Alaska’s Roadmap to Address Alzheimer’s Disease and Related Dementias

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Power of Aging in Alaska Symposium  
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Overview
Vision

• Alaska will identify Alzheimer’s disease and related dementias as a public health priority due to the increasing number of Alaskans affected, and build on strong partnerships to address the challenges of this condition with safe and quality supports, from prevention, early detection, to end of life.

Mission

• To improve public awareness, promote prevention, early detection, long-term services and supports, safety, appropriate housing, and caregiver supports for all Alaskans with Alzheimer’s disease and related dementias.
Purpose

• A guide for implementing strategies to improve the quality of life for Alaskans with ADRD and their caregivers.
Guiding Principles

• Early detection and planning can vastly improve quality of life and ease the financial burden for individuals with ADRD and their caregivers.

• Individuals with ADRD will be able to reside in their homes and communities for as long as possible.
What is Alzheimer’s Disease and Related Dementias (ADRD)?

Alzheimer’s Disease is the most common form of dementia, caused by the death of brain cells and the atrophy of the brain.

Other more commonly known related dementias include vascular, mixed dementia, Parkinson’s, and Lewy Body dementia.

Symptoms typically associated with ADRD include:

- Loss of memory and language ability
- Loss of balance and thinking abilities
- Changes in personality and behavior

Source: Alzheimer’s Association
What is Alzheimer’s Disease and Related Dementias (ADRD)?

Alzheimer’s Disease and related dementias most commonly affect people over the age of 65, although approximately 4% of diagnoses are in younger people aged 30-64.

There is no known cure or mechanism to slow progression.

Source: Alzheimer’s Association, 2012 letter on younger onset
Process Overview

Core Team Guidance

Needs Assessment: ACoA Forums + Survey

Review: Alaska Plans; National and State ADRD Plans

Research: Trends + Best Practices

Power of Aging in Alaska Symposium Presentation (May)

Draft Road Map

Stakeholder Review (August)

Core Team Meeting (June)

Core Team Finalization (September - October)

Final Alaska’s Road Map to Address ADRD (November conference presentation)
Needs Assessment: Caregiver Community Forums

Caregiver community forums were held in seven communities in 2012-2013 to understand the needs of individuals with Alzheimer’s disease and their caregivers.

<table>
<thead>
<tr>
<th>Community</th>
<th>Participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>Anchorage</td>
<td>50</td>
</tr>
<tr>
<td>Juneau</td>
<td>15</td>
</tr>
<tr>
<td>Fairbanks</td>
<td>32</td>
</tr>
<tr>
<td>Homer</td>
<td>18</td>
</tr>
<tr>
<td>Soldotna</td>
<td>28</td>
</tr>
<tr>
<td>Kodiak</td>
<td>12</td>
</tr>
<tr>
<td>Mat-Su, Palmer</td>
<td>6</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>161</strong></td>
</tr>
</tbody>
</table>

Source: Alaska Commission on Aging, 2014
Needs Assessment: Caregiver Community Forums

Findings from Community Forums:

• Lack of public awareness and misunderstanding about Alzheimer’s disease and related dementia
• Inadequate services for people with ADRD
• Unpaid caregivers are often stressed and unprepared
• Acute need for safe and appropriate housing for seniors with ADRD and those with challenging behaviors
• Critical need to improve safety for persons with ADRD

Source: Alaska Commission on Aging, 2014
Needs Assessment: Unpaid Caregiver Survey

Unpaid caregiver characteristics:

- 80% of caregiving for persons with ADRD is provided by unpaid caregivers
- Most commonly immediate family members
- Survey respondents were (n=52)
  - 62% women, 23% age 65+, 50% have some college education, 70% are married or in a long-term relationship
- Dementia caregiving tasks include help with instrumental activities of daily living, activities of daily living, medication management, coordinating care, medical appointments, managing behavioral symptoms, supervision, and coordinating decision-making with other family members regarding care plans

Source: Alaska Commission on Aging, 2014
Needs Assessment: Unpaid Caregiver Survey

What is the most difficult challenge you face as a caregiver?

- Creates a financial burden (15%)
- Interferes with my work (15%)
- Contributes to my health problems (13%)
- No difficulties (1%)
- Limits personal time (14%)
- Affects family relationships (14%)
- Does not leave enough time for my family (10%)
- Creates stress and makes me feel depressed (18%)
- Affects family relationships (14%)
- Creates a financial burden (15%)
- Interferes with my work (15%)
- Contributes to my health problems (13%)
- No difficulties (1%)
- Limits personal time (14%)
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Source: Alaska Commission on Aging, 2014
Needs Assessment: Unpaid Caregiver Survey

Which support services do you or the person you care for use?

~31% use Adult Day
~25% use Transportation + Support Groups
~23% use Personal Care Assistance and Respite

Source: Alaska Commission on Aging, 2014
Background Data + Trends
The above projections do not include persons with related dementias and those younger than 65.

Nationwide Estimated Lifetime Risks for Alzheimer's by Age and Sex

Source: Adapted from Alzheimer’s Association, 2014 Facts and Figures based on data from the Framingham Study, Seshadri et al.
Value of Alaska’s Unpaid Caregivers

In 2013, 33 thousand Alaska caregivers provided 37 millions hours of unpaid care valued at $466 million.

The cost of healthcare for caregivers in Alaska in 2012 was $26 million higher than for Alaskans who are not caregivers.

Alaska ADRD Roadmap Goals

1. Promote ADRD Awareness and Early Diagnosis.

2. Slow increasing cost of care and increase funding for needed services.

3. Emphasize quality control, not quantity control, to improve services and reduce the rate of increase for long-term costs.

4. Improve system to center around the person with ADRD.
Alaska ADRD Roadmap Goals

5. Develop a dementia savvy workforce.

6. Reduce stress and provide training to unpaid caregivers.

7. Provide safe and appropriate housing for seniors with ADRD and those with challenging behaviors.

8. Increase knowledge of ADRD prevalence and treatment in Alaska.
Thank you!

To Learn More, Contact
Alaska Commission on Aging: 907-465-3250
Alzheimer’s Resource of Alaska: 800-478-1080
Division of Senior & Disabilities Services: 800-478-9996
The Trust: 907-269-7960
Alaska Pioneer Homes: 907-465-4416
AARP Alaska: 866-227-7447