimer’s Disease

Normal

Alzheimer’s disease

Cognitive function

Preclinical

Aging

MCI

Dementia

Years
Push back diagnosis so intervention starts as early as possible

### Cognitive continuum of aging

<table>
<thead>
<tr>
<th>Normal</th>
<th>Preclinical (Presymptomatic)</th>
<th>MCI</th>
<th>AD</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Thinking effectively but more slowly</td>
<td>• APOE-e4 risk gene</td>
<td>• Subjective problem in memory or another domain, informant corroborated and measurable on tests</td>
<td>• Clear deficits in 2 or more core cognitive domains (memory, language, problem solving, visual interpretation)</td>
</tr>
<tr>
<td>• Forgetting a name or appointment but remembering later</td>
<td>• Multiple protein or gene “barcodes”</td>
<td>• Normal overall cognition and ADLs</td>
<td>• ADLs affected</td>
</tr>
<tr>
<td>• Occasionally misplacing things</td>
<td>• Family history</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Tau or amyloid in CSF or blood</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>• MRI, PET</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

MCI = mild cognitive impairment  
APOE = apolipoprotein E  
CSF = cerebrospinal fluid  
MRI = magnetic resonance imaging  
PET = positron emission tomography  
ADLs = activities of daily living
The Alzheimer’s Challenging Behaviors Task Force
The Community: 80%
Goal: Stabilize and support whenever possible

LTC Program or Facility: 20%
Goal: Treat in Place whenever possible

Task Force
Crisis Intervention and Prevention Road Map

EARLY ID/SUPPORT/DIVERSION
Physician ED/OR, Early Stage Services, Mobile Crisis, First Responder Coordination, Facility Staff Training

Chapter 55 Protective Placement Facility(ies)

Aftermath Placement
Thank you for your time!

Alzheimer’s Association, Southeastern Wisconsin Chapter
620 S. 76th St.
Milwaukee, WI 53204

800-272-3900
www.alz.org/sewi