Alzheimer’s Disease and Other Dementia: The Pandemic Affecting Your Practice—2019 Update

Friday, November 22, 2019
9 a.m.–12:15 p.m.

3 Mental Health/Substance Use credits
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**Schedule**  

**Faculty**

1. **How the Global Dementia Pandemic Continues to Affect Your Law Practice**  
   — Tim Nay, *Law Offices of Nay and Friedenberg LLC, Portland, Oregon*  
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2. **Presentation Slides: The Changing Face of Alzheimer Disease (Major Neurocognitive Disorder)**  
   — Elizabeth Eckstrom, MD, *Professor of Medicine, Division of General Internal Medicine and Geriatrics School of Medicine, Oregon Health & Science University, Portland, Oregon*  
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3. **Presentation Slides: The Impact of Dementia: Helping Families Navigate the Path of Decline**  
   — Allison Lindauer, RN, PhD, *Oregon Health & Science University, Portland, Oregon*  
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4. **The Face of Alzheimer's**  
   — Heidi Rowell, *Program Director, Alzheimer's Association Oregon Chapter, Portland, Oregon*  
   4–i
SCHEDULE

8:00 Registration

9:00 How the Global Dementia Pandemic Continues to Affect Your Law Practice
   Tim Nay, Law Offices of Nay and Friedenberg LLC, Portland

9:15 The Changing Face of Alzheimer’s Disease
   ✦ Dementia in our community
   ✦ Symptoms of dementia—is it Alzheimer’s?
   ✦ Current treatments and management
   ✦ What the future holds for the epidemic of dementia
   Elizabeth Eckstrom, MD, Professor of Medicine, Division of General Internal Medicine and Geriatrics School of Medicine, Oregon Health & Science University, Portland

10:30 Break

10:45 The Impact of Dementia and the Tough Decisions
   ✦ Psychosocial and economic impact
   ✦ The challenges of dementia
   ✦ Key decisions over time
   ✦ The needs of family caregivers
   Allison Lindauer, RN, PhD, Oregon Health & Science University, Portland

11:30 The Face of Alzheimer’s
   ✦ Ten warning signs
   ✦ Common challenges
   ✦ Alzheimer’s Association programs and services
   ✦ National Alzheimer’s Plan 2025
   Heidi Rowell, Program Director, Alzheimer’s Association Oregon Chapter, Portland

12:15 Adjourn
FACULTY

Elizabeth Eckstrom, **MD**, *Professor of Medicine, Division of General Internal Medicine and Geriatrics School of Medicine, Oregon Health & Science University, Portland*. Dr. Eckstrom is a professor and Chief of Geriatrics at OHSU. She practices both primary care and consultative geriatrics and focuses on promoting a healthy lifestyle in older adults and in educating all health professionals to be competent in the care of older adults. Her research has focused on interprofessional education, tai chi to improve health in older adults, and falls prevention. She teaches medical students and internal medicine residents and works with inpatient teams to improve quality of care for older hospitalized patients throughout the institution. Dr. Eckstrom is a codirector of the OHSU Healthy Aging Alliance.

Allison Lindauer, **RN, PhD**, *Oregon Health & Science University, Portland*. Dr. Lindauer is a nationally certified gerontological nurse practitioner with a PhD in gerontological nursing. She is focused on providing high-quality, culturally relevant care to older adults. Her clinical work involves caring for those with dementia at Oregon Health & Science University’s Layton Aging and Alzheimer’s Disease Center. Dr. Lindauer is the Outreach, Recruitment and Education Leader at the Layton Center, one of 31 NIA-funded Alzheimer’s Research Disease Centers in the nation. Dr. Lindauer’s research focuses on using technology to advance caregiving science using telehealth. Dr. Lindauer serves on Gerontological Society of America and Alzheimer’s Association International Conference (Professional Interest Area: Technology) committees.

Tim Nay, *Law Offices of Nay and Friedenberg LLC, Portland*. Mr. Nay is the founding president and a Fellow of the National Academy of Elder Law Attorneys and winner of its 2007 President’s Award. He is a founding member and past chair of the Oregon State Bar Elder Law Section, is past president of the Oregon Gerontological Association and the Alzheimer’s Association of Oregon, was one of four founding members and the first secretary of the National Alliance of Medicare Set Aside Professionals, is a member of the Academy of Special Needs Planners Advisory Board, and is a member and annual sponsor of the Oregon Trial Lawyers Association. He is licensed to practice law in Oregon and Washington, and he has held professional clinical social work licensure in Texas, Idaho, and Oregon.

Heidi Rowell, *Program Director, Alzheimer’s Association Oregon Chapter, Portland*. Ms. Rowell helps provide support to people and families living with dementia. She has been in the long-term care industry for over 15 years and has worked in many older adult settings, including senior housing and in-home care. She has performed many roles on both the operations and marketing side of the long-term care business.
Chapter 1

How the Global Dementia Pandemic Continues to Affect Your Law Practice

TIM NAY
Law Offices of Nay and Friedenberg LLC
Portland, Oregon

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How the Global Dementia Pandemic Continues to Affect Your Law Practice ........................................... 1–1
Disorders Causing or Simulating Dementia ........................................................................................................... 1–3
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What is a pandemic? The term *pandemic* is both an adjective and a noun. The Oxford English Dictionary defines a pandemic as an out-break of a disease occurring over a wide geographic area and affecting an exceptionally high proportion of the population. The roots of the global dementia pandemic are set in the post-World War II population explosion known as the Baby Boom.

The return of soldiers from the war triggered an explosion of birth rates in many countries around the world, especially Europe, Asia, North America, and Australasia. Many demographers describe the births between 1946 and 1964 as the Baby Boom generation, although the increased birth rates actually began in 1943 and began to decline after 1957.

Live births in the U.S. surged from 222,721 in January 1946 to 233,452 in May 1946. In October 1946, 339,499 babies were born. By the end of the decade, about 32 million babies had been born, compared to 24 million in the 1930’s. In 1954, annual birth first topped 4 million and did not drop below that figure until 1965, when four out of ten Americans were under the age of 20.¹ Boomers throughout the world began reaching adulthood in the 1960s, and today the oldest members of this huge demographic are approaching their mid-70s.

In less than twenty years, the oldest boomers will begin celebrating their 90th birthdays in increasing numbers. The survivors of the 4 million babies born per year from 1954 through 1964 will swell the number of 80-year olds to unprecedented numbers starting in 2032. In addition, increased life expectancy resulting from advances in medicine has already increased the number of octogenarians in North America, Europe, Asia, and Australasia.

Dementia is not one clinical entity, but many different entities that produce global intellectual decline in multiple cognitive abilities, including memory, calculation, visual-spatial skills, executive function and judgment, language, orientation to time, place, and person, and decreased ability to perform the activities of daily living. These deficits result in significant impairment in social and/or occupational functioning. Dementia is *not* normal aging.

Alzheimer’s dementia impacts the individual and spouse and potentially multiple generations of the individual’s family. The high cost of Alzheimer’s care is estimated to total $290 billion in 2019, increasing to $1.1 trillion in 2050. These costs are not covered by Medicare, Medicare supplement insurance or major medical insurance, leading to potential impoverishment of spouses and multiple generations of families.

Epidemiologists have conclusively shown that the incidence of dementia is most often, although not always, positively correlated with increased age. As a result, members of the boomer generation are coping with the dementia issues of their parents in greater numbers than any demographic “generation” in history because their parents are living longer than ever. These symptoms are now affecting boomers themselves.

In 1982, Congress requested its Office of Technology Assessment (OTA) to prepare a comprehensive report on the impact of Alzheimer’s disease (AD) and other dementias on individuals, their families, communities, the health care industry, and public policy. In April 1987, OTA published its findings on *Losing a Million Minds: Confronting the Tragedy of Alzheimer’s Disease and Other Dementias.*

OTA estimated that 1.5 million Americans suffered from dementia symptoms so severe that they required full-time care and that another 1 to 5 million Americans had mild or moderate dementia. OTA then projected a 60-percent increase by the year 2000. Their estimates were low, not just in the U.S. but in all developed countries as post-WWII populations continue to grow older.

Today, the Alzheimer’s Association, [www.alz.org](http://www.alz.org), estimates that more than 5.8 million Americans, up from 4.5 million in 2006, have moderate to severe AD, with over 65,000 Oregonians affected now, predicting that number will swell to 84,000 by 2025, a 29-percent increase. 5.8 million Americans currently live with AD. One in ten persons over age 65 and nearly half of those over 85 have AD. Almost two thirds of Americans with AD are women.

A Gallup poll commissioned by the Association found that one in ten Americans said that they had a family member with AD and one in three knew someone with the disease. By 2050, the Association estimates that between 11 and 16 million Americans will have Alzheimer’s dementia alone.

Attorney, CPAs, financial planners, and all professional service providers will be increasingly confronted with the medical, psychosocial, ethical, and legal challenges presented by the rapidly developing dementia pandemic, both in their own families and appearing “live” in their offices. Will you be able to meet the challenges posed to your clients and their families?

This program, presented by a highly experienced, multidisciplinary faculty, will help identify and respond to the medical and psychosocial dimensions of the dementia pandemic and enable you to effectively and compassionately assist your clients and their families.
10. Losing a Million Minds: Confronting the Tragedy of Alzheimer’s Disease and Other Dementias

Table 1-1.—Disorders Causing or Simulating Dementia

<table>
<thead>
<tr>
<th>Disorders causing dementia:</th>
<th>Vascular dementia</th>
</tr>
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<tbody>
<tr>
<td>Degenerative diseases:</td>
<td></td>
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<tr>
<td>Alzheimer’s disease</td>
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<td>Pick’s disease</td>
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<td>Huntington’s disease</td>
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<tr>
<td>Progressive supranuclear palsy</td>
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<tr>
<td>Parkinson’s disease (not all cases)</td>
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<tr>
<td>Cerebella degenerations</td>
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<tr>
<td>Amyotrophic lateral sclerosis (ALS) (not all cases)</td>
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<tr>
<td>Parkinson-ALS-dementia complex of Guam and other island areas</td>
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<tr>
<td>Rare genetic and metabolic diseases (Hallervorden-Spatz, Kufs’, Wilson’s, late-onset metachromatic leukodystrophy, adrenoleukodystrophy)</td>
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<tr>
<td>Vascular dementia:</td>
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<tr>
<td>Multi-infarct dementia</td>
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<tr>
<td>Cortical micro-infarcts</td>
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<td>Lacunar dementia (larger infarcts)</td>
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<tr>
<td>Binswanger disease</td>
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<td>Cerebral embolic disease (fat, air, thrombus fragments)</td>
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<tr>
<td>Anoxic dementia:</td>
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<td>Cardiac arrest</td>
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<td>Cardiac failure (severe)</td>
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<td>Carbon monoxide</td>
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<td>Traumatic dementia:</td>
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<td>Dementia pugilistic (boxer’s dementia)</td>
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<tr>
<td>Head injuries (open or closed)</td>
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<tr>
<td>Infectious dementia:</td>
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<td>Acquired immune deficiency syndrome (AIDS)</td>
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<tr>
<td>AIDS dementia</td>
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<td>Opportunistic infections</td>
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<td>Creutzfeld-Jakob disease (subacute spongiform encephalopathy)</td>
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<tr>
<td>Progressive multifocal leukoencephalopathy</td>
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<tr>
<td>Post-encephalitic dementia</td>
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<tr>
<td>Behcet’s syndrome</td>
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<td>Herpes encephalitis</td>
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<td>Fungal meningitis or encephalitis</td>
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<tr>
<td>Bacterial meningitis or encephalitis</td>
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<tr>
<td>Parasitic encephalitis</td>
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<tr>
<td>Brain abscess</td>
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<tr>
<td>Neurosyphilis (general paresis)</td>
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<tr>
<td>Normal pressure hydrocephalus (communicating hydrocephalus of adults)</td>
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<tr>
<td>Space-occupying lesions:</td>
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<tr>
<td>Chronic or acute subdural hematoma</td>
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<td>Primary brain tumor</td>
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<tr>
<td>Metastatic tumors (carcinoma, leukemia, lymphoma, sarcoma)</td>
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<tr>
<td>Multiple sclerosis (some cases)</td>
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<tr>
<td>Auto-immune disorders:</td>
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<tr>
<td>Disseminated lupus erythematosis</td>
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</tbody>
</table>

How The Global Dementia Pandemic Affects Your Practice

Tim Nay, MSW, JD
Law Offices of Nay & Friedenberg LLC
Portland, Oregon
November 22, 2019

Definition of Pandemic

- Adjective or noun.
- Outbreak of disease occurring over a wide geographic area.
- Affecting an exceptionally high proportion of the population.
- Dementia correlated with increased age.
- The Baby Boom and increased life expectancy fueling the dementia pandemic.
The Baby Boom

• The surge of births between 1943-1964.
• Seen in North America, Europe, Asia and Australasia.
• 32 million U.S. births between 1940-1949 compared to 24 million from 1930-1939.
• 48 million U.S. births or more 1954-1964.
• Globally, the oldest Boomers reached age 60 in 2003, age 80 in 2023.

The Baby Boom

The fastest growing segment of population in North America, Europe and Australasia: Age 85 and older.
Chapter 1—How the Global Dementia Pandemic Continues to Affect Your Law Practice

Special Report: America at 300 Million,
Time Magazine, October 30, 2006

1915
100 Million

Age Distribution

0-4
35-39
75+

8%
4%
1.3%

1967
200 Million

Age Distribution

0-4
35-39
75+

4%
3.6%
Chapter 1—How the Global Dementia Pandemic Continues to Affect Your Law Practice

Special Report: America at 300 Million, Time Magazine, October 30, 2006

### 2006

**300 Million**

**Age Distribution**

<table>
<thead>
<tr>
<th>Age Group</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>0-4</td>
<td>6.1%</td>
</tr>
<tr>
<td>35-39</td>
<td>4%</td>
</tr>
<tr>
<td>75+</td>
<td>4%</td>
</tr>
</tbody>
</table>

Special Report: America at 300 Million, Time Magazine, October 30, 2006

### 2040-50

**400 Million**

**Projected Age Distribution**

<table>
<thead>
<tr>
<th>Age Group</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>0-4</td>
<td>11.6%</td>
</tr>
<tr>
<td>35-39</td>
<td>4%</td>
</tr>
<tr>
<td>75+</td>
<td>4%</td>
</tr>
</tbody>
</table>

Special Report: America at 300 Million, Time Magazine, October 30, 2006
Dementia and Aging

• Dementia: Not one clinical entity.
• Over 50 identified diagnostic categories.
• Incidence most often correlated with increased age.
• See Table 1.1, “Disorders Causing or Simulating Dementia.”

Features of Dementia

• Multi-faceted global intellectual decline.
• Memory impairment, short term first.
• Reduced ability to perform calculations.
• Impaired visual-spatial orientation.
• Deficits in executive function & judgment.
• Decreased language abilities.
• Impaired orientation to time, place, person.
• Decreased self care skills.
Chapter 1—How the Global Dementia Pandemic Continues to Affect Your Law Practice

Features of Dementia

- Significant impairment in social and occupational functioning.
- Alzheimer’s Disease is the most common form of dementia.
- Dementia is NOT normal aging.
- Benign Forgetfulness or Age Associated Memory Impairment is NOT Alzheimer’s Disease.

Dementia Demographics: Then and Now

- 1987: Losing A Million Minds: Confronting The Tragedy of Alzheimer’s Disease and Other Dementias published by the Office of Technology Assessment.
- Estimated that 1.5 million Americans with dementia required full time care.
- Estimated that another one to five million Americans had mild or moderate dementia.
- Predicted a 60% increase by year 2000.
Dementia Demographics
Then and Now

• 2019: The Alzheimer’s Association estimates that over 5.8 million Americans live with AD.

• Oregonians with AD estimated to exceed 65,000 now and 84,000 by 2025, a 29% increase. A.D. is the 6th leading cause of death in the U.S.

• One in ten persons over 65 and half of those over 85 have AD.

Dementia Demographics
Then and Now

• A recent Gallup poll found 1 in 10 Americans had a family member with AD.

• 1 in 3 knew someone with AD.

• By 2050, the Alzheimer’s Association estimates that 11 to 14 million Americans will have AD.

• Cost of care: $290 billion 2019; $1.1 trillion in 2050.
How The Dementia Pandemic Will Affect Your Practice

• People with dementia will be seen increasingly by attorneys, accountants, financial planners, insurance agents and other professional service providers.
• This includes themselves, their parents, spouses, children and clients.
• As we age, some of us will become part of the dementia pandemic.

How The Dementia Demographic Will Affect Your Practice

Specific challenges raised by dementia:
1. Surrogate Legal/Financial/Medical Decision Making
2. Cognitive Capacity Determinations
3. Effect On Families, Family Dynamics
4. Cost of Care
5. Medicaid Eligibility
6. Who Is Your Client?
Chapter 2

Presentation Slides: The Changing Face of Alzheimer Disease (Major Neurocognitive Disorder)

ELIZABETH ECKSTROM, MD
Professor of Medicine
Division of General Internal Medicine and Geriatrics School of Medicine
Oregon Health & Science University
Portland, Oregon
65,000 People in Oregon
84,000 by 2025
What Epidemic is this?

The Changing Face of Alzheimer Disease
(Major Neurocognitive Disorder)

ELIZABETH ECKSTROM, MD, MPH
OREGON HEALTH & SCIENCE UNIVERSITY
OREGON CLINICAL & TRANSLATIONAL RESEARCH INSTITUTE

Today we will discuss

Symptoms of Dementia- and how do you tell what type it is?
How do you manage dementia with patients and families?
What is the prognosis?
Can we be hopeful for the future?
The Burden of Dementia

Over 5 million Americans have dementia; by 2050, up to 16 million will have dementia

6th leading cause of death in the US and in Oregon

In 2014, dementia cost $214 billion, including $150 billion in costs to Medicare and Medicaid. Dementia costs more than cancer and heart disease COMBINED

Nearly one in every five dollars of Medicare spending is spent on people with dementia

Mrs. Atkinson

82 and living independently

Her husband died 6 months ago.

Increasing “forgetfulness” worse since her husband died

Having trouble paying the bills
New DSM-V Terminology: Major Neurocognitive Disorder (MCD)

Clear deficits in objective assessment of:
- **Complex attention** (sustained attention, divided attention, selective attention, processing speed)
- **Executive ability** (planning, decision making, response to feedback/error correction, mental flexibility)
- **Learning and memory** (immediate or recent)
- **Language** (expressive and receptive)
- **Visuoconstructual perceptual ability**
- **Social cognition (emotions, behavioral regulation)**

Deficits interfere with independence (IADLs)

---

Minor Neurocognitive Disorder (Mild Cognitive Impairment)

Minor cognitive *decline from a previous level of performance*

- No interference with function but greater effort and compensatory strategies required to maintain independence.
- 50% progress to dementia within 7.6 years
- Probably a pre-dementia state as almost all patients with MCI will develop dementia in 7-14 years
- Amnestic MCI- memory loss key feature, progresses to Alzheimer
- Non-Amnestic MCI- decline in executive function (or another brain area) without memory decline
Dementia Quick Screen-Consider for everyone over 75


- **3-Item recall**
  - ask the patient to remember the names of three objects (pencil, truck, book)
  - the patient fails the screen if she is unable to remember at least 2 of 3 objects in one minute (after the clock draw)

- **Clock Draw**
  - ask patient to draw a large circle, fill in the numbers on a clock face, and set the hands at 11:10

---

**Abnormal Face**

**Clock Draw**- tests memory, visual-spatial, executive function, abstraction

**Abnormal Numbers**

**Abnormal Hands**

Bottom Line- if not PERFECT, patient has some cognitive impairment
MoCA

Now has a certification program so potentially someone in your office could be trained to do it.
Alzheimer Dementia

- Impairment in **learning and retaining new information** plus at least one:
  - **Complex attention** (sustained attention, divided attention, selective attention, processing speed)
  - **Executive ability** (planning, decision making, response to feedback/error correction, mental flexibility)
  - **Language** (expressive and receptive)
  - **Visuoconstructional perceptual ability**
  - **Social cognition** (emotions, behavioral regulation)

Prognosis?

---

**MoCA**

In Alzheimer Disease, impairments in memory, orientation, and at least one other area
Vascular Dementia

- Signs of a stroke or mini-stroke (TIA) such as weakness, speech difficulty, gait disturbance
- Signs of stroke on CT scan or MRI
- Cognitive decline happens within 3 months of stroke or has abrupt, fluctuating or stepwise deterioration

- Prognosis?

MoCA

In Vascular Dementia, impairments in visuospatial, attention, and maybe language and abstraction

Can have memory deficits and is often MIXED Alzheimer and Vascular Dementia
Lewy Body Dementia

Parkinsonian findings: shuffling gait, rigidity, trouble swallowing
Fluctuation in LOC and cognition
Well formed visual hallucinations
Attention, executive function and visual-spatial abnormalities may be more prominent than memory problems
REM sleep disorders (ie frightening dreams)
Prognosis?

MoCA

In Lewy Body Dementia, impairments in visuospatial, attention, and maybe language and abstraction
Frontotemporal Dementia

• Decline in personal or social interpersonal conduct
  • loss of empathy, socially inappropriate behaviors (rude, irresponsible, sexually explicit), mental rigidity, inflexibility in relationships or severe apathy

• Impaired reasoning and difficulty with tasks out of proportion to impairments in memory, visual-spatial skills

• May have marked language, gait abnormalities

• May have younger age of onset

Prognosis?

MoCA

Frontotemporal dementia patients may test much better than their function might suggest- memory might be normal!
Conversations with patients

**MOCA**

Mild Cognitive Impairment

Early Dementia

Conversations with patient:
- “What are your wishes?”
- “What's it going to look like?”
- “We're there now.”
  - Plan: Assisted living options
  - What is our safety plan?
  - Psychotic or behavior symptoms
  - Day-night reversal symptoms
  - Safe Return Alz. Assoc. Bracelet
  - CONSIDER DONEPEZIL

Moderate Dementia

Conversations with caregiver:
- Loss of verbal interaction
- Loss of mobility
- Incontinence
- Aspiration/choking
- Weight loss
- Increased ADL needs
  - Discontinue yearly cognitive testing
  - FAST staging for prognosis (7c = hospice)
  - Med reduction vs continue MEMANTINE

Advanced Dementia

Up to ½ of years advanced dementia

Slide thanks to Mary Pickett, MD

Mrs. Atkinson

MOCA: oriented
- X4 of 6, registers 5 items, but able to recall only 1 of 5
- misses trails and clock, misses 2 on attention, in total she scored 18/30
Key Information for Patients and Families

<table>
<thead>
<tr>
<th>Diagnosis</th>
<th>What to expect in the course of illness</th>
</tr>
</thead>
<tbody>
<tr>
<td>Treatments</td>
<td>Are there medications to slow progression? <em>(none eliminate or cure)</em></td>
</tr>
<tr>
<td>What resources can we provide?</td>
<td>Education <em>(Alz. Assn)</em></td>
</tr>
<tr>
<td>What plans should they make?</td>
<td>Caregiver support</td>
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<tr>
<td></td>
<td>Retiring from Driving</td>
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<tr>
<td></td>
<td>Increasing caregiver management of meds as patient status declines</td>
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<td></td>
<td>Feeding when can’t swallow</td>
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<td></td>
<td>Care- by whom and where</td>
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<td></td>
<td>End of Life; Allowing Natural Death</td>
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</tbody>
</table>

Dementia Advance Planning

“Allow natural death” for patients with dementia

Eventually patients with dementia cannot eat or swallow on their own, feeding tubes do not prolong life or improve quality of life; best to address early in course

Hospice eligibility in dementia: Patient can no longer perform own ADLs, plus can speak no more than 6 words at a time, plus have another dementia related comorbidity (aspiration pneumonia, weight loss >10% body weight, etc).

Consideration of memory units, home caregiving, other options
Mrs. Atkinson

What type of dementia does she have?

What do you need to tell her daughter?

What else do you need to attend to?

Table 1. Hospice Guidelines for Estimating Survival of Less Than 6 Months in a Patient with Dementia.

<table>
<thead>
<tr>
<th>Stage</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stage 1:</td>
<td>Has no objective or subjective difficulties</td>
</tr>
<tr>
<td>Stage 2:</td>
<td>Has subjective complaints of forgetting</td>
</tr>
<tr>
<td>Stage 3:</td>
<td>Has decreased job functioning that is evident to coworkers and difficulty traveling to new locations</td>
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<tr>
<td>Stage 4:</td>
<td>Has decreased ability to perform complex tasks (e.g., planning dinner for guests, handling finances)</td>
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<tr>
<td>Stage 5:</td>
<td>Requires assistance in choosing proper clothes for the day, season, or occasion</td>
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<tr>
<td>Stage 6a:</td>
<td>Cannot dress without assistance, occasionally or frequently</td>
</tr>
<tr>
<td>Stage 6b:</td>
<td>Cannot bathe without assistance, occasionally or frequently</td>
</tr>
<tr>
<td>Stage 6c:</td>
<td>Cannot perform mechanics of toileting</td>
</tr>
<tr>
<td>Stage 6d:</td>
<td>Incontinent of urine, occasionally or frequently</td>
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<tr>
<td>Stage 6e:</td>
<td>Incontinent of bowel, occasionally or frequently</td>
</tr>
<tr>
<td>Stage 7a:</td>
<td>Has speech limited to fewer than six intelligible words during an average day</td>
</tr>
<tr>
<td>Stage 7b:</td>
<td>Has speech limited to one intelligible word during an average day</td>
</tr>
<tr>
<td>Stage 7c:</td>
<td>Is unable to ambulate independently</td>
</tr>
</tbody>
</table>
Is the future all doom and gloom in dementia care?

NO!! Good news is the INCIDENCE of dementia is going down

Prevalence is still going UP do to increasing older adults

Over 30% of dementia is preventable with lifestyle factors- start now!

Exercise for Brain Health
Elizabeth’s Exercise Prescription

- Aerobic Exercise for 30 minutes daily (such as biking)
- Balance exercise like tai chi for one hour 3 days per week
- Strength training twice per week

What about cognitive training?

Cognitive training improves brain health and may delay onset of functional impairment by 6 years.

The number of people affected by 2050 would be reduced by 38% which would be of great public health significance.
## Diet

### Other Steps

**Minimize Medications**
- Avoid sleeping pills, anticholinergics, and antihistamines
- Review medications at every visit and reduce if possible
- If you try a medication for a symptom and it doesn’t help – stop it!

**Maintain sleep**
- “Ideal” is about 7 hours per night
- “Normal” is 5-9 hours per night
- Older people often have a “split” night- sleeping earlier (9 pm- midnight) and again later (3-7 am)
- Exercise every morning, turn off the TV and computer after 6 pm, avoid caffeine and alcohol to allow optimal sleep
- Don’t use sleeping pills!
Thank you for all you do to help keep our older adults healthy and happy!

Questions?
Elizabeth Eckstrom, MD, MPH
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Chapter 3

Presentation Slides: The Impact of Dementia: Helping Families Navigate the Path of Decline

Allison Lindauer, RN, PhD
Oregon Health & Science University
Portland, Oregon
The Impact of Dementia: Helping Families Navigate the Path of Decline

Allison Lindauer, PhD, NP
Assistant Professor,
Layton Aging and Alzheimer’s Disease Center & OHSU School of Nursing

About us…

The Layton Aging & Alzheimer’s Disease Center at OHSU is one of 30 NIH Alzheimer’s Disease Centers in the United States and the only one of its kind in Oregon.

The Layton Center conducts studies of promising treatments, technologies for patient support, genetics, neuroimaging and pathology.

Along with research, we also provide evaluation and treatment for persons with dementia and their family members.

Lindauer@ohsu.edu
503-494-7615
Objectives

- Psychosocial and economic impact
- The challenges of dementia
- Key decisions over time
- The needs of family caregivers

Review

- Alzheimer’s disease and related dementias are a group of neurodegenerative conditions that affect the entire family
- Families need care and support across the disease spectrum
- Burden, grief, confusion can affect decision-making
- The experience can result in personal growth, new relationships and pride.
A common story

Linda is a teacher in a large elementary school. She has been at the school for over 20 years and is a respected leader and mentor. Linda and Carl have been married for 30 years.

Linda has growing concerns about Carl’s memory. He is forgetting important dates (her birthday), spending more money and getting lost driving in familiar neighborhoods. Carl’s doctor tells them she thinks Carl’s memory is “just normal aging.”

Carl is annoyed with Linda and tells her she is “looking for something that’s not there.”

Linda is worried about Carl, but also wonders if she is imagining things. Linda and Carl’s daughter, Ashley, also has some concerns about Carl’s memory, but she lives 500 miles away and doesn’t feel like she should “judge” her dad.

Early stage

Challenges of dementia

- Anosognosia, fear, therapeutic nihilism, stigma

Psychosocial and economic impact

- Frustration, grief, burden
- Financial challenges (medical expenses, time off work)

The needs of family caregivers

- Validation: If a friend or family member expresses concern about memory, believe them and get an assessment.
- POA, FMLA

Key decisions

- Change doctors? See a specialist? Enlist daughter? Ignore?
- Advance directives: Engage Carl as a meaningful partner
Dementia as a Cultural Metaphor
Zeilig, 2013, *The Gerontologist*

“Above all, for most of us, the word dementia like AD invokes a profound dread. Dementia has replaced cancer as the scourge of modern times (Van Gorp & Vercruysse, 2012, p. 1274). The discourses of the scientific community reinforce this pervasive sense of horror about dementia and AD. For example, the prevalence of dementias is described in dramatic terms as an “epidemic” and a “crisis” (Mandell & Green, 2011, p. 4). The economic burden of disease is often noted (Knapp & Prince, 2007) and AD is frequently referred to as a ‘plague.’” (p.260)

---

**Early Stage: “Need to know”**

- About 50% of those with dementia do not have a formal diagnosis
- The diagnosis is emotionally difficult, but can be validating
  - Allows lifestyle changes
  - Opportunities to engage in research
  - Access to support
  - An opportunity to plan ahead: POA, FMLA, Advance Directive, finances, POLST
  - A review of priorities
Family meeting

• “Please don’t say ‘dementia’ or ‘Alzheimer’s’ in front of Carl. He doesn’t think he has a problem.”
  – Meet one-to-one
  – Family as experts
  – Use “memory loss” or “memory changes.”
  – Other approaches?

A common story

Carl agreed to see a clinician who is familiar with dementia. After cognitive testing and a brain MRI, the clinician informed them that the diagnosis is Alzheimer’s disease, early stage.

Over the next three years, Carl’s dementia progressed. His memory worsened, but it was the behavioral symptoms that were most distressing to Linda. Carl would walk out of the house and wander in the neighborhood. Linda put locks on the doors. However, Carl would get very irritated: “I need to get to work, dammit!”

Linda took early retirement to care for Carl (“I promised him I would never institutionalize him”). Linda did all the cooking, grocery shopping, laundry. She reminded Carl to bathe and brush his teeth.

Over time, Carl became more irritable and disinhibited. Gradually, visits from friends tapered off. Linda felt lonely and depressed. Ashley visited every 6 months, but the visits were upsetting.
Moderate stage

**Challenges of dementia**
- Personality changes, behavioral symptoms, need for supervision

**Psychosocial and economic impact**
- Isolation, depression, grief, anger, burden
- Increasing risk: Depression, hypertension, cognitive impairment
- Financial challenges: Early retirement, pay for respite?

**The needs of family caregivers**
- Anticipatory guidance
- Referral for support (including family)
- Financial planning

**Key decisions**
- POA, advance directive, POLST: Need clarity on who makes decisions
- Respite for Linda
- Facilitate effective decision-making

Moderate stage: “More and Less”

- More behavioral symptoms
- More need for supervision and care
- More demands on time
- More stress
- Greater expense
- More guilt, grief, frustration

- Less support
- Less sleep
- Less money
- Less self-care

“Your so-called friends disappear, because they don’t want to have to be involved. They perceive they could be called on and so you’re left with perhaps two or three people who’ve got problems of their own.”

(Green, Pound, Brearly, Smith, 2019, p.3)
Who provides care in Oregon?

- 67,000 Oregonians with dementia, projected to increase to 84,000 by 2025
  - (23,000 new cancer diagnoses in 2019 in Oregon)
- 186,000 caregivers in Oregon
- Unpaid care provided by families valued at 2.7 billion
- No effective treatments, no cure
- Average course of dementia 4-8 years

Caregiver risks

- Burden
- Depression
- Hypertension
- Immune function
- Sleep

(Fonareva, 2014)

- Attention
- Concentration
- Processing speed
- 6-fold increase in risk of developing dementia (spouses)

(Norton et al., 2010)

Protective: Exercise, respite, education
Lack of choice in the caregiving role caused feelings of obligation, distress and resentment. In some instances, the unwillingness of other family members to assist in the care of the parent with dementia lead to one person feeling they had no choice in adopting the role of primary caregiver...

Participants also noted that once they had been established as the primary caregiver, other family members were even less likely to offer help and support. This sense of expectation and lack of appreciation was a source of frustration and isolation for the caregiver.

(Tatangelo et al. 2018, p. e372)
Financial issues

Dementia is expensive:

• Total health care spending in the last 5 years of life for those with dementia: $287,083
• Total health care spending in the last 5 years of life for those without dementia: $183,001
• Medicare does not cover non-rehabilitative nursing care or in-home care.
• Families must “spend down” to assets valued at $2,000 (can keep home worth <585,000, clothing, household furnishings)

In residential care, Certified Nursing Assistants (CNA's) make, on average $31,310/year (poverty level for family of 4=$25,7500).
A common story

Carl’s dementia advances. He needs help with all his needs (bathing, dressing, personal care). He no longer recognizes Linda or his daughter. He is less irritable, but paces in the house a lot (“he’s wearing down a path in our carpet”). He goes to bed around 7, sleeps until about 2, and is very active from 2 until late morning. Linda sleeps when he does, but she is feeling worn out. Carl attends an adult day program 3 days/week, but even with this, Linda is exhausted. She is considering placing Carl in memory care, a plan their daughter supports.

Carl’s sister Cathy, pays a visit to them. She lives out of state. She is grateful to Linda for her care, but thinks Linda’s plan to place him is a bad idea: “I know it will just kill him.”

Late stage dementia

• Family caregivers often exhausted
• Placement allows for normal life, but grief and burden persist
• Limbo is difficult, often wish for the death of the person with dementia
Impact on the family

Challenges of dementia
- Unable to care for self, dependent on others for most care
- Unable to communicate needs verbally (e.g., pain, hunger)

Psychosocial and economic impact
- Guilt, grief, gratitude
- Financial challenges: How to pay for care?

The needs of family caregivers
- Help stay focused, recognize decisions are often not clear
- How to stay financially solvent

Key decisions
- Stand by decision maker
- Identify appropriate facility and how to fund
- Plan to avoid re-location

A common story

Carl is now in memory care. Linda likes the facility and is generally happy with the care. Cathy is angry and not speaking to Linda. Carl seems generally content.

Carl spend most of his days in bed, needs full care. Based on a nurse’s recommendation, Carl now receives hospice services. The hospice pastor is working with Linda to reconcile with Cathy.
Impact on the family

**Challenges of dementia**
- Unable to care for self, dependent on others for all care
- A “shell of himself.”

**Psychosocial and economic impact**
- Guilt, grief, gratitude, acceptance
- Wishing for death

**The needs of family caregivers**
- Plan for death
- Plan for life changes after death

**Key decisions**
- Burial and inheritance decisions

**Advance directives are active documents**

“I returned to find Mom slumped in her wheelchair, completely unresponsive. I called Mom’s doctor. They told me it was my decision. Mom is DNR: Do Not Resuscitate. Do Not Intubate. Do Not Hospitalize. I could change my mind anytime, but sending her to the hospital would mean aggressive, life-extending treatment. Wow. This was a first. This was not black or white. I hit the gray line.”

A common story

Carl dies a year after hospice care has started. His death is peaceful. Linda and Ashley visited the evening of his death and were able to say goodbye. Cathy remains bitter.

Early in the disease process, Carl asked to be cremated and have a celebration of life event. Linda and Ashley were able to follow his wishes. Cathy did not attend. Linda and Ashley mailed the scrapbooks from Carl’s childhood to Cathy, with a loving note, hoping she’ll reach out.

Impact on the family

Challenges of dementia

- A dignified death

Psychosocial and economic impact

- Grief plus relief

The needs of family caregivers

- Plan for life changes after death

Key decisions

- Burial and inheritance decisions
Summary

• Alzheimer’s disease and related dementias are a group of neurodegenerative conditions that affect the entire family
• Families need care and support across the disease spectrum
• Burden, grief, confusion can affect decision-making
• The experience can result in personal growth, new relationships and pride.

Thank You
# Chapter 4

## The Face of Alzheimer’s

**Heidi Rowell**  
Program Director  
Alzheimer’s Association Oregon Chapter  
Portland, Oregon

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10 Warning Signs of Alzheimer’s
10 Warning Signs of Alzheimer’s

1. Memory loss that disrupts daily life.

2. Challenges in planning or solving problems.
10 Warning Signs of Alzheimer’s

3 Difficulty completing familiar tasks.

4 Confusion with time or place.
10 Warning Signs of Alzheimer’s

5. Trouble understanding visual images and spatial relationships.

6. New problems with words in speaking or writing.
10 Warning Signs of Alzheimer’s

7. Misplacing things and losing the ability to retrace steps.

8. Decreased or poor judgment.
10 Warning Signs of Alzheimer’s

9 Withdrawal from work or social activities.

10 Changes in mood and personality.
10 Warning Signs of Alzheimer’s

• It’s possible for individuals to experience one or more of these signs in varying degrees.
• It’s not necessary to experience every sign in order to raise concern.
• If you notice one or more signs in yourself or another person it’s important to see a doctor.
• Visit alz.org/10signs to learn more about the 10 Warning Signs of Alzheimer’s.
Common Challenges

• Stigma and diagnosis rate
• Education and support needed for caregivers

Common Challenges

• Challenging behaviors
• Difficult conversations
• Caregiver burnout
Alzheimer’s Association
Resources

Mission

To eliminate Alzheimer’s disease through the advancement of research; to provide and enhance care and support for all affected; and to reduce the risk of dementia through the promotion of brain health.
Vision

A world without Alzheimer’s disease®.

Who We Are

We are the leading, global voluntary health organization in Alzheimer's care and support, and the largest private, nonprofit funder of Alzheimer's research.

Serving all 36 counties in Oregon as well as Clark and Skamania counties in Washington, we are here to help. We provide education and support to all those facing Alzheimer's and other dementias. We are also committed to advocating for the needs and rights of those facing dementia and advancing critical research towards a cure.
2019 Facts & Figures

Alzheimer’s Disease is the 6th leading cause of death in the United States.

Nearly two-thirds of those with Alzheimer’s are women.

More than 16 million Americans provide unpaid care for people with Alzheimer’s or other dementias.

Breast cancer and prostate cancer combined.

More than 5 million Americans are living with Alzheimer’s.

Every 65 seconds, someone in the United States develops the disease.

What Do We Do?
Enhance Care and Support

The Association provides and enhances care and support for all those impacted by Alzheimer’s disease.

- Provide a free 24/7 Helpline (1-800-272-3900) that receives more than 310,000 calls annually.

- Host ALZConnected® (alzconnected.org), a forum for connecting people with the disease, caregivers and family members. Over 400,000 people find support and answers to their questions through this online community.

- Offer face-to-face support groups and educational sessions in communities nationwide.

Increase Concern & Awareness

We increase concern and awareness of Alzheimer’s disease and the Alzheimer’s Association in many ways.

- Provide educational programs and workshops about the basics and 10 Warning Signs of Alzheimer’s Disease.

- Implement far-reaching campaigns to promote the power of early detection.

- Offer a variety of free resources at alz.org®, which receives more than 2 million visits each month.
Strengthen Diversity & Inclusion

Initiatives to increase diversity and inclusion are necessary to effectively address the organization’s full mission.

Our efforts focus on populations that historically have disproportionate burden of Alzheimer’s and dementia to address health equity.

• African American
• Latino
• LGBTQ

Advance Public Policy

The Association is the leading voice in Alzheimer’s policy, advocating at the global, federal and state level.

Help pass landmark legislation, such as the National Alzheimer’s Project Act, which mandated a national plan to fight Alzheimer’s disease.

Ensure federal policy and our research agenda reflects the urgency of the Alzheimer’s epidemic.

Led the way to the passage of a historic $414 million increase for Alzheimer’s disease research funding.
Chapter 4—The Face of Alzheimer’s

Accelerate Research

The Alzheimer’s Association is the highest impact nonprofit funder of Alzheimer's disease research in the world, ranking in overall impact behind only the Chinese and United States governments.

- Invest over $475 million in nearly 3,000 scientific investigations.
- Convene global research leaders to achieve landmark accomplishments, such as new diagnostic criteria.
- Support cutting-edge projects that investigate methods of prevention and treatment.

Care & Support Overview
Care Consultations

Our confidential care consultations help with decision-making support, crisis assistance and education on issues families face daily.

• Consultations are provided in person and by phone

Support Groups

We provide support groups for caregivers and families dealing with Alzheimer’s disease and other dementias.

• Early-stage & ongoing for the caregiver
• In person and via phone
Chapter 4—The Face of Alzheimer’s

Education

• 10 Warning Signs of Alzheimer’s Disease
• Understanding Alzheimer’s and Dementia
• Getting Started
• Dementia Conversations
• Legal and Financial Planning for Alzheimer’s
• Living With Alzheimer’s Series (Offered for caregivers and people living with the disease)
• Effective Communication Strategies
• Understanding and Responding to Dementia-Related Behavior
• Healthy Living for Your Brain and Body

Early-Stage Engagement

Early-stage programs engage those living with early-stage Alzheimer’s disease to improve quality of life. Programs focus on arts engagement, emotional support, physical activity and more.

• Memories in the Making
• Sing Here Now
• artNOW
• Reflections and Connections
Chapter 4—The Face of Alzheimer’s

24/7 Helpline

The Alzheimer’s Association 24/7 Helpline provides reliable information and support to all those who need assistance. Call us toll-free anytime day or night at 1.800.272.3900.

- Confidential care consultation provided by master's level clinicians
- More than 200 languages and dialects
- Referrals to local community programs, services and ongoing support

Free Resources

- **24/7 Helpline**: 800-272-3900
- **Online caregiver center**: alz.org/care/
- **TrialMatch**: alz.org/trialmatch
- **AlzConnected®**: alzconnected.org
- **Alzheimer’s Navigator®**: alzheimersnavigator.org
- **Community Resource Finder**: communityresourcefinder.org
- **Alzheimer’s Association MedicAlert® + Alzheimer’s Association Safe Return®**: alz.org/safereturn
THERE IS HOPE

Scientists believe we are at a tipping point. We have the scientists, research methodology, technology and the will to overcome Alzheimer’s.
National Plan to Address Alzheimer’s Disease

The National Alzheimer’s Project Act (NAPA)—bipartisan legislation unanimously approved by Congress—required the creation of an annually updated national strategic plan to address the rapidly escalating Alzheimer’s crisis.

**Five Goals:**

- Prevent and effectively treat Alzheimer’s disease by 2025
- Enhance care quality and efficiency
- Expand supports for people with Alzheimer’s disease and their families
- Enhance public awareness and engagement
- Improve data to track progress.

The Plan calls for coordinating research efforts with international public and private entities.
Alzheimer’s Association
Global Research Investment

$167 million
500+ projects
27 countries

Connector • Convener • Funder • Catalyst
It's never too late or too early to incorporate healthy habits.

Alzheimer’s and Related Dementia Research Funding at the NIH

2011: $448M  
2012: $503M  
2013: $504M  
2014: $562M  
2015: $631M  
2016: $951M  
2017: $1.4B  
2018: $1.9B  
2019: $2.3B

We’re here for you day or night – whenever you need us.

24/7 HELPLINE
800.272.3900 | alz.org

Alzheimer’s Navigator
Community Resource Finder
Dementia Caregiver Center

Services and support for you and your family:
Education • Support Groups • Early-Stage Programs • Advocacy • Research
OREGON & SW WASHINGTON CHAPTER
ABOUT THE OREGON & SW WASHINGTON CHAPTER

We are the leading, global voluntary health organization in Alzheimer’s care and support, and the largest private, nonprofit funder of Alzheimer's research. We serve the state of Oregon, and Clark and Skamania counties in SW Washington.

OUR MISSION
To eliminate Alzheimer’s disease through the advancement of research; to provide and enhance care and support for all affected; and to reduce the risk of dementia through the promotion of brain health.

OUR VISION
A world without Alzheimer’s disease®.
PROGRAMS & SERVICES

24/7 HELPLINE – 800-272-3900
The 24/7 Helpline provides reliable information and support to all those who need assistance.

CARE CONSULTATIONS
Our confidential care consultations help with decision-making support, crisis assistance and education on issues families face daily.

ONLINE CAREGIVER CENTER
Find the resources and information you need online, including our Community Resource Finder and Care Team Calendar.

COMMUNITY EDUCATIONAL PROGRAMS
We offer a variety of free educational programs both online and in person in your local community.

SUPPORT GROUPS
We provide support groups for caregivers and families dealing with Alzheimer’s disease and other dementias.

EARLY-STAGE ENGAGEMENT PROGRAMS
Early-stage programs engage those living with early-stage Alzheimer’s disease to improve quality of life. Programs focus on arts engagement, emotional support, physical activity and more.

SAFETY SERVICES
Our MedicAlert® + Alzheimer’s Association Safe Return® services are designed to support individuals with a diagnosis of Alzheimer’s disease or another dementia and their caregivers.

HEALTH CARE PROVIDER OUTREACH
We assist health care providers in connecting patients to our free services through our fax referral program, “Purple Packet” support materials and prescription pads.
EDUCATIONAL PROGRAMS

Educational opportunities are available for anyone interested in learning more about Alzheimer’s disease, including family and professional caregivers, people with memory loss, and the general public. Community classes are offered online and in person.

SNAPSHOT OF CLASSES

**Understanding Alzheimer’s and Dementia**
This program provides information on detection, causes and risk factors, stages of the disease, and treatment, among other topics.

**Know the 10 Signs: Early Detection Matters**
This training covers the 10 Warning Signs of Alzheimer’s disease. The class will separate myth from reality, address commonly-held fears about Alzheimer’s in America and educate participants how to recognize the signs in daily life.

**Effective Communication Strategies**
This class decodes the verbal and behavioral messages delivered by someone with dementia and identifies strategies to help connect and communicate at each stage of the disease.

EDUCATIONAL PROGRAMS OFFERED

- Know the 10 Signs: Early Detection Matters
- Understanding Alzheimer’s and Dementia
- Getting Started
- Dementia Conversations
- Legal and Financial Planning for Alzheimer’s
- Living With Alzheimer’s Series *(Offered for caregivers and people living with the disease)*
- Effective Communication Strategies
- Understanding and Responding to Dementia-Related Behavior
- Healthy Living for Your Brain and Body

*To learn more or register, please call 1-800-272-3900.*
MAKING A DIFFERENCE

RESEARCH

alz.org/research

The Alzheimer’s Association is committed to accelerating the global effort to eliminate Alzheimer’s disease. We are the largest nonprofit funder of Alzheimer’s research. Help advance research with our TrialMatch® clinical studies matching service. Learn more: www.alz.org/trialmatch.

ADVOCACY

alz.org/advocacy

We are the leading voice for Alzheimer’s disease advocacy, fighting for critical Alzheimer’s research, prevention and care initiatives at the state and federal level. The Alzheimer’s Impact Movement (AIM) is the advocacy arm of the Alzheimer’s Association. Learn more: www.alzimpact.org.

VOLUNTEER OPPORTUNITIES

alz.org/oregon

Our volunteers are passionate and inspired, and they want to make a difference in the fight against Alzheimer’s disease. We offer a wide variety of opportunities to meet your specific talents and needs.
CHAPTER EVENTS

Reason to Hope Community Breakfast
*Portland*
Educational event that shares our mission with the community and raises funds for the cause.

[alz.org/oregon]

Advocacy Day
*Salem & Olympia*
Make your voice heard at the Oregon State Capitol in Salem or the Washington State Capitol in Olympia.

[alz.org/oregon]

Discovery Conference
*Seattle*
Attend a day packed with evidence-based information and education about dementia.

[alzwa.org]

Advocacy Forum
*Washington, D.C.*
Join more than 1,000 advocates in Washington, D.C. to advocate for research and care and support services.

[alz.org/forum]
ACROSS OREGON & SW WASHINGTON

Memories in the Making
Art Auction & Gala
Portland
Silent and live auction that benefits Memories in the Making®, a fine arts watercolor program for people with dementia.

Mimaa.org

The Longest Day®
Nationwide
Teams across the nation select an activity they love – from swimming to scrapbooking – to help end Alzheimer’s.

Alz.org/TLD

Walk to End Alzheimer’s®
Central Oregon, Eugene, Willamette Valley, Portland, Roseburg, Southern Oregon, Vancouver
The world’s largest event to raise awareness and funds for Alzheimer’s care, support and research.

Alz.org/walk

McGinty Conference on Alzheimer’s
Portland
Oregon’s leading dementia research and education event for caregivers.

Alz.org/oregon
The Alzheimer’s Association is the leading voluntary health organization in Alzheimer’s care, support and research. Our mission is to eliminate Alzheimer’s disease through the advancement of research; to provide and enhance care and support for all affected; and to reduce the risk of dementia through the promotion of brain health.

Our vision is a world without Alzheimer’s disease®.
2019 ALZHEIMER’S DISEASE FACTS AND FIGURES

Alzheimer’s Disease is the 6th leading cause of death in the United States

5.8 MILLION Americans are living with Alzheimer’s

BY 2050, this number is projected to rise to nearly 14 MILLION

MORE THAN 16 MILLION AMERICANS provide unpaid care for people with Alzheimer’s or other dementias

These caregivers provided an estimated 18.5 BILLION HOURS valued at nearly $234 BILLION

IN 2019, Alzheimer’s and other dementias will cost the nation $290 BILLION

BY 2050, these costs could rise as high as $1.1 TRILLION

82% of seniors say it’s important to have their thinking or memory checked

BUT ONLY 16% say they receive regular cognitive assessments

EVERY 65 SECONDS someone in the United States develops the disease

Between 2000 and 2017 deaths from heart disease have decreased 9% while deaths from Alzheimer’s disease have increased 145%

1 IN 3 seniors dies with Alzheimer’s or another dementia

It kills more than breast cancer and prostate cancer COMBINED
Chapter 4—The Face of Alzheimer’s

Alzheimer’s Disease and Other Dementia: The Pandemic Affecting Your Practice—2019 Update

For more information, view the 2019 Alzheimer’s Disease Facts and Figures report at alz.org/facts.

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Alzheimer’s Association is a not-for-profit 501(c)(3) organization.
TAKE CARE OF YOURSELF
HOW TO RECOGNIZE AND MANAGE CAREGIVER STRESS
10 COMMON SIGNS OF CAREGIVER STRESS

1. **Denial** about the disease and its effect on the person who has been diagnosed. *I know Mom is going to get better.*

2. **Anger** at the person living with Alzheimer’s or frustration that he or she can’t do the things that once came naturally. *He knows how to get dressed — he’s just being stubborn.*

3. **Social withdrawal** from friends and activities. *I don’t care about visiting neighbors anymore.*

4. **Anxiety** about the future. *What happens when he needs more care than I can provide?*

5. **Depression** that affects your ability to cope. *I just don’t care anymore.*

6. **Exhaustion** that interferes with daily tasks. *I’m too tired for this.*

7. **Sleeplessness** caused by worrying. *What if she wanders out of the house?*

8. **Irritability** that triggers negative responses. *Leave me alone!*

9. **Lack of concentration** that disrupts familiar tasks. *I was so busy, I forgot my appointment.*

10. **Health problems** that begin to take a mental and physical toll. *I can’t remember the last time I felt good.*
10 WAYS TO MANAGE STRESS AND BE A HEALTHIER CAREGIVER

Are you so overwhelmed by taking care of someone else that you’ve neglected your own physical, mental and emotional well-being? To avoid putting your own health at risk, consider the following tips.

1. **Take a break.**
   Consider using respite care services to allow you a temporary rest from caregiving while the person with Alzheimer’s continues to receive care in a safe environment. Visit [alz.org/care](http://alz.org/care) to learn more.

2. **Seek out community resources.**
   Visit Alzheimer’s Association & AARP Community Resource Finder ([alz.org/CRF](http://alz.org/CRF)) to access a database of dementia and aging-related resources in your area. Adult day programs, in-home assistance, companions and meal delivery are just some of the services that can help you manage daily tasks.

3. **Become an educated caregiver.**
   As the disease progresses, it may become necessary to adopt new caregiving skills. The Association offers programs to help you better understand and cope with common behavioral and personality changes that may occur. Visit the Alzheimer’s and Dementia Caregiver Center ([alz.org/care](http://alz.org/care)) to learn more and access care training resources, including free online workshops.
4. **Get help and find support.**
   Our 24/7 Helpline (800.272.3900). ALZConnected® online social networking community (alzconnected.org) and local support groups (alz.org/CRF) are good resources. If stress becomes overwhelming, seek help from a doctor or counselor.

5. **Take care of your own health.**
   Try to eat well, exercise and get plenty of rest. Making sure that you are healthy can help you be a better caregiver.

6. **Manage your level of stress.**
   Stress can cause physical problems (blurred vision, stomach irritation, high blood pressure) and changes in behavior (irritability, lack of concentration, change in appetite). Note your symptoms and discuss with a doctor, as needed.

7. **Accept changes as they occur.**
   People with Alzheimer’s change over time and so do their needs. They may require care beyond what you can provide on your own. Becoming aware of community resources — from home care services to residential care — can make the transition easier. So will the support and assistance of those around you.
8. **Make legal and financial plans.**
   Putting legal and financial plans in place after an Alzheimer’s diagnosis allows the person living with the disease to participate in decision-making. Having these plans in place can provide comfort to the entire family. Many documents, including advance directives, can be prepared without the help of a legal professional. However, if you’re unsure about how to complete documents or make financial plans, you may want to seek assistance from an attorney specializing in elder law, a financial advisor who is familiar with elder or long-term care planning, or both.

9. **Know you’re doing your best.**
   Remember that the care you provide makes a difference and that you’re doing the best you can. You may feel guilty because you can’t do more, but care needs increase as Alzheimer’s progresses. Regardless of how care is delivered, you can make sure that the person with the disease is well cared for and safe.

10. **Visit your doctor regularly.**
    Take time to get regular checkups and pay attention to any exhaustion, stress, sleeplessness or changes in appetite or behavior. Ignoring symptoms can cause your physical and mental health to decline.
The Alzheimer’s and Dementia Caregiver Center provides information and resources, such as:

» Alzheimer’s Navigator® – Assess your needs and create customized action plans.

» Community Resource Finder – Find local resources.

» ALZConnected® – Connect with others affected by dementia.

» Safety Center – Access information and tips.

The Alzheimer’s Association is the leading voluntary health organization in Alzheimer’s care, support and research. Our mission is to eliminate Alzheimer’s disease through the advancement of research; to provide and enhance care and support for all affected; and to reduce the risk of dementia through the promotion of brain health.

Our vision is a world without Alzheimer’s disease®.

800.272.3900 | alz.org®

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ONLINE CAREGIVER RESOURCES
ALZ.ORG/CARE
HELP AND SUPPORT FOR CAREGIVERS

Caring for a person living with Alzheimer’s or another dementia often involves a team of people. Whether you provide daily care, participate in financial, legal or care-related decision-making, or simply care about a person living with the disease — there’s much to do and plenty to know. The Alzheimer’s Association® offers a variety of resources and support at alz.org/care.

Find reliable information on:

» Caregiving in the early, middle and late stages of Alzheimer’s disease.

» Behaviors.

» Daily care.

» Caregiving skills and training.

» Respite care.

» Care options and coordination.

» Costs you may face.

» Legal documents.

» Safety.

» Working with doctors.
ALZHEIMER’S ASSOCIATION
TOOLS AND RESOURCES

**ALZConnected®**
Our online community where people living with dementia, caregivers and others affected by the disease can share questions, experiences and practical tips via message boards or create private groups organized around specific topics.

**LiveWell Online Resources**
Free interactive tools that help users navigate the personal and emotional challenges accompanying an Alzheimer’s diagnosis and provide personalized steps for living well with the disease.

**Alzheimer’s Navigator®**
An interactive tool for people living with dementia and their caregivers that evaluates needs, outlines action steps and links users to local services and Association programs.

**Alzheimer’s Association & AARP Community Resource Finder**
A database of dementia and aging–related resources powered by CareLike®, including local programs and services.

[alz.org/care](http://alz.org/care)
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BEHAVIORS

HOW TO RESPOND WHEN DEMENTIA CAUSES UNPREDICTABLE BEHAVIORS
ALZHEIMER’S AND DEMENTIA-RELATED BEHAVIORS

Alzheimer’s and other dementias can cause people to act in different and unpredictable ways. Some individuals become anxious or aggressive. Others repeat certain questions or gestures. Many misinterpret what they hear.

These types of reactions can lead to misunderstanding, frustration and tension, particularly between the person living with dementia and his or her caregiver. It’s important to understand that the person is not trying to be difficult and the behavior can be a form of communication.
Chapter 4—The Face of Alzheimer's

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1. **IDENTIFY BEHAVIORS**

The following three-step approach can help you identify common dementia-related behaviors and their causes.

1. **Examine the behavior**
   - What was the behavior? Was it harmful?
   - Did something trigger it?
   - What happened immediately after?
   - Could something be causing the person pain?
   - Could this be related to medications or illness? Consult a physician to be sure.

2. **Explore potential solutions**
   - Are the person’s needs being met?
   - Can adapting the surroundings comfort the person?
   - How can you change your reaction or approach?

3. **Try different responses**
   - Did your new response help?
   - Do you need to explore other potential solutions? If so, what can you do differently?

2. **ANGER AND AGGRESSION**

Aggressive behavior may be verbal (shouting, name calling) or physical (hitting, pushing). It’s important to try to figure out what’s causing the anger and try to prevent it from happening, when possible.

**HOW TO RESPOND:**

**Rule out pain as the cause of the behavior**

Pain can trigger aggressive behavior for a person living with dementia.
Try to identify the immediate cause
Think about what happened right before and whether it may have triggered the behavior.

Focus on feelings, not facts
Look for the feelings behind the words or actions.

Try not to get upset
Be positive and reassuring. Speak slowly in a soft tone.

Limit distractions
Examine the person’s surroundings and adapt them to avoid other similar situations.

Try a relaxing activity
Use music, massage or exercise to help soothe the person.

Shift the focus to another activity
If a situation or activity causes an aggressive response, try something different.

Speak calmly
Using a calm tone, try to reassure the person.
Take a break
If the person is in a safe environment and you are able, walk away and take a moment for yourself.

Ensure safety
Make sure you and the person are safe. If he or she is unable to calm down, seek assistance from others. Always call 911 in emergency situations. If you do call 911, make sure to tell responders the person is living with dementia, which may cause them to act aggressively.

DEMENTIA-RELATED BEHAVIORS MAY BE DUE TO:

» Physical pain or discomfort: Illnesses, medication, hunger or thirst.

» Overstimulation: Loud noises or a busy environment.

» Unfamiliar surroundings: New places or the inability to recognize home.

» Complicated tasks: Difficulty with activities or chores.

» Frustrating interactions: Inability to communicate effectively may cause fear, sadness or anxiety.

3. ANXIETY OR AGITATION
People living with dementia can become anxious or agitated for many reasons. It can help to learn what triggers this response by considering the person’s surroundings, time of day and what has just occurred, and evaluating potential sources of pain, hunger, need for sleep and sudden changes.
HOW TO RESPOND:

Check for pain
Pain can often trigger anxiety or agitation. Sources include being in an uncomfortable situation, injury, reaction to medication or a urinary tract infection.

Listen to the frustration
Find out what may be causing the anxiety and try to understand.

Provide reassurance
Speak in calming tones and phrases. Let the individual know you’re there for support.

Involves the person in activities
Engage the person in art, music or other activities to promote relaxation.

Modify the environment
Decrease noise and distractions or relocate the person.

Find outlets for energy
The person may be looking for something to do. Take a walk or go for a car ride.
FORGETFULNESS AND CONFUSION

A person living with Alzheimer’s disease may not recognize familiar people, places or things. He or she may forget relationships, call family members by other names or become confused about where home is. The purpose of common items, such as a pen or fork, may also be forgotten. These situations can be difficult for caregivers.

HOW TO RESPOND:

Stay calm
Not being recognized can be painful. It may help to talk about it with a friend or family member.

Respond with a brief explanation
Don’t overwhelm the person with complex responses. Instead, clarify with a simple explanation.
Show photos and other reminders
Use photographs and other thought-provoking items to remind the person of important relationships and places.

Offer corrections as suggestions
Avoid explanations that sound like scolding. Try responses like, “I thought it was a fork” or “I think he is your grandson Peter.”

Try not to take it personally
Alzheimer’s causes forgetfulness, but your support and understanding will continue to be appreciated.

5. REPETITIVE ACTIONS
A person living with Alzheimer’s disease may do or say something over and over again — like repeating a word, question or activity. The person may also pace or undo what has just been done. In most cases, he or she is likely looking for comfort, security and familiarity. These actions are rarely harmful, but can be stressful for the caregiver.

HOW TO RESPOND:

Look for a reason
Try to find out if there is a specific cause or trigger for the repetitive behavior.

Focus on the emotion
Rather than reacting to what the person is doing, respond to how he or she is feeling.

Turn the action or behavior into an activity
If the person is rubbing a hand across the table, provide a cloth and ask for help with dusting.
Stay calm and be patient
Reassure the person with a calm voice and gentle touch.

Provide an answer
Give the person the answer that he or she is looking for, even if you have to repeat it several times. It may help to write it down and post it in a prominent location.

Engage the person in an activity
The individual may simply be bored and need a distraction. Engage the person in an activity like taking a walk or working on a puzzle.

Use memory aids
Offer reminders like notes, photographs, clocks or calendars.
NEW SUSPICIONS

Memory loss and confusion may cause a person living with Alzheimer’s to perceive things in new and unusual ways. Individuals may become suspicious of those around them, even accusing others of theft, infidelity or other improper behavior. Sometimes a person living with the disease may misinterpret what he or she sees and hears.

HOW TO RESPOND:

Don’t take offense
Listen to what is troubling the person and try to be understanding. Then offer reassurance, respond to the feeling and let the person know you care.

Don’t argue or try to convince
Allow the individual to express his or her ideas and acknowledge what was said.

Offer a simple answer
Share your thoughts, but keep it simple. Lengthy explanations can be overwhelming.

Switch the focus to another activity
Engage the individual in an activity or ask for help with a chore.

Duplicate any lost items
If the person often searches for a specific item, have several available. For example, if the individual is always looking for his or her wallet, purchase two of the same kind.
WANDERING AND GETTING LOST

It's common for a person living with dementia to wander and become lost, and it can happen at any stage of the disease. In fact, six in 10 individuals with Alzheimer’s will wander at some point. They may try to go home when already there or attempt to recreate a familiar routine, such as going to school or work.

As the disease progresses, the person living with Alzheimer’s will need increased supervision. At some point, it will no longer be safe to leave him or her alone.

HOW TO RESPOND:

Encourage activity
Keeping the person living with Alzheimer’s active and engaged can help discourage wandering behavior by reducing anxiety and restlessness. Involve the person in chores, such as doing dishes, folding laundry or preparing dinner. If the person shows interest in getting out of the house, consider safe outdoor activities such as an accompanied walk or gardening.

Inform others
Make sure friends, family and neighbors know that the person is living with Alzheimer’s and that wandering may occur.

Make the home safe
Install deadbolt or slide-bolt locks on exterior doors and limit access to potentially dangerous areas within the home.
Be prepared
Consider enrolling in a wandering response service. Contact the Alzheimer’s Association 24/7 Helpline (800.272.3900) for more information.

MAKE SAFETY A PRIORITY
Visit alz.org/safety for a robust offering of safety information, tips and resources.
8 TROUBLE WITH SLEEP

People living with dementia may experience changes in their sleep schedule or have problems sleeping. Although the exact cause is unknown, these changes result from the disease’s impact on the brain.

HOW TO RESPOND:

Make a comfortable environment
Maintain a comfortable temperature in the sleeping area. Use night lights and take other steps to keep the person safe, such as installing appropriate door and window locks.

Maintain a schedule
As much as possible, encourage a regular routine of waking up, meals and going to bed.

Manage naps
If the person has trouble sleeping at night, it can be helpful to limit daytime naps.

Exercise
Try to include some type of exercise, as appropriate for the person, during the day. Physical activity may promote restfulness at night.

Avoid stimulants
Reduce or avoid alcohol, caffeine and nicotine, which can all affect ability to sleep. Discourage watching television during periods of wakefulness at night, as it can be stimulating.

Talk to a doctor
Discuss sleep disturbances with a doctor to help identify causes and possible solutions. Most experts encourage the use of non-drug measures rather than medication.
HELP AND SUPPORT FOR CAREGIVERS

Visit alz.org/care to access reliable information and resources, including:

» Alzheimer’s Navigator: Assess your needs and create customized action plans.

» Alzheimer’s Association & AARP Community Resource Finder: Find local resources.

» ALZConnected: Connect with other caregivers who can relate to your situation.
alz.org/care

Access reliable information and resources, such as:

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» Community Resource Finder – Find local resources.

» ALZConnected® – Connect with other caregivers who can relate to your situation.

» Safety Resources – Access information and tools.

alz.org/CRF

We’re in communities nationwide.

800.272.3900

24/7 Helpline – Available all day, every day.

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STAYING SAFE
STEPS TO TAKE FOR A PERSON LIVING WITH DEMENTIA
MAKE SAFETY A PRIORITY BEFORE IT’S A PROBLEM

Safety is essential for everyone, but the need for a comprehensive safety plan is particularly important for a person living with Alzheimer’s as the disease progresses. Alzheimer’s causes a number of changes in the brain and body that may affect safety. Depending on the stage of the disease, these can include:

» Judgment: forgetting how to use household appliances.
» Sense of time and place: getting lost on one’s own street.
» Behavior: becoming easily confused, suspicious or fearful.
» Physical ability: having trouble with balance.
» Senses: experiencing changes in vision, hearing, sensitivity to temperature or depth perception.

Taking measures to improve safety can prevent injuries, and help a person living with dementia feel at ease and maintain his or her independence longer.

Visit alz.org/safety for a comprehensive offering of safety information, tips and resources.
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1. SAFETY

AT HOME

If safety measures are in place, an individual living with Alzheimer’s can live in the comfort of his or her own home or a caregiver’s residence. As the disease progresses, the person’s abilities will change. But with some creativity and flexibility, the home can be adapted to support these changes.

Evaluate your environment
A person living with dementia may be more prone to safety hazards in certain areas of the home or outdoors. Monitor garages, work rooms, basements and outside areas, where there are more likely to be tools, chemicals, cleaning supplies and other potentially hazardous items.

Avoid injury during daily activities
Most accidents in the home occur during daily activities such as eating, bathing and using the restroom. Take special precautions at these times.

» Avoid serving food and beverages that are too hot. The person living with dementia may not remember to check the temperature.

» Install walk-in showers. Add grab bars to the shower or tub and at the edge of the vanity to allow for independent, safe movement.

» Add textured stickers to slippery surfaces. Apply adhesives to keep throw rugs and carpeting in place, or remove rugs completely.

» Monitor the hot water temperature in the shower or bath. Consider installing an automatic thermometer.

Adapt to vision limitations
Dementia sometimes causes changes in vision that make it difficult for a person to decipher between colors and understand what he or she sees.
» Changes in levels of light can be disorienting. Create an even level by adding extra lights in entries, outside landings, and areas between rooms, stairways and bathrooms.

» Use night lights in hallways, bedrooms and bathrooms.

**Beware of dangerous objects and substances**

Even the most basic appliance or household object can become dangerous. Consider how you can ensure these items do not become safety hazards.

» Use appliances that have an auto shut-off feature. Keep them away from water sources such as sinks.

» Install a hidden gas valve or circuit breaker on the stove so a person living with dementia cannot turn it on, or remove the knobs.

» Store grills, lawn mowers, power tools, knives and cleaning products in a secure place.

» Discard toxic plants and decorative fruits that may be mistaken for real food.
» Remove vitamins, prescription drugs, sugar substitutes and seasonings from the kitchen table and counters. Medications should be kept in a locked area at all times.

» Supervise the use of tobacco and alcohol. Both may have harmful side effects and may interact dangerously with some medications.
Firearms in the home
In the vast majority of cases, the presence of firearms or other weapons in a household creates no problems for responsible gun owners and others in the home. However, if someone is living with Alzheimer’s or another dementia, firearms can pose a significant risk for everyone. Consider the following:

» **Locking or disabling a gun may not be enough.**

As the disease progresses, people living with Alzheimer’s sometimes misperceive danger and may do whatever seems necessary to protect themselves — even if no true threat exists. This can include breaking into a gun cabinet, finding ammunition and loading a gun. Just because the gun is locked or disabled doesn’t mean the person living with dementia is protected from harming themselves or others.

» **Consider removing guns from the home to fully protect the family from an accident.**

Family members sometimes attempt to hide their firearms or ammunition to prevent the person living with dementia from accessing them. They may lock the guns in an attic or the trunk of a car, or keep ammunition outside of the home. These are good first steps, but they do not ensure that the person will not find the gun — or appear to be holding a loaded weapon, thereby causing those around the person to react.

Just as legal, financial, care and driving plans are best made early in the disease process, it’s important to consider current and future gun safety. Put plans in place for what to do with firearms or other weapons both now and in the future when the person is no longer capable of handling them safely.
2. **WANDERING AND GETTING LOST**

Six in 10 people living with dementia will wander and become lost; many do so repeatedly. And it can happen at any stage of the disease. If not found within 24 hours, up to half of wandering individuals will suffer serious injury or death. It’s important to be aware of the risk factors.

**Signs of wandering behavior**

Wandering or confusion about location may be an issue when the person:

» Forgets how to get to familiar places.

» Returns from a regular walk or drive later than usual.

» Talks about fulfilling former obligations, like going to work.

» Tries or wants to “go home,” even when at home.

» Is restless, makes repetitive movements or paces.

» Has a hard time locating familiar places like the bathroom, bedroom or dining room.

» Acts as if doing a hobby or chore, but nothing gets done (e.g., moves around pots and dirt without actually planting anything).

» Acts nervous or anxious in crowded areas, such as markets or restaurants.

**Tips to reduce wandering**

» Provide opportunities for the person to engage in structured, meaningful activities throughout the day.

» Make sure the person gets some exercise, which can reduce anxiety, agitation and restlessness.
» Place deadbolts either high or low on exterior doors if you worry about wandering at night.

» Ensure all basic needs are met, including toileting, nutrition and hydration.

» Involve the person in daily activities, such as folding laundry or preparing dinner.

» Reassure the person if he or she feels lost, abandoned or disoriented.

» If the person is still able to drive, consider using a GPS device to help if they get lost.

» If the person is no longer driving, remove access to car keys — a person living with dementia may not just wander by foot. The person may forget that he or she can no longer drive.

» Avoid busy places that are confusing and can cause disorientation, such as shopping malls.

» Do not leave someone living with dementia unsupervised in new surroundings.

WE CAN HELP

MedicAlert® + Alzheimer's Association Safe Return® is a 24-hour nationwide emergency response service for individuals living with Alzheimer's or another dementia who wander or have a medical emergency. We provide assistance no matter when or where the person is reported missing.

» Call the Alzheimer’s Association® at 800.272.3900 to learn more.

» Call 888.572.8566 or visit alz.org/safety to enroll.
3. **DRIVING AND ALZHEIMER’S**

Driving demands good judgment, quick reaction time and split-second decision-making. Because of the progressive nature of Alzheimer’s, a person living with the disease will eventually become unable to drive.

It’s helpful to have a conversation early on about how independence can be maintained when the person can no longer drive. Putting a plan in place can help ease the transition.

Signs that it may be time to stop driving:

» Forgetting how to locate familiar places.
» Failing to observe traffic signals.
» Making slow or poor decisions.
» Driving at inappropriate speeds.
» Becoming angry and confused while driving.
» Hitting curbs.
» Using poor lane control.
» Making errors at intersections.
» Confusing the brake and gas pedals.
» Returning from a routine drive later than usual.
DEMENTIA AND DRIVING RESOURCES

Visit alz.org/driving for helpful information and resources, including:

» Videos of four different families discussing driving and dementia.
» Tips and strategies for planning ahead and handling resistance.
» Common signs of unsafe driving.
» Resources for alternative methods of transportation.
» Additional information on driving and safety.

The information and resources available on alz.org/driving are a product of a cooperative agreement between the Alzheimer's Association and the National Highway Traffic Safety Administration (NHTSA).
TRAVELING AND ALZHEIMER’S

A dementia diagnosis does not necessarily mean that it’s time to stop traveling; however, doing so does require careful planning. The following may help facilitate a safe and enjoyable trip:

» Pack copies of important documents (see page 13), medication, travel itinerary, water, snacks and activities.

» It can be helpful to stick with the familiar. If possible, travel to familiar destinations that involve minimal changes to daily routine.

» A change in environment can trigger wandering behavior. Consider enrolling in MedicAlert + Safe Return. If you are already enrolled, notify the program of travel plans.

» If staying in a hotel, consider informing the staff about your specific needs ahead of time so they can prepare to assist.

» Travel during the time of day that is best for the person living with dementia.

» Contact the Alzheimer’s Association to find the nearest office that can provide assistance at your travel destination.

Air travel

Moving through airports requires focus and attention, as the level of activity can be distracting, overwhelming and difficult to understand. Here are a few things to keep in mind for air travel:

» Avoid flights that require tight connections.

» Even if walking is not difficult, consider requesting a wheelchair so that an attendant can help you get from place to place. Most airlines ask for at least 48 hours notice.
» Contact the Transportation Security Administration (TSA) at least 72 hours prior to travel for information about what to expect during the security screening. While at the airport, remind the person what is involved and consider telling the agent at the security checkpoint that the person has dementia.

» Do not hesitate to ask for assistance from airport employees and in-flight crew.

» If the person needs help using the restroom, look for companion care bathrooms so you can more easily assist and will not have to leave the person unattended.

» Stay with the person at all times.
5. EMERGENCY PREPAREDNESS

Disaster situations, such as a hurricane or fire, or other emergency situations can significantly impact everyone’s safety, but they can be especially upsetting and confusing for individuals living with dementia. Being prepared for an emergency is crucial.

Prepare an emergency kit that includes:

» Copies of important documents.
» A couple sets of extra clothing.
» Extra medication.
» Incontinence products.
» Identification items, such as a MedicAlert + Safe Return ID bracelet.
» A recent picture of the person living with dementia.
» Bottled water.
» Favorite items or foods.
If an emergency occurs and you need to evacuate, make sure your plans are compatible with the specific needs of the person living with dementia. For example, if he or she uses a walker or wheelchair, be sure your emergency plan takes this into consideration.

If an individual lives in a residential facility, learn about its disaster and evacuation plans. Find out who is responsible for evacuating the person in the event of an emergency.

Staying safe becomes increasingly important as Alzheimer’s disease progresses. With appropriate planning and accommodation, you can ensure that everyone is as safe as possible.

**IMPORTANT DOCUMENTS TO KEEP ON HAND**

Keep copies of the following documents in an easily accessible location at home as well as in another secure location away from home.

» Doctors’ names and contact information.

» A list of current medications and dosages.

» Phone numbers and addresses of local police and fire departments, hospitals and poison control.

» A list of food and drug allergies.

» Copies of legal papers, such as a living will, advance directives and power of attorney.

» Names and contact information of friends and family members to call in case of an emergency.

» Insurance information, including policy number and member name.
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