Alzheimer’s Disease and Other Dementias: The Continuing Pandemic Affecting Your Practice

Friday, January 22, 2016
9 a.m.—4:30 p.m.
5.5 General CLE credits and 1 Ethics credit
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7. **Helping Those in Need: Clients with Diminished Capacity** .................................................. 7–i
   — Mark Fucile, Fucile & Reising LLP, Portland, Oregon
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, 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

  Jeffrey Kaye, MD, Oregon Health & Science University and Portland Veterans Affairs Medical Center, 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

  Vicki Schmall, Ph.D., Aging Concerns, West Linn

11:30  The Face of Alzheimer’s
  ◆ Ten warning signs
  ◆ Common challenges
  ◆ Alzheimer’s Association programs and services
  ◆ National Alzheimer’s Plan 2025

  Kristina Barragan, Alzheimer’s Association Oregon Chapter, Portland

12:15  Lunch

1:15  Assessing and Maximizing Decision-Making Capacity
  ◆ Legal standards for minimum capacity to consent or act
  ◆ Methods for maximizing capacity
  ◆ Techniques and strategies for interviewing clients
  ◆ Assessment tools for nonmedical professionals

  Darin Dooley, Law Offices of Nay & Friedenberg, Portland
  Tim Nay, Law Offices of Nay & Friedenberg, Portland

2:15  Legal and Nonlegal Services Needed by Clients with Dementia: The Attorney’s Perspective
  ◆ Non-Medicaid services and source of payment
  ◆ Medicaid nonfinancial issues
  ◆ Long-term care and Medicaid myths
  ◆ Estate planning nuances
  ◆ Family caregiving concerns

  Cinda Conroyd, Douglas Conroyd Gibb & Pacheco PC, Salem
  Penny Davis, Davis Pagnano McNeil & Vigna LLP, Portland
  Sam Friedenberg, Law Offices of Nay & Friedenberg, Portland
3:15  Break

3:30  Legal Ethics Guidelines and Challenges: Representing Clients with Dementia and Their Families
  ✦ Loss of capacity to retain counsel and ability to direct counsel; the contours of ORPC 1.14, Client with Diminished Capacity
  ✦ Representing a client subject to a protective proceeding—maintaining a “normal” relationship
  ✦ Representing the couple—when does estate planning end and adversity begin?
  ✦ Working with fiduciaries for an incapacitated person

  Wesley Fitzwater, Fitzwater Meyer Hollis & Marmion LLP, Portland
  Mark Fucile, Fucile & Reising LLP, Portland
  Mark Williams, Gaydos Churnside & Balthrop PC, Eugene

4:30  Adjourn
Kristina Barragan, *Alzheimer’s Association Oregon Chapter, Portland.* Ms. Barragan is the Central Oregon Regional Coordinator for the Alzheimer’s Association Oregon Chapter. She works directly with individuals with the disease and their caregivers by providing education class opportunities, facilitating and managing support groups, offering early-stage programs that focus on art therapy, social engagement, and physical health, and helping clients connect with local resources and plan for their long-term care needs. She holds a Master’s in Urban Planning from UCLA with an emphasis on Housing and Community Development.

Cinda Conroyd, *Douglas Conroyd Gibb & Pacheco PC, Salem.* Ms. Conroyd’s practice emphasizes elder law, particularly as it relates to Medicaid planning. Ms. Conroyd is a member of the National Association of Elder Law Attorneys, is active in the Alzheimer’s Network, is past chair of the Oregon State Bar Elder Law Section and remains active with its Agency and Professional Relations Committee, and frequently speaks to local organizations regarding elder law.

Penny Davis, *Davis Pagnano McNeil & Vigna LLP, Portland.* Ms. Davis has practiced elder law in Oregon for more than 30 years. She started her career working on issues involving Medicaid eligibility, incapacity, and long-term care services as the staff attorney for the Senior Law Project at Multnomah County Legal Aid Service. She has continued to represent clients through the many changes in these areas. She is past chair of the Oregon State Bar Elder Law and Health Law sections. Ms. Davis has published a number of articles on elder law topics and makes presentations to professional and community groups on long-term care planning, estate and disability planning, and other elder law issues.

Darin Dooley, *Law Offices of Nay & Friedenberg, Portland.* Mr. Dooley practices in the areas of estate planning, elder law, Medicaid, special needs planning, probate, estate tax planning, and trust administration. He is a member of the Oregon State Bar Estate Planning and Administration Section, the Oregon State Bar Elder Law Section Executive Committee, and the Multnomah Bar Association.

Wesley Fitzwater, *Fitzwater Meyer Hollis & Marmion LLP, Portland.* Mr. Fitzwater’s practice emphasizes legal and crisis issues faced by the elderly and their families, including incapacity, guardianship and conservatorship, long-term care, and end-of-life concerns. He is a member of the Multnomah Bar Association, the Clackamas County Bar Association, the Oregon State Bar Elder Law and Estate Planning and Administration sections, the Clackamas County Elder Abuse Coordinated Community Response Team, the Multnomah and Clackamas County probate court advisory committees, the National Academy of Elder Law Attorneys, and the Guardian/Conservator Association of Oregon. Mr. Fitzwater is a frequent speaker to senior groups and Oregon attorneys. He is an author and instructor on topics including long-term care and Medicaid planning, incapacity, guardianships and conservatorships, and legal ethics and professionalism. He is coeditor of the Oregon State Bar publication *The Elder Law Handbook.* Among other recognition, he is the 2006 recipient of the Oregon State Bar President’s Membership Service Award.

Sam Friedenberg, *Law Offices of Nay & Friedenberg, Portland.* Mr. Friedenberg’s practice areas include elder law, estate planning, and inheritance tax planning, trust administration, settlement planning, special needs planning, Medicaid, probate, wrongful death probate, and guardianships/conservatorships. He is a member of the National Academy of Elder Law Attorneys, member and past chair of the Oregon State Bar Elder Law Section Agency and Professional Relations Committee, and a past member of the Oregon State Bar Uniform Trial Court Rules Committee and Multnomah County Probate Advisory Committee.
FACULTY (Continued)

Mark Fucile, *Fucile & Reising LLP, Portland*. Mr. Fucile handles professional responsibility, regulatory, and attorney-client privilege issues for lawyers, law firms, and corporate and governmental legal departments throughout the Northwest. Mr. Fucile is the inaugural chair of the Washington State Bar Association Committee on Professional Ethics and past chair of its predecessor, the WSBA Rules of Professional Conduct Committee. He is a member of the Idaho State Bar Section on Professionalism and Ethics and a former member of the Oregon State Bar Legal Ethics Committee. Mr. Fucile writes the quarterly “Ethics and the Law” column for the WSBA *NWLawyer* and the monthly “Ethics Focus” column for the Multnomah Bar Association *Multnomah Lawyer*, and he is a regular contributor on legal ethics to the WSBA *NWSidebar* blog. He also is a contributing author/editor for the current editions of the WSBA *Legal Ethics Deskbook*, the WSBA *Law of Lawyering in Washington*, and the OSB *The Ethical Oregon Lawyer*. Mr. Fucile teaches legal ethics as an adjunct professor at the University of Oregon School of Law Portland campus. He is admitted to practice in Oregon, Washington, Idaho, Alaska, and the District of Columbia.

Jeffrey Kaye, MD, *Oregon Health & Science University and Portland Veterans Affairs Medical Center, Portland*. Dr. Kaye is the Layton Professor of Neurology and Biomedical Engineering at Oregon Health and Science University (OHSU). He directs the NIA Layton Aging and Alzheimer’s Disease Center at OHSU and is a geriatric neurologist at the Portland Veterans Affairs Medical Center. He also directs the Oregon Center for Aging and Technology. Dr. Kaye’s research over the past two decades has focused on the question of why some individuals remain protected from dementia and functional decline at advanced ages while others succumb at much earlier times. This work has relied on a number of approaches ranging across the fields of genetics, neuroimaging, physiology, and continuous life activity monitoring. He leads several longitudinal studies on aging using ubiquitous, unobtrusive technologies for assessment of older adults in their homes to detect changes signaling imminent functional decline. Dr. Kaye has received the Charles Dolan Hatfield Research Award for his work. He serves on many national and international panels and review boards in the fields of geriatrics, neurology, and technology, including as a commissioner for the Center for Aging Services and Technology, on the Advisory Council of AgeTech West, and as chair of the International Society to Advance Alzheimer’s Research & Treatment. He is an author of over 300 scientific publications and holds several major grant awards from federal agencies, national foundations, and industrial sponsors.

Tim Nay, *Law Offices of Nay and Friedenberg, 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.

Vicki Schmall, Ph.D., *Aging Concerns, West Linn*. Dr. Schmall is Executive Director and Gerontology & Training Specialist with Aging Concerns. She is also Professor Emerita of Oregon State University, where she was director of the gerontology program and the Gerontology Specialist in the OSU Extension Service. Dr. Schmall’s areas of expertise include family decision-making and caregiving in later life, aging and health-related changes, family communication and caregiving issues, mental health issues, sensitivity training on aging-related changes, learning and memory in later life, late-life sexuality, and curriculum design and training. She has conducted over 1,700 workshops for staff of health care organizations and community agencies, families, older adults, and professionals throughout the United States and in Canada, Guam, Thailand, and China. She has authored over 100 professional articles and book chapters and written 8 nationally distributed training manuals. She is lead author of the book, *The Caregiver Helpbook: Powerful Tools for Caregiving*. Dr. Schmall has received many awards and recognitions for her work in aging, including national awards from the American Society on Aging, American Health Care Association, AARP, the Institute for Elderly Suicide Prevention, and the JFR Foundation.
Mark Williams, Gaydos Churnside & Balthrop PC, Eugene. Mr. Williams’s practice comprises all facets of elder law, including contested guardianships and conservatorships for individuals and working with professional fiduciaries. He advises clients on planning for long-term care, special needs trusts, and Medicaid spend-downs. He also has substantial experience in estate planning matters, working with clients on wills, trusts, domestic partnerships, and taxable estates. He is a member of the National Academy of Elder Law Attorneys, the Oregon Law Institute Board of Directors, the State of Oregon Continuing Care Retirement Communities Advisory Council, the Oregon State Bar Elder Law Section, and the Oregon State Bar Legal Ethics Committee. Mr. Williams is an adjunct professor at the Concordia University College of Health and Social Services and adjunct instructor and lecturer at the University of Oregon Law School.
Chapter 1

How the Global Dementia Pandemic Continues to Affect Your Law Practice

Tim Nay, MSW
Law Offices of Nay & Friedenberg
Portland, Oregon

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How the Global Dementia Pandemic Continues to Affect Your Practice ............................... 1–1
Appendix—Table 1-1, Disorders Causing or Simulating Dementia, from U.S. Congress, Office of Technology Assessment, Losing a Million Minds: Confronting the Tragedy of Alzheimer’s Disease and Other Dementias, OTA-BA-323 (Washington, DC: U.S. Government Printing Office, April 1987) ................................................................. 1–3
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 70s.

In 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.

AD 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 $226 billion in 2015, 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.

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, estimates that more than 5.3 million Americans, up from 4.5 million in 2006, have moderate to severe AD, with over 60,000 Oregonians affected now, predicting that number will swell to 110,000 by 2025, a 93-percent increase. 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.

Attorneys, 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, psychosocial, ethical, and legal dimensions of the dementia pandemic and enable you to effectively and compassionately assist your clients and their families.
### APPENDIX—DISORDERS CAUSING OR SIMULATING DEMENTIA

**Table 1-1.—Disorders Causing or Simulating Dementia**

<table>
<thead>
<tr>
<th>Disorders causing dementia:</th>
<th>Vasculitis</th>
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<tr>
<td>Degenerative diseases:</td>
<td>Toxic dementia:</td>
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<tr>
<td>Alzheimer's disease</td>
<td>Alcoholic dementia</td>
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<td>Pick's disease</td>
<td>Metallic dementia (e.g., lead, mercury, arsenic, manganese)</td>
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<td>Huntington's disease</td>
<td>Organic poisons (e.g., solvents, some insecticides)</td>
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<td>Progressive supranuclear palsy</td>
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<td>Parkinson's disease (not all cases)</td>
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<td>Cerebellar degenerations</td>
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<tr>
<td>Amyotrophic lateral sclerosis (ALS) (not all cases)</td>
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<td>Parkinson-ALS-dementia complex of Guam and other island areas</td>
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<td>Rare genetic and metabolic diseases (Hallervorden-Spatz, Kufs', Wilson's, late-onset metachromatic leukodystrophy, adrenoleukodystrophy)</td>
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<td>Vascular dementia:</td>
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<td>Multi-infarct dementia</td>
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<td>Cortical micro-infarcts</td>
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<td>Lacunar dementia (larger infarcts)</td>
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<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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<td>Head injuries (open or closed)</td>
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<td>Infectious dementia:</td>
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<td>Acquired immune deficiency syndrome (AIDS)</td>
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<td>AIDS dementia</td>
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<td>Opportunistic infections</td>
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<td>Creutzfeldt-Jakob disease (subacute spongiform encephalopathy)</td>
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<td>Progressive multifocal leukoencephalopathy</td>
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<td>Post-encephalitic dementia</td>
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<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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<td>Bacterial meningitis or encephalitis</td>
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<tr>
<td>Parasitic encephalitis</td>
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<td>Brain abscess</td>
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<td>Neurosyphilis (general paresis)</td>
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<td>Normal pressure hydrocephalus (communicating hydrocephalus of adults)</td>
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<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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<td>Auto-immune disorders:</td>
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<tr>
<td>Disseminated lupus erythematosis</td>
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</table>

**Source:** Adapted from R. Katzman, B. Leaker, and N. Bernstein, "Accuracy of Diagnosis and Consequences of Misdiagnosis of Disorders Causing Dementia," contract report prepared for the Office of Technology Assessment, U.S. Congress, 1985.
Chapter 2

The Changing Face of Alzheimer’s Disease—Presentation Slides

JEFFREY KAYE, MD
Oregon Health & Science University and Portland Veterans Affairs Medical Center
Portland, Oregon
The Changing Face of Alzheimer’s Disease

Jeffrey Kaye, MD
Layton Professor of Neurology & Biomedical Engineering
Oregon Center for Aging & Technology
Layton Aging & Alzheimer's Disease Center

Outline

• Some definitions – the basics
• Dementia in our community
• Symptoms of dementia – is it Alzheimer’s?
• Current treatments and management
• What the future holds for the epidemic of dementia
What are normal changes with aging?

<table>
<thead>
<tr>
<th>No significant decline</th>
<th>Decline</th>
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<tbody>
<tr>
<td>• Crystallized intelligence</td>
<td>• Processing Speed</td>
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<tr>
<td>• Vocabulary</td>
<td>• Visual spatial function</td>
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<tr>
<td>• Comprehension</td>
<td>• Memory</td>
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</tbody>
</table>

These changes should not interfere with a person’s ability to function independently

What is dementia?

Criteria for dementia

Cognitive impairment detected through a combination of (1) history-taking from the patient and an informant and (2) an objective cognitive assessment.

Cognitive or behavioral symptoms that:

1. Interfere with the ability to function at work or at usual activities; and

2. Represent a decline from previous levels of functioning and;

3. Are not explained by delirium or major psychiatric disorder;

4. A minimum of two of the following domains:
   a. Impaired ability to acquire and remember new information
   b. Impaired reasoning and handling of complex tasks, poor judgment
   c. Impaired visuospatial abilities
   d. Impaired language
   e. Changes in personality, behavior, or comportment

Recommendations from the National Institute on Aging-Alzheimer’s Association workgroups on diagnostic guidelines for Alzheimer’s disease. Alzheimer’s and Dementia, May 2011
What is “in between”?  
Mild Cognitive Impairment (MCI)

- Concern for change in cognition compared with previous abilities
- Objective impairment in ≥ 1 cognitive domains (1 – 1.5 sd below age-adjusted norms)
  - Memory (amnestic MCI)
  - Executive function
  - Attention
  - Language
  - Visual spatial skills
- **Preserved independence in functional abilities**


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A Continuum:  
Natural History of MCI and AD-Dementia

- **MCI**
  - MMSE 24–30
  - Mild subjective/objective memory loss
  - Normal function

- **Mild AD**
  - MMSE 20–23
  - Forgetfulness
  - Repetitive questions
  - Daily function impaired

- **Moderate AD**
  - MMSE 10–19
  - Progression of cognitive deficits
  - Short-term memory loss
  - Word-finding difficulties

- **Severe AD**
  - MMSE 0–9
  - Behavior change
  - Altered sleep patterns
  - Total dependence for ADL’s

But not all MCI leads to dementia....!
MCI and Dementia Risk

- Those with MCI progress to dementia in higher proportions than cognitively normal people
  - Proportions vary across MCI definitions, population selection, follow up interval (2.8% - 20%)
  - Rates of progression from MCI to dementia are consistently lower in community settings than in specialty clinical and research programs
  - Greatest risk for dementia:
    - Amnestic MCI, single domain
    - Amnestic MCI, multi-domain (highest risk)


Factors affecting individual differences

- Genetics
- Experience
- Cognitive Reserve
- Health/brain disease

Can’t Change

Can Change!
Chapter 2—The Changing Face of Alzheimer’s Disease—Presentation Slides

Most Common Forms of Dementia

- Frontotemporal dementia 15%
- Other 10%
- Dementia with Lewy bodies 15%
- Vascular dementia 10%
- Alzheimer disease 50%

**Figure 1-2** Causes of dementia by percentage of patients.

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What is Alzheimer’s Disease?
In the beginning... *The discovery of ‘Alzheimer’s disease’*

“Considering everything, it seems we are dealing here with a special illness. An increasing number of similar cases have been observed during the last years. This fact should persuade us *not to be satisfied with classifying clinically undetermined cases by forcing them into the categories of recognized illnesses.*”

- A. Alzheimer. “On an Unusual Illness of the Cerebral Cortex” (1907)

How Auguste Deter Presented...

Diagnostic criteria for Alzheimer’s Disease

- Meets diagnostic criteria for dementia
- Insidious onset with slow progressive decline
- Clear-cut history of worsening of cognition by report or observation
- The initial and most prominent cognitive deficits are in memory, language, visualspatial or executive function.

The “Non-Alzheimer” Forms of Dementia

Dementia with Lewy Bodies

- **Features**
  - Dementia
  - Parkinsonism (rigidity & bradykinesia > tremor)
  - Marked fluctuations in cognition
  - Hallucinations (visual 93%, auditory 50%)
  - Visuospatial and executive dysfunction> memory
  - REM sleep behavior disorder
- **Distinguished from Parkinson’s disease by dementia preceding parkinsonism**
- **Parkinsonism poorly responsive to levodopa**
- **Pathology: α-synuclein**

McKeith et al. Neurology 2005;65
Frontotemporal Dementias

- Decline in personal or social interpersonal conduct
  - Loss of empathy
  - Disinhibition
  - Socially inappropriate behaviors
  - Mental rigidity, inflexibility in relationships or severe apathy
- Impaired reasoning and difficulty with tasks out of proportion to impairments in memory, visual-spatial skills
- Marked language abnormalities
- Younger age of onset and more rapid decline

Vascular dementia

- Dementia
- 1 or more of the following:
  - Onset within 3 months of a stroke
  - Abrupt cognitive deterioration
  - Fluctuating stepwise progression
- Focal neurologic signs
- Vascular lesions on brain imaging

**Why do we care about dementia & Alzheimer’s?**

*The Facts*

- Over 5 Million living with Alzheimer’s today; 60-80,000 in Oregon
- 1 in 9 over age 65; 1 in 3 over age 85
- Over 15 million providing care or support
- The most expensive disease in America
- The third leading cause of death
- No effective therapy; Last FDA approved drug in 2003
- Research funding ~1/10 cancer, heart disease...
- 10 Million with AD by 2035 if nothing changes

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**What can be done?**

*Change the way we see Alzheimer’s*

1. Changing How We See the Brain with Alzheimer’s
2. Changing How We Diagnose & Assess Alzheimer’s
3. Changing How We Find Meaningful Treatments
4. Changing How We Help People with Alzheimer’s Now
1. Changing How We See the Brain with Alzheimer’s

We need a better understanding of the underlying brain pathologies

We need to know the cause “Alzheimer’s disease”?

• Half the population of older adults without cognitive impairment die with significant AD pathology.
• AD pathology explains only a third of the variation in cognitive function.
• Treatments targeted to classic AD (amyloid) pathology have all failed.
There are likely multiple drivers of ‘Alzheimer’s’

Finding the major drivers of brain degeneration

Novel proteins associated with dementia - Aquaporin 1

Brain tissue from the OHSU research brain bank treated to reveal a new protein associated with dementia in the older population. The protein appears as brown clumps in the photos. The brain tissue is from volunteers carefully assessed at the Layton Center during life who generously donated their brains for this research when they died. The top row are those who never developed cognitive impairment; the bottom row are those who had cognitive impairment.

Dr. R. Woltjer, Neuropathology Core Leader, Layton Center
Finding the major drivers of brain degeneration

Glyphatic System - “waste disposal dysfunction”

Dr. Jeffrey Iliff, Anesthesia & Perioperative Medicine

2. Changing How We Diagnose & Assess Alzheimer’s

We need better diagnostics

• Current cognitive tests alone are not very sensitive to early changes.
• Self-report of functional change is imprecise.
• No definitive lab tests: blood tests or CSF (used for research or to rule out medical illness).
• Some genetic markers - used primarily in research: apolipoprotein E4 as a risk factor.
• Brain imaging has been helpful and is a major change occurring in dementia diagnostics.
Identifying signatures of brain pathologies *during life*

[Images of brain scans and graphs]

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$100M$ IDEAS: CMS Blesses Study to Evaluate Amyloid Scans in Clinical Practice

16 Apr 2015

Two years after they first ran against a wall trying to get amyloid scans reimbursed by insurance, researchers now have their chance to prove the costly procedure is worth it. The Centers for Medicare & Medicaid Services (CMS) has approved the protocol for a four-year, $100 million study called Imaging Dementia—Evidence for Amyloid Scanning (IDEAS) was spearheaded by Maria Carrillo of the Alzheimer’s Association and will be managed by the American College of Radiology (ACR) in Reston, Virginia. This massive study aims to examine how well amyloid imaging performs in clinics outside the small, rarefied world of clinical trials and tertiary academic care. IDEAS will measure whether getting a scan can affect the diagnosis, management, and future healthcare of people whose cognitive symptoms cannot be definitively attributed to a cause by clinical diagnosis alone. *More knowledge*

---

**ANNOTATE**

To make an annotation you must *Login* or *Register*. 

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**ALZFORUM**

Networking for a Cure

[ALZFORUM website interface]
3. Changing How We Find Meaningful Treatments

*We need meaningful treatments*

- Currently two classes of medications: Cholinesterase inhibitors and memantine
- Both are symptomatic treatments; don’t prevent progression.
- Other medication treatments are symptomatic (sleep disturbance, depression, agitation)
- *Hundreds of potential new treatments exist – we need to dramatically ramp up the testing of these many therapies.*

---

**The challenge of clinical trials**

*Developing a new medicine takes an average of 10-15 years; For every 5,000-10,000 compounds in the pipeline, only 1 is approved.*

**Drug Discovery and Development: A LONG, RISKY ROAD**

[Diagram showing the phases of drug discovery and development, from preclinical to FDA review and large-scale manufacturing.]
Many therapies to test – one example: Centella Asiatica as a treatment for Alzheimer’s disease

- A4 - anti-amyloid treatment of asymptomatic Alzheimer’s
- Omega 3 - PUFA for the vascular component of age-related cognitive decline
- FYN - AZD0530 (saracatinib), a Phase IIa Multi-Center Study of 18F-FDG PET, Safety, and Tolerability of AZD0530 in Mild Alzheimer’s Disease
- Merck - MK-7622: Phase IIa/IIb, Multicenter, Randomized, Double-Blind, Placebo-Controlled, Parallel Group Trial to Evaluate the Efficacy and Safety of MK-7622 as an Adjunctive Therapy to Donepezil for Symptomatic Treatment in Subjects with Alzheimer’s Disease.
- Eisai - BAN2401-G000-201 an anti-amyloid agent (to evaluate safety, tolerability and efficacy of BAN2401 in subjects with early Alzheimer’s disease.
- Lundbeck - Idalopirdine (Lu AE58054) as adjunctive therapy for mild-moderate Alzheimer’s disease.

Current Clinical Trials at the Layton Aging & Alzheimer’s Disease Center
Can we do more effective, faster clinical trials?

Developing a new medicine can take decades—a risk of 10-15 years; For every 5,000-10,000 compounds tested, only 1 is approved.

Drug Discovery and Development: Drug, RISKY ROAD

PRE-DISCOVERY

5,000 - 10,000 COMPOUNDS

250

3 - 6 YEARS

PHASE 1

PHASE 2

PHASE 3

NUMBER OF VOLUNTEERS

20 - 80

100 - 300

1,000 - 3,000

6 - 7 YEARS

0.5 - 2 YEARS

The Opportunity of Home-based Technologies


Home ‘Life Lab’ Platform for Rapid Assessment of New Therapies

Every Day Cognition: Computer use changes over time with cognitive decline (without formal cognitive tests)

- At Baseline: Mean 1.5 hours on computer/per day
- Over time:
  - Less use days per month
  - Less use time when in session
  - More variable in use pattern over time


ACTNOW! - Alzheimer’s Comprehensive Treatment Network of Oregon and Washington

A new on-line community of volunteers to speed development of new treatments.

Alzheimer’s. You can make a difference.

www.alzactnow.org  actnow@ohsu.edu
4. Changing How We Help People with Alzheimer’s Now

Even in the best scenarios new treatments take time to develop. What is available now?

• Good ‘old fashion’ medical care – dementia best practices
• The three ‘engagements’: mental, social and physical
• Proactive Planning: different stages emphasize different needs

Key Clinician Tasks in Caring for Patients with Dementia

• Identify areas of impairment, severity, and functional consequences
• Determine etiology
• Treat cognitive impairment/behavior problems
• Manage co-morbidities / review medications
• Safety issues: e.g., driving, being alone
• Caregiver care and counseling
• Legal issues: e.g. decision-making capacity, advanced directives
• End of Life Care
Dementia Evaluation Summary

<table>
<thead>
<tr>
<th>Dementia Evaluation</th>
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<tr>
<td><strong>History</strong></td>
<td>From patient and informant</td>
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<td></td>
<td>Onset and early symptoms</td>
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<tr>
<td></td>
<td>Characterize cognition</td>
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<td></td>
<td>Functional status</td>
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<tr>
<td><strong>Cognition</strong></td>
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<td>Montreal Cognitive Assessment</td>
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<td>St. Louis University Mental Status</td>
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<td><strong>Depression/Behavior Screening</strong></td>
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<td><strong>Neurologic Examination</strong></td>
<td>Focal findings</td>
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<td></td>
<td>Parkinsonism</td>
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<td>Gait impairment</td>
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<td>Neuropathy</td>
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<td>Visual field testing</td>
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<td></td>
<td>Apraxia, myoclonus</td>
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<tr>
<td><strong>Tests</strong></td>
<td>Labs: CBC, Chem 7, Kidney and Liver function, B12, TSH</td>
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<tr>
<td></td>
<td>(VDRL, HIV, CSF study, other)</td>
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<tr>
<td></td>
<td>Imaging: CT or MRI brain (PET or SPECT)</td>
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<td>Sleep study</td>
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</tbody>
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Today's best practices for sustaining brain health across the spectrum of needs
Alzheimer’s Care via Telemedicine for Oregon (ACT-ON): A Direct-to-Home Dementia Care Telemedicine Program

Background
Over 60,000 Oregonians have Alzheimer’s Disease or a related dementia, but for many, access to care is limited.

ACT-ON increases access to dementia care by addressing these barriers

Limited access to care for persons with Alzheimer’s Disease and their caregivers

Funded through the Oregon Health Authority’s federal State Innovation Model (SIM) grant. The SIM grant supports projects that advance Oregon’s health system transformation efforts. Support also was provided by NIA Center grants P30 AG008017 and P30 AG024978.

What you can do to ACTNOW!

• Join ACTNOW!: www.alzactnow.org
• Be an active advocate
• Be a research participant
• Be a citizen-scientist
• Be a generous funder

“We need to be the change we wish to see…”

- Mahatma Ghandi
Thank you to the many research volunteers and families and my many colleagues at OHSU and around the world for their amazing dedication to being the change agents we need!
Chapter 3

Helping Memory-Impaired Elders: A Guide for Caregivers

VICKI SCHMALL, PH.D.
Aging Concerns
West Linn, Oregon

1Reprinted with permission of author.
Helping Memory-impaired Elders

A GUIDE FOR CAREGIVERS

PNW 314
Reprinted August 2005

A Pacific Northwest Extension Publication
Oregon State University • Washington State University • University of Idaho
Chapter 3—Helping Memory-Impaired Elders: A Guide for Caregivers

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Acknowledgments
Photos by Rod Schmall, West Linn, OR.
For several years Joe had known he was having memory problems. He compensated by writing himself notes of once-familiar names, telephone numbers, and things he had to do. Sometimes he became annoyed when people tried to help by reminding him. He silently worried about becoming “senile.” He was, after all, 64 years old.

Recently, Joe encountered a detour while driving home from the neighborhood grocery store. He arrived home 2 hours late. He had become lost 3 blocks from home. He felt frustrated and afraid, but he covered up by telling his worried wife that he had run into an old friend.

Joe’s work suffered. His employer suggested early retirement. Joe felt worthless. Growing old was depressing.

Joe mistakenly accepted his problems as the inevitable result of aging. He is not alone. Many people, including some health professionals, share this myth and label older adults who have memory problems as senile. Others fear that aging leads to senility or loss of memory.

Getting older does not necessarily mean losing one’s intellectual abilities. Actually, the word senility has been misused. It is derived from a Latin word that means “to grow old.”

Dementia is the more appropriate word to describe the significant change.
Chapter 3—Helping Memory-Impaired Elders: A Guide for Caregivers

This publication is designed to give family and professional caregivers a fuller understanding of dementia in later life and ways to cope more effectively with the changes resulting from it.

In addition to general care guidelines, the publication outlines approaches for handling specific problems—driving, wandering, money management, hiding items, catastrophic reactions, hallucinations, eating, and incontinence—and how to communicate with a memory-impaired person.

Progressive loss of mental abilities that some older people experience. Symptoms of dementia include impairment in thinking, learning, memory, and judgment, and changes in personality, mood, and behavior.

Dementia is the result of a disease process. It is more common with advancing age but is not a normal part of growing older. Dementia is more common today than it was 100 years ago because many more people are surviving to age 85 and beyond.

Most people experience some changes in memory as they grow older. For example, information processing and recall are slower, and it may take more time to learn new information. However, these changes do not interfere with a person’s daily functioning.

Many other factors can affect memory. These include stress, fatigue, illness, grief, or information overload. Frequently, people don’t remember something because they didn’t concentrate in the first place, and the information wasn’t filed in the brain’s memory bank.

Adults concerned about their forgetfulness should ask themselves “How did I know I forgot?” The answer: “Because I remembered later.” In a dementing illness, these memories cannot be recalled because they have been erased from the mind.

Confusion and cognitive impairment sometimes are caused by treatable illnesses, reactions to medications, drug toxicity, alcohol abuse, depression, poor nutrition, infections, and metabolic disorders such as a thyroid problem.

Any memory loss that interferes with a person’s lifestyle, work or daily functioning should be evaluated. A variety of diagnostic tools can help physicians assess whether a memory problem is significant. Finding the cause of memory loss is critical to appropriate treatment.

**Causes of dementia**

The onset and course of dementia depend on the nature of the particular disease causing it. Symptoms can vary widely, and no two afflicted persons follow precisely the same course or rate of progression.

Alzheimer’s (ALZ-hy-merz) disease is the most common cause of dementia in the United States.
The disease destroys nerve cells throughout the cerebral cortex, the outer layer of the brain. Often the first symptoms include difficulty remembering recent experiences. This is because early in the disease, the brain loses the ability to record new information, experiences, and events.

As the disease progresses, the person loses more and more of her memory and other abilities. Eventually, she is not able to function independently. The time from onset to total disability varies from 3 to 20 years.

Alzheimer’s disease is diagnosed by ruling out all other causes of the symptoms. As of 2005, there was still no way to be certain of a diagnosis of Alzheimer’s disease without a brain biopsy or autopsy. However, if diagnostic testing is comprehensive, one can be fairly certain that a diagnosis of probable Alzheimer’s is accurate.

Currently, there is no known cure or prevention for Alzheimer’s disease. Researchers, however, are making great strides in understanding the disease and in helping the afflicted person and his or her family to function better.

The second most common cause of dementia is vascular dementia. The brain’s blood supply is interrupted, resulting in small strokes in the brain. The person may lose some function with a small stroke (or a series of small strokes) and stay at that level of impairment until the next mini-stroke. He may even appear to improve slightly for a time. Symptoms depend on which area of the brain has been damaged.

Progressive dementia may also be due to Pick’s disease, Creutzfeld-Jakob disease, Huntington’s disease, Parkinson’s disease, AIDS, or other, relatively rare, conditions.

**The family’s adjustments**

The person with dementia is not the only one affected by the disease—the person’s family is, too. Coping with the changes and problems associated with a progressive dementing illness places tremendous stress on families. The loss of the mind is difficult for everyone to accept. As dementia progresses, the affected person slowly loses insight into his or her condition. For the family, however, losing the person they have always known, though still physically present, can be very painful. Family members have said:

It’s like looking after a 6-foot 2-year-old who is accustomed to doing what he wants to do.

It’s very, very hard to watch someone you love die very, very slowly. We go through many emotions—hurt, anger (at them, at ourselves), frustration, bitterness. We feel helpless!

It’s like a funeral that never ends.

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*Dementia due to an underlying medical condition may be partly or completely reversible. Early evaluation is important, because treatable conditions may become irreversible if left untreated.*
Everyone who supports and cares for the impaired person benefits from information about the disease.

Denial is common early in the disease. The impaired person usually looks healthy, can talk about familiar topics, and sometimes even seems to improve. Many changes are subtle, and early in the disease the impaired person often is adept at compensating for memory loss. She may write herself “memory notes,” make light of the changes, blame others (“Who took my purse?”), or attribute memory loss to stress or other pressures.

Family members may attribute the person’s inability to carry out tasks to laziness or stubbornness, and this leads to arguments. When a disease is diagnosed, family members may have strong guilt feelings or may blame themselves for not being aware of the changes earlier. However, the subtle beginnings of dementia are difficult for even the professional to diagnose.

Dementia also means tasks and responsibilities gradually shift from the impaired person to the caregiver. The added responsibility can be overwhelming.

Many caregivers become socially and emotionally isolated. The caregiver may not be able to leave the impaired person alone at home. The person may become easily upset in public, may be unable to tolerate being around people, and may lose social graces. Friends and family may stop visiting if they do not understand the disease or if they find it difficult to see the deterioration in the person or to accept the behavior and personality changes. Caregivers comment:

To go out is scary, not knowing what I’ll find when I get back. My last night away was 4 years ago.

During the 5 years of caring for my husband, I left home only to buy food and medications. I prayed nothing would happen while I was away.

I feel like a prisoner in my own home.

Usually, we just stay at home because I don’t know how he will act. If we have dinner with friends, he may refuse to eat and want to go home, so our social life is negligible.

I need my friends more now than ever, but so many no longer visit or call. I know it’s painful for them, too.

The healthy spouse also loses a companion, a sex partner, and someone with whom to share life’s joys and problems.

Caregivers must be realistic about what they can do. Eventually, the impaired person may need round-the-clock care and supervision. No caregiver can provide total care without help. Those who try usually become physically and emotionally exhausted. The most common reasons for placing a memory-impaired person in a care facility are that the caregiver can’t manage alone any longer, becomes ill, or dies.
Self-care for the caregiver

Caregivers must take care of themselves as well as the person with dementia. Here are self-care guidelines for the caregiver.

Learn about the disease. Everyone who supports and cares for the impaired person benefits from information about the disease. Learning what can be expected as the disease progresses and how to deal with behavioral changes enables families to better understand and accept the impaired person, to plan, and to set realistic expectations. Unrealistic expectations can compound problems by increasing anxiety and agitation in the person and stress for the caregiver.

Don’t hide. This is a disease, not a crime. Some families are inclined to hide their family member’s illness. Explaining the disease to others may be difficult, but it helps if family, friends, and neighbors understand the impaired person’s behavior and the stress of caregiving. People need to know the following.

- Dementia causes the brain to fail, just as heart and kidney diseases cause those organs to fail.
- The disorder is not contagious.
- People afflicted by the disease are not “insane” or “crazy.”
- The disease causes the mind to deteriorate gradually. Individuals are less and less able to remember, use good judgment, control their behavior, and perform seemingly simple tasks like dressing themselves.

Ask for and accept help. Do not try to go it alone. Look for sources of help and information inside and outside your family. Let family and friends know how they can help.

Be specific with your request. And be appreciative. Don’t be a martyr—this is likely to turn off caring helpers. Realize that some people will help more than others.

Contact county and state health and social service agencies that serve older people, adult community or senior centers, local offices of Social Security and (if the impaired person served in the military) the Veterans Administration. Home health and home care agencies can help with personal care and housekeeping chores. Meal delivery, transportation, and shopping services also may be available.
In addition, the Alzheimer’s Association has chapters in most states. Chapters offer information and support through toll-free telephone numbers, websites, and support groups. Look in the community pages of your telephone book and in your local newspaper under “Meetings,” visit the Alzheimer’s Association online at http://www.alz.org/, or call the state or county senior services department or the community education department of your local hospital.

Maintain meaningful relationships. Build and fortify your relationships early in the disease. Family and friends can be a source of great comfort, help, and pleasure.

Caregivers who take time away from their responsibilities to meet their own needs for companionship and recreation generally feel less trapped and less isolated, and they are better able to care for the impaired person.

Take a break from caregiving.

Regular breaks from caregiving, also called respite, are essential. They allow the caregiver to rest physically and emotionally. Breaks are as important to health as diet and exercise—and taking breaks is not selfish! Breaks benefit the impaired person as well.

Consider family members, friends, neighbors, fraternal and church groups to which you belong, or college and nursing students for assistance and a break from caregiving. In some communities, adult day programs and/or in-home respite care are available. Some care facilities also offer adult day programs and short stays for older adults, so caregivers can take a short break or a needed vacation.

Be frank with anyone giving respite care. Family members not involved directly in care may not realize the demands of caregiving or may fear the responsibility. Give respite care providers the following information.

- Emergency telephone numbers, including the name and number of the doctor, preferred hospital and ambulance service, nearest relative or friend to contact, local police and fire departments, or an emergency dispatch number (if there is one)
• How to reach the caregiver
• Estimated time of the caregiver's return
• Special instructions for relating to and caring for the impaired person and managing difficult behavior; for example, “When Fred picks at his clothes, it may mean he needs to use the toilet.”

List things that are stressful to the person, things to do to soothe and comfort the person (e.g., play the classical music tape, or go with Dad on a walk), and signs that trouble is brewing (e.g., Dad says “I want to go home”; Mom starts to wring her hands).

Be honest about any problems. Sooner or later, a substitute care provider may have to confront difficult behavior. Workbooks such as The Carebook: A Workbook for Caregiver Peace of Mind (see page 33) give a step-by-step guide to information that would help any substitute care provider. A brief note reminding the memory-impaired person of the caregiver’s whereabouts and hour of return may reduce questioning and anxiety. This information is also important when the person is left in an unfamiliar place for a short time.

Understand and accept feelings as normal human responses. Families and caregivers dealing with a dementing illness have mixed and powerful feelings—
grief, anger, sadness, embarrassment, shame, guilt. Remember that feelings are not good or bad, right or wrong. And they are not deeds. They are responses that everyone has, especially when dealing with the stress of a chronic, progressive illness.

Anger is a normal response to frustration. Caregivers often feel trapped. They may feel angry at God for what has happened, at the strange and embarrassing behaviors of the memory-impaired person, at others who offer advice but don’t help.

No matter how much a caregiver loves the memory-impaired person, dealing with that person’s behavior can be exhausting and difficult. Caregivers, too, have emotional limitations, and they need opportunities to express their anger, frustration, and hurt. They need to acknowledge their right to feel angry, and then they need to do something constructive about it. It’s important to find someone who is willing to listen to and understand such feelings.

Guilt feelings are common. Caregivers may feel guilty about their anger, misdeeds of the past, wishing for the impaired person’s death, or about mistakes or outbursts in dealing with the person. Caregivers must forgive themselves and consider that the impaired person has already forgotten.
Adult sons and daughters who are caregivers commonly experience divided loyalties. Competing demands from children, spouse, other family members, and a job can overwhelm the most dedicated caregiver. The caregiver’s personal needs may be overlooked or ignored.

If it’s not possible to balance responsibilities, set priorities. Children’s needs and family unity should come first. Professional help may be needed to sort through complex and emotionally charged problems and adjustments.

**Make realistic commitments.** Nearly everyone has made an emotionally laden promise based on an unknown future. One of the most common is a promise never to place a family member in a care facility.

Unforeseen circumstances may make it impossible to keep some promises. Recognize that conditions under which such promises were made were quite different from the current situation. A realistic commitment doesn’t include words such as “always,” “never,” or “forever.” It’s a pledge to do something, but not everything, regardless of what happens.

It’s important not to let old promises or guilt guide decisions. They reduce objectivity and your ability to make the best choice. Consider what is best for you and your family as well as for your memory-impaired family member. It’s critical not to sacrifice your own physical and emotional health.

**Hope for the best, plan for the worst.** Caregivers need to look at a broad range of questions in planning.

- What are the legal and financial aspects of progressive mental impairment? What should be done, and when? For information, see *If You Became Incapacitated, Who Would Make Decisions for You?* (page 33).
- Where are important documents and valuables? For information, see *Where Are Your Valuable Papers?* (page 33).
- How can family, friends, and community services help with care?
- What arrangements can be made for respite?
- What should be done in an emergency?
- What community services could help the memory-impaired person or the caregiver?
- Under what conditions would a care facility be best? What does this mean financially and personally?

A time may come when placement in a care facility is best for everyone. It’s often a very difficult decision. Some families hesitate to plan for the possibility...
until a crisis occurs; for example, a change in the memory-impaired person’s health or the caregiver’s unexpected illness or death. Being informed and prepared helps avoid making unsatisfactory choices.

The Alzheimer’s Association says placement may be desirable if the impaired person wanders, is a danger to self or others, is unable to care for himself in the most basic ways, or frequently interrupts another’s sleep.

**Join a support group.** Family support groups can be a tremendous source of information and understanding. Sharing among people who are coping with a family member who has the same kinds of issues reduces feelings of isolation and guilt. Caregivers also learn from each other how to more effectively handle challenging behaviors, involve their family in caregiving, and make tough decisions.

For more information, contact the Alzheimer’s Association’s national office, 225 North Michigan Avenue, Floor 17, Chicago, IL 60601. A 24-hour toll-free line (1-800-272-3900) gives information and referral nationwide to local chapters. The website is http://www.alz.org/

The Alzheimer’s Association also publishes a quarterly newsletter that reports current research about dementing illnesses and offers practical suggestions for coping.

For information about the nearest support group in Oregon, contact the Alzheimer’s Association Oregon Chapter, 1311 NW 21st Ave., Portland, OR 97209. Toll-free 1-800-733-0402; Web http://www.alz.org/oregon/

Washington has a Western and Central Washington State Chapter at 12721 30th Ave. NE, Suite 101, Seattle, WA 98125. Toll-free 1-800-848-7097; Web http://www.alzwa.org/

An Inland Northwest Chapter serves eastern Washington and northern Idaho at 601 W. Maxwell, Suite 4, Spokane, WA 99201. Toll-free 1-800-6659; Web http://www.inwalza.org/
In Idaho, contact the Alzheimer’s Association Idaho Regional Office, 1111 S. Orchard St., Suite 200, Boise, ID 83705; 208-384-1788; toll-free 1-800-272-3900.
The Alzheimer’s Disease Education and Referral Center, a service of the National Institute on Aging, provides information and publications on Alzheimer’s disease. Toll-free 1-800-438-4380; Web http://www.alzheimers.org/

**General guidelines for caregivers**
The amount of care, supervision, and help a memory-impaired person needs depends on the extent of the disease. The following guidelines will improve the quality of life for everyone.

**Keep expectations realistic.**
Keeping expectations realistic reduces frustration. Know what you can expect from the memory-impaired person. Forcing the person to do something he cannot do, or does not want to do, only makes the situation worse.

Neuropsychological testing may be helpful. It can identify which cognitive abilities are still intact and provide a realistic measure of what the person can do. The impaired person’s physician should be able to direct you to specialists who can administer assessment tools.

**Maintain a calm atmosphere.**
Being around a lot of activity, rushed, or in a chaotic environment tends to increase confusion and restlessness. Even small amounts of excitement can agitate some individuals. For example, it’s often more difficult for the person to eat a meal if the television is playing or if young children are running around.

The more secure and comfortable a person feels, the less likely she will have behavior problems. If she becomes upset or resistant, it’s important to remain calm. If necessary, remove the person from the upsetting situation to a quiet, unhurried environment.

Avoid confronting or overloading the individual with stimulating experiences. Alternate activity with quiet times throughout a day and over a week. Plan simple family events or outings after quiet days or on otherwise quiet days.

Keep your voice calm and reassuring. The tone of your voice and the feelings expressed are as important as your words. In fact, the person will tend to respond more to the tone of your message than to its content.

Arguing and scolding usually will only cause the person to overreact. Remember: The person’s behavior is a result of the disease, not stubbornness or willfulness.

**The more secure and comfortable a person feels, the less likely she will have behavior problems.**

Alzheimer’s Disease and Other Dementias: The Continuing Pandemic Affecting Your Practice

Archival Copy. For current information, see the OSU Extension Catalog: https://catalog.extension.oregonstate.edu
**Be consistent.** Avoid changes and surprises. People with a dementing illness generally do best in familiar, well-organized environments with consistent routines. Many have difficulty coping with change, even seemingly minor changes such as rearranging bedroom furniture. Create a routine by doing things the same way at the same time each day. This will make it easier to get through everyday tasks (e.g., bathing, eating, and dressing). If you go on walks, go out the same door, at the same time, and use the same route.

Establish a schedule of daily activities based on the impaired person’s lifelong patterns, if possible. Plan more difficult tasks for the person’s best time of day. Keep in mind that the memory-impaired tend to have short attention spans, 30 minutes or less.

Post the schedule. This not only helps the person who can still read, but it also makes it easier for anyone who helps in the home.

When you must make changes, prepare and support the person but avoid lengthy explanations. Take care when planning a trip or vacation. Some people become agitated and more confused in unfamiliar surroundings.

**Simplify tasks.** Tasks that previously were easy for the person may become too difficult. Reevaluate skills when the person becomes frustrated by a task or refuses to cooperate.

Breaking down complex tasks into simple steps and giving the person step-by-step instructions may enable her to continue to do some tasks. For example, the person may be able to help set the table as long as she can deal with items one at a time.

**In caring for the memory-impaired…**

- Keep expectations realistic.
- Maintain a calm atmosphere.
- Be consistent.
- Simplify tasks.
- Limit choices.
- Use repetition.
- Use memory aids.
- Encourage recognition rather than recall.
- Make the environment safe.
- Use reminiscence.
- Approach the person slowly and from the front.
- Treat the person as an adult.
- Reassure and praise.
- Maintain your sense of humor.
Demonstrating each step also may help; for example, brushing your teeth at the same time as the impaired person. Occasionally, helping the person with the first step of a familiar activity enables him to complete the activity. For example, when you assist him with one sock, he might be able to put on the other sock and perhaps even the shoes.

Limit choices. Limiting the choices the person has to make reduces confusion. For example, remove seldom-worn and out-of-season clothing from the closet. Limit food choices, and put out only the utensil(s) the person will need at mealtimes.

Use repetition. Memory-impaired people need frequent, calm reminders. They simply may not remember what they are told because the brain no longer has the ability to retain information. Be prepared to repeat the same instructions daily, sometimes several times in succession.

Think about parts of activities that the person previously enjoyed and can still do. For example, the individual who enjoyed cooking (but for whom cooking is now too complex) may still be able to stir batter, wash the vegetables, or tear lettuce for a salad. The former gardener may find satisfaction in raking the yard or watering plants.

Use memory aids. The success of memory aids depends on the severity of the disease. In early to moderate cases of memory impairment, memory aids can help promote better orientation.

(continued on page 14)
**Make the environment safe**

Caregivers continually need to be aware of sources of danger. Don’t expect the person with dementia to take responsibility for his or her own safety. Even a mildly impaired person may have lost the judgment needed to avoid accidents.

Three potential dangers are smoking, cooking, and driving. Others are stairs, swimming pools, and windows from which the person could fall. Memory-impaired people sometimes forget they are smoking or forget to put out their cigarettes. If possible, encourage the person to give up smoking. Otherwise, supervise the smoking. Keep matches, lighters, and smoking materials out of reach.

The person may turn on the stove and forget it, or put flammable materials in the oven. Removing knobs from the stove may solve the problem. Or remove the fuse or open the circuit breaker when you’re not cooking. If you have questions about how to make a stove inoperative, consult your utility company.

Hot tap water can be dangerous. Lower the temperature setting on your water heater to 120°F to prevent burns. Check the temperature of bath water before the person enters. Install grab bars in the bathtub and shower and by the toilet. Use a rubber mat or no-skid decals on the tub’s bottom to prevent falls. Don’t use bath oils; they make the tub slippery.

Lock up potentially dangerous items. These include medications, firearms, power tools, small appliances, knives and other sharp objects, razor blades, alcohol, poisons, and cleaning supplies.

The memory-impaired person may not know what is edible and what isn’t. Make sure that poisonous items such as cleaning fluids are inaccessible. Remove items that resemble food, such as plastic fruit or rocks in a jar that might be mistaken for candy. If the person begins putting inappropriate items in her mouth, remove plants, buttons, small knickknacks, and other items that might be swallowed.

Remove locks on bedroom and bathroom doors to avoid accidental locking. Lock windows or limit how far they open so the person cannot climb out. Install locks on outside doors to prevent the wanderer from leaving the house unnoticed. A hard-to-reach lock on the kitchen door also may be helpful.

Awakening in the dark can be disorienting. Installing night-lights in the bedroom, hallway, and bathroom and/or a strip of glow-in-the-dark tape from bedroom to bathroom increases nighttime safety and helps orient the person.

Be sure stairs are safe. In every room, remove objects a person might trip over, such as scatter rugs, footstools, and electrical cords.

Because memory-impaired people are at greater risk for accidents, it’s helpful to know first-aid procedures. Contact your local Red Cross chapter about classes.
Caregivers need to be aware of sources of danger....

Even a mildly impaired person may have lost the judgment needed to avoid accidents.

Signs, clocks, calendars, seasonal decorations, and a schedule of the day’s activities reinforce memory.

Give cues. For example, put labels on drawers, cupboards, appliances, and doors. When the person can no longer comprehend the written word, replace word labels with pictures. Mark off days on a calendar with a large felt pen so the person will see the current date.

Autographed photos may help the person to remember family members and close friends. However, expect fluctuations in the person’s ability to recognize people, even close family members. Don’t take it personally when you are not recognized.

Instruct family and friends when the person may no longer recognize them. Let them know that the lack of recognition is due to the disease, not to the impaired person’s feelings toward them, and that some individuals deteriorate to the point where they don’t even recognize themselves in the mirror.

Encourage recognition rather than recall. It’s easier to recognize than to recall information. Limit the demands for recall of facts, names, and schedules. For example, post a schedule of the day’s activities. Name events, and give the names of family members and friends who visit.

When speaking to a person who has difficulty remembering you, state your name and relationship to the person; for example, “I’m Jane, your daughter. I’m here to visit you.” Avoid saying “Who am I?” when the person can no longer remember who you are.

Use reminiscence. Talking about the past may help the person become involved in what she can remember. It can also build self-esteem since the past generally was a time when the person felt independent and productive.

People who seem to have little memory often respond to discussions about significant personal experiences (e.g., weddings, children’s births, hobbies) and unique historical events (e.g., the Great Depression). Old photographs, special holidays, and familiar songs often evoke memories and reminiscing.

Approach the person slowly and from the front. Moving quickly, pushing or pulling the person, or approaching from behind may startle a person with dementia. It can also stimulate agitation, hitting behavior, and resistance.

Treat the person as an adult. Include the person in adult conversations and activities. Avoid talking down to him or talking about him as if he weren’t present. Don’t treat him as a child because then he is more likely to respond with childlike behavior.
Maintain an attitude of respect and dignity and allow the person to be as independent as possible, even if tasks are not done as well as you would like. A person with dementia needs to feel that his dignity remains intact.

**Reassure and praise.** People with dementia also need a feeling of success and self-esteem. Provide praise for tasks accomplished. Tasks such as cooking, bathing, dressing, and remembering to go to the bathroom, which are relatively easy for the healthy person, become increasingly difficult for the memory-impaired.

Look for activities that give the person a sense of accomplishment and fun. Small accomplishments are tremendous victories for people whose memories are impaired. Whether singing, dancing, gardening, or playing with a grandchild, continue to involve the person in activities that are meaningful and enjoyable.

**Maintain your sense of humor.** Families find a sense of humor especially helpful in dealing with trying situations—for example, discovering garden tools in the refrigerator or finding that, after spending half an hour dressing Dad, he has removed all clothing to use the toilet.

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**Responding to challenging behaviors**

Dementia can cause a person to act in different and unpredictable ways, which challenge the caregiver. In dealing with a difficult behavior, it’s important to accept the behavior as a reality of the disease, try to work through it, and not take the behavior personally. There is no one “best approach” that is guaranteed to work. You may need to try several approaches. It also helps to keep the following in mind.

- Difficult behavior is not willful.
- The impaired person is always right—from his or her point of view.
- The impaired person loses the ability to learn and to record information and events.
- The past becomes more real and lovable than the present.
Emotions and feelings remain largely intact.

The memory-impaired person cannot change—but everyone else must.

Connect, don’t correct.

Use distraction.

**Difficult behavior is not willful.**

Irritating, rude, stubborn, and socially inappropriate behaviors are usually beyond the control of the person with dementia. The caregiver who blames the impaired person for his behavior or views it as being done on purpose may be setting up a self-destructive pattern of anger and frustration.

Key elements in responding effectively to difficult behavior are to:

- Recognize that the person is not intentionally being difficult
- Define the behavior, not the person, as the problem
- Look at the behavior as reflecting a need rather than simply as a problem

Try to understand the “why” of the behavior. Behavior usually does not occur in a void. There is a reason for it. The behavior serves a purpose but is not done on purpose. If you can discover that purpose, you often can devise an appropriate way to meet the need, and then the behavior may lessen or stop.

**The patient is always right—from her point of view.** Try to understand the world of the person with dementia and her perceptions, thoughts, and feelings. This will help you to better develop strategies to address a difficult situation.

For example, a radio talk show playing in an adjoining room may seem as if people are in the next room. A tree branch hitting against a window when the wind blows may seem as if somebody is trying to break into the house. Ice cubes dropping into the bin of an automatic ice maker may sound like something breaking. The woman who no longer recognizes herself in the mirror may accuse her husband of having another woman in the house. A person may no longer know that shooting, violence, or other activity on television programs is not real.

**The impaired person loses the ability to learn and to record information and events.** It’s easy to get frustrated when a memory-impaired person says he will wait but then does not, or agrees to give up a car or to move to another home, then is adamant the next day that no such agreement was made. Early in the disease process, dementia steals the brain’s ability to record information and events. Thus, the
person can no longer remember information shared, instructions given, or agreements made just minutes earlier.

The person may not remember your visit a few hours ago or an event that he attended and enjoyed. Sometimes family and friends feel it’s not worthwhile to visit or to engage the person in an activity because “it won’t be remembered anyway.” It becomes important then to look at the joy that is created for the moment.

**The past becomes more real and lovable than the present.** As dementia progresses, it increasingly erases stored memories. “Today” for the person may be what was 10, 20, or 40 years earlier. The person may talk about a family member or friend, long dead, as if she is alive.

Also, the person may not recognize the people around him. For example, a man may not know his grandchild or may think that his daughter, who looks a lot like her mother, is his wife or that his nephew is his brother.

**Emotions and feelings remain largely intact.** People with dementia are memory impaired but not without feeling. They can feel love, caring, joy, embarrassment, and other emotions.

Sometimes, a feeling will be remembered long after an event has occurred. For example:

It was Abraham Lincoln’s birthday, and the 16th U.S. president was being discussed at the adult day program. To the surprise of staff, a male participant recited part of the Gettysburg Address. He received applause and a lot of praise. When his wife came to pick him up, he excitedly told her, “I did it, I did it.” When she asked what he’d done, he couldn’t remember. Yet the feeling of what had happened was still with him.

Emotions are very infectious, and people with dementia often mirror the emotions around them. If you are tense, annoyed, or angry, the memory-impaired person may show the same emotion.

**The person cannot change. We must change our behavior or the environment.** An important key in meeting the challenges of caring for someone with dementia is modifying the environment or our own behavior—*not* trying to change the person’s behavior. Trying to reason with the person or expecting him to change are not effective strategies. The disease “steals” these abilities from people. It’s also important to stay flexible. For example, if the person resists taking a bath in the morning, try again later.

**Focus on feelings, not facts.** If you argue about the “facts” or try to convince the person she is wrong, you’re likely to make the situation worse and convey that you are unfriendly or not to be trusted.
An Alzheimer’s disease Bill of Rights*

Every person diagnosed with Alzheimer’s disease or a related disorder deserves the following rights.

- To be informed of one’s diagnosis
- To have appropriate, ongoing medical care
- To be productive in work and play for as long as possible
- To be treated as an adult, not as a child
- To have expressed feelings taken seriously
- To be free from psychotropic medications, if possible

- To live in a safe, structured, and predictable environment
- To enjoy meaningful activities that fill each day
- To be outdoors on a regular basis
- To have physical contact, including hugging, caressing, and hand-holding
- To be with individuals who know one’s life story, including cultural and religious traditions
- To be cared for by individuals well trained in dementia care


Connect. Don’t correct. If the person says something you know can’t be true—for example, “My mother is coming to see me today,” and you know her mother died 20 years ago—don’t argue about the correctness of what she says. Either let it go or look for the feeling behind the words. If the person seems pleased that her mother is going to visit, you might say something like “Tell me about your mother.” On the other hand, if she is upset, you might use distraction. The goal is to create a feeling of comfort and to connect with the person in a positive way.

Focus on feelings, not facts. If you argue about the “facts” or try to convince the person she is wrong, you’re likely to make the situation worse and convey that you are unfriendly or not to be trusted. Try to connect with the person as a friend (see The Best Friends Approach to Alzheimer’s Care, page 33).

Use distraction. The person with dementia tends to be highly distractable. Often you can interrupt difficult behavior or avoid potential problems by diverting the person’s attention. For example, you might divert the person who wants to go home (when he’s already at home) by saying “Let’s have lunch first.” Avoid saying “This is your home” because that is more likely to lead to a disagreement.
Approaches to specific problems

In addition to the general care and management guidelines, the following approaches to specific problems may be helpful.

Driving

Families have a responsibility to act when the memory-impaired person no longer drives safely. The ability to make quick and reasoned decisions in traffic may be affected early in the disease. Getting lost and near-misses in traffic are clues to problems.

Don’t rely on daylight hours and familiar routes to delay this difficult decision. Detours, accidents, children, and animals can surprise the driver. Remember that the impaired person generally doesn’t cope well with changes. If possible, involve the person in the decision. Be gentle but firm. Some will accept giving up driving; others will strongly resist.

Giving up driving is difficult for many people because a car represents independence and adulthood. Feelings of frustration or anger may be directed at the caregiver. Assure the person that he will stay mobile and that you will arrange transportation and regular outings.

The family physician can help by advising the state Department of Motor Vehicles, in writing, that for reasons of health the person should no longer be licensed to drive. A person often will stop driving on the order of his or her physician.

Some memory-impaired adults will not remember that they no longer have a driver’s license or that they agreed to quit driving. A written prescription from the doctor stating simply “No driving” may remind the impaired person and divert blame away from the family. If necessary, hide car keys or disable the car. A car mechanic can show you how.

For more information, see Driving Decisions in Later Life, PNW 510 (back cover).

Managing money

Problems balancing a checkbook may be an early sign of cognitive decline. Forgetting to pay bills, squandering money, or hiding cash are also early symptoms. Eventually, someone must take over the person’s financial matters.

Take care of financial and legal planning early to guarantee a safe financial future for both the impaired person and the caregiver. This may include obtaining a durable power of attorney, conservatorship, and/or guardianship.

Consult an attorney for advice. There are laws that protect the impaired, and they vary from state to state. Banks also offer services and information that may be useful.
Giving up control over money is often difficult because it means another loss of freedom and independence. The person may accuse the family of stealing. Recognize the person’s sense of loss and inability to comprehend the reality of the situation. Giving the person small amounts of spending money may help.

Talk to managers of stores or restaurants the impaired person is likely to visit. Explain the nature of the person’s problem. Make arrangements to pay for or return unwanted items the impaired person may have been unable to pay for or forgot to pay for.

Remember, police respond to the apparent act. They do not make judgments about intent. With information about the impaired person, store owners often are very helpful.

For more information, see Helping Your Older Family Member Handle Finances, PNW 344 (back cover).

**Repetitive questions**

Being asked the same question five times in 15 minutes can try anyone’s patience. It may help to understand that each time is like the first time to the person with dementia. The person may no longer be able to remember answers—or even that she asked the question before.

Sometimes, reassuring the person reduces repetitive questions.

Simple written reminders also may aid a failing memory, particularly in the early stages of dementia.

Look for a need that may underlie a repetitive question. For example, the person who continually asks “When do we eat?” may be asking because she is hungry. Giving a snack, even though it’s an hour before dinner, may stop the repetitive question.

**Wandering**

Individuals with dementia may become disoriented and lost in their own neighborhoods or far from home. Any person who can get around alone is at risk. Wandering is common and potentially dangerous. Traffic, weather, bodies of water, crime, missed medications, and exhaustion put the wanderer at risk.

The wanderer may not realize he is lost, may not remember where home is, and may not think of (or be able to use) a telephone.

A high fence with locked gates may allow the person to freely wander and exercise outdoors. This may be particularly important to the person who spent considerable time outdoors before the illness.

Approach a wanderer slowly and calmly. Offer reassurance. Walk with the person a short distance in the direction he is walking. Then, gently ask him to walk you back home. Another strategy is to
direct the wanderer to a pleasant activity; for example, you might say “We have cookies and ice cream inside.”

Avoid moving the person hurriedly, scolding, restraining, or using physical force. These approaches generally will make the person more agitated and confused and may result in striking-out behavior. Logic and reasoning will not be understood. Sometimes, medication can lessen wandering behavior.

Alert neighbors and local merchants to the memory-impaired person's problems and ask them to contact you if they see the person leaving the area.

Have the impaired person wear an identification or medical-alert bracelet that gives his name, address, and telephone number and includes the phrase “memory-impaired” or “brain-impaired.” Giving the diagnosis, such as “Alzheimer's disease” or “dementia,” may not be as helpful because others may not know what that means.

Membership in the Alzheimer's Association's program "Safe Return" provides registration in a national database and access to a nationwide alert system of law enforcement agencies, a 24-hour toll-free telephone number to contact when the person is lost, an identification bracelet or necklace, wallet cards, and clothing labels. The person who finds the wanderer can call the Safe Return number. The operator immediately calls the family members or caregivers listed.
Safeguards in the home include:
- Installing locks at the top or bottom of doors, out of the direct line of sight
- Disguising exits by painting doors the same color as the wall or covering the doors with curtains
- Installing electronic alarms or warning bells that sound when outside doors are opened
- Using dead-bolt locks that you can lock on the inside with a key

A room with a safety gate across the open door (often used for small children) may provide an area where the person can pace and explore safely. However, if the person is a “climber,” a gate could be hazardous.

Never leave the impaired person alone in a parked car. He may wander away or cause an accident by starting the car or releasing the brake. Prevent him from leaving a moving car by locking doors and using seat belts.

Wandering frequently occurs at night and may be the result of disorientation. Nighttime wandering also can be a sign of congestive heart failure. A medical checkup may be indicated. Wandering at night and other frequent occurrences at night may be the result of disorientation.

These include stress, medication, fear, and failure to recognize his surroundings. Look for possible reasons for wandering behavior.
- Did the person used to enjoy walking and outdoor activity, or walk to reduce stress?
- Is the person bored?
- Is there somewhere the person wants to go? Is the person searching for something?
- Was the person trying to get away from someone or from an unfamiliar or uncomfortable situation?
- Did an unusual noise attract the person’s attention, such as a fire truck going by, road construction, or a neighbor’s remodeling project?
- Was the person overstimulated by activity or noise in the home?
- Did the environment change at home, or is the person in a new environment?

Wandering behavior can be triggered by a variety of circumstances
- Does the person seem to be searching for some satisfaction? Calling out “I want to go home” or “Where is my mother?” may indicate a search for security.
- Is the wandering directed toward a goal? Commenting on the need to perform a task or gesturing as if performing a task may indicate a need to do something or to be busy.

Is there a pattern to the wandering behavior? The wandering may seem to have no specific cause other than being part of the disease process.

Some wandering behavior stems from the need to exercise. If this seems true, you may reduce the wandering by taking the person on frequent walks or providing other exercise such as raking leaves or sweeping the driveway. Regular exercise also can relieve tension and help the person sleep better.
night can be particularly disruptive to the caregiver’s sleep—and thus to the caregiver’s physical and emotional well-being. Keeping the person awake and active during the day generally promotes better sleep at night.

If medication taken during the day to control behavior is making the person sleepy, talk with the doctor. Changing the medicine or the dosage schedule may reduce daytime drowsiness and encourage sleep at night. Make sure the person empties his bladder before going to bed.

The quiet and darkness of a home at night may also increase restlessness. Using a night-light or playing the radio softly may reduce wandering and confusion on wakening.

**Sundowning**

Individuals with a progressive dementing illness sometimes experience more confusion and behavior problems in the late afternoon and evening. This sometimes is called *sundowning*.

The cause is unknown but may be due in part to dim light as darkness approaches, resulting in confusion. The impaired person may be tired and less able to cope with stress or, alternatively, may grow restless as activities gear down at the end of the day.

Evaluate the person’s daily activities. Behavior problems might be managed by:

- Lowering the noise level and decreasing activities in the evening hours
- Providing regular daily activities, such as exercise
- Restricting the person’s intake of caffeine-rich liquids and foods
- Increasing lighting in the evening and using night-lights

It may help to alternate activity (including dressing and meals) with quiet time. Include a 30-minute rest period each morning and afternoon. Reduce all noise and distractions during this time (soft music may be the exception).

If the behavior occurs in the evening after a trip to a restaurant, a friend or family member’s home, a store, or a vacation spot, it may
You often can avoid catastrophic reactions by simplifying a task, a request, or the environment.

mean the person can’t cope with the activity any longer. Be prepared to gear down.

Catastrophic reactions
Memory-impaired individuals sometimes overreact when a request, task, or situation overwhelms their thinking ability. Stubbornness, pacing, wandering, and weeping are common reactions. Rapidly changing moods, anger, and aggressive behavior also may occur. Look for clues about what may be upsetting the person. Was the reaction the result of mounting frustration? Overstimulation? Misinterpretation of requests, events, or activities? Inability to perform a task? Fatigue?

A catastrophic reaction can be triggered by being asked to think of several things at once; small mishaps; strange noises, people, and places; a confusing, unpredictable environment; and scolding and arguing. Signs of an impending outburst may be refusals, restlessness, and blushing.

You often can avoid catastrophic reactions by simplifying a task, a request, or the environment. After minor mishaps, allow time for the person to calm down. It may work to ignore the behavior, leave the room, and let the person be alone if she is acting out and there is no risk of injury. Otherwise, calmly remove her from the stressful situation.

Most memory-impaired people are easily distracted. Try to divert the person from the situation. Distract her with a favorite treat or activity. Do something familiar together such as having a glass of juice or going for a walk. Soft music, holding hands, and rocking may help calm her. It also may help to bring in another person to spend time with her.

Avoid explaining, arguing with, or restraining the person. Usually, these approaches will make her only more confused, angry, or combative. Recognize that feelings of distress may linger after she has forgotten the situation. And remember that the behavior is beyond her control—and can’t always be prevented even by the most experienced caregiver.

Sometimes, increased agitation and irritability are the result of internal discomfort—for example, pain or constipation—and the person isn’t able to put this discomfort into words. Any sudden deterioration in functioning or behavior may be a warning signal of a fall or illness. Check with the person’s doctor. Correcting even minor physical and medical problems often improves the person’s functioning.

If you are alone and your safety is in jeopardy, don’t hesitate to leave and call for help.
Call 9-1-1 (or the emergency-services number in your area) or call the police. Explain that the person cannot help his behavior but that the situation is getting out of control and you need help.

Seek professional help about reducing future violent episodes and about how to cope with them if they do occur. Due to the progressive nature of dementia, aggressive behaviors will lessen over time.

**Hallucinations and delusions**

Individuals with dementia may see or hear things that exist only in their minds. For example, one person kept seeing a cow on top of the neighbor’s house. Another saw rats running under her bed. Such hallucinations can be disturbing and a source of intense fear, or they may be a source of laughter and humor for the person.

The impaired person may say things have been stolen or that someone is going to harm him. These delusions can make him fearful and resistant to all attempts at care and help.

Respond calmly to what the person is *feeling* and provide reassurance. Remember that his experiences and beliefs are based on his reality. For example, say “I don’t see the cow on the roof, but it must be funny” (if the person finds it humorous that a cow is on the roof) or “I didn’t see the rats run under your bed. But don’t worry, I will take care of them.”

Do not argue or try to reason with the person. It usually makes matters worse. The person can’t stop the hallucinations just because they’re illogical or unreal to someone else, nor will he be able to remember your reasoning or rationally weigh your points.

It may help to touch the person gently and offer reassurance that you will see that things are all right. Some caregivers choose to ignore the behavior if the impaired person is not upset and has forgotten the situation. Again, it may help to distract the individual. Medication may lessen the intensity, frequency, and anxiety of the hallucinations and delusions.

**Hiding and losing things**

Memory-impaired individuals sometimes lose things, hide objects, or put them in “safe” (and promptly forgotten) places. They may not return items to their customary places but are adamant that they always keep an object in a certain place. When the object is not in that spot, the person may accuse the caregiver or others of stealing his possessions.
Remain calm if accusations are directed at you. Keep in mind that the person truly cannot remember that they did something with an item. Again, arguing or trying to reason with the person rarely works. It’s better to remain calm and offer to look for the missing item. Look for lost items in dresser drawers, boxes, coat pockets, shoes, and wastebaskets and under cushions and mattresses.

Reduce hiding places by locking closets, cupboards, and rooms the person doesn’t use. Keep important and valued items locked up. Hide a spare set of household and car keys in case your set disappears.

Note where lost items are found, as a reminder of where to look next time something is lost. Check garbage cans before emptying if these become hiding places.

**Bathing and grooming**

Most people feel and act better when they are well groomed. Early in the disease, a checklist of activities—brush teeth, wash face, shave, comb hair, etc.—put by the bathroom mirror helps some people with grooming activities.

However, as memory loss progresses, some individuals resist bathing and changing clothes. Reminders about the necessity of these activities and using simple explanations may work.

Bathing instructions written by a physician on a prescription pad, “bath twice weekly,” may help persuade the person to bathe. Avoid arguing whether he needs a bath or shower. If possible, try to maintain his lifelong routine. For example, if he took a shower before breakfast, try to follow this habit.

Bathing also may become frightening. The person may not be able to understand that someone who is undressing him is being helpful and is not trying to harm him. Water rushing out the pipe, going down the drain, or hitting against his body may be frightening. Remember, his brain may no longer process information accurately.

You may need to lower your expectations about frequency of bathing when it becomes a struggle for both you and the
impaired person. A sponge bath may be the best alternative. If the bathroom is warm and the atmosphere is calm, the person may be more cooperative.

Some families find it helpful to fill the tub with 3 to 4 inches of water before the person enters the bathroom, to use a shower chair for both baths and showers, to install grab bars, to use a shower head on a flexible hose, and to play soft music.

Bathing is a private activity, and for some people it can be embarrassing to receive assistance. Allow the person to do as much as possible for himself. However, never leave him alone in the bathtub or shower.

Simplify bathing and dressing. Encourage dressing by laying out clothes in the order in which they’re put on. When necessary, show the person what to do. There are many steps in taking a bath and getting dressed. The person may no longer be able to remember these steps or do them in the correct sequence. It helps to break down a task into small steps, giving the person step-by-step instructions such as “unbutton your shirt,” “take off your shirt,” etc.

Provide clothes that can be put on and taken off easily and that enable the person to dress independently. You can replace clothing that has buttons, hooks, snaps, ties, and zippers with slip-over and slip-on shirts, skirts, pants, and shoes. This also means fidgeting fingers can’t unzip or unbutton clothing in public.

Wash-and-wear clothing is easiest to care for. Don’t argue if the person wants to wear the same clothing every day or insists on sleeping with a hat on. This is not harmful. If the person prefers to wear only one outfit, you can make life easier by buying another one just like it.

**Meal times**

If you go out to eat, try to select a restaurant that is small, quiet, and familiar. Problems are more likely to develop in large, noisy, dimly lit settings. Depending on the degree of memory loss, the person may or may not be able to order.

At home, keep menus familiar. Sometimes the impaired person will eat only one food several times a day or develop specific likes and dislikes. Accept the behavior if it doesn’t interfere with overall nutrition and dietary restrictions. It’s better for a person to eat what she wants than not eat at all. However, if she is on a restricted diet because of a condition like diabetes or high blood pressure, you may need to put restricted foods out of her reach.

**Consistency at meal times and a calm atmosphere without distractions usually help the person to function best.**
Some individuals forget to eat. Others forget they have eaten—and want to eat constantly. Setting out a small tray of nutritious snacks or serving less food more often is sometimes a solution. With increasing brain deterioration, people frequently lose their coordination and table manners. They may lose the ability to use a knife and fork or to make proper food choices. For example, they might put gravy on salad instead of on potatoes.

Consistency at meal times and a calm atmosphere without distractions usually help the person to function best. Set the table in the same way, serve meals at the same time each day, and seat the person at the same place.

Remove unnecessary utensils, condiments, and foods. A person may become confused if she has to choose among them. Sometimes it helps to serve only one food at a time.

Prepare the person’s plate. Cut food into small pieces. Use finger foods when she can no longer use utensils. Serve soup in a cup if she has difficulty handling a spoon. Use a plastic cloth on the table, spill-proof containers, and smocks with the bottom edge turned up into a big pocket to catch crumbs.

Avoid foods the person may not chew thoroughly, such as nuts, popcorn, and raw carrots. Liquids and solids offered together may be confusing—it’s hard to know whether to chew or to swallow. Serve foods and drinks lukewarm, not hot, because the person may have lost the ability to judge temperatures.

Foods of a soft, even consistency (like purées) are easiest to swallow. Thin liquids (water, apple juice, coffee) are the hardest to swallow. A person who has difficulty swallowing should sit up straight with her head tilted forward slightly—never back—and should remain seated at least 15 minutes after eating. If she begins stuffing too much food into her mouth, remind her to swallow. Don’t allow her to lie down or walk around with food in her mouth.
If you have to spoon-feed the person, it may help to talk with a nurse or speech pathologist who specializes in swallowing about the best procedure to follow. As the disease progresses, you may need to remind the person to swallow after each bite.

Learn the Heimlich method from a medical professional or the Red Cross. It can save the life of a choking person. Contact the doctor if the person stops eating or begins losing weight. These may be symptoms of a complicating disease.

**Incontinence**

Caregivers report that incontinence is such a difficult problem to manage that it is often the “last straw,” prompting them to place the person in a care facility. Incontinence has many medical causes, such as infection, that can be treated. Therefore, when incontinence begins, it’s important to get a medical evaluation.

At first, loss of bladder or bowel control may be only occasional or during sleep. Later, the person may not be able to respond to the body’s signal to void or to remember the acceptable places and ways to eliminate bodily wastes. A man, for example, may urinate in the closet or wastebasket or on the sidewalk in town.

Establishing a regular toileting routine often helps. You may need to remind the person every 2 or 3 hours, on rising in the morning, after meals, and before bedtime to go to the bathroom. It often works better to say “It’s time to go to the bathroom” than to ask “Do you have to go to the bathroom?”

Take the person to the toilet at the time of day he usually has a bowel movement. Observe behavior for cues. For example, sudden restlessness or picking at clothes may indicate he needs to use the toilet. Be aware that he may need some assistance to undress or to use the toilet.

Limit fluid intake after the evening meal. Getting the person up once during the night or placing a commode or urinal bottle near the bed may help prevent accidents. Using night-lights may also help the person’s orientation and ability to find the bathroom.

When a regular toileting schedule does not work, use incontinence products. Special clothing with disposable pads, absorbent undergarments (sometimes called adult diapers), protective bedding, and disposable bed pads are available from medical supply, home health, and/or drug stores. Consult the physician or a nurse for additional products available for bladder and bowel incontinence.
When the person no longer understands speech, touch can become the most meaningful way to communicate.

When a person is incontinent, it’s important to keep the anal and genital area as clean and dry as possible. Also, watch for redness and other signs of skin irritation.

**Communicating with the memory-impaired person**

The effects of dementia on communication vary with each person and the progression of the illness. Early in the disease, communicating isn’t too difficult, although the person may have problems finding the correct word, especially nouns. The person may substitute phrases for words he cannot remember. For example, if he cannot think of the word “coffee” he may tell you “It’s what I drink in the morning.” If he cannot think of the word “garbage collector,” he may say “The guy who empties those big cans into that big truck.” Language also may be punctuated with indefinite words such as “thing,” “this,” “that,” and “there.”

As dementia progresses, communication becomes increasingly difficult. The person may have difficulty expressing himself in words, easily lose his train of thought, and lose the ability to understand what has been said. As a result, he may not be able to understand instructions or to report physical needs, discomfort, or pain to caregivers.

Late in the disease, a person’s vocabulary may be reduced to a few words. Some individuals use curse words often (this is not purposeful but a part of the disease process) or revert to speaking in their first language. When the memory-impaired person can no longer communicate verbally, be sensitive to nonverbal behavior—facial expressions, tone of voice, body position, and eyes.

Many people with dementia are far more sensitive to a speaker’s tone of voice and body language than to the actual words spoken. Therefore, it’s important to be aware of how you’re communicating, not just what you’re saying. Also, consider age-related changes in vision and hearing. Good lighting, a quiet environment, hearing aids, and eyeglasses may help to increase the person’s understanding of what you say.

If the person cannot take telephone messages, disconnect the telephone when you’re out or unable to answer it yourself. Or install a telephone answering machine, use voicemail, or subscribe to an answering service.

Kindness, patience, and respect go a long way in communicating effectively with a person who has dementia. Effective communication also takes flexibility. As the disease progresses, the person’s way of communicating will...
change. You will need to change your expectations and how you communicate with him.

Experts suggest the following guidelines for talking with the person who has dementia.

**Call the person by name.** Before asking a person to do something, address her by name to get her attention. In some instances, a person may better recognize a childhood nickname than her given name. Sometimes, a memory-impaired woman may not respond to her married name because she no longer remembers the name or the marriage.

**Speak slowly and clearly.** Memory-impaired people need more time to comprehend a message. Allow the person time to process information and respond.

**Talk about real actions and objects.** People lose the ability to deal with abstract concepts such as planning and using judgment to avoid potential danger.

**Keep statements short and simple.** Limit statements to one idea at a time; for example, “Your hair looks pretty” and “Please come here.” Give instructions one step at a time. Long sentences and complex instructions are likely to overwhelm the impaired person.

**Be specific.** Statements that are specific frequently help the person grasp what you are saying. “Pick up your glass on the table” is preferable to “Pick up your glass” because it gives the person more specific information and may help to focus actions.
Keep questions simple. Ask one-part questions—for example, “Do you want orange juice?” which can be answered with a yes or a no or by a gesture. Avoid open-ended questions such as “What do you want to drink?” or “What do you want to wear today?” Also avoid multiple-choice questions such as “Do you want tea or coffee, and do you want it now or with dessert?” Such questions add to confusion and stress. Eventually, even questions requiring only a yes or no reply are difficult for some people. When this occurs, say “Here’s your orange juice” rather than ask “Do you want orange juice?” It’s less confusing to provide the solution than to ask a question. Avoid quizzing the person; for example, “Do you know my name?” “What is this I am holding?” “What day is today?” “Do you remember when...?” Such questions can frustrate and agitate the person who can no longer answer.

Use names or nouns, not pronouns. For example, instead of saying “Your best friend is coming to see you. She wants to make cookies with you,” it is better to say “Your friend Cynthia is coming to see you. Cynthia wants to make cookies with you.” Instead of saying “I found it,” say “I found your wallet.”

Use positive statements. It’s easier for memory-impaired people to understand what you want them to do than what you don’t want them to do. For example, say “Please stay inside with me” rather than “Don’t go outside.” Say “Let’s go here” instead of “Don’t go there” and “Please sit in this chair” rather than “Don’t sit there.” You’re less likely to get the desired response if you use negative words such as “no” or “don’t.”

Use nonverbal communication. Communication is more than just words. Your nonverbal communication should reinforce your words. Gestures, pointing, demonstration, facial expressions, and visual aids help communicate to the person what you want done. Using objects such as a comb or toothbrush helps identify activities. Sometimes, pictures help convey an idea.

Be aware of your feelings and attitudes. They often are communicated, unintentionally, through tone of voice and facial expression. Also, be sure your words and body language are consistent. If they contradict each other, the person is more likely to respond to your body language. For example, if your words say something sweet, but your body language says you are irritated and upset, your body language usually is the stronger message.
Use the person’s vocabulary. For example, if the person uses the word “potty” for toileting activities, then use that word, too. Tender hugs, holding hands, gently combing the hair, and giving a massage can communicate acceptance, love, and caring. Touch is also soothing and can reduce feelings of isolation. However, the need for touch must be met on an individual basis. Each person has a different level of comfort with touch. Sometimes a person with dementia may misinterpret the meaning of a touch. If this occurs, respond calmly.

There are special techniques for communicating with people who have specific medical conditions such as stroke, Parkinson’s disease, and Alzheimer’s disease. Contact the support groups and related organizations for information and materials.

Summary

A time may come when the personal care and safety needs of the impaired person exceed the resources and abilities of the most dedicated in-home caregiver. Placement in a care facility may be the next logical step.

Families facing this difficult decision must realize they have not failed, broken a promise, or abandoned a loved one. They have given up only the physical chores of daily care.

As one nursing home administrator said, “Anyone can give a bed bath or help a person to dress, but only a family member knows the favorite treats, events, and memories that are meaningful to the person.”

For more information


Oregon State University

Extension publications

Where Are Your Valuable Papers?
EC 1234.
If You Became Incapacitated, Who Would Make Decisions for You?
FS 332.
Chapter 3—Helping Memory-Impaired Elders: A Guide for Caregivers

Archival Copy. For current information, see the OSU Extension Catalog: https://catalog.extension.oregonstate.edu

Pacific Northwest Extension publications

Coping with Caregiving: How to Manage Stress When Caring for Elderly Relatives, PNW 315.
Living Arrangements in Later Life, PNW 318.
Helping Your Older Family Member Handle Finances, PNW 344.
Driving Decisions in Later Life, PNW 510.
Making Decisions about a Nursing Home, PNW 563.
Sensory Changes in Later Life, PNW 196.
Depression in Later Life: Recognition and Treatment, PNW 347.
Hiring and Working Successfully with In-home Care Providers, PNW 547.

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Chapter 4

The Face of Alzheimer’s

KRISTINA BARRAGAN
Alzheimer’s Association Oregon Chapter
Portland, Oregon

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Chapter 4—The Face of Alzheimer’s

The Face of Alzheimer’s

presented by the

Alzheimer’s Association Oregon Chapter

A lzheimer’s is no longer an emerging crisis – it is here.

Individuals Living with Alzheimer’s

• 44 million people are living with Alzheimer’s worldwide
  • Over 5 million people in the US

• 115 million people will be living with Alzheimer’s world-wide by the 2050

Prevalence of Alzheimer’s by Sex in US

• 65 and older, 1 in 9 has Alzheimer’s
  • 1 in 6 for women
  • 1 in 11 for men

• 85 and older, 1 in 3 has Alzheimer’s
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Alzheimer’s Disease is a Worldwide Epidemic

www.worldlifeexpectancy.com

The Public Health Road Map

Assure a Competent Workforce

Monitor and Evaluate

Develop Policy and Mobilize Partnerships

Educate and Empower

The Healthy Brain Initiative

The Public Health Road Map for State and National Partnerships, 2015–2018

Alzheimer’s Disease and Other Dementias: The Continuing Pandemic Affecting Your Practice
Chapter 4—The Face of Alzheimer’s

Diagnosis of Alzheimer’s

Only 45% of people with Alzheimer’s disease or their caregivers report BEING TOLD OF THEIR DIAGNOSIS.

More than 90% of people with the four most common types of cancer have been TOLD OF THEIR DIAGNOSIS.

Unbalanced Spending

$100 on research vs. $26,000 on care

$153 billion

$586 million

NIH Alzheimer’s Research Funding

Medicare and Medicaid Spending on Alzheimer’s Care
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### Alzheimer’s is Underfunded

**% Change in Deaths (2000-2010)**

- Alzheimer’s Disease: 0.9%
- Breast Cancer: 2%
- Prostate Cancer: 8%
- Heart Disease: 16%
- Stroke: 23%
- HIV: 42%

**Research Funding Est. FY13 (in Billions)**

- Cancer: 5.4
- Heart Disease: 4
- HIV: 2
- Diabetes: 1
- Alzheimer’s: 0.45

---

### National Plan to Address Alzheimer’s Disease

#### National Plan to Address Alzheimer’s Disease

**Five Goals**

1. Prevent and Effectively Treat Alzheimer’s Disease by 2025
2. Enhance Care Quality and Efficiency
3. Expand Supports for People with Alzheimer’s Disease and Their Families
4. Enhance Public Awareness and Engagement
5. Improve Data to Track Progress

---

Alzheimer’s Disease and Other Dementias: The Continuing Pandemic Affecting Your Practice 4–4
### Common Challenges with Alzheimer’s Disease

- Stigma and Diagnosis Rate
- Education and Support needed for Caregivers
- Challenging Behaviors
- Difficult Conversations
- Caregiver Burnout

---

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

OUR VISION: A world without Alzheimer’s.
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.

The Oregon Chapter of the Alzheimer’s Association was founded in 1982. For 30 years, our staff has been providing support and services to individuals throughout Oregon.

Chapter Programs and Services
24/7 Helpline

- Trained staff provides information about Alzheimer’s disease, referrals to local resources, and support
- Care consultations provided by master’s level clinicians for crisis assistance and education
- Local staff review calls daily and provide follow up when needed
- Translation service provides support in over 170 languages and dialects

Support Groups

Groups for both caregivers and for those with Alzheimer’s disease
- Provide support for general caregiving challenges as well as topical presentations by professionals in related fields
- 60+ groups throughout the state
Chapter 4—The Face of Alzheimer’s

Community Education

- Specialized presentations developed by a national team
- Designed to raise awareness and provide practical strategies for care and support
- Topics include Alzheimer’s Awareness and Education as well as workshops featuring strategies for managing a diagnosis
- Presentations are free of charge and open to the community
- Annual McGinty Conference on Alzheimer’s

Education Programs

20,000 education programs annually and offer online information in 15 languages.
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The 10 Warning Signs

Memory changes that disrupt daily life

1. Forgetting something recently learned
2. Asking the same information over and over
3. Relying on memory aids or family members for things you used to handle alone
Challenges in planning or solving problems

- Problems developing or following a plan
- Problems working with numbers
- Problems following a familiar recipe
- Difficulty keeping track of bills
- Challenges concentrating
- Taking longer than before to do common tasks

Difficulty completing familiar tasks

- Difficulty completing daily tasks
- Trouble driving to once-familiar places
- Problems managing a budget at work
- Difficulty remembering rules of a favorite game
**Confusion with time or place**

4. Losing track of dates, seasons and passage of time

4. Forgetting where one is or how one got there

**Trouble understanding visual images and spatial relationships**

5. Diminishing ability to track visual surroundings
   - Difficulty reading
   - Trouble judging distance
   - Problems determining color or contrast
New problems with words in speaking or writing

6

- Problems following or joining a conversation
- Difficulty tracking conversations
  - Stopping in the middle of conversations, unable to continue
  - Repeating what was already said
- Trouble with vocabulary
  - Difficulty finding the right word
  - Calling things the wrong name

Misplacing things and losing the ability to retrace steps

7

- Putting things in unusual places
e.g., wallet in fruit bowl
- Having increasing difficulty retracing steps to locate a missing item
- Accusing others of stealing
Decreased or poor judgment

8  ▶ Changes in decision making and judgment
  ▶ Poor judgment with money
    • Giving large amounts to telemarketers
    • Spending more impulsively
    • Wearing clothing inappropriate to the weather or season

Withdrawal from work or social activities

9  ▶ Withdrawing from
    • Hobbies
    • Social activities
    • Work projects
    • Family gatherings
  ▶ Losing track of a favorite sports team
  ▶ Forgetting how to engage in a favorite hobby
  ▶ Avoiding social situations
Changes in mood and personality

10. Increasingly displaying signs of:
   - Confusion
   - Suspicion
   - Fear
   - Anxiety
   - Agitation

MedicAlert + Safe Return

- 24-hour nationwide emergency response service for individuals with Alzheimer's who may wander
- Hotline activates the resources of law enforcement, medical professionals and local chapter staff to assist when an incident - either wandering or medical emergency - occurs
Online Resources

- Caregiver Center
- Dementia and Driving Center
- Alzheimer’s Navigator
- ALZConnected
- Community Resource Finder
- EssentiALZ/CARES
- Safety Center
- E-learning site

www.alz.org/care
Chapter 4—The Face of Alzheimer’s

www.alz.org

I Have Alzheimer's Disease

If you have been diagnosed with Alzheimer’s or another dementia, you are not alone.

There are people who understand what you are going through, and help is available. There is much you can do in the early stage to cope with the changes ahead.

What you need to know Live your best life

> Newly diagnosed > Taking care of yourself

Community Resource Finder

Get easy access to a comprehensive listing of Alzheimer’s and dementia resources, community programs and services.

START YOUR SEARCH ADDITIONAL RESOURCES

- Alzheimer’s Association Programs and Events
- Housing Options
- Care at Home
- Medical Services
- Community Services

How to Use This Tool
Learn More
Share Your Opinion
Provider Support

The Alzheimer’s Association does not endorse any of the providers listed here. The information contained in the Community Resource Finder is thought to be reliable but is not guaranteed to be accurate. It is compiled from provider descriptions of their own services and other public data sources and is subject to change without notice. For assistance in how to determine the best care option for your situation, call the 24/7 Helpline at 800-272-3900.

Community Resource Finder Powered by Care.Life Powered by Care.Life
WE ADVOCATE

The Association is the leading voice for Alzheimer's disease advocacy, fighting for critical Alzheimer's research, prevention and care initiatives at the state and federal level.

We diligently work to make Alzheimer’s a national priority.

Advocacy Efforts in Oregon - SPADO

**Goal 1: Enhance Public Awareness and Engagement**

**Goal 2: Optimize Care Quality and Efficiency**

**Goal 3: Protect Individuals with Dementia**

**Goal 4: Improve Access to Quality Care**

**Goal 5: Comprehend, Prevent, and Effectively Treat Dementia and its Impact**

State Plan for Alzheimer’s Disease and Related Dementias in Oregon

July 2012
Research

WE ADVANCE RESEARCH

As the largest, private non-profit funder of Alzheimer’s research, the Association is committed to accelerating progress of new treatments, preventions and ultimately, a cure.

We have been part of every major research advancement over the past 30 years.

5 Million Reasons to be the Face of Alzheimer’s

More than 5 million Americans have Alzheimer’s disease

More than 15 million Americans care for an individual with Alzheimer’s or dementia
2015 ALZHEIMER’S DISEASE FACTS AND FIGURES

It’s the only cause of death in the top 10 in America that CANNOT BE PREVENTED, CURED OR SLOWED.

Alzheimer’s disease is the 6TH LEADING CAUSE OF DEATH IN THE UNITED STATES.

SENIORS dies with Alzheimer’s or another dementia.

ALMOST TWO THIRDS of Americans with Alzheimer’s disease are women.

EVERY 67 SECONDS someone in the United States develops the disease.

Only 45% of people with ALZHEIMER’S disease or their caregivers report BEING TOLD OF THEIR DIAGNOSIS.

More than 90% of people with the four most common types of CANCER have been TOLD OF THEIR DIAGNOSIS.

By 2050, these costs could rise as high as $1.1 TRILLION.

In 2015, Alzheimer’s and other dementias will cost the nation $226 BILLION.

alzheimer’s association
THE BRAINS BEHIND SAVING YOURS™
Chapter 4—The Face of Alzheimer’s

Over 5 million Americans are living with Alzheimer’s, and as many as 16 million will have the disease in 2050. The cost of caring for those with Alzheimer’s and other dementias is estimated to total $226 billion in 2015, increasing to $1.1 trillion (in today’s dollars) by mid-century.

Nearly one in every three seniors who dies each year has Alzheimer’s or another dementia.

### Oregon Alzheimer’s Statistics

#### Number of people aged 65 and older with Alzheimer’s by age

<table>
<thead>
<tr>
<th>Year</th>
<th>65-74</th>
<th>75-84</th>
<th>85+</th>
<th>TOTAL</th>
</tr>
</thead>
<tbody>
<tr>
<td>2015</td>
<td>8,900</td>
<td>24,000</td>
<td>27,000</td>
<td>60,000</td>
</tr>
<tr>
<td>2020</td>
<td>12,000</td>
<td>29,000</td>
<td>28,000</td>
<td>69,000</td>
</tr>
<tr>
<td>2025</td>
<td>13,000</td>
<td>40,000</td>
<td>32,000</td>
<td>84,000</td>
</tr>
</tbody>
</table>

#### Percentage of seniors with Alzheimer’s disease

- 10%

#### Number of deaths from Alzheimer’s disease in 2012

- 1,312
  - 6th leading cause of death in Oregon
  - 10th highest Alzheimer’s death rate in America

### Alzheimer’s and Dementia Caregivers

<table>
<thead>
<tr>
<th>Year</th>
<th># of Caregivers</th>
<th>Total Hours of Unpaid Care</th>
<th>Total Value of Unpaid Care</th>
<th>Higher Health Costs of Caregivers</th>
</tr>
</thead>
<tbody>
<tr>
<td>2012</td>
<td>167,000</td>
<td>191,000,000</td>
<td>$2,352,000,000</td>
<td>$96,000,000</td>
</tr>
<tr>
<td>2013</td>
<td>173,000</td>
<td>196,000,000</td>
<td>$2,446,000,000</td>
<td>$100,000,000</td>
</tr>
</tbody>
</table>
| 2014 | 175,000         | 199,000,000               | $2,422,000,000            | $105,000,000                     

For more information, view the 2015 Alzheimer’s Disease Facts and Figures report at alz.org/facts.
Currently, more than 5 million Americans are living with Alzheimer’s disease, and over 15 million are serving as their caregivers. The Alzheimer’s Association® works to address the global Alzheimer’s disease epidemic by providing education and support to the millions who face dementia every day, while advancing critical research toward methods of treatment, prevention and, ultimately, a cure.

**We provide care and support to those in need.**

- Our free nationwide 24/7 Helpline (800.272.3900) receives nearly 300,000 calls annually and is staffed by specialists and master’s-level clinicians who offer information and referrals.

- We offer peer- or professionally led support groups for caregivers and others dealing with Alzheimer’s disease.

- Our Alzheimer’s and Dementia Caregiver Center ([alz.org/care](http://alz.org/care)) provides easy access to in-depth information and online tools.

- We offer safety services, including MedicAlert® + Alzheimer’s Association Safe Return®, providing assistance when someone with the disease wanders or has a medical emergency.

- We provide the world’s most comprehensive portfolio of meaningful early-stage programs.
We educate and raise awareness to grow understanding.

› Our education programs for the general public, both online and in person, feature information on topics such as diagnosis, warning signs, communication, living with Alzheimer’s disease and caregiving techniques.

› We provide health care professionals with the tools to diagnose Alzheimer’s and to educate people with the disease on available therapies and resources.

› We educate our nation’s lawmakers on the Alzheimer’s crisis and engage them in our efforts to fight the disease.

The Alzheimer’s Association Green-Field Library (alz.org/library), is the nation’s largest resource center devoted to increasing knowledge about Alzheimer’s disease.

› Our awareness campaigns explain the difference between Alzheimer’s and typical aging, and the power of early detection.

We advocate for the needs and rights of those facing Alzheimer’s disease.

› We recruit advocates, nationwide, so that the need for Alzheimer’s care, education and research is heard at every level of government.

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

› We call on the federal government to increase research funding and improve access to Alzheimer’s diagnosis and care planning.

We accelerate research across the globe.

› As the world’s largest nonprofit funder of Alzheimer’s research, we have awarded more than $335 million to over 2,250 proposals, providing funding for critical advancements.

› We bring the global research community together to collaborate, connect and address common challenges. The Alzheimer’s Association International Conference® is the world’s largest forum for the dementia research community.

› We drive support for transformational projects such as the Dominantly inherited Alzheimer’s Network Trials Unit (DIANTU)
Join the cause.

› **Volunteer** with the Alzheimer’s Association. Plan an event, facilitate a support group or sign up for another opportunity to advance the cause.

› **Advocate** for those affected by Alzheimer’s and urge legislators make the disease a national priority.

› **Participate** in Walk to End Alzheimer’s®, the world’s largest event to raise awareness and funds for Alzheimer’s disease care, support and research.

› **Start a team** for The Longest Day®. Honor the strength, heart and endurance of those facing Alzheimer’s with a day of activity June 21 - the summer solstice.

› **Donate** to advance vital research and provide care and support programs.

› **Register** for Alzheimer’s Association TrialMatch® ([alz.org/trialmatch](http://alz.org/trialmatch)), a free, easy-to-use clinical studies matching service that connects individuals with Alzheimer’s, caregivers, healthy volunteers and physicians with current studies.

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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.**

**Alzheimer’s Association**
**Oregon Chapter**
**1650 NW Naito Parkway**
**Portland, OR 97209**

1 (800) 272-3900
Alzheimer's disease and erratic behaviors

Alzheimer's disease 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 with dementia and the caregiver. It's important to understand that the person is not trying to be difficult and that all behavior is communication.
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 causes and solutions? If so, what can you do differently?

---

**The Alzheimer’s Association® offers suggestions for responding to dementia-related behaviors.**

1. Identify behaviors........................................... p.3
2. Aggression.................................................... p.4
3. Anxiety or agitation........................................ p.5
4. Confusion........................................................ p.6
5. Repetition.................................................... p.7
6. Suspicion.................................................... p.8
7. Wandering and getting lost........................ p.9
8. Trouble with sleep........................................ p.10

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**Negative behavior may be related 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.
2. aggression

Aggressive behavior may be verbal (shouting, name calling) or physical (hitting, pushing). It’s important to try to understand what is causing the anger, as it can occur suddenly with no apparent reason or can result from a frustrating situation.

How to respond:

Rule out pain as the cause of the behavior
Pain can cause a person with dementia to act aggressively.

Try to identify the immediate cause
Think about what happened right before, which 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 the person is unable to calm down, seek assistance from others. Always call 911 in emergency situations.

3. anxiety or agitation

People with dementia can become anxious or agitated for many reasons. It can help to learn what triggers this response by looking at the person’s surroundings, the time of day, 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.

Provide reassurance
Use calming phrases. Let the individual know you are there.

Involve the person in activities
Engage the person in art, music or other activities to distract him or her from anxiety and 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.
Chapter 4—The Face of Alzheimer’s

4. confusion

A person 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, but try not to make your hurt apparent.

**Respond with a brief explanation**
Don’t overwhelm the person with lengthy 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 “I thought it was a fork,” or “I think he is your grandson Peter.”

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

5. repetition

A person 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 his or her 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 that are meaningful to the individual like notes, clocks, calendars or photographs.
6. suspicion

Memory loss and confusion may cause a person 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 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 be reassuring, respond to the feeling and let the person know you care.

Don’t argue or try to convince
Allow the individual to express ideas. Acknowledge his or her opinions.

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.

7. wandering and getting lost

It’s common for a person with Alzheimer’s to wander and/or 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 with dementia will need increased supervision. At some point, it will no longer be safe for him or her to be left alone.

How to respond:

Encourage activity
Keeping the person with Alzheimer’s active and engaged can help discourage wandering behavior by reducing anxiety and restlessness. Involve the person in activities 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 has 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.

Consider signing up for a location-management service
MedicAlert® + Alzheimer’s Association Safe Return® is a 24-hour, nationwide emergency response service for individuals with dementia who wander or have a medical emergency. Alzheimer’s Association Comfort Zone® is a Web application that allows family members to monitor a person’s location. Call 800.272.3900 or visit alz.org/safety to learn more about these services.
8. trouble with sleep

People with dementia may have problems sleeping or experience changes in their sleep schedule. Sleep changes somehow result from the impact of Alzheimer’s disease on the brain. However, the exact cause is unknown.

How to respond:

Make a comfortable environment
The sleeping area should be at a comfortable temperature. Provide nightlights and other ways to keep the person safe, such as appropriate door and window locks.

Maintain a schedule
As much as possible, encourage a regular routine of meals, waking up 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.
**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 with Alzheimer’s or frustration that he or she can’t do the things they used to be able to do. 
   *He knows how to get dressed — he’s just being stubborn.*

3. **Social withdrawal** from friends and activities that used to make you feel good. 
   *I don’t care about visiting with the neighbors anymore.*

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

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

6. **Exhaustion** that makes it nearly impossible to complete necessary daily tasks. 
   *I’m too tired for this.*

7. **Sleeplessness** caused by a never-ending list of concerns. 
   *What if she wanders out of the house or falls and hurts herself?*

8. **Irritability** that leads to moodiness and triggers negative responses and actions. 
   *Leave me alone!* 

9. **Lack of concentration** that makes it difficult to perform 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.*

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Support available all day, every day

If you experience any of these signs, contact our 24/7 Helpline at 800.272.3900.

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Chapter 4—The Face of Alzheimer’s

**Alzheimer’s Association**

**Take care of yourself**

How to recognize and manage caregiver stress

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Alzheimer’s Disease and Other Dementias: The Continuing Pandemic Affecting Your Practice
10 ways to manage stress and be a healthier caregiver

Are you so overwhelmed by taking care of someone else that you have neglected your own physical, mental and emotional well-being? If you find yourself not taking care of your own needs, you may be putting your health at risk.

1. **Find time for yourself.**
   Consider taking advantage of respite care so you can spend time doing something you enjoy. Respite care gives caregivers a temporary rest from caregiving, while the person with Alzheimer’s disease continues to receive care in a safe environment. Visit alz.org/care to learn more.

2. **Know what community resources are available.**
   Contact the Alzheimer’s Association® or use our online Community Resource Finder (alz.org/CRF) to find dementia care 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, new caregiving skills may be necessary. 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 at alz.org/care to learn more and access care training resources, including free online workshops.

4. **Get help and find support.**
   Seek the support of family, friends and people who can relate to your situation. Use our online Care Team Calendar (alz.org/carecalendar) to organize family and friends who want to help. Our 24/7 Helpline (800.272.3900), ALZConnected online social networking community (alzconnected.org) and local support groups (alz.org/findus) are all good sources for finding comfort and reassurance. If stress becomes overwhelming, seek professional help.

5. **Take care of yourself.**
   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. Try to find relaxation techniques that work for you.

7. **Accept changes as they occur.**
   People with Alzheimer’s disease 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 is important so that the person with the disease can participate. Having future plans can provide comfort to the entire family. Many documents, including advance directives, can be prepared without the help of an attorney. However, if you are unsure about how to complete legal documents or make financial plans, you may want to seek assistance from an attorney specializing in elder law and/or a financial advisor who is familiar with elder or long-term care planning.

9. **Know you’re doing your best.**
Remember that the care you provide makes a difference and that you are doing the best you can. You may feel guilty because you can’t do more, but individual care needs change as Alzheimer’s progresses. You can’t promise how care will be delivered, but 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 be aware of what your body is telling you. Pay attention to any exhaustion, stress, sleeplessness or changes in appetite or behavior. Ignoring symptoms can cause your physical and mental health to decline.

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### Caregiver stress checkup

Do you experience any of these signs of stress?

- Denial
- Anger
- Social withdrawal
- Anxiety
- Depression
- Exhaustion
- Sleeplessness
- Irritability
- Lack of concentration
- Health problems

**When stress is a concern, contact the Alzheimer’s Association at 800.272.3900 for information and support.**
Caring for a person with Alzheimer’s or dementia often involves a team of people. Whether you provide daily care (e.g., assisting with meals and bathing), participate in the decision making (e.g., making care arrangements and legal and financial plans) or simply care about a person with the disease — there’s much to do and plenty to know. But it doesn’t have to be a lot of work to find the resources and support you need. The Alzheimer’s Association® Alzheimer’s and Dementia Caregiver Center (alz.org/care) can help.

Get reliable information on:

- Early-, middle- and late-stage caregiving
- Behaviors
- Daily care
- Caregiving skills and training
- Respite care
- Care facilities
- Costs that may be faced
- Legal documents
- Safety
Access Alzheimer’s Association tools:

**ALZConnected®**  
A community where people with Alzheimer’s and other dementias, 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.

**Alzheimer’s Navigator®**  
An interactive tool for people living with dementia and those who participate in providing care and making care-related decisions that evaluates needs, outlines action steps and links the user to local services and Association programs.

**Community Resource Finder**  
A comprehensive database powered by CareLike® that allows people to easily locate dementia resources, programs and services in their area.

**Care Team Calendar**  
A free, personalized tool, powered by Lotsa Helping Hands, that makes it easy to organize family and friends who want to help with caregiving and share activities and information among the care team.

alz.org/care

The Alzheimer’s and Dementia Caregiver Center provides reliable information and easy access to helpful resources.

alz.org/training

Free online workshop series:  
Living with Alzheimer’s: For Caregivers

alz.org/findus

Support groups, education programs and more available in communities nationwide.

800.272.3900

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

alzheimer’s association®

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®.

800.272.3900 | alz.org®

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Six out of 10 people with Alzheimer’s will wander

You can’t know when it will happen, but you’ll know what to do when it does.

It is common for a person with dementia to wander and become lost; many do repeatedly. Wandering can be dangerous—even life threatening. The stress can weigh heavily on caregivers and family.

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

How it works

If an individual with Alzheimer’s or a related dementia wanders and becomes lost, caregivers can call the emergency response line to report it. A community support network will be activated, including local Association chapters and law enforcement agencies, to help reunite the family member or caregiver with the person who wandered.

If a citizen or emergency personnel finds the member, they can call the toll-free number listed on the member’s ID jewelry. MediAlert + Safe Return will notify the member’s listed contacts, making sure the person is returned home.

Cost

$55 + $7 shipping and handling fee includes:

» Member’s ID jewelry with personalized information and MediAlert + Safe Return’s 24-hour emergency toll-free number.

» Personalized emergency wallet card.

» 24-hour emergency response service.

» Personal health record (PHR).

» Six Steps to a Safe Return magnet.

An optional caregiver membership is available for $35. Call or go online to find out more.

Four easy ways to join:

Mail a registration form. Forms are available through your local Alzheimer’s Association chapter.

Call 1.888.572.8566.

Visit medicalert.org/safereturn and register online.

Fax registration form to 1.800.863.3429.
Chapter 5

Assessing and Maximizing Decision-Making Capacity

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I. CAPACITY IS NOT A THING

“Rather than being a thing, capacity is a shifting network of values and circumstances.” ¹ Incapacity is the flip side of the same coin. In practice, cognitive function is but one of legal capacity’s many elements. “Capacity is the black hole of legal ethics. Many questions find their way into the capacity category but few answers ever emerge. Nor has the collective wisdom of the bar shed much light on the issue.”² Individuals are presumed to have capacity.

Legal capacity is a conflict driven, retrospective determination by a trial court, reviewed by appellate courts, based upon an evidentiary record, state law and fairness considerations. A trial court judge and justices of the Court of Appeals and Supreme Court are potentially there in the room with you every time you assess and document your client’s capacity. In the author’s experience, legal capacity conflicts are driven by disputes regarding decision making control and economic estate interests by beneficiaries.

Practice Tip: During every initial interview with your client, his/her family or significant others, make inquiry regarding problematic relationships in the cast of characters. Specifically ask if anyone in the client’s life is likely to oppose or attempt to derail your client’s decision making or will try to turn cognitive changes into financial gain. If so, spend more time documenting the six criteria, below, from The Handbook. Repeat at the signing appointment. Consider a referral to the client’s primary care physician for a cognitive assessment as close in time as possible to the day of signing.

Rules of professional responsibility for attorneys yield no safe harbor tests or definitions of capacity or incapacity. If a client makes a decision we view as appropriate, is capacity present? Conversely, if a client makes an inappropriate decision in our view, is capacity absent? Many clients without apparent cognitive impairment make self defeating decisions. We should not “…confuse incapacity with eccentricity or lack of prudence.”³

Compounding the difficulty for attorneys making assessments of client capacity is the ever present fear of malpractice exposure and/or professional discipline resulting from the outcome of decisions we facilitate. Attorneys must balance the opposing bioethical principles of client autonomy and paternalism in capacity assessment. But when autonomous decision making may result in catastrophic financial consequences or death, the lines between capacity and incapacity are easily blurred. Attorney malpractice exposure and/or professional discipline concerns are heightened.


¹ Margulies, Peter, Access, Connection and Voice: A Contextual Approach To Representing Senior Citizens of Questionable Capacity, 62 Fordham L. Rev. 5 1073, 1083 (March 1994).
² Id. at 1082.
³ Id. at 1082.
assessment tools such as the Mini-Mental Status Exam unless trained to do so. The Handbook also cautions against videotaping a client executing a legal transaction. The tape may exaggerate cognitive impairment to a viewer or finder of fact. Unless the attorney video tapes all clients, opposing counsel may argue that the taping proves incapacity.

Instead, The Handbook emphasizes the following criteria for attorney capacity assessments, creating a “sliding scale” of capacity:

1. Ability to articulate reasoning behind the decision. Can your client articulate the reasons for his decision and are the reasons consistent with your client’s goals and objectives?

2. The extent to which the client’s cognition fluctuates from time to time.

3. The client’s ability to understand the consequences of a decision.

4. The substantive fairness of the decision. We cannot “look the other way” if a client is being taken advantage of in a blatantly unfair transaction. Judging the fairness of a transaction risks substituting the attorney’s own values and beliefs over the client’s stated wishes so self awareness and caution must be used.

5. The consistency of a decision with a client’s known long term commitments and values. Although we all can change our values over time, a decision consistent with our client’s long term perspective may be easier to support.

6. Irreversibility of the decision. “The law historically has attached importance to protecting parties from irreversible events. Doing something that cannot later be adjusted later calls for caution on the part of the attorney.”

“Of these six factors, the first three are “functional” in the sense that they reflect the cognitive functioning of the individual. These may be supported by observation of the signs of diminished capacity. The latter three are “substantive” in that they look at the content and nature of the decision itself. Under the Margulies approach, the latter three factors may be thought of as substantive “levers” that modulate a kind of sliding scale of capacity. The greater the concerns under the latter three substantive variables... the greater the level of functioning demanded under the first three variables... In other words, the higher the risk (as measured by the client’s own values, the finality and fairness), the more one must probe to ensure decisional capacity.”

The Handbook provides a useful four page “Capacity Worksheet for Lawyers” at pages 23-26. Appendix B offers a two axis, four cell risk management grid weighing the level of anecdotal evidence of diminished capacity and the potential for irreversible adverse decisional outcomes.

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4 Id. at 1087.
When the decision falls in cell number 4, consider a referral to a medical/mental health professional for a formal clinical assessment before effectuating the decision. Chapter VI of The Handbook provides comprehensive information, guidelines and a checklist to facilitate effective referrals.

II. THE MANY FORMS OF CAPACITY

Clinical Capacity

Clinical capacity is a multifaceted assessment of cognitive function by medical or behavioral sciences professionals. Clinical assessments of capacity are one of many possible evidentiary elements used in a determination of legal capacity.

Diminished Capacity

Mild Cognitive Impairment, MCI, is described by the Alzheimer’s Association as a slight but noticeable and measurable decline in cognitive abilities, including memory and thinking skills. A person with MCI is at an increased risk of developing Alzheimer’s or another dementia. Mild cognitive impairment causes cognitive changes that are serious enough to be noticed by the individuals experiencing them or to other people, but the changes are not severe enough to interfere with daily life or independent function. A person with early MCI may have legal and clinical capacity.

Decisional Capacity

The medical/ethics literature defines decisional capacity a person’s ability to make their own health care decisions, based upon evidence of “informed consent.” Informed consent requires understanding the benefits and burdens of the decision.

The term also applies to the ethical principle of autonomy in providing long term care to individuals with moderate to severe dementia. A person may have capacity for some purposes but not others. Absent legal or clinical capacity, a person in long term care should still be afforded as much decisional capacity related to comfort, preferences and personal dignity as possible. Late stage AD obliterates decisional capacity.

Prior to late stage dementia, an individual’s cognitive function can vary widely based upon time of day, setting, medication, stress and other factors. “Windows of lucidity”, describing brief occasional periods of inexplicable higher cognitive function are often seen by families and professionals.

During these moments, a person with advanced dementia may regain legal capacity as measured by attorney assessment and case law, then return to moderate/severe cognitive impairment. In

the author’s experience, occasionally clients with mild to moderate dementia display windows of lucidity during some office visits. Family members may be startled by the improved cognition and communication.

Legal Capacity

Elder law and estate planning attorneys frequently must make a determination of the decision making capacity of their clients. The attorney needs to understand the legal requirements regarding capacity in various circumstances. The question of legal capacity can arise in various situations, including the execution of a will or other estate planning documents, financial transactions, medical treatment decisions, and the choice of where to live. The legal requirements for capacity are primarily based on case law but are also codified in statutes. The attorney must apply these legal requirements to the client’s specific situation. As the attorney-client relationship continues over time, the attorney should re-evaluate the client’s ability to make decisions. For an in-depth discussion concerning ethics and the representation of a client with waning mental capacity, see The Ethical Oregon Lawyer, Chapter 18 (Oregon CLE 2015).

Presumption of Capacity: An attorney should presume that the client has the necessary mental capacity to make legal choices.7 Oregon law presumes a person to be competent absent an adjudication of incompetence.8 A diagnosis of dementia, whether from Alzheimer’s disease (the most common cause of dementia), Lewy body dementia, vascular dementia, etc., by itself does not mean a person lacks the requisite capacity to act. Failing memory is not necessarily a symptom of dementia. Memory disorders, personality changes, and impaired reasoning may be symptoms of dementia, and may be severe enough to interfere with the client performing daily activities. It is only when the effects of dementia prevent the client from having the necessary understanding for a specific act that the presumption of capacity is overcome.

The requisite capacity is based on the intended action. That is, capacity is not a ‘one size fits all’ determination. Rather, the requirements for capacity to perform a specific act cover a spectrum, as discussed below.

Testamentary Capacity: The standard for testamentary capacity in Oregon is well established.9 The person must -

1) Be able to understand the nature of the act in which he or she is engaged;
2) Know the nature and extent of his or her property. An exact accounting is not required;

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9 See Kastner v. Husband, 231 Or 133, 372 P2d 520 (1962), In re Phillips’ Will, 107 Or 612, 213 P 627 (1923). See also, In re Bond’s Estate, 172 Or. 509, 519 (1943), “in order to execute a will, the testator must have sufficient mental capacity to understand the nature of the business in which he is engaged, know the kind and extent of his property and be able to bring to mind the persons who are properly the objects of his bounty.”
3) Know, without prompting, the claims, if any, of those who are, should or might be, the natural objects of his bounty; and

4) Be cognizant of the scope and reach of the provisions of the document.

Even if a testator suffers from dementia to the extent that testamentary capacity may be impaired, there can be lucid moments during which testamentary capacity exists.10 “The mere presence of such mental affliction does not necessarily establish legal inability thus to dispose of property.”11 A will is valid if capacity exists at the time of the execution, notwithstanding the dementia of the testator before and after execution.”12 Even when there are signs or symptoms of mental incompetence, the testator may have ‘lucid intervals’ during which he or she has the capacity required to make a will.13 The Oregon Court of Appeals defined a “lucid interval” as “[a] temporary restoration of testamentary capacity.”14 However, clear and convincing proof is required to show that a legal act is performed during a lucid interval.15

The critical point in time for determining testamentary capacity is at the moment the will is executed. Moreover, in determining testamentary capacity, the testimony of witnesses and the attorney present is given more weight than the testimony of family members or others not present at the time of execution.16 There is also a presumption of competency when there is proof that a will has been properly executed.17 The same degree of mental capacity is necessary to revoke a will as to execute one.18 Finally, it is worth noting that a person may have testamentary capacity while lacking the capacity to execute a deed, convey property, or enter into a contract.19

The capacity to create, amend, revoke, or add property to a revocable trust is the same as the capacity to make a will.20 This seems to be at odds with the common law requirement that, to establish a trust, the Trustor must have the legal capacity to execute the conveyance(s) to fund the trust.21 Arguably, a revocable trust, as a will substitute, can be viewed as a testamentary document designed to avoid probate so that the testamentary capacity is the appropriate standard.

Capacity to Execute a Durable Power of Attorney: A power of attorney for finances is a written creation of an agency relationship.22 The agency relationship presumes the principal has the ability to understand and approve the authority given to the agent to act on the principal’s

10 In re Provolt’s Estate, 175 Or. 128, 151 P.2d 736 (1944).
11 Id at 132.
12 In re Provolt’s Estate, 175 Or. 128, 151 P.2d 736 (1944).
13 Uribe v. Olson, 42 Or App at 651, Gentry v. Briggs, 32 Or App at 50.
14 Gentry v. Briggs, 32 Or App at 50, note 1.
16 In re Fredericks’ Estate, 204 Or. 378, 282 P.2d 352, 356, citing Trombly v. McKenny, 191 Or. 90.
17 In re Andersen’s Estate, 192 Or 441, 235 P.2d 869, 876 (1951).
18 In re Dougan’s Estate, 152 Or 235, 253, 53 P2d 511 (1936).
19 Meister v. Finley, 208 Or 223, 234, 300 P2d 778 (1956).
20 ORS 130.500.
22 Scott v. Hall, 177 Or 403, 163 P2d 517 (1945).
However, unless the power of attorney states otherwise, the agent may still exercise the powers granted even when the principal becomes financially incapable. Financially incapable is defined as a condition in which a person is unable to manage financial resources effectively for reasons including, but not limited to, mental illness, mental retardation, physical illness or disability, chronic use of drugs or controlled substances, chronic intoxication, confinement, detention by a foreign power or disappearance. The capacity to execute a valid power of attorney requires that, at the time of the execution of the document, the grantor is able to comprehend the nature of the business in which the grantor is engaged. It appears that this is a broad view. That is, the grantor needs to understand the purpose, intent, and effect of granting authority to the agent, but not necessarily be able to perform every act or power granted to the agent.

Capacity to Execute Deeds, Contracts, and Lifetime Gifts: The same basic standard applies to executing a deed, entering into a contract, or making a lifetime gift. The capacity required in all three situations is higher than testamentary capacity. For example, greater competency is required in the execution and delivery of a deed than in executing a will. The test of capacity to make a deed requires that the grantor has the ability to understand the nature and effect of the act in which he or she is engaged and the business which he or she is transacting. The greater competency required to execute a deed versus a will is due to the irrevocable nature of a deed; a will may be revoked while a deed may not. Thus, the grantor must be able to reason, exercise judgment, and compete with the other party to the transaction. Capacity is measured as of the date of execution and delivery of the deed.

Oregon’s transfer on death deed is unique from other statutory deeds. The capacity required to make or revoke a transfer on death deed is the same as that required to make a will. Arguably, this is based on the fact that a transfer on death deed is revocable, does not convey a present interest in the real property, and requires no consideration. In this way, a transfer on death deed more closely resembles a will rather than other types of deeds. This intent is reflected in the legislative history of Oregon’s transfer on death deed.

24 ORS 127.005(1)(b) – (2).
25 See ORS 125.005(3).
28 First Christian Church v. McReynolds at 72.
29 Id at 73.
30 Legler v. Legler, 187 Or 273, 308, 211 P2d 233 (1949)
31 ORS 93.948 et seq.
32 ORS 93.959.
33 ORS 93.955, ORS 93.967, and ORS 93.030.
A person can enter into a contract if the person has the ability to understand the nature and effect of the act.\textsuperscript{34} Even if a person is easily influenced, is dependent on others, states that he or she does not understand the contract itself, or has below-average intelligence, the person can enter into a legal contract.\textsuperscript{35} The test of contractual capacity is measured as of the time of execution of the contract.\textsuperscript{36}

An inter vivos gift requires the same degree of capacity as entering into a contract.\textsuperscript{37}

**Capacity to Make Health Care Decisions:** In Oregon, a capable adult is authorized by statute to make health care decisions.\textsuperscript{38} There is a presumption that an adult has the requisite mental capacity to give informed consent even if a guardian has been appointed for the person.\textsuperscript{39} The standard for mental capacity to consent to or refuse proposed medical treatment is the ability to understand the basic information necessary for informed consent and to understand the nature and consequences of authorizing treatment.\textsuperscript{40} The procedure for obtaining informed consent is described in ORS 677.097. In construing this statute, the Oregon Supreme Court has found that a physician must take into account the mental state and capabilities of the patient when explaining a proposed treatment.\textsuperscript{41} The court held that the concept of “informed consent” presupposes that the patient is capable of understanding the risks of a proposed treatment and alternatives, and also of using that information in a rational decision-making process.\textsuperscript{42}

**Capacity to Retain Counsel:** The capacity to retain counsel is analogous to the capacity to contract (see above). Oregon Rules of Professional Conduct, Rule 1.14, deals with representing a client with diminished capacity. In general, attorneys owe a duty of competent and diligent representation to their clients.\textsuperscript{43} When the client’s capacity is diminished, for whatever reason, the attorney should attempt to maintain a normal attorney-client relationship, as far as reasonably possible.\textsuperscript{44} A respondent in a protective proceeding has the right to contact and retain legal counsel.\textsuperscript{45}

**Capacity in Guardianship/Conservatorship Protective Proceedings:**\textsuperscript{46} When working with a client with diminished capacity who is under either a guardianship or a conservatorship, the

\begin{footnotesize}
\begin{enumerate}
\item[34] Kruse v. Coos Head Timber Co., 248 Or 294 (1967).
\item[35] Id.
\item[36] Uribe v. Olson, 42 Or App 647, 651, 601 P2d 818 (1979);
\item[37] Kugel v. Pletz, 22 Or App 249 (1975).
\item[38] ORS 127.507. See also ORS 441.098.
\item[39] ORS 125.300.
\item[41] Macy v. Blatchford, 330 Or 444, 8 P3d 204 (2000).
\item[42] Id. at 454.
\item[43] ORPC 1.1, 1.3, and 1.6
\item[44] ORPC 1.14
\item[45] ORS 125.300(3), ORS 125.080(3).
\item[46] Thank you to Sam Friedenberg for allowing us access to his materials for the forthcoming OSB Elder Law handbook.
\end{enumerate}
\end{footnotesize}
attorney needs to be very familiar with the statutes defining the term incapacitated person and the case law interpreting these statutes.\textsuperscript{47}

The term guardian applies to the guardianship of the person.\textsuperscript{48} A guardian may be appointed if the conditions for the appointment of a guardian have been established.\textsuperscript{49} Clear and convincing evidence is required showing that the respondent is incapacitated and the appointment of a guardian is necessary to provide continuing care and supervision of the incapacitated person.\textsuperscript{50} In this context, incapacitated means that a person’s ability to receive and evaluate information effectively or communicate decisions is impaired to such an extent that the person presently lacks the capacity to meet the essential requirement for the person’s physical health or safety or to manage the person’s financial resources.\textsuperscript{51} “Meeting the essential requirement for physical health and safety” means the actions necessary to provide the health care, food, shelter, clothing, personal hygiene, and other care without which serious physical injury or illness is likely to occur.\textsuperscript{52}

The term conservator applies to the traditional functions of the “guardian of the estate” and is defined as a person appointed to administer the estate of the protected person.\textsuperscript{53} There is no requirement that a person lack legal mental capacity before being subject to the appointment of a conservator.\textsuperscript{54} A conservator may be appointed if it is shown by clear and convincing evidence that the respondent is financially incapable and has money and property that requires management or protection.\textsuperscript{55} Financially incapable means that a person is unable to manage his or her financial resources effectively for reasons including, but not limited to, mental illness, mental deficiency, physical illness or disability, chronic use of drugs or controlled substances, chronic intoxication, confinement, detention by a foreign power, or disappearance.\textsuperscript{56} “Manage financial resources” means the actions necessary to obtain, administer, and dispose of real and personal property, intangible property, business property, benefits, and income.\textsuperscript{57}

A protected person still retains the right to act unless that right has been specifically restricted by the court. The protected person under a guardianship is not presumed to be incompetent and retains all legal and civil rights except those expressly limited by court order or expressly granted to the guardian by the court.\textsuperscript{58} If mentally competent, a protected person under a conservatorship

\textsuperscript{47} For an in-depth analysis of determining competency in guardianship proceedings see Counseling Elderly Clients, Chapter 8 (Oregon CLE Program Materials 1998).
\textsuperscript{48} See ORS 125.005(4).
\textsuperscript{49} ORS 125.300.
\textsuperscript{50} ORS 125.305(1).
\textsuperscript{51} ORS 125.005(5), (3).
\textsuperscript{52} Id.
\textsuperscript{53} See ORS 125.005(1), ORS 125.420.
\textsuperscript{54} ORS 125.005(3).
\textsuperscript{55} ORS 125.400.
\textsuperscript{56} ORS 125.005(3).
\textsuperscript{57} ORS 125.005(3).
\textsuperscript{58} ORS 125.300(2)–(3).
may still make a will, change beneficiaries on life insurance and annuity policies, and exercise a power of appointment or a right to share in a deceased spouse’s estate.59 However, when either a guardian or conservator has been appointed because the person lacks mental capacity, a rebuttable presumption arises that the person lacks testamentary capacity.60

A conservator may allow the protected person to possess and control property and funds for living requirements as appropriate to the needs and capacities of the protected person.61 However, a protected person under a conservatorship cannot convey or encumber the person’s estate, or make any contract or election affecting the person’s estate, other than as provided in ORS 125.455(1) and ORS 125.420.62

III. “STEALTH MODE” CAPACITY ASSESSMENT

We often have no way of determining the mental status of the new client before the first interview. At the start of an initial interview, the client and whoever accompanies the client expect us to begin the process of forming a working relationship and addressing the matters about which we have expertise. They do not expect us to conduct a capacity assessment. Nonetheless, we must do so in “stealth mode” and document the file to support our decisions regarding how to proceed.

Attorneys and other personal service professionals can learn to gather valid, reliable information about the client’s level of function from an array of observable client behaviors and reports of the client’s significant others. Even without a prior clinical assessment by a medical or mental health professional, family members often report upon intake that the client exhibits some level of cognitive impairment. Reports from significant others involved with the individual are extremely relevant and should be documented. Lack of insight and denial by the person with dementia, especially in moderate and severe dementia, is common.

The tables63 of Appendix A give clear and concise descriptions of how a person with progressive dementia changes over time. Use the tables as a guide for things to look and listen for. The following suggestions may be helpful.

1. Begin your stealth mode capacity assessment by observing the individual’s appearance including grooming, clothing, facial expressions, responsiveness to your greeting and manner of walking.

2. Evaluate the person’s ability to consistently respond with logical, sequential and goal oriented responses to specific questions and the goals of representation. Ask questions that

59 ORS 125.455(1).
61 ORS 125.420.
62 ORS 125.455(2).
63 From Losing a Million Minds: Confronting the Tragedy of Alzheimer’s Disease and Other Dementia, Office of Technology Assessment, Washington D.C., 1987.
can’t be answered with a “yes” or “no” answer. Do you observe unexpected pauses and/or difficulty finding words?

3. Is the individual still driving? Does s/he participate in financial affairs, bill paying, household maintenance, shopping, meal preparation, and medication management? Can the individual use the phone, TV remote or other household equipment?

4. Does s/he remain engaged in hobbies, social events, sports or other past activities?

5. Determine if assistance is required for dressing, bathing, toileting, eating, walking or transfers to/from bed, chair, toilet, etc.

Making these inquiries, documenting the responses, then reviewing the Tables of Appendix A, creates a functional cognitive assessment and an evidentiary record upon which an expert witness can base an opinion regarding capacity. With this information, we can assess, document and weigh what we know about the client’s level of function and capacity.

**IV. MAXIMIZING CAPACITY**

1. Inquiries for evidence of dementia should be couched as “memory changes.” To minimize defensiveness, avoid inquiring about Alzheimer’s, dementia or “memory problems.”

2. Prior to the first interview, send user-friendly, basic client information forms by mail or download if the client or significant other can complete and bring them to the first meeting.

3. If first-call screening identifies a dementia issue, most likely it will be spontaneously discussed by the person making the first call. Determine if formal cognitive assessments have been made.

4. If a case presents dementia issues, gently ask how long the issues have been observed. Most dementias progress slowly. The earlier the symptoms are observed, generally the faster the progression of symptoms. If symptoms appeared abruptly, “overnight,” strongly urge an immediate referral to a multidisciplinary “Geriatric Assessment Program.” The symptoms may be caused by an undiagnosed treatable condition.

5. State of the art assessment programs generally involve a complete physical exam, brain imaging and neuropsychological testing to arrive at a tentative diagnosis and ruling out treatable conditions causing the memory changes.

6. Although the first descriptions of A.D. by Dr. Alois Alzheimer appeared in 1906, we still have no positive diagnostic test for Alzheimer’s Disease other than a post mortem brain tissue biopsy. Determine the client’s ability to articulate the reasons for the decision and assess the client’s understanding of the consequences.

7. That said, even the most experienced diagnosticians in every discipline make mistakes. Individuals with even moderate dementia can mask their deficits during an interview when formal mental status testing is not conducted.
8. Use extreme caution in initiating a strategy for the client or completing a transaction if you sense unfairness or inconsistency with prior patterns of action.

9. Evaluate the influence of others on the client’s decision-making. Sometimes the influence is selfless, wise, and fair, but sometimes the opposite is true. Know the difference.

10. Encourage the client to execute a durable financial power of attorney or revocable living trust with a reliable, trustworthy fiduciary.

11. Obtain a written, notarized authorization from the client to communicate with family members or other significant others. If the relationship goals are related to the client’s assets and income, notarized authorizations to communicate with financial entities are needed. Financial entities have recently begun to demand notarization of authorizations. Patriot Act requirements have added a new layer to financial transactions.

12. Schedule interviews and signings during the client’s best times of the day. Reschedule if the client is having a bad day.

13. Include witnesses in the room at signing appointments to create handwritten records of contemporaneous discussions leading to the signing of documents.

14. Be familiar with resources for help in your community and refer freely.

15. Ask the client to schedule a visit with the primary care physician on the day of document execution, and request the doctor to make a statement in writing regarding the client’s ability to make decisions.
## Table 2-1.—Brief Cognitive Rating Scale

**Part 1: Concentration**

<table>
<thead>
<tr>
<th>No.</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>No objective or subjective evidence of deficit in concentration.</td>
</tr>
<tr>
<td>2.</td>
<td>Subjective decrement in concentration ability.</td>
</tr>
<tr>
<td>3.</td>
<td>Minor signs of poor concentration (e.g., subtraction of serials 7s from 100).</td>
</tr>
<tr>
<td>4.</td>
<td>Definite concentration deficit for persons of their background (e.g., marked deficit on serial 7s; frequent deficit in subtraction of serial 4s from 40).</td>
</tr>
<tr>
<td>5.</td>
<td>Marked concentration deficit (e.g., giving months backwards or serials 2s from 20).</td>
</tr>
<tr>
<td>6.</td>
<td>Forgets the concentration task. Frequently begins to count forward when asked to count backwards from 10 by 1s.</td>
</tr>
<tr>
<td>7.</td>
<td>Marked difficulty counting forward to 10 by 1s.</td>
</tr>
</tbody>
</table>

**Part 2: Recent Memory**

<table>
<thead>
<tr>
<th>No.</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>No objective or subjective evidence of deficit in recent memory.</td>
</tr>
<tr>
<td>2.</td>
<td>Subjective impairment only (e.g., forgetting names more than formerly).</td>
</tr>
<tr>
<td>3.</td>
<td>Deficit in recall of specific events evident upon detailed questioning. No deficit in the recall of major recent events.</td>
</tr>
<tr>
<td>4.</td>
<td>Cannot recall major events of previous weekend or week. Scanty knowledge (not detailed) of current events, favorite TV shows, etc.</td>
</tr>
<tr>
<td>5.</td>
<td>Unsure of weather; may not know current president or current address.</td>
</tr>
<tr>
<td>6.</td>
<td>Occasional knowledge of some recent events. Little or no idea of current address.</td>
</tr>
<tr>
<td>7.</td>
<td>No knowledge of recent events.</td>
</tr>
</tbody>
</table>

**Part 3: Past Memory**

<table>
<thead>
<tr>
<th>No.</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>No subjective or objective impairment in past memory.</td>
</tr>
<tr>
<td>2.</td>
<td>Subjective impairment only, can recall two or more primary school teachers.</td>
</tr>
<tr>
<td>3.</td>
<td>Some gaps in past memory upon detailed questioning. Able to recall at least one childhood teacher and/or childhood friend.</td>
</tr>
<tr>
<td>4.</td>
<td>Clear-cut deficit, the spouse recalls more of the patient's past than the patient. Cannot recall childhood friends and/or teachers but knows the names of schools attended. Confuses chronology in reciting personal history.</td>
</tr>
<tr>
<td>5.</td>
<td>Major past events sometimes not recalled (e.g., names of schools attended).</td>
</tr>
<tr>
<td>6.</td>
<td>Some residual memory of past (e.g., may recall country of birth or former occupation; may or may not recall mother's name; may or may not recall father's name).</td>
</tr>
<tr>
<td>7.</td>
<td>No memory of past (cannot recall country, State, or town of origin; cannot recall names of parents, etc.).</td>
</tr>
</tbody>
</table>

**Part 4: Orientation**

<table>
<thead>
<tr>
<th>No.</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>No deficit in memory for time, place, identity of self or others.</td>
</tr>
<tr>
<td>2.</td>
<td>Subjective impairment only, knows time to nearest hour, location.</td>
</tr>
<tr>
<td>3.</td>
<td>Any mistake in time of 2 hours or more; day of the week of 1 day or more; date of 3 days or more.</td>
</tr>
<tr>
<td>4.</td>
<td>Mistakes in month of 10 days or more; or year of 1 month or more.</td>
</tr>
<tr>
<td>5.</td>
<td>Unsure of month and/or year and/or season; unsure of locale.</td>
</tr>
<tr>
<td>6.</td>
<td>No idea of date. Identifies spouse but may not recall name. Knows own name.</td>
</tr>
<tr>
<td>7.</td>
<td>Cannot identify spouse. May be unsure of personal identity.</td>
</tr>
</tbody>
</table>

**Part 5: Functioning and Self-Care**

<table>
<thead>
<tr>
<th>No.</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>No difficulty, either subjectively or objectively.</td>
</tr>
<tr>
<td>2.</td>
<td>Complains of forgetting location of objects. Subjective work difficulties.</td>
</tr>
<tr>
<td>3.</td>
<td>Decreased job functioning evident to co-workers, difficulty in traveling to new locations.</td>
</tr>
<tr>
<td>4.</td>
<td>Decreased ability to perform complex tasks (e.g., planning dinner for guests, handling finances, marketing, etc.).</td>
</tr>
<tr>
<td>5.</td>
<td>Requires assistance in choosing proper clothing.</td>
</tr>
<tr>
<td>6.</td>
<td>Requires assistance in feeding, and/or toileting, and/or bathing, and/or ambulating.</td>
</tr>
<tr>
<td>7.</td>
<td>Requires constant assistance in all activities of daily life.</td>
</tr>
</tbody>
</table>

**Source:** B. S. Ferris, and deLeon, “Senile Dementia of the Type: Diagnostic and Differential Features With Special Reference to Functional Assessment Staging,” Second International Symposium, 1984.
## Table 2-1.—Brief Cognitive Rating Scale

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<th>Axis 1: Concentration</th>
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<td>3. Minor signs of poor concentration (e.g., subtraction of serials 7s from 100).</td>
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<td>4. Definite concentration deficit for persons of their background (e.g., marked deficit on serial 7s; frequent deficit in subtraction of serial 4s from 40).</td>
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<tr>
<td>5. Marked concentration deficit (e.g., giving months backwards or serials 2s from 20).</td>
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</tbody>
</table>

<table>
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<tr>
<th>Axis //: Recent memory</th>
<th></th>
</tr>
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<tbody>
<tr>
<td>1. No objective or subjective evidence of deficit in recent memory.</td>
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<tr>
<td>2. Subjective impairment only (e.g., forgetting names more than formerly).</td>
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<tr>
<td>3. Deficit in recall of specific events evident upon detailed questioning. No deficit in the recall of major recent events.</td>
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<td>4. Cannot recall major events of previous weekend or week. Scanty knowledge (not detailed) of current events, favorite TV shows, etc.</td>
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<tr>
<td>5. Unsure of weather; may not know current president or current address.</td>
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</tr>
<tr>
<td>6. Occasional knowledge of some recent events. Little or no idea of current address.</td>
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<tr>
<td>7. No knowledge of recent events.</td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Axis III: Past memory</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1. No subjective or objective impairment in past memory.</td>
<td></td>
</tr>
<tr>
<td>2. Subjective impairment only, can recall two or more primary school teachers.</td>
<td></td>
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<td>3. Some gaps in past memory upon detailed questioning. Able to recall at least one childhood teacher and/or childhood friend.</td>
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<tr>
<td>4. Clear-cut deficit, the spouse recalls more of the patient's past than the patient. Cannot recall childhood friends and/or teachers but knows the names of schools attended. Confuses chronology in reciting personal history.</td>
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<tr>
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</tr>
<tr>
<td>7. No memory of past (cannot recall country, State, or town of origin; cannot recall names of parents, etc.).</td>
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</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Axis IV: Orientation</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1. No deficit in memory for time, place, identity of self or others.</td>
<td></td>
</tr>
<tr>
<td>2. Subjective impairment only, knows time to nearest hour, location.</td>
<td></td>
</tr>
<tr>
<td>3. Any mistake in time of 2 hours or more; day of the week of 1 day or more; date of 3 days or more.</td>
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<tr>
<td>4. Mistakes in month of 10 days or more; or year of 1 month or more.</td>
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<td>5. Unsure of month and/or year and/or season; unsure of locale.</td>
<td></td>
</tr>
<tr>
<td>6. No idea of date. Identifies spouse but may not recall name. Knows own name.</td>
<td></td>
</tr>
<tr>
<td>7. Cannot identify spouse. May be unsure of personal identity.</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Axis V: Functioning and self-care</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1. No difficulty, either subjectively or objectively.</td>
<td></td>
</tr>
<tr>
<td>2. Complaints of forgetting location of objects. Subjective work difficulties.</td>
<td></td>
</tr>
<tr>
<td>3. Decreased job functioning evident to co-workers, difficulty in traveling to new locations.</td>
<td></td>
</tr>
<tr>
<td>4. Decreased ability to perform complex tasks (e.g., planning dinner for guests, handling finances, marketing, etc.).</td>
<td></td>
</tr>
<tr>
<td>5. Requires assistance in choosing proper clothing.</td>
<td></td>
</tr>
<tr>
<td>6. Requires assistance in feeding, and/or toileting, and/or bathing, and/or ambulating.</td>
<td></td>
</tr>
<tr>
<td>7. Requires constant assistance in all activities of daily life.</td>
<td></td>
</tr>
</tbody>
</table>

## Table 2-2.—The Global Deterioration Scale (GDS) for Age-Associated Cognitive Decline and Alzheimer’s Disease

<table>
<thead>
<tr>
<th>GDS stage</th>
<th>Clinical phase</th>
<th>Clinical characteristic</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 No cognitive decline</td>
<td>Normal</td>
<td>No subjective complaints of memory deficit. No memory deficit evident on clinical interview.</td>
</tr>
<tr>
<td>2 Very mild cognitive decline</td>
<td>Forgetfulness</td>
<td>Subjective complaints of memory deficit, most frequently in following areas: a) forgetting where one has placed familiar objects; b) forgetting names one formerly knew well. No objective evidence of memory deficit on clinical interview. No objective deficits in employment or social situations. Appropriate concern with respect to symptomatology.</td>
</tr>
<tr>
<td>3 Mild cognitive decline</td>
<td>Early confusional</td>
<td>Earliest clear-cut deficits. Manifestations in more than one of the following areas: a) patient may have gotten lost when traveling to an unfamiliar location; b) co-workers become aware of patient’s relatively poor performance; c) word and name finding deficits become evident to intimates; d) patient may read a passage or a book and retain relatively little material; e) patient may demonstrate decreased facility in remembering names upon introduction to new people; f) patient may have lost or misplaced an object of value; g) concentration deficit may be evident on clinical testing. Objective evidence of memory deficit obtained only with an intensive interview conducted by a trained geriatric psychiatrist. Decreased performance in demanding employment and social settings. Denial begins to become manifest in patient. Mild to moderate anxiety accompanies symptoms.</td>
</tr>
<tr>
<td>4 Moderate cognitive decline</td>
<td>Late confusional</td>
<td>Clear-cut deficit on careful clinical interview. Deficits manifest in following areas: a) decreased knowledge of current and recent events; b) may exhibit some deficit in memory of personal history; c) concentration deficit elicited on serial subtractions; d) decreased ability to travel, handle finances, etc. Frequently no deficit in following areas: a) orientation to time and person; b) recognition of familiar persons and faces; c) ability to travel to familiar areas. Inability to perform complex tasks. Denial is dominant defense mechanism. Flatten of affect and withdrawal from challenging situations occur.</td>
</tr>
<tr>
<td>5 Moderately severe decline</td>
<td>Early dementia</td>
<td>Patients can no longer survive without some assistance. Patients are unable during interview to recall a major relevant aspect of their current lives: e.g., the names of close members of their family (such as grandchildren), the name of the high school or college from which they graduated. Frequently some disorientation to time (date, day of week, season, etc.) or to place. An educated person may have difficulty counting back from 40 by 4s or from 20 by 2s. Persons at this stage retain knowledge of many major facts regarding themselves and others. They invariably know their own names and generally know their spouse’s and children’s names. They require no assistance with toileting or eating, but may have some difficulty choosing the proper clothing to wear.</td>
</tr>
<tr>
<td>6 Severe cognitive decline</td>
<td>Middle dementia</td>
<td>May occasionally forget the name of the spouse upon whom they are entirely dependent for survival. Will be largely unaware of all recent events and experiences in their lives. Retain some knowledge of their past lives, but this is very sketchy. Generally unaware of their surroundings, the year, the season, etc. May have difficulty counting from 10, both backward and sometimes forward. Will require some assistance with activities of daily living, e.g., may become incontinent, will require travel assistance, but occasionally will display ability to travel to familiar locations. Diurnal rhythm frequently disturbed. Almost always recall their own name. Frequently continue to be able to distinguish familiar from unfamiliar persons in their environment. Personality and emotional changes occur. These are quite variable and include: a) delusional behavior, e.g., patients may accuse their spouse of being an impostor, may talk to imaginary figures in the environment, or to their own reflection in the mirror; b) obsessive symptoms, e.g., person may continuously repeat simple cleaning activities; c) anxiety symptoms, agitation, and even previously non-existent violent behavior may occur; d) cognitive abulia, i.e., loss of willpower because an individual cannot carry a thought long enough to determine a purposeful course of action.</td>
</tr>
<tr>
<td>7 Very severe cognitive decline</td>
<td>Late dementia</td>
<td>All verbal abilities are lost. Frequently there is no speech at all—only grunting. Incontinent of urine; requires assistance toileting and feeding. Lose basic psychomotor skills, e.g., ability to walk. The brain appears to no longer be able to tell the body what to do. Generalized and cortical neurologic signs and symptoms are frequently present.</td>
</tr>
</tbody>
</table>

Table 2-3.—Clinical Dementia Rating (CDR) Scale

<table>
<thead>
<tr>
<th></th>
<th>Healthy CDR 0</th>
<th>Questionable dementia CDR 0.5</th>
<th>Mild dementia CDR 1</th>
<th>Moderate dementia CDR 2</th>
<th>Severe dementia CDR 3</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Memory</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>No memory loss or slight inconsistent forgetfulness</td>
<td>Mild consistent forgetfulness; partial recollection of events; &quot;benign&quot; forgetfulness</td>
<td>Moderate memory loss, more marked for recent events; defect learned material retained; new interferes with everyday activities material rapidly lost</td>
<td>Severe memory loss; only highly Severe memory loss; only fragments remain</td>
<td></td>
</tr>
<tr>
<td><strong>Orientation</strong></td>
<td></td>
<td>Fully oriented</td>
<td>Some difficulty with time relationships; oriented for place and person at examination but may have geographic disorientation</td>
<td>Usually disoriented in time, often Orientation to person only to place</td>
<td></td>
</tr>
<tr>
<td><strong>Judgment and problem-solving</strong></td>
<td>Solves everyday problems well; judgment good in relation to past performance</td>
<td>Only doubtful impairment in solving problems, similarities, differences</td>
<td>Moderate difficulty in handling complex problems; social judgment usually maintained</td>
<td>Severely impaired in handling problems, similarities, differences; social judgment usually impaired</td>
<td>Unable to make judgments or solve problems</td>
</tr>
<tr>
<td><strong>Community affairs</strong></td>
<td>Independent function at usual level in job, shopping, business and financial affairs, volunteer and social groups</td>
<td>Only doubtful or mild impairment in these activities</td>
<td>Unable to function independently at these activities though may still be engaged in some; may still appear normal to casual inspection</td>
<td>Appears well enough to be taken to functions outside a family home</td>
<td>Appears too ill to be taken to functions outside a family home</td>
</tr>
<tr>
<td><strong>Home and hobbies</strong></td>
<td>Life at home, hobbies, intellectual interests well maintained</td>
<td>Life at home, hobbies, intellectual interests slightly impaired</td>
<td>Mild but definite impairment of function at home; more difficult chores abandoned; more complicated hobbies and interests abandoned</td>
<td>Only simple chores preserved; very restricted interests, poorly sustained</td>
<td>No significant function in home outside of own room</td>
</tr>
<tr>
<td><strong>Personal care</strong></td>
<td>Fully capable of self-care</td>
<td>Needs prompting</td>
<td>Requires assistance in dressing, keeping of personal hygiene and effects</td>
<td>Requires much help with personal care; often incontinent</td>
<td></td>
</tr>
</tbody>
</table>

### Table 2-4.—Ability of Dementia Patient To Do Basic Tasks

<table>
<thead>
<tr>
<th>Task</th>
<th>Percent of total respondents</th>
</tr>
</thead>
<tbody>
<tr>
<td>Walk without assistance.</td>
<td>35  26  35  5</td>
</tr>
<tr>
<td>Eat without assistance</td>
<td>30  32  34  5</td>
</tr>
<tr>
<td>Dress without assistance</td>
<td>14  28  52  5</td>
</tr>
<tr>
<td>Perform simple household tasks, such as setting the table or simple home repairs</td>
<td>6   19  69  5</td>
</tr>
<tr>
<td>Cope with small sums of money.</td>
<td>5   15  73  6</td>
</tr>
</tbody>
</table>

NOTE: This table is percentage horizontally. Also totals may not add because of rounding.


### Table 2-5.—Assessment of Dementia Patient’s Eating Skills

<table>
<thead>
<tr>
<th>Eating skills</th>
<th>Percentage of total respondents</th>
</tr>
</thead>
<tbody>
<tr>
<td>Eats cleanly, with proper utensils</td>
<td>36</td>
</tr>
<tr>
<td>Eats messily</td>
<td>23</td>
</tr>
<tr>
<td>Only eats simple solids, like crackers, by self.</td>
<td>6</td>
</tr>
<tr>
<td>Has to be fed by others</td>
<td>28</td>
</tr>
<tr>
<td>Is tube fed</td>
<td>4</td>
</tr>
<tr>
<td>No answer</td>
<td>4</td>
</tr>
</tbody>
</table>


### Table 2-6.—Assessment of Dementia Patient’s Toilet Skills

<table>
<thead>
<tr>
<th>Toilet skills</th>
<th>Percentage of total respondents</th>
</tr>
</thead>
<tbody>
<tr>
<td>Independent/fully functional</td>
<td>23</td>
</tr>
<tr>
<td>Has occasional accidents/needs some help or reminder</td>
<td>25</td>
</tr>
<tr>
<td>Has frequent wet beds or accidents</td>
<td>12</td>
</tr>
<tr>
<td>Is doubly incontinent (has bowel and urine accidents)</td>
<td>36</td>
</tr>
<tr>
<td>No answer</td>
<td>4</td>
</tr>
</tbody>
</table>

### APPENDIX B—RISK MANAGEMENT GRID

<table>
<thead>
<tr>
<th>Potential for Adverse Decisional Outcome</th>
<th>Level of Anecdotal Evidence of Diminished Capability</th>
</tr>
</thead>
<tbody>
<tr>
<td>Low</td>
<td>Low</td>
</tr>
<tr>
<td></td>
<td>1</td>
</tr>
<tr>
<td>High</td>
<td>Low</td>
</tr>
<tr>
<td></td>
<td>2</td>
</tr>
<tr>
<td>Low</td>
<td>High</td>
</tr>
<tr>
<td></td>
<td>3</td>
</tr>
<tr>
<td>High</td>
<td>High</td>
</tr>
<tr>
<td></td>
<td>4</td>
</tr>
</tbody>
</table>
Chapter 6

Legal and Nonlegal Services Needed by Clients with Dementia: The Attorney’s Perspective

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I. NON-MEDICAID SERVICES AND SUPPORTS

A. Funding Sources. Someone who has been diagnosed with Alzheimer’s Disease can expect to have significant expenses for long term care services. Paying for living expenses and long term care can be a major concern for clients.

1. A person with early-onset Alzheimer’s Disease who is under age 65 and not able to work may qualify for Social Security Disability Income (SSDI) benefits and/or Supplemental Security Income (SSI) benefits. It is one of the conditions on the Social Security Administration’s Compassionate Allowances list, giving applicants expedited access to benefits. Those over age 65 do not have to prove disability in order to receive Social Security retirement or SSI benefits. SSI benefits are based on financial need. For a single individual in 2016, the countable resource limit is $2,000 and the federal benefit rate is $733 per month. SSDI and retirement benefits are based on employment history, not on financial need.

2. Potential employment-related benefits that may provide funds for a person disabled due to Alzheimer’s Disease include paid sick leave, short term disability benefits, pension plans, and flexible spending accounts.

3. A person who is disabled due to early-onset Alzheimer’s Disease may be able to withdraw funds from an IRA before age 59½ without having to pay the 10% early withdrawal penalty.

4. Borrowing against a life insurance policy or surrendering a whole life insurance policy for care may be an option. Some companies waive future premiums if the insured becomes disabled. Some policies provide an option for accelerated death benefits (paid prior to the insured’s death) if the insured is diagnosed with a terminal illness.

5. A homeowner age 62 or older can use a reverse mortgage to convert some of the equity in his or her home into cash to pay for care and other expenses.

6. Government programs to assist people who are elderly or disabled and who have limited income and resources include SNAP (fka food stamps) and subsidized housing.

B. Programs and Resources for Care. There are many federal, state, and community programs that may provide care or help pay for care needed by people who have Alzheimer’s Disease. Medicare, Medicaid, VA benefits, and long term care insurance are addressed elsewhere in this chapter.

1. Oregon Project Independence (OPI) is a state program administered by Aging and People with Disabilities to help people age 60 or older and those with Alzheimer’s Disease remain at home, http://www.oregon.gov/DHS/SENIORS-DISABILITIES/LTC/Pages/index. It provides in-home and respite care to people who meet the priority level requirements. ORS 410.410 et seq; OAR 411-032-0020. OPI charges hourly rates for services based on income. People who qualify for Medicaid assistance are not eligible for OPI.

2. Meals on Wheels People, 503-736-6325, www.mealsonwheelspeople.org, provide hot lunches at dining centers and home-delivered meals for people age 60 and older in Multnomah and Washington Counties in Oregon as well as in Clark County in Washington. Local Loaves and Fishes programs and senior centers provide hot lunches in other areas.
3. There are local programs for transportation for people who are elderly or who have disabilities, such as the Tri-Met LIFT, Ride Connection, shuttle services, and dial-a-bus services.

4. There are a variety of family caregiver support groups, adult day care programs, and respite care services throughout the state. The only PACE (Program of All-Inclusive Care for the Elderly) is the Providence ElderPlace program headquartered in Portland.


6. Types of care facilities in Oregon include nursing facilities, residential care facilities, assisted living facilities, and adult foster care homes. DHS issues memory care endorsements for residential care facilities, assisted living facilities, and nursing facilities that meet certain standards for dementia care training and services, OAR 411-057-0100 et seq.

7. Local and community resources change from time to time. Health care professionals and organizations which serve people with Alzheimer’s Disease are good sources of information about current resources. Some options are:
- Oregon Chapter of the Alzheimer’s Association, 1-800-272-3900, www.alz.org/oregon/;
- Alzheimer’s Network of Oregon (Marion, Polk, Linn, and Benton Counties), 503-364-8100, www.alznet.org;
- OHSU Layton Aging and Alzheimer’s Disease Center, 503-494-6976, www.ohsu.edu/research/alzheimers ;
II. Non-Medicaid Ways to Pay for Long-Term Care

The cost of long term care is expensive and is growing rapidly. The cost of community-based care such as adult foster homes or assisted living facilities start at around $3,000.00 per month and go as high as $6,500.00 per month. Nursing home costs average between $8,000.00 and $10,000.00 per month. Planning for these costs is an important part of a person’s planning process. Other than Medicaid, what options does a person have to pay for long term care?

A. Pay Privately.

Although not all persons have the option of paying privately for any extended amount of time, paying privately is an option to consider for many people. The idea of paying $6,000.00 per month in care costs sounds devastating to a person's finances, but that is not always the case. In addition, a person’s preferences and priorities must be considered. It should not be assumed that a client wants to protect his assets and plan for Medicaid eligibility. In my experience, clients seem to fall into two general categories: the clients in the first category believe that they have saved his or her money for a rainy day, the rainy day is here, and it is perfectly fine to spend all of his or her money on care needs. The second category of clients believe that they worked very hard for their money, they have paid a significant amount of money into the system, and if there is a way to protect assets to pass on to their children and qualify him or her for Medicaid, that is what that client would want to have happen. Neither position is right or wrong. It is important for an attorney to not assume that Medicaid planning is always what the client wants to have happen. The client sometimes just needs assurance that it is okay to spend his or her money on care.
Take for example the following scenarios:

1. Joe is 85 and single, he has $3,500.00 in net monthly income, he owns his own home valued at approximately $150,000.00, and he has $175,000.00 in investments and bank accounts. Joe needs to enter an assisted living facility, and he has been told that the cost will be approximately $6,000.00 per month. Joe has three children, two of which are doing well and one child struggles to make ends meet.

   Joe visits an attorney to complete a power of attorney, and finds out his options on payment for care. A private pay option should be discussed as well.

   In Joe's case, if his house sells, the proceeds plus his investment and bank accounts total roughly $325,000.00. Joe's net income of $3,500.00 per month can be used to pay towards his care. If care costs are $6,000.00, he will need $2,500.00 per month to pay for his monthly care costs. At $2,500.00 per month times 12 months, Joe will use $30,000.00 per year of his assets to pay for care. If Joe lives four years, that is $120,000.00 that would be spent on his care, leaving approximately $255,000.00 remaining at his death. There are many assumptions that go into this calculation, but it is a scenario that should be discussed along with the Medicaid planning options.

2. Jim and Sue meet with an attorney to discuss Medicaid planning because they have been told that their finances will be devastated when Jim, who has been diagnosed with Alzheimer's, needs care. Their assets consist of a house worth $400,000.00 and $800,000.00 in a brokerage account.

   All of the earnings on that brokerage account are reinvested. At a 4% earnings rate, if that amount were drawn out rather than reinvested, that would provide $32,000.00 per year in helping to pay for care. That money plus fixed income may be sufficient to pay for care for a few years.
without even decreasing the net value of the estate. And if it depletes resources of $12,000.00 - $24,000.00 per year, with an estate that size, maybe that is acceptable to the clients. By doing the calculations to help the client to see that they can afford to pay for long term care without being financially devastated can be a real service to the client.

3. If the client truly does not want to complete Medicaid planning and the home is the only major source of value, a reverse mortgage may be a way to provide for liquidity to pay for the in home care costs.

B. Long Term Care Insurance

If clients come to an attorney’s office prior to needing long term care, long term care insurance should be discussed as an option for paying for future long term care. The person must be in general good health to qualify for long term care insurance. The premiums are expensive and are the main reason that people do not buy long term care insurance. However, the annual premium is almost always less expensive than the cost of one month of a low level of care.

There are numerous long term care insurance products in the market today. The traditional long term care insurance plans pay a daily amount towards care after a deductible period, and usually pays for a certain number of years. In the last several years, policies have improved:

1. Long term health care insurance must cover more than skilled nursing care. Generally, this insurance will cover intermediate care and custodial care provided in a nursing home, adult foster home, residential care facility, and in-home health services.

2. Policies must provide for the treatment of Alzheimer’s disease and related dementias diagnosed after the policy is purchased.
3. Benefits in a policy must be based on how impaired the person is which is based on activities of daily living such as eating, bathing, walking, toileting and dressing. In addition, cognitive ability must be considered.

4. A policy must offer in-home care. A person may decline the offer.

5. Policies can no longer require a hospital stay before paying for long term care.

6. When looking at long term care policies, ask the following questions:

   a. How long will benefits be paid?
   
   b. Is the policy guaranteed renewable?
   
   c. What is the deductible?
   
   d. Are the premiums fixed?
   
   e. Is there a premium waiver?
   
   f. What is the daily benefit? Is the daily benefit different for nursing home, as opposed to an assisted living?
   
   g. Is there an inflation factor?
   
   h. How financially stable is the company. How is it rated?

7. Obtain the brochures on long term health care insurance from the State Insurance Division. The brochure includes a checklist of what you should be looking for in a policy. Talk with the Consumer Advocate at the Insurance Division, phone number 1-888-877-4894 or askadvocate.ins@oregon.gov.

C. Veteran’s Administration (VA) Aid and Attendance Program. (VA Benefits that Increase Income to Pay for Long Term Care)

1. A Veteran or Widow(er) of a Veteran may be able to obtain additional income from the VA, to help pay for the cost of long term care. A person who is either
housebound, in need of assistance with his or her activities of daily living, or living in a nursing home, may qualify to receive VA Pension with Aid and Attendance (A&A). A&A pays a monthly cash payment in an amount up to a maximum of the permissible family income limit as defined in subparagraph 2,f below.

2. All of the following criteria must be met before the Veteran/Widow(er) can receive A&A benefits:
   a. The Veteran must have served at least 90 days of active service, and at least one of those days during a wartime period.
   b. The Veteran must have received a discharge other than dishonorable.
   c. The claimant must have a permanent and total disability, caused without the willful misconduct of the claimant (age 65+ = disability).
   d. The Veteran/Widow(er) must personally sign the Application.
   e. Claimant must be blind, living in a nursing home; or needs assistance with the activities of daily living, including cognition matters, either at home, a foster home, or assisted living, or similar community.
   f. The applicant’s countable income cannot exceed the maximum permissible family income limits. Countable income is all income attributable to the applicant, the applicant's spouse, and the applicant's dependent children. However, unreimbursed medical expenses paid by the family members may be used to reduce the
countable income. *The most beneficial unreimbursed expenses that may reduce countable income are the costs of home health care, assisted living facilities, or nursing homes.* The permissible family income limits for 2016 for A&A benefits are:

1. Veteran w/no dependents $1,788.00/month
2. Veteran w/one dependent (spouse) $2,120.00/month
3. Widow(er) with no dependents $1,149.00/month
4. Healthy Veteran with ill spouse $1,404.00/month

In addition to income, the VA considers the net worth of the individual seeking benefits. The standard is whether the person has "sufficient means" to pay for his or her own care. The VA has begun instructing caseworkers to perform an "age analysis" to determine financial need. The VA considers $80,000 or less in assets, whether married or single, to meet the requirements. However, due to the age analysis, a person who is 98 years of age who has $80,000 may not be eligible; whereas, a person who is 78 years of age who has $80,000 may be considered eligible. All assets are considered regardless of how titled. The home is exempt, so long as the applicant or spouse continues to live in the home, or so long as there is an intent/desire to return to the home.

3. As of June 23, 2008, the VA began requiring that persons assisting a Veteran or their family members with the presentation and prosecution of a claim be accredited through the VA. To protect yourself and your clients, make sure that they are
using an accredited agent. To determine whether a person is accredited, you can go to
www.va.gov/ogc/apps/accreditation/index.html and type in the name for confirmation.

4. The Veterans Administration (VA) is in the process of changing its rules to include a 3 year look-back period. They have not yet published the final rules. These rules will affect the planning strategies and no planning should be done without further consulting with an attorney or other advocate accredited by the VA.

5. The speed in which the VA process claims is unpredictable. Awards can take anywhere from two to twenty-four months to process. This unpredictability can cause difficulty in the planning process.
III. Family Care Giving Issues

What if a family member wishes to provide paid care for another member of the family who has Alzheimer’s or another dementia? This outline will address issues arising from this employment.

A. While on Medicaid. This outline will not cover Medicaid payment for in-home care. That subject is enormous. Suggested resources:

- Home Care Worker Guide. (DHS 9046, Revision 11/2011) A comprehensive guide for DHS reimbursed home-care workers. [https://apps.state.or.us/Forms/Served/se9046a.pdf](https://apps.state.or.us/Forms/Served/se9046a.pdf)

- Task List. (SDS Form 0598 Revised 08/07) A two page list of tasks a home care worker would undertake.

- Blake, Dady K., “Medicaid and the in-home caregiver” (Elder Law Newsletter, Volume 15, No. 1, January 2012).

- Morgan, Kit, “What Medicaid covers if the beneficiary is at home” (Elder Law Newsletter, Volume 11, No. 2, April 2008).

- Note that Affordable Care Act K Plan services are available.

B. Personal Care Contract. A family member may provide paid care for an Alzheimer’s or dementia patient.

1. Written Contract. Even with a family care-giver it is best to have a written contract. The contract can be general or specific but, in all events, sets out the expectations of the parties.

2. Forms. Many forms are available on the web, e.g., at www.elderlawanswers.com or www.care.com. Also see Solkoff, Scott M., “Personal Service

3. Medicaid Look-back. One reason for a written agreement is that if funds run out and a later Medicaid application is necessary, having a formal pre-application situation will make the application a smoother process. The only Medicaid administrative rule on point presumes that services provided for fee at the time were intended to be provided without compensation. OAR 461-140-0242(4)(b).

Another Medicaid rule states that fair market value can be predicated on a ‘prior agreement’. OAR 461-140-0250(2)(c)(B).

4. Method of Payment. Payment could be (1) periodic (weekly, bi-monthly or monthly) or (2) deferred until a future event. However, periodic compensation in the form of an hourly wage is the custom in the market and, therefore, is much preferred.

Families have tried personal care contracts with deferred payment with mixed success. One contract failed because the Massachusetts agency determined that the value of the care contract was not ascertainable. Forman v. Director of the Office of Medicaid (Mass. App. Ct. 10-P-728, April 6, 2001). Five consolidated cases involving transfers for prospective care services were found to be disqualifying transfers for less than fair market value. Matter of Barbato v. N.Y. State (N.Y. Sup. Ct., App. Div., 4th Dept., No. 711 TP 08-02216, August 21, 2009).

On the other hand, a written care agreement from 1989 calling for the payment of $1,000 per month, due upon demand, was found to be a binding contract on the State of Louisiana. Carpenter v. State of Louisiana Dept. of Health and Hospitals (La. Ct. App., 1st, No. 2005 CA
Chapter 6—Legal and Nonlegal Services Needed by Clients with Dementia: The Attorney’s Perspective


Two attractions of deferring the compensation are that the disabled person or spouse find it more palatable and, maybe, particularly if an inheritance, it is not taxable income.

5. **Compensation: reasonableness.** It goes without saying that compensation should be reasonable. Of course, economics within families tend to have different dynamic that economics in the market place, but failure to meet this simple requirement could lead to a later Medicaid disqualification, family wrath, APS involvement and accusations of elder abuse. OAR 461-001-0000(30) and OAR 461-140-0210.

In one case involving a later Medicaid application, a contract for services interfered with Medicaid because the court found that the payment to a care-giver at the sale of the house amounted to a disqualifying transfer since the rate charged for services, $15.50 to $17 per hour, was more than fair market value. The court relied evidence that nighttime services in the community were paid at a lower wage. Swartz v. N.Y. State Dept. of Health (N.Y. Sup. Ct. App. Div. 3rd Dept., No. 513524, June 14, 2012). Similar facts existed in P.W. v. Div. of Medical Assistance and Health Services (N.J. Super. Ct., A pp. Div. No. A-4756-11T3, April 29, 2014).

6. **Court Approval.** Court approval of the contract services may not help as at least one instance of court-approved transfers for care services and expenses resulted in a Medicaid denial. In this case a later court review found that there was a lack of credible documentary evidence of the care services. V.M. v. Dept. of Human Services (N.J. App., No. A-5886-09T3, May 23, 2011).
C. Threshold Issue: Employee or Independent Contractor. Paying for care triggers a number of business and tax rules. The threshold determination is whether the in-home caregiver is an employee or independent contractor. Why it matters:

- The obligations of the employer and employee differ greatly.
- An independent contractor is self-employed and has significant tax obligations but also greater tax deductions.
- An employer of an employee has greater tax and other obligations than that of an independent contractor.
- Having employees includes other obligations.

1. Analysis. The worker is an employee unless he/she meets criteria for an independent contractor. The criteria for establishing an independent contractor is difficult to meet.

2. Oregon. Under Oregon law, workers who provide services for pay will be considered employees unless they meet specific requirements to be considered independent contractors. In general, an independent contractor will need to be (1) free from direction and control as to how services are provided and (2) will need to be providing those services as part of his or her operation of an independently established business. ORS 670.600. The Bureau of Labor and Industries uses an “economic reality” test to determine the employment relationship. It has five factors:

(1) The degree of control exercised by the alleged employer
(2) The extent of the relative investments of the worker and alleged employer
(3) The degree to which the worker's opportunity for profit and loss is determined by the alleged employer
(4) The skill and initiative required in performing the job
(5) The permanency of the relationship

1 From In the Matter of Geoffrey Enterprises, Inc. 15 BOLI 148 (1996) adopting test from Circle C Investments, Inc., 998 F.2d 324 (5th Cir. 1993).
The statute defining an independently established business requires that three of five factors be met. ORS 670.600 (3). These include:

1. maintaining a separate business location
2. who bears the risk of loss in the business
3. having at least two clients and the level of advertising and marketing
4. the person makes a significant investment in the business
5. authority to hire other persons to assist

In one Oregon case, parent caregivers of disabled adult children were being paid by agencies for care. The court found the parents employees and not independent contractors because they were not “customarily engaged in an independently established business” as delineated in ORS 670.600(3). Kirwan and Beach v. Department of Revenue, No TC-M D 210038N, Tax Court of Oregon, August 20, 2012.

Most in-home caregivers will be employees and the sections that follow will address the employer obligations. If the worker is an independent contractor, the employer need not make employer deductions. The worker pays federal and state self-employment tax, files quarterly estimates, can write off certain expenses, etc. The employee requirements are too great to summarize here.


https://www.angelo.edu/services/sbdc/documents/library_resources/IRS%20Factor%20Test.pdf
4. **$1,000 Threshold.** Employer obligations apply once the in-home caregiver reaches the $1,000 per quarter payroll threshold. These are set forth below.

5. **Self-Employed.** Claiming to be self-employed requires first qualifying as a contractor so it cannot be used as a way around the employment rules.

6. **Possible Exceptions.** There *may be* some gray area situations where one can argue that the in-home caregiver is a contractor even though the rigorous Oregon requirements are not met. It probably would require that the hours be irregular (i.e., on call) and that the period of employment be relatively short.

**D. Employer Obligations - Federal**

1. **Caregiver’s Soc. Sec. Number or EIN.** In all events, get the caregiver’s Social Security number. This can be done by photocopying the SS card or having the employee complete IRS Form W-9.

2. **Federal EIN.** The employer will need federal EIN. IRS Form SS4 at IRS.gov. If employer is a trust with its own EIN, may not need a second federal EIN.

3. **Income Taxes, Federal and State.** The IRS and the ODR do not require the employer to withhold the employee’s tax obligation.
   
   a. If employer withholds:
      
      i. Employer must have employee complete form W-4.
      
      ii. Employer must arrange payroll deductions each paycheck.

      Consider payroll service.

   b. If employer will not withhold, there should be a written agreement with the employee that it is her obligation to pay the taxes. She must file quarterly withholding reports.
4. **FICA (Social Security) and Medicare.**

   a. **Employee Contribution.** The IRS and SSA requires the employer to withhold 7.65% of wages each paycheck for any employee if total wages will exceed $2,000 for the calendar year (2016). The FICA rate is 6.2% and the Medicare rate is 1.45%.

   b. **Employer Contribution.** The employer contributes the exact same rate (7.65%) and amount. The contributed amount is shown on Schedule H of the 1040 return and paid by April 15 of the following year. If the employer is a trust, it is more complicated.

   c. **Special Situations.** There are additional taxes if wages exceed $200,000 and caps on the withholdings once they reach $118,500 (2016). Also, payments to the employer’s children under 21 or to the employer’s parents are subject to special rules. See IRS Publication 926.

5. **Federal Unemployment Tax (FUTA).** If the employer pays more than $1,000 in combined wages per quarter, the employer must pay FUTA. However, no tax is paid on wages over $7,000 per year. The rate is 6% of wages, hence the tax is between $42 and $420 per year. The tax is not paid by the employee or withheld from the paycheck. Instead the employer pays it annually at a standard rate. For domestic workers, it is calculated as part of the Schedule H to form 1040 due April 15 of the following year. A credit is available for paid Oregon unemployment taxes.

6. **Annual Federal Filing Obligations.** Annually, the employer will need to file:

   a. IRS Form W-2, Wage and Tax Statement, to the employee by January 31 of the following year.
b. IRS Form W-3, Transmittal of Wage and Tax Statements, with a copy of the W-2, with the SSA by January 31 of the following year. It shows total earnings, Medicare wages, Social Security wages and withholding.

c. Schedule H to IRS Form 1040. This Schedule would show withheld wages, if any, FICA and Medicare withholding and FUTA. It is due April 15 of the following year. If the employer has no federal tax liability, he or she can file Schedule H by itself.

E. Employer Obligations - Oregon

1. Employment Department Number. Once a domestic employee has a total payroll of $1,000 per quarter, then the employer must register with the Employment Department of the State of Oregon. The Department issues an Oregon Business Identification Number. This is not a Business Registry Number. The employer will receive a packet with forms to file quarterly as well as an annual reconciliation. The employer will also receive a tax rate for unemployment insurance.

2. Oregon Unemployment Tax. The employer is supposed to file quarterly forms with payment per the assigned rate. There is no withholding from the employee for this. There is also an annual reconciliation form due January 31 of the following year. If quarterly filings are done, the reconciliation will not have any payment. Some employers will not pay quarterly and just send the amount with the annual reconciliation, but it is unclear whether this is correct.

3. Oregon Income Tax. Oregon income tax withholding is not required for household employees. If the employer and caregiver agree, then IRS Form W-4 must be completed by the worker.
3. **Local Taxes.** Review for local taxes. In the Portland area, domestic employees are exempt from Tri-M et tax.

4. **Annual Oregon Filing Obligations.**
   
   a. Form OA Domestic. This form informs the ODR the number of employees, unemployment insurance and other information. It is due by January 31 of the following year.
   
   b. Form 132 Domestic. This form reports hours worked by the employee for unemployment insurance. Payment due by January 31 of the following year.
   
   c. Form WR, Oregon Annual Withholding Tax Reconciliation Report. For employers who withhold taxes, this is the reconciliation report. It is due March 15 of the following year.

F. **Employer’s Liability for Harm of Employee.** There is no requirement in Oregon that a domestic worker have worker’s compensation insurance. ORS 656.027(1). However, having such insurance may be prudent. Apparently this law may change. A dequate homeowner’s liability insurance is critical.

G. **Minimum Wage.** Domestic workers who are employees (but not independent contractors) are exempt from federal and Oregon Minimum wage laws. This law too may change.

H. **Gift.** There may be instances where the *consideration* for caregiving can be structured as a gift rather than as income.

1. **Medicaid.** Obviously this will not work without consideration of the Medicaid gift rules.
2. **Advantages.** The obvious advantage is that employer/employee rules do not apply and the receipt of funds is not taxable income. IRC 102(a). This possibility is not what the taxing authorities condone.

   **a. Presumption.** Gifts to employees are taxable. IRC 102(c). The obvious reason is that it is difficult to avoid the issue of consideration.

   **b. Related Parties.** There might be an exception for related parties.

   • At one point a regulation was proposed that would allow gifts to employees that were natural objects of the donor’s bounty. Proposed Regulation Section 1.102-1(f). It is not in place.

   • There is also at least one case that allowed a gift under these circumstances, but it was not a caregiver context. *Lane v. United States*, 286 F.3d 723 (4th Cir. 2002).

   • There must be “detached and disinterested generosity... out of affection, respect, admiration, charity or like impulses.” *Commissioner v. Duberstein*, 363 U.S. 278, 285 (1960).

   • *De minimis* gifts to employees are excluded from taxable income. IRC 132(a)(4).

     Examples can be found in regulations 26 CFR 1.132-0* et seq.*

I. **Miscellaneous.** There are other issues that should also be reviewed.

   • Immigration rules apply.

   • One can deduct the Social Security tax, FUTA, Medicare tax and state unemployment tax as a deductible Schedule A medical expense if purely for medical services.

IV. Frequently Asked Non-Financial Medicaid Questions

Most discussions of Medicaid eligibility begin and end with financial eligibility questions of resources, income, transfers and trusts. This section addresses some non-financial questions commonly asked by clients.

A. What Facilities Accept Medicaid. Do all facilities accept Medicaid? No. Medicaid is the “800 pound gorilla” because of its buying power. The result is that Medicaid’s reimbursement rate to the facility is lower than private pay rate. One figure given is that the reimbursement rate averages 71 per cent of the private pay rate. Over 90 percent of nursing homes participate with Medicaid. A lower percent of foster homes and assisted living facilities participate.

B. Quality of Care. Is the quality of care paid by Medicaid the same as for care paid privately? Yes. Although this is a problem in some states, both Oregon and Washington have avoided it. The federal law prohibits this “Medicaid Discrimination” and, fortunately, the State and advocacy groups enforce it.

C. Double v. Single Room. Can the facility ask the patient to move from a single to a double room? Yes, with regard to ALF and RCFs and no with regard to nursing facilities. Although the latter usually only have double rooms. The reason is more-or-less the same as in the next question. 42 USC 1396r (c)(4)(A) and (B) and (5).

D. Private Pay Requirement. Can the facility ask that the prospective patient first pay privately for some period of time as a condition of admission? This issue is quite controversial because the law is unclear.
On the one hand, a nursing facility must establish and maintain identical policies regarding services for all individuals regardless of the source of payment and cannot require the patient to waive any rights to benefits. 42 USC 1396r(c)(4) and (5). OAR 411-070-0010 (2).

On the other hand, (1) the federal and Oregon statues applies only to “nursing facilities”, (2) federal law allows continuing care facilities to require spend down and (3) facilities can request a charitable contributions. 42 USC 1396r(c)(4) and (5).

The best answer is ‘yes’, with regard to ALFs, RCFs and AFHs, and ‘no’ with regard to nursing facilities.

This ambiguity is captured in a DHS Administrator Alert, DHS, March 6, 2013:

The requirement of duration of private pay may not violate a specific Medicaid law because Medicaid does not regulate community based care. However, the enforcement would require Medicaid-eligible residents to pay more than the Medicaid rate for services and would also deter private pay resident who may be eligible for Medicaid from applying. Both of these acts violate the law. Regardless of the legality, the practice of requiring duration of stay agreements offends the public policy underlying Medicaid law. The Department is therefore requesting that providers who have Medicaid contracts refrain from requiring the duration of private pay agreements.

One interpretation would conclude that if the resident is in community based care and still has resources, then the facility may require a duration of private pay. If the resident is already Medicaid eligible, then the facility may not require the duration of private pay. And if the resident has resources, is admitted, and using valid legal means becomes eligible, then the facility cannot enforce the duration of pay.


E. Medicaid Control of Decisions. Does the State control decisions about Medicaid recipient? Yes, but only about how the recipient’s income is spent (excluding her personal
allowance). The state does not actually manage the assets, if any, or any other part of the recipient’s life.

**F. Facility Charging or Family Paying More Than Medicaid Rate.** It is important to note that if an applicant qualifies for Medicaid, the provider cannot charge the family for the difference between the private pay rate and the Medicaid rate. OAR 411-070-0010 (2). Reciprocally, the family cannot pay more and it is illegal for the operator to accept additional payment.

**G. What Else Will Medicaid Pay For?**

1. **Qualified Medicare Beneficiary Program.** Medicaid may also create eligibility for the Qualified Beneficiary Program (QMB). The state pays the Medicare premiums, co-payments and deductibles for people who meet the program’s income and resource standards. There are different levels of eligibility and the benefit package depends on the person’s income level. OAR 461-135-0730. In 2015, the income limit is $1,001 (Oregon, individual) and $1,348 (Oregon, couple) per month for an individual and the resource limit is $7,280 (individual) and $10,930 (couple). OAR 461-155-0290 et seq.; OAR 461-160-0015.

Note: As of 1/1/16 DHS has by rule removed the resource limits for all QMB programs.

2. **Medical Coverage.** Medicaid also pays for a broad range of health care services. Oregon covers inpatient and outpatient hospital services, prescription drugs, durable medical equipment and supplies, physician services, eyeglasses, dental care, mental health care and medical transportation. However, the Oregon Health Plan limits the scope of coverage for services other than long term care. There is a prioritized list of conditions and treatments. The state does not pay for treatments that are below the cut-off point on the list. Under the Oregon Health Plan, most eligible people have to enroll in capitated managed care plans which provide
and control the services. The purpose of this system is to contain health care costs. ORS 414.610 et seq.

3. **Medicare Part B Premium.** Once a person who has Medicare coverage is found eligible for Medicaid, the state begins to pay the Medicare Part B premium.
V. Medicaid - Service Priority Rule

A. Summary. Medicaid eligibility for long term care (OSIPM) will also be contingent on the applicant needing a level of assistance with his or her activities of daily living (ADLs). This is commonly referred to as the “disability requirement.” The different levels of assistance with ADLs are categorized as Service Priorities and may be found at OAR 411-015-0000 et seq.

To properly advise the client, the legal practitioner must also have a basic understanding of the Service Priorities. Rules can be found at:


B. Assessment Process. As a practical matter, as part of the eligibility application process, an intake worker will be sent to assess the ADLs of the client. OAR 411-015-0006(2)(b) The assessment is done on the Client Assessment and Planning System (CA/PS) program. The regulation summarizes the CA/PS as:

(a) Is the single entry data system used for:

(A) Completing a comprehensive and holistic assessment;

(B) Surveying an individual's physical, mental, and social functioning; and

(C) Identifying risk factors, individual choices and preferences, and the status of service needs. OAR 411-015-0005(15)(a).

The purpose of the CA/PS is summarized as:

(b) The CA/PS documents the level of need and calculates the individual's service priority level in accordance with these rules, calculates the service payment rates, and accommodates individual participation in service planning. OAR 411-015-0005(15)(b).
The application process is to be completed within 45 days of the date of the request. OAR 461-115-0190. The Service Priority assessment must occur within this timeline.

C. Activities of Daily Living. The assessment takes into account the client’s ADLs. These are, “those personal functional activities required by an individual for continued well-being which are essential for health and safety. Activities include eating, dressing, grooming, bathing, personal hygiene, mobility (ambulation and transfer), elimination (toileting, bowel and bladder management), and cognition, and behavior.” OAR 411-015-0006(1).

A summary of ADLs from the regulation is:

Bathing/Personal hygiene. OAR 461-015-0006(4)
- Bathe/Hair washing
- Shave/ Care of mouth

Cognition/Behavior. OAR 461-015-0006(5)
- Adaptation (Need for reassurance)
- Awareness (Awareness of health & safety)
- Judgment (Need for protection /monitoring
- Memory (Ability to use information)
- Orientation (To person/place or time)
- Danger to self/others (Including disruption)
- Demands on others (Disrupts living arrangements/needs)
- Wandering

Dressing/Grooming. OAR 461-015-0006(6)
- Dressing and undressing
- Miscellaneous hair & nail care

Eating. OAR 461-015-0006(7)

Elimination. OAR 461-015-0006(8)
- Bladder/bowel/ toileting

Mobility. OAR 461-015-0006(9)
- History of falls
- Ambulation
- Transfer
In addition, the rule covers Instrumental Activities of Daily Living, OAR 461-015-0007, consisting of:

- Housekeeping
- Laundry
- Meal preparation
- Medication Management
- Shopping
- Transportation

**D. Time Frame.** The assessment should take into consideration needs in the thirty days previous to and subsequent to the assessment date. OAR 461-015-0006(2)(b) and OAR 461-015-0007(2)(b).

**E. Funding Service Priorities - Background.** Historically all levels of care were reimbursed by the Medicaid program and the Service Priorities determined the reimbursement rate. Medicaid eligibility issues focused on financial (resources and income) eligibility and not on disability. However, because of the State’s budgetary difficulties in 2000 – 2002, Executive Letters were issued by the Agency in early 2003 eliminating reimbursement for levels 10 to 17. As of April 1, 2003 levels 10 and 11 were restored and as of July 1, 2004, levels 12 and 13 were restored. OAR 411-015-0015(1)(a).

As of the date of this material, January 2016, Service Priorities 1 to 13 are serviced.

The agency, by rule, may change the Service Priorities served (funded) and the practitioner is urged to keep current on the issue. OAR 411-015-0015.

**F. Priority of Services.** The agency has established 18 levels of care, ranging from “Requires Full Assistance in Mobility, Eating, Elimination and Cognition.” at the highest level (Level 1) to “Requires Assistance in Bathing or Dressing.” at the lowest level (Level 17). Level 18 states that the client “[i]s independent in the above levels but requires structured living for
supervision for complex medical problems or a complex medication regime.” OAR 411-015-0010(1) to (18). The different levels are defined with great detail at OAR 411-015-0006.

**G. Covered Population.** Keep in mind that not all folks who need long term care come in under the Medicaid OSIPM umbrella. See OAR 411-015-0015(1) and (2).

The Service Priorities do apply to applicants in their homes for in-home care. OAR 411-030-0040(1).

**H. Issues Arising with Dementia**

The ADLs most likely to fail for an Alzheimer’s or dementia patient are cognition and elimination.

1. **Cognition.** The ADL to focus on is cognition. The usual rule that the assessment is only to take into account behavior within 30 days before and after the assessment “may be expanded” when assessing cognition. OAR 461-015-0006(5)(b). Invariably, this will involve anecdotal information that can be provided by family with knowledge of the client’s care needs.

   Service Priority number 3, requires “Full Assistance” with “Mobility, or Cognition, or Eating.” (Italics added.) OAR 461-015-0010(3). Full assistance is required for 3 of 8 components: Adaptation, Awareness, Judgment, Memory, Orientation, Danger to self or others, Demands on others, and Wandering. OAR 461-015-0006 (5)(d)(A)-(H).

2. **Elimination.** Another ADL to focus on is elimination because dementia so often is accompanied by incontinence. Service Priority numbers 4 and 13 address elimination without needing other ADL problems. Priority 4 requires Full Assistance and 13 requiring Assistance. Other rules combine elimination with other ADLs: rules 5, 7, 8, 9, and 11.
I. Failure to Qualify

a. There has been some controversy about whether the CA/PS assessment is accurate, is employed properly, is coordinated with the OAR, is biased toward physical ailments, and more. The Agency stands by the accuracy of the process but has an ongoing review. The practitioner is advised to review the results in the event of a discrepancy between the assessment results and the actual situation. An independent assessor may need to be hired, especially if there is a strong feeling for an appeal.

b. If a client disagrees with the Service Priority assessment, leading to a denial of services, he or she may request a hearing. The Administrative Hearing Request form is AFS Form 443 and is available with the Agency. The Agency has current policy which calls for a reassessment upon a timely filed hearing request.

c. Service Priority requirements may disqualify applicants but the disqualification may only apply to long term care Medicaid. Other benefits may continue. For example, Oregon Project Independence is still funded through priority 18. OAR 411-015-0015(1)(b). An SSI eligible client may also still retain his or her “medical card” (OMAP Medical Care Identification) for medical benefits. The practitioner should review for other public benefits.
VI. Medicaid Myths

Medicaid is a joint federal–state sponsored program which pays for medical care and custodial care, including intermediate level of care provided in nursing homes, adult foster homes, residential care facilities, assisted living facilities, and in home care services. The rules to qualify for Medicaid are complex and can be difficult to understand. People obtain information about Medicaid from various sources, not all of which are reliable sources. Below are 10 myths related to the Medicaid rules that I hear in my practice on a regular basis.

A. Myth Number One: I do not need to worry about paying for long term care because I have Medicare and a supplemental insurance plan.

While Medicare does provide some coverage for nursing home expenses, the coverage is quite limited and does not cover any intermediate or custodial long term care. Medicare covers only up to 100 days of skilled nursing care, and even then covers only the first 20 days in full and pays a co-pay for the 21st through the one hundredth day.

Although Medicare is an excellent health insurance program, the benefits do not extend to long term care benefits and should not be relied upon for that purpose.

B. Myth Number Two: My spouse cannot qualify for Medicaid because we own our home.

A house is an exempt asset for Medicaid purposes for so long as one of the spouses resides in the home. If the asset is exempt, Medicaid does not count the asset as an available resource for eligibility purposes. Other exempt assets that are not accounted for Medicaid eligibility purposes include personal belongings and household furnishings, one vehicle, an irrevocable prepaid burial plan, and medical equipment.

Note that if the house is counted as an exempt asset, and then the character of the exempt asset changes, for example the home is sold, then Medicaid may count a portion, usually 50%, of
the proceeds as available to the Medicaid recipient spouse. This may disqualify the Medicaid recipient spouse until a spend down occurs or those assets can be protected.

C. **Myth Number Three:** My spouse does not qualify for Medicaid because we have to spend down to zero resources before Medicaid kicks in.

Medicaid does have a resource test as one of its eligibility tests. For a single person, the applicant is allowed to retain $2,000.00 plus any exempt assets.

However for a married couple, the rules are significantly more generous because Medicaid acknowledges that a healthy spouse should not be impoverished due to the illness of the other spouse. The calculation to determine how many assets a healthy spouse is allowed to retain is as follows:

1. The State looks at all of the resources of both spouses on the first day of continuing care and counts all available resources, regardless of which spouse owns the resource.
2. The State then excludes the exempt resources such as the home, vehicle, personal property, and the burial fund.
3. The resulting number is divided by two. The healthy spouse is allowed to keep one-half of the resources up to a maximum of $119,220.00 or if the one-half is less then $23,844.00, the community spouse is allowed to keep the full $23,844.00. Note that these numbers are adjusted annually.
4. The Medicaid applicant spouse is allowed to retain $2,000.00 in resources. The balance after those two amounts are retained are what is considered to be the amount that needs to be spent down or protected before Medicaid qualification is obtained.

D. **Myth Number Four:** If I ever need Medicaid in the future, I will just give my assets away prior to applying for Medicaid.
The State does not like a person to give his or her assets away, but the State cannot prevent the person from doing so. What Medicaid rules can do is disqualify the person making a gift from Medicaid benefits for a period of time.

On the Medicaid application, the applicant is asked if he or she has given away any assets in the last 60 months. If gifts were given prior to 60 months from the date of the Medicaid application, then those gifts do not impact the Medicaid application and do not need to be disclosed. However, if gifts are made within the 60 month timeframe, those gifts must be disclosed. The Medicaid rules allow the State to total the value of the gifts, and divide that total by $7,663.00. The resulting number is the number of months of disqualification for the Medicaid applicant. The kicker is that the disqualification period does not start running until the applicant has actually applied for Medicaid, and meets all of the Medicaid criteria, but for the gift. The application will then be denied. The denial triggers the disqualification period to start running.

**E. Myth Number Five:** I do not qualify for Medicaid because my income is too high.

One of the Medicaid eligibility tests is an income test. Unlike the resource test where the State looks at resources of both husband and wife, on the income test, only the income of the Medicaid applicant is considered. Under the basic rules, if an applicant's gross monthly income is greater than $2,199.00 per month, then the person has too much income to qualify for Medicaid. However, there is an exception that can fix any over income issue. If the applicant creates an Income Cap Trust, and each month deposits his or her income into the trust, then Medicaid does not count the money in the trust as income, so the applicant is under the income
limit. The money deposited into the Income Cap Trust must be distributed monthly according to the Medicaid rules.

**F. Myth Number Six:** I do not want my mom on Medicaid because the quality of care is so much less than the care provided for a private pay person.

Although there are some persons that agree with this statement, I disagree with it. In Oregon, Medicaid pays for the same care services as received by a private pay resident. There are no Medicaid "wings" of a facility. Medicaid residents are intermingled with private pay residents. It is unlikely that the hands-on caregivers know which persons are Medicaid and which are private pay. I have not seen the type of pay being the distinguishing factor in the quality of care.

The factors that I see make a difference in the quality of care is family or friend participation. If the person has no one to advocate for them by encouraging the facility to provide the care it is being paid to provide, then that person is more likely to go to the bottom of the list to obtain assistant such as bathing and dressing. The old adage that the "squeaky wheel gets the attention" has merit in this situation.

**G. Myth Number Seven:** I will qualify for Medicaid because we have moved all of our assets to my husband’s name.

Although transfers to spouses are permitted transfers so there is no disqualification period attached to that transfer, resources of both husband and wife are counted for the resource part of the eligibility test, regardless of titling. See Myth Number Two above.

**H. Myth Number Eight:** I do not want to qualify for Medicaid because my spouse does not have enough income on which to live, and the State will take all of my income.
Under the income test for Medicaid eligibility purposes, the State looks only at the income of the applicant's spouse. However, the Medicaid rules describe how the Medicaid recipient's monthly income is distributed once that person has qualified for Medicaid. The Medicaid rules allow for the Medicaid recipient to retain a certain amount of income for his or her spending money. The amount depends on the type of facility in which he or she resides, and may be $60.00 or $163.00 per month. One of the next allowed categories is a community spouse income allowance. Current Medicaid rules state that the healthy spouse's income should be a minimum of $1,991.25 per month. If the gross monthly income for the healthy spouse is only $700.00, then that person's spousal income allowance is $1,291.25 per month ($1,991.25 - $700.00). If the Medicaid recipient's income is sufficient enough to transfer $1,291.25 per month to the healthy spouse, then that transfer is allowed. If the healthy spouse has high shelter costs due to a mortgage or high rent then the amount of the income allowance may be adjusted upward. The Medicaid rules also allow the Medicaid recipient's income to be used to pay for his or her spouse's health insurance and Medicare part B premium that is deducted from his or her Social Security check.

I. Myth Number Nine: I do not want to be on Medicaid because then I cannot choose the facility in which I live.

Medicaid does not require any person to live in a particular facility. Any restriction is from the facilities themselves. In order for Medicaid to pay a facility, the facility must have a Medicaid contract. If the facility does not have a Medicaid contract, then it cannot accept any Medicaid resident. Almost all nursing homes have Medicaid contracts. There are only a handful of exceptions throughout the State. The majority of adult foster homes and assisted living facilities have Medicaid contracts, but even if the adult foster home or assisted living facility has
a Medicaid contract, the adult foster home or assisted-living facility may require the resident to pay privately for a certain amount of time before converting to Medicaid. Although a facility, other than a nursing home, can refuse to take a new resident as a Medicaid resident initially, once the resident is actually in the adult foster home or assisted living facility, the adult foster home or assisted living facility cannot refuse to allow the person to convert to Medicaid.

J. **Myth Number 10:** My resources are not counted for my spouse’s Medicaid eligibility because we completed a Premarital Agreement prior to getting married.

Unfortunately, the State does not recognize a Premarital Agreement. From a legal standpoint, the Premarital Agreement only applies to what happens with the assets in the event of a death or a divorce. It does not apply to how the Medicaid rules treat available resources, and the Medicaid resource rule looks at resources of both husband and wife.

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There are many exceptions to and different ways of interpreting the Medicaid rules. If a family believes that long term care may be an issue in the future, I would highly recommend that the family use a reliable source, such as an elder law attorney, to determine what options are available to them for planning for long term care.
VII. ESTATE PLANNING NUANCES

A. Introduction. Estate planning often includes advising a client about Oregon’s advance directive for health care, drafting a durable financial power of attorney, or doing other planning for disability and incapacity. Preparing the documents that will be needed to manage the client’s health care and finances during any period of incapacity and making sure the documents will be available when they are needed are critically important when representing a client who has been diagnosed with Alzheimer’s Disease or who is likely to become incapacitated or financially incapable due to another medical condition.

B. Advance Directive for Health Care. Oregon’s advance directive for health care statutes allow a capable adult (the principal) to name a trusted family member or friend as a health care representative with the power to make decisions about health care, including long term care, when the principal is not capable of making and communicating those decisions. The principal can give health care instructions for the health care representative and providers to follow. There is a separate Declaration for Mental Health Treatment, ORS 127.700 et seq.

1. The statutory form and the requirements for executing it are in ORS 127.505 et seq. Copies of the executed advance directive should be given to the principal’s health care providers, the health care representative, and the alternate health care representative.
   a. Oregon recognizes an advance directive (also known as a power of attorney for health care) executed by a resident of another state that complies with that state’s laws. ORS 127.515(5).
   b. Most hospitals are required to provide the advance directive form and information to patients upon admission. Some health plans make the form available on their websites.

   Practice Tip: The US Dept. of Veterans Affairs (VA) does not use the Oregon advance directive form or other state forms. Instead, it has created VA Form 10-0137, the VA Advance Directive Durable Power of Attorney for Health Care and Living Will, available online at http://www.va.gov/vaforms/medical/pdf/vha-10-0137-fill.pdf. A client who gets his or her medical care from VA facilities should be advised to complete the VA form.

   c. Part C of the advance directive form offers choices for instructions related to end-of-life care. The principal may add personalized health care instructions or create and attach an addendum based on the principal’s medical history and beliefs. For example, a person who has stage 4 cancer might include instructions about surgery or chemotherapy. A Jehovah’s Witness might include instructions refusing blood transfusions; a Catholic might insert directions that follow the teachings of the Catholic Church related to end-of-life care; an Orthodox Jew might attach a Halactic Living Will based on Jewish law and custom; and a Muslim might add instructions consistent with Shariah law.

   d. A capable principal may revoke an advance directive or a health care decision made by his or her health care representative “at any time and in any manner.” ORS 127.545. The revocation is effective when the principal communicates it to his or her attending physician, health care provider, or health care representative. Executing a valid advance directive revokes any prior advance directive.

   e. A court may determine the validity of an advance directive, remove a health care representative, or revoke or suspend an advance directive in response to a petition filed under
ORS 127.550 or in a guardianship proceeding under ORS chapter 125.

2. The health care representative has the authority to make health care decisions during any period when the attending physician determines that the principal lacks the ability to make and communicate health care decisions.

   a. The health care representative has a duty to act consistently with the principal’s wishes, if known, and in the principal’s best interests if his or her wishes are not known. ORS 127.535.

   b. The health care representative does not have the power to make decisions about withholding or withdrawing life-sustaining treatment unless that power is given in Part B of the advance directive and the principal is in one of the four end-of-life situations described in Part C. The health care representative cannot make decisions about convulsive treatment, psychosurgery, sterilization, or abortion. The statutes no longer prohibit the health care representative from making decisions about admission to or retention in a health care facility for care or treatment of mental illness.

   c. The health care representative for an incapable principal is the principal’s “personal representative” under the Health Insurance Portability and Accountability Act (HIPAA) of 1996, Public Law 104-191, and is entitled to receive the principal’s protected health information and review the principal’s medical records. 45 CFR 164.502(g); ORS 125.535(7) and 192.556(10)(b).

   d. The authority of a health care representative named in a valid advance directive supersedes the authority of a court-appointed guardian. ORS 127.545(6).

3. Oregon law does not give the spouse, adult children, or other relatives the power to make health care decisions for an incapable adult with the exception of certain end-of-life decisions described in ORS 127.635(2). ORS 127.760 allows a hospital to appoint a health care provider with limited authority to give informed consent on behalf of a hospital patient who is incapacitated and who does not appear to have a health care representative or a guardian.

   a. If there is no advance directive for health care, a family member, friend, or professional fiduciary may need to petition the court to appoint a guardian who will have the legal authority to make health care decisions under ORS 125.005 et seq

   b. If there is an advance directive, a guardianship may be needed if an incapable principal challenges decisions made by the health care representative, if the health care representative neglects or abuses the principal, or if there are other problems.

   Practice Tip: The American Bar Association has developed a smartphone app that allows clients and surrogate decision makers to import and store advance directives and other health care documents on their smartphones to make the information easily accessible, www.americanbar.org/groups/law_aging/MyHealthCareWishesApp.

C. Physician Orders for Life-Sustaining Treatment (POLST). The role of the bright pink POLST form is to document the treatment preferences for a person who is frail or who has a serious illness in the form of physician orders for first responders and other health care providers to follow. The POLST does not take the place of an advance directive. It does not address most types of medical treatment and cannot be used to appoint a surrogate decision maker.

   1. The patient’s physician, nurse practitioner, or physician’s assistant can sign the POLST form with orders about resuscitation or non-resuscitation (“DNR”) after discussing the patient’s preferences with the patient or, if the patient is incapable, his or her health care
Chapter 6—Legal and Nonlegal Services Needed by Clients with Dementia: The Attorney’s Perspective

representative, guardian, or other recognized surrogate decision maker. ORS 127.663 et seq. There is more information about the POLST form in English and Spanish at www.or.polst.org.

2. Oregon has a statewide POLST Registry. A physician, nurse practitioner, or physician’s assistant who signs or revises a POLST has to submit it to the POLST registry unless the patient opts out. A patients also may submit his or her POLST to the POLST registry.
   a. A copy of a completed POLST form is entered into a secure electronic database. The patient retains the original POLST and will receive a packet from the POLST registry with a confirmation letter, a registry ID refrigerator magnet and stickers with the registry ID number.
   b. First responders, hospital emergency departments, and ICUs can contact the POLST registry 24 hours a day, seven days a week, to find out whether the patient has a POLST and the POLST orders. Other treating providers can contact the POLST registry as well.
   c. A more recent POLST revokes a prior POLST. A patient who revokes a POLST in writing can submit the revocation to the POLST registry in order to have the revoked POLST removed from the active records.

D. Authorization to Disclose Health Information. Doctors, facilities, and other health care providers are prohibited from disclosing information about a patient’s condition or treatment without the patient’s authorization under federal HIPAA regulations and ORS 192.553 et seq.
   1. ORS 192.566 contains an optional authorization form. Some health care providers and health plans prefer to have a patient sign the provider’s or health plan’s form.
   2. Health care providers are authorized to release protected health information (PHI) to a patient’s “personal representative,” which is defined to include a court-appointed guardian who has authority to make health care decisions and a health care representative named in an advance directive for health care for an incapable principal ORS 192.556(10).

   Practice Tip: If a document such as a trust agreement or a springing power of attorney provides for a physician to determine whether the settlor, trustee, or principal is financially incapable, the physician is likely to require an appropriate authorization before disclosing the requested information to the successor trustee, agent, etc.. The client can sign an authorization form when he or she executes the planning document.

E. Disposition of Remains. A client may make advance arrangements for the disposition of his or her remains by purchasing a cemetery plot or niche, signing a contract with a funeral services provider for burial or cremation services, and/or signing an Appointment of Person to Make Decisions Concerning Disposition of Remains form that meets the requirements in ORS 97.130. If the decedent did not sign a contract or a form delegating the authority to make the disposition arrangements, the statute gives priority to the surviving spouse, followed by an adult child, a parent, a sibling, or the guardian to make the disposition arrangements.

   Practice Tip: The Medicaid program does not count a prepaid funeral or burial plan as a resource, provided that the plan is irrevocable and has no cash value. OAR 461-145-0040.

F. Financial Power of Attorney. Unlike some states, Oregon has not adopted a statutory form for a financial power of attorney. A capable adult (the principal) can sign a general power of attorney naming a trusted family member or friend as an agent (also called an attorneys-in-fact) to manage finances and property. ORS 127.002 et seq.
Under common law, a financial power of attorney is an agreement between the principal and the agent that authorizes the agent to do acts specified in the document for the benefit of the principal.

Some banks, credit unions, brokerages, and government agencies have limited power of attorney forms or signature cards that allow a client to authorize a trusted family member or friend to act with regard to a specific asset or account, give instructions concerning investments, or to have access to account statements and records. IRS Form 2848 and Oregon DMV Form 735-500 are examples of limited power of attorney forms used by agencies.

Practice Tip: It is not unusual for a bank or credit union employee to respond to a client’s request to add an authorized signer by setting up a joint account, making the second signer an owner of the account with right of survivorship. Adding a joint owner with right of survivorship to an account may change the client’s estate plan. Assets in a joint account are subject to the claims of the joint account holder’s creditors, which places the client’s account at risk if the joint owner is sued, gets divorced, or has financial difficulties.

The power of attorney becomes effective when the principal signs it unless it provides that it will become effective upon a future event, such as the principal becoming financially incapable. The principal should choose whether to give copies of the executed power of attorney to the agent(s) or to arrange for the agent(s) to receive copies in the future.

ORS 127.005(1)(c) changes the common law by making financial powers of attorney “durable,” which means that the agent can act after the principal becomes financially incapable unless the document limits the period when the agent can act.

A capable principal or a conservator appointed for the principal may revoke a financial power of attorney. ORS 127.005(5). The authority of the agent(s) terminates at the principal’s death. As one title company stated, “[D]ead people cannot sign documents.”

Examples of provisions that may be useful when drafting a financial power of attorney for a client who has been diagnosed with Alzheimer’s Disease:

- Real Estate. I specifically authorize my Agent to take all these actions as to any real estate (as defined in ORS 696.010) that I now own or that is later acquired by me or on my behalf, including my interest in the residence located at [insert address] and legally described as [insert legal description]. Note: Although the principal’s signature does not have to be notarized in order for a power of attorney to be valid, the principal’s signature does have to be notarized in order for the power of attorney to be recorded and used in a real estate transaction.

- Transfer on Death Deed. Revoke any transfer on death deed executed and recorded by me, or make and deliver a transfer on death deed on my behalf, provided that the revocation or the execution of the transfer on death deed is consistent with my existing estate plan to the extent reasonably possible. Note: The transfer on death deed must expressly grant the agent the authority to revoke the deed. See ORS 93.965(2).

- Government Benefits. Perform any act necessary or desirable (including acting as representative payee) in order for me to qualify for and receive all types of government benefits, including Medicare, Medicaid, Social Security, veterans’, and workers’ compensation benefits.

Optional provision allowing transfer to caregiving child: The power granted under this paragraph shall include the power to transfer my interest in my residence to [insert name of son or daughter who may meet the Medicaid program’s caregiving child requirements], provided that the transfer will not make me ineligible for
Medicaid or other government benefits at a time when I may need those government benefits to help pay for my long term care or support.

Optional provision allowing transfer to disabled child: The power granted under this paragraph shall include the power to transfer assets including my interest in my residence to [insert name of son or daughter who is disabled according to Social Security disability criteria] or to a trust established for [his/her] benefit, provided that the transfer will not make me ineligible for Medicaid or other government benefits at a time when I may need those government benefits to help pay for my long term care or support.

d. Transfers to My Spouse. In the event that I require long term care, transfer my interest in individual and jointly-held property to or for the sole benefit of my spouse in order to protect my spouse from impoverishment, provided that the transfer will not disqualify me from receiving government benefits at a time when I need such benefits. This power includes the authority to transfer my interest in our residence.

e. Notice and Accounting. Within thirty (30) days after my Agent begins to act under this power of attorney, my Agent shall notify me, my spouse, and the alternate agent named in this document in writing. My Agent shall prepare a statement of account at least once a year. The first statement of account shall include an inventory of my assets, together with all receipts, disbursements, and asset changes or investment transactions since my Agent began to act. Each subsequent statement of account shall include the same information for the period since the prior statement of account. Copies of documents showing the ownership of assets and a copy of my most recent personal tax return shall be attached to the accounting. My Agent shall mail a copy of the accounting to me, to my spouse, and to the alternate agent named in this document.

f. Fiduciary Positions. Resign from or renounce on my behalf fiduciary positions, including personal representative, trustee, conservator, guardian, attorney-in-fact, and officer or director of a corporation; and discharge me from further responsibility by filing accountings with a court or settling by formal or informal methods.

g. Trusts. Establish a revocable or irrevocable trust, amend or terminate an existing trust, and transfer any of my real or personal property to a trust, provided that income and principal are payable during my lifetime solely to me or for my benefit and/or to my spouse or for my spouse’s benefit and that the trust is consistent with my existing estate plan to the extent reasonably possible.

h. Nomination of Guardian and Conservator. To the extent permitted by state law, I nominate my Agent to act as my guardian if I become incapacitated and my conservator if I become financially incapable. If my Agent is unable or unwilling to act as my guardian or conservator, I nominate [insert name] to act as my guardian or conservator.

6. Oregon law does not give the spouse, adult children, or other relatives the power to manage the finances of a financially incapable person.

a. If there is no one authorized to manage the finances for a financially incapable person, a family member, friend, or professional fiduciary may need to petition the court to appoint a conservator who will have the legal authority to manage finances under ORS 125.

b. If there is a financial power of attorney, a conservatorship may be needed if the power of attorney is not accepted, if a financially incapable person disagrees with decisions made by the agent, if the agent financially abuses the principal, or if there are other problems.

7. Banks, title companies, and other third parties commonly view financial powers of attorney as increasing their risk of liability, both because of the potential that the power of
attorney being presented is fraudulent and because of concerns about whether a legitimate power of attorney has been revoked and whether the agent has the authority to make a particular transaction. ORS 127.035 limits the liability of third parties who reasonably and in good faith rely upon the authority of an agent under a power of attorney.

a. A national study on elder abuse found that the majority of abusers were adult children, spouses, and other relatives of the victim. Those with substance abuse issues, mental illness, or financial pressures are more likely to become abusers. A 2014 study by the Oregon Department of Human Services (DHS) found that 19% of the perpetrators in substantiated cases of elder financial abuse were people named as agents in the elders’ financial powers of attorney. 33% of the perpetrators held a fiduciary position in relation to the elder, such as agent, trustee, representative payee, or conservator.

b. Provisions requiring the agent to provide periodic accountings to the principal or others, placing limits on gifts and self-dealing, including standards for compensation to be paid to the agent, and revoking prior financial powers of attorney offer some protection against elder financial abuse.

G. Revocable Living Trust. Revocable living trusts are popular estate planning tools. The settlor can name a trusted family member or friend or trust professional to administer the trust immediately or when the settlor becomes financially incapable, as well as after the settlor’s death. ORS 130.001 et seq. Funding the trust is vital as the trust agreement and the trustee will control only the assets that have been transferred to the trust.

1. A revocable living trust can include a wide variety of instructions to the trustee or successor trustee about how the trust assets should be managed and used.

2. Examples of quality of life provisions that may be useful when drafting a revocable living trust for a client who has been diagnosed with Alzheimer’s Disease:

   a. Trust Purpose. The primary purpose of this trust is to provide me with the highest possible quality of life. My trustee shall give priority to my needs and preferences and is authorized to make liberal distributions of income or principal to accomplish this purpose. The rights of the remainder beneficiaries of the trust are secondary to my rights as a trust beneficiary.

   b. Preference to Remain in My Home. In the event that I need long term care services, I direct my trustee to use income and principal of the trust to allow me to remain in my home as long as possible rather than placing me in a nursing home or other care facility, even though the cost of keeping me in my home may be more than the cost of similar care provided in a care facility. My trustee may arrange for housekeeping, laundry, meal preparation, personal care, health care, and other services and for any structural modifications which may be necessary to allow me to remain in my home. In addition, my trustee may retain a geriatric care manager to establish and supervise home care for me and to develop a home care plan.

   c. Visitors and Companions. My trustee may pay the reasonable expenses of relatives to enable them to travel to the place where I reside in order to visit me. In addition, my trustee shall arrange for volunteer companions or pay for companion services to provide me with social interaction if I am living in my home or in a facility where social interaction to meet my needs is not adequately available to me. My trustee shall consider my personal preferences when selecting companions.

3. If the settlor is the initial trustee, he or she may choose to resign and have the successor trustee take over the management responsibilities for the trust. See ORS 130.620. The trust should include a definition of financial incapability and provisions for the transition to the
successor trustee.
   a. Options include giving the successor trustee the power to make the determination after consulting with the trustee’s physician and/or close family members; having the trustee’s adult children make the determination; and having the trustee’s physician and a second physician make the determination. Having a court determine financial incapability provides more due process protections for the client, but is likely to take more time and cost more money.
   b. Providing a successor trustee with an authorization to disclose protected health information signed by the trustee if the successor trustee may have to consult with the trustee’s physician or obtain a physician’s opinion on whether the trustee is financially incapable is discussed supra.

4. Flexibility is an important consideration when planning for incapacity. Some trust provisions create potential traps. A classic example is a joint trust for a married couple that becomes irrevocable and cannot be amended once one spouse becomes financially incapable. That provision traps the couple’s assets in the trust where they will continue to be available to pay for the support of either spouse, preventing the spouse who does not need long term care services from protecting a portion of the trust assets for his or her use if the ill spouse needs Medicaid assistance to help pay for long term care services.

   Practice Tip: A trap trust may be able to be modified or terminated by the court under ORS 130.195 et seq.

H. Will. A will is the primary estate planning document for many people. It does not take effect until the testator’s death, so the testator can make changes and inter vivos transfers as long as the testator has the requisite capacity.

1. A client may not realize that his or her will does not control assets owned with right of survivorship, such as joint accounts, or assets with beneficiary designations, such as life insurance policies, IRAs, and TOD/POD accounts. Ownership with survivorship and beneficiary designations are part of the client’s estate plan.

2. When the first spouse dies, the surviving spouse is entitled to receive a percentage of the deceased spouse’s augmented estate pursuant to ORS 114.600 et seq, regardless of the provisions of the deceased spouse’s will or other estate planning arrangements. The percentage varies, with the maximum being 33% for a marriage of 15 years or longer. Oregon’s Medicaid program considers the elective share to be an available resource and requires a surviving spouse who is receiving Medicaid assistance for long term care and who does not receive a share equal to or greater than the elective share to claim the elective share. See OAR 461-120-0330.

I. Medicaid Estate Recovery. The Oregon Department of Human Services (DHS) or the Oregon Health Authority (OHA) has a claim against the estate of a deceased Medicaid recipient for the amount of Medicaid assistance paid after age 55 or for a person who was permanently institutionalized. ORS 416.350.

1. “Estate” is defined as any interest in money or property that the person has at the time of his or her death, an expanded definition that allows the state to make estate recovery claims against property which is not probated, such as joint bank accounts. If a probate estate does not have sufficient assets to pay all of the claims, the Medicaid claim has the priority given under ORS 115.125(1)(i) and (j).

2. The claim cannot be collected while there is a surviving spouse or a minor or
disabled child. OAR 461-135-0835 states that DHS can make a claim against the estate of the surviving spouse for the Medicaid assistance that his or her spouse received to the extent that the surviving spouse received assets through probate or operation of law when the Medicaid recipient died or by transfers made to the surviving spouse in the 60 months that preceded a request for Medicaid assistance. The Court of Appeals decided that the 2008 expansion of DHS’ authority to include spousal transfers violated federal Medicaid law in *Nay v. Department of Human Services*, 267 Or App 240 (2014). DHS has appealed that decision to the Oregon Supreme Court.

3. DHS does not have the authority to file a lien against real or personal property to recover Medicaid assistance. The Medicaid agency does have a statutory lien on personal injury judgments and settlements for repayment of Medicaid and other assistance received following the injury. ORS 416.510 et seq.

J. Representative Payees and VA Fiduciaries. The Social Security Administration (SSA) and the U.S. Department of Veterans Affairs (VA) have their own processes for naming fiduciaries to manage Social Security benefits and VA benefits, respectively. The federal agencies do not recognize the authority of a conservator appointed by a state court or an agent named in a financial power of attorney.

1. SSA can appoint a representative payee for a person who is not capable of managing his or her own Social Security benefits. The representative payee is usually a family member or friend. Information about the SSA representative payee program is available online at [www.ssa.gov/payee/](http://www.ssa.gov/payee/).

2. The VA can appoint a fiduciary for a veteran who is not capable of managing his or her own VA benefits. The fiduciary is usually a family member or friend. Information about the VA fiduciary program is available online at [http://benefits.va.gov/fiduciary/](http://benefits.va.gov/fiduciary/).

K. Planning for a Financially Incapable Beneficiary. A client may want to name a person who has Alzheimer’s Disease as a beneficiary of the client’s estate or of a particular asset. The client’s gift may have unintended consequences if the beneficiary is financially incapable or if the beneficiary gets government benefits based on financial need. If a financially incapable beneficiary receives an inheritance, it may be necessary to have a conservator appointed by the court to take charge of the inheritance and manage it for the beneficiary. Receiving an inheritance is likely to make a beneficiary who gets Medicaid assistance or other needs-based government benefits ineligible for those benefits.

1. If a proposed beneficiary is financially incapable or is likely to be financially incapable due to Alzheimer’s disease or another serious health condition, then the client can consider including a trust for that beneficiary in the client’s estate plan. In addition, the attorney can counsel the client not to name a financially incapable beneficiary as a beneficiary of a life insurance policy, annuity contract, IRA or other retirement plan, POD/TOD account, and similar assets.

2. If a proposed beneficiary gets Medicaid assistance, SSI benefits, or other government benefits based financial need, and is expected to continue to need those benefits, then the client can consider including a special needs trust for that beneficiary in the client’s estate plan. A special needs trust is a non-support trust that would be used to supplement, rather than replace, the beneficiary’s needs-based government benefits.
Chapter 7

Helping Those in Need: Clients with Diminished Capacity

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Helping Those in Need: Clients with Diminished Capacity

As lawyers, we are often called on to evaluate others. Opposing counsel we are negotiating against, witnesses we will be cross-examining or juries to whom we will be presenting a case are all ready examples. One of the most difficult situations a lawyer can face, however, is determining whether a client has the requisite capacity to make decisions. Lawyers who practice elder law or estate planning face this issue more frequently than the rest of us. But, even a business lawyer can unexpectedly encounter this situation if a long-time client, due to age or infirmity, no longer seems have the capacity to make decisions in the client’s interest.

RPC 1.14 addresses clients with diminished capacity from two related perspectives. First, it outlines the duty a lawyer has to a client in that situation to maintain as normal a professional relationship as possible. Second, it deals with the difficult circumstance when a lawyer concludes that a client may be in need of a guardian or similar fiduciary to protect the client. In this column, we’ll look at both elements of the rule.

**General Duty.** RPC 1.14(a) counsels that when a lawyer has a client whose “capacity to make adequately considered decisions in connection with a representation is diminished . . . the lawyer shall, as far as reasonably possible, maintain a normal client-lawyer relationship with the client.” The comments to ABA Model Rule 1.14 upon which Oregon’s corresponding rule is based note that even a client with some diminished capacity may be capable of making a wide range of routine decisions. The comments also stress maintaining both direct communication with the client and as normal a relationship as possible within the constraints involved.

**Protecting the Client.** RPC 1.14(b) and (c) address the very difficult circumstance when a lawyer concludes that due to a client’s diminished capacity, the client “is at risk of substantial

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physical, financial or other harm unless action is taken[.]” In that situation, RPC 1.14(b) allows a lawyer to “take reasonably necessary protective action, including consulting with individuals or entities that have the ability to take action to protect the client and, in appropriate cases, seeking the appointment of a guardian ad litem, conservator or guardian.” RPC 1.14(c), in turn, finds that the lawyer in that situation is impliedly authorized to reveal sufficient otherwise confidential information necessary to protect the client’s interests.

Comment 6 to ABA Model Rule 1.14 outlines the factors the lawyer should consider in balancing the extent of the client’s diminished capacity against the possible actions necessary to protect the client: “the client’s ability to articulate reasoning leading to a decision, variability of state of mind and ability to appreciate consequences of a decision; the substantive fairness of a decision; and the consistency of a decision with the known long-term commitments and values of the client.” OSB Formal Ethics Opinion 2005-41, which addresses the Oregon rule specifically, also counsels that if the lawyer concludes that protective action is necessary, the action should be tailored to the particular circumstances, using the following example: “If . . . Lawyer expects that Client’s questionable behavior can be addressed by Lawyer raising the issue with Client’s spouse or child, a more extreme course of action, such as seeking appointment of a guardian, would be inappropriate.”

ABA Formal Ethics Opinion 96-404, which discusses Model Rule 1.14 in detail, highlights three important qualifiers.

The first relates to the lawyer’s assessment of the client’s capacity. The opinion notes that the focus is on whether the client can act in the client’s own interest. In other words, the fact that a client simply makes different decisions than ones the lawyer would make or, for the
client’s own reasons, makes what the lawyer considers “bad” decisions, doesn’t necessarily mean that the client’s capacity to make decisions is compromised.

The second concerns seeking the assistance of family members. The opinion encourages this oftentimes critical channel of consultation. At the same time, it also counsels that although Model Rule 1.14(b) allows the lawyer to seek protective action for the client’s benefit, the lawyer should not generally represent a third party seeking formal protective action (even if a family member) due to the potential conflict between the interests of the client and the third party.

The third involves the guardian sought. As the opinion puts it: “Seeking the appointment of a guardian for a client is to be distinguished from seeking to be the guardian, and the Committee cautions that a lawyer who files a guardianship petition under Rule 1.14(b) should not act as or seek to have himself appointed guardian except in the most exigent of circumstances, that is, where immediate and irreparable harm will result from the slightest delay.”
Contextual and Resource Summary

Contextual Materials

Former Oregon DR 7-101(C)
A dopted effective January 2, 1990
Replaced by Oregon RPC 1.14 effective January 1, 2005

Oregon RPC 1.14
Based on ABA Model Rule 1.14
Note: Oregon’s RPCs do not include the accompanying ABA Model Rule comments.

ABA Model Rule 1.14 and Accompanying Comments
(“Client with Diminished Capacity”)  
Adopted by the ABA in 1983 and amended in 2002
Available on the ABA Center for Professional Responsibility’s web site at:

Restatement (Third) of the Law Governing Lawyers (2000), § 24
(“A Client with Diminished Capacity”)

ORS 9.330 (“Scope of Attorney’s Authority”)

Resources

ABA Formal Ethics Opinion 96-404 (1996)
(“Client under a Disability”)  
Available on the ABA Center for Professional Responsibility’s web site

(“Competence and Diligence: Client with Diminished Capacity”)  
Available on the Oregon State Bar web site

(“Competence and Diligence: Requesting a Guardian ad Litem in a Juvenile Dependency Case”)  
Available on the Oregon State Bar web site

Ethical Oregon Lawyer, Chapter 18, Revised 2015
(“Representing Clients with Diminished Capacity and Disability”)  
Available in the “Bar Books” section of the members-only OSB web site