Dementia: A How-To Approach for Clinicians

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Alzheimer’s in Oregon

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>
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<tbody>
<tr>
<td>2015</td>
<td>8,900</td>
<td>24,000</td>
<td>27,000</td>
<td>60,000</td>
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<tr>
<td>2020</td>
<td>12,000</td>
<td>29,000</td>
<td>28,000</td>
<td>69,000</td>
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<tr>
<td>2025</td>
<td>13,000</td>
<td>40,000</td>
<td>32,000</td>
<td>84,000</td>
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Percentage change from 2015

- 2015: 40.0%
- 2020: 15.0%
Causes of Death in Oregon: 2012 statistics

1. Cancer
2. Heart disease
3. COPD
4. Stroke
5. Accidental Death
6. Alzheimer’s dementia
Talk Objectives

- Feel comfortable with natural history of Alzheimer’s
- How to: Look for dementia in your panel – recognizing the undiagnosed
- How to: Use a new tool for diagnosing Alzheimer’s
- How to: Talk to families – tips to give them
- How to: Use the common meds for dementia
- How to: think about treating “agitation”
Dementia: Some Clarifying Points

- Dementia (Major NCD) = impairment of two or more cognitive functions with interruption of person’s ability to live independently safely and effectively

- Mild Cognitive Impairment (Mild NCD) = impairment of one or more cognitive function but person is still able to live independently; high risk for dementia in future
Brain Functions: What it Does

- Language (receptive and expressive; talking and reading)
- Memory and Learning (immediate or recent)
- Visuoconstruction-perceptual ability
- Attention (sustained, divided and processing speed)
- Executive Function (planning and completing tasks, decision-making, response to feedback/correction)
- Social cognition (emotions, behavior regulation)
- Calculation/arithmetic
Dementia: Epidemiology

- Alzheimer's Disease: 70%
- Vascular Dementia: 17%
- Other Dementia: 13%

The Other Dementias

- **Vascular dementia** – changes in cognitive function believed etiologically related to previous CVAs
- **Mixed dementia** – combination of AD and vascular dementia
- **Lewy Body dementia** – early presentation with getting lost, poor job performance, falls, shuffling gait, visual hallucinations, REM sleep disorder, fluctuating LOC (“blank out” spells); diagnosis often missed or confused with NPH
- **Frontotemporal dementia** – presentation in middle-aged adults with personality changes, marked rude behavior, impulsive behaviors, hypersexual or hyper-oral
- **Dementia with Parkinson’s, HIV, alcohol**
Dementia: Brain Failure
### Alzheimer’s Disease’s Progression: FAST scale

<table>
<thead>
<tr>
<th>Stage 1</th>
<th>Stage 2</th>
<th>Stage 3-4</th>
<th>Stage 5-6</th>
<th>Stage 7</th>
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</table>
| • Normal adult | • MCI | • Early/mild dementia
Forgets recent conversations, has trouble paying bills; irritable/anxious; possibly paranoid; stops going to events they used to enjoy | • Moderate dementia
Increasing confusion; may not recognize family and friends, has trouble reading/writing; may not know how to get in and out of car, use phone; loss of impulse control | • Severe dementia
Sleeps most of day, few words, weight loss |
Oregon Families in 2011 Town Halls: Their Concerns with PCP Care

- My doctor will not even talk me about it because ‘nothing can be done.’”

- “We were not given proper knowledge right from the start. Not told what to expect.”

- “The professionals were not talking about anything but ‘everyone gets dementia if they live long enough.’”

- “We need a protocol in all medical offices for diagnosing Alzheimer’s, and support of the person and their caregiver with proper resource information…. Very necessary.”
Overlooked cases rate – 35-90% in primary care

To detect, look for:

- Family present at visit to “help”
- Patient vague on details, decreased engagement
- Patient turns to family for answers or patient can’t answer questions that they should know (family head nodding sideways in background)
- Patient repeats themselves within one conversation
- Frequent joking, evading questions, “everyone I know is like me” or makes excuses
- New anxiety, new psych symptoms (eg paranoia)
- Has functional decline – can’t navigate world independently

Valcour, Arch Intern Med. 2000; 160: 2964-2968
HOW TO: MAKING THE DIAGNOSIS

2015 Algorithm Tool developed by State Plan for Alzheimer’s Disease in Oregon (SPADO)

JUST RELEASED to help us diagnose our patients
Alzheimer’s Association App

Alzheimer’s Disease – Diagnosis and Management

Interactive Tools
Cognitive Assessment Algorithm
Safety and Driving
Pharmacologic Management
Behaviors
Professional Resources
Patient Resources
Find a Clinical Study - TrialMatch®
About the Alzheimer’s Association / Find a Chapter
MD E-news

800.272.3900 | alz.org
A. Do you notice signs/symptoms of dementia? (Based on review of health records and patient observation)

B. Rule out delirium and other reversible causes, and conduct brief assessment*

For example:
1) Patient Assessment: Mini-Cog, General Practitioner assessment of Cognition (CPCOG), or Memory Impairment Screen (MIS)
2) Informant Assessment (if possible): Short form of the Informant Questionnaire on Cognitive Decline in the Elderly (Short IQCODE), or AD8 Dementia Screening Interview

*Assessments can be performed by any trained office staff

Does brief assessment trigger concerns?

ASK: Has patient or informant observed signs/symptoms of dementia?

Follow-up during subsequent visit
**MINI-COG™**

Instructions:
- Give 3 words, ask client to repeat words
- Do Clock Drawing
- Ask for 3 words previously given
- If recall 0, or 1-2 words & impaired clock, then likely dementia

Not affected by education level, culture

Takes 3 – 5 minutes

99% sensitive and 93% specific

Clock Drawing

Elements:
- # 1-12
- # are in correct sequence
- Spacing is appropriate
- Hand placement correct
### AD8 Dementia Screening Interview

<table>
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<tr>
<th>Remember, &quot;Yes, a change&quot; indicates that there has been a change in the last several years caused by cognitive (thinking and memory) problems.</th>
<th>YES, A change</th>
<th>NO, No change</th>
<th>N/A, Don’t know</th>
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<tbody>
<tr>
<td>1. Problems with judgment (e.g., problems making decisions, bad financial decisions, problems with thinking)</td>
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<td>2. Less interest in hobbies/activities</td>
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<td>3. Repeats the same things over and over (questions, stories, or statements)</td>
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<td>4. Trouble learning how to use a tool, appliance, or gadget (e.g., VCR, computer, microwave, remote control)</td>
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<td>5. Forgets correct month or year</td>
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<tr>
<td>6. Trouble handling complicated financial affairs (e.g., balancing checkbook, income taxes, paying bills)</td>
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<td>7. Trouble remembering appointments</td>
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<tr>
<td>8. Daily problems with thinking and/or memory</td>
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</tbody>
</table>

**TOTAL AD8 SCORE**

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Adapted from Gahm JS et al. The AD8: a brief informant interview to detect dementia. Neurology 2000;55:559-564

Copyright 2000. The AD8 is a copyrighted instrument of the Alzheimer’s Disease Research Center, Washington University, St. Louis, Missouri. All rights reserved.
Dementia: What Providers Need to Know and Do
At Annual Wellness Visits or Regular Office Visits
State Plan for Alzheimer's Disease and Related Dementias in Oregon (SPADO)

C. Conduct full dementia evaluation OR consult with/refer to specialist (neurologist, geriatric psychiatrist, neuropsychologist, geriatrician/geriatric nurse practitioner)

Does brief assessment trigger concerns?

ASK: Has patient or informant observed signs/symptoms of dementia?

Follow-up during subsequent visit

Follow-up during subsequent visit

Follow-up during subsequent visit
Next Steps: Full Dementia Evaluation

- Takes more than one office visit – usually two at least, sometimes more

- What I do: History
  - HPI – Look for content of what they say – paragraphs? Single word answers? Detail or no detail? They may or may not see their difficulties.
  - Medical history focusing on:
    - functional assessment (validated by family) – need help with transportation, bills, meds, housekeeping? We need to know that their cognition is affecting their daily life
    - alcohol
    - med review
  - ROS – assess for depression, anxiety, irritability
Medicines that interfere with cognition

- **Benzodiazepines**
- **Anticholinergics**
  - Opioids, Benadryl and antihistamines, antipsychotics, antispasmodics (incontinence medicines); antiemetics
- **Hypnotics**
  - Ambien, Sonata, Lunesta
- **Skeletal muscle relaxants**
  - Soma, Flexeril
- **Any med that reduces BP <120**

Full Dementia Evaluation

Physical exam:
General exam plus check ears for wax and overall hearing/vision
Focal neuro deficits? Evidence of prior CVA
Increased motor tone or tremor? Parkinson’s or Lewy Body
Gait abnormalities?

Cognitive Testing: SLUMS
SLUMS

- Validated for diagnosis of dementia AND for Mild Cognitive Impairment
- Takes 5-10 minutes
- Tests multiple brain functions
- “I do this with all my patients” – normalize it
- Not validated for repeating over time to follow disease
Why SLUMS?

- MMSE: proprietary, ie licensed, longer, not useful for MCI
- MOCA: longer, more useful for the less common dementias
- No significant difference between MOCA and SLUMS for detection MCI and dementia in Veterans study

Lab exam ordered at end of visit:
CBC, CMP, thyroid, B12. No RPR unless concern.
Noncontrast CT if concerns about neuro exam focality or young presentation or history of head trauma
Patients with FAST stage 5 -7 symptoms with normal neuro exam, age >80, need no imaging
Dementia: What Providers Need to Know and Do

At Annual Wellness Visits or Regular Office Visits

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

D. Support the patient & family care partners

- Discuss diagnosis, treatment options, and planning for the future

- Offer these resources to care partners:
  - Help is Here: When someone you love has dementia
  - Dementia Diagnosis: What Families Need to Know and Do

- Familiarize yourself with these resources:
  - Help is Here: When someone you love has dementia
  - The Alzheimer’s Network of Oregon: alznet.org
  - The Aging and Disability Resource Connection of Oregon (ADRC): adrcforegon.org
  - Physician Pocketcards on Alzheimer’s Disease
  - Differentiating Types of Dementia, Depression & Delirium
Importance of Diagnosis AND Disclosure

- Consider medications; modify risks (esp CV risks)
- Empower patients and families to address and plan for future needs
- Patients and families may be relieved to know the reason for the changes they see in the patient
- Realize and support caregiver burden
- Early link for patient and family to informal and formal support; link to you the PCP as an ally
- Advanced care planning
Disclosing the Diagnosis

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.
Disclosure: Separate Visit

- Suggest patient return with family after labs done
- Be straightforward and direct, but compassionate, about diagnosis. “Dementia, probably Alzheimer’s, which means this..... Brain not working.....brain is failing in what it used to do.... You can still have great days, but there will be good days and bad days.
- “I will support you and your family on your journey”
- Give them resources
Resources: Family needs! At time of diagnosis

» Help is Here: When someone you love has dementia
(my book available for free in all PMG clinics: ask your care manager or www.dementiahelpishere.org)

» Aging and Disability Resource Connection of Oregon: adrcoforegon.org

» www.oregoncarepartners.com – free online and in-person training for caregivers
HOW TO: What I Tell Families

- Dementia waxes and wanes: some days it will seem “cured”
- Don’t argue! You will never win – and you will spoil the mood.
- Go to their world. Leave yours behind.
- You can have good moments – and treasure them.
- They will turn on you: it is the dementia talking, not the person.
Detection in the Office Practice

Opportunities to detect:

- Wellness exam
- Routine follow-up
- Hospital stay complicated by delirium, change in mental status
- Family reaching out with concerns
Case: Treatment

- 78 year old woman with new diagnosis of AD, early.
- Daughter asks, “What can you do to treat this? Isn’t there a drug??”
FDA- approved drugs for Alzheimer’s

- Acetylcholinesterase inhibitors
  - Donepezil (Aricept)
  - Rivestigmine (Exelon)
  - Galatamine (Razadyne)
- Inhibitor of Glutamate binding
  - Memantine (Namenda)
Do the drugs work???

DOMINO Trial: NEJM 2012 for Moderate-Severe Alzheimer’s

- Double-blind randomized controlled trial comparing four arms of therapy for pts with MMSE 5-13 already on AchEI:
  - donepezil 10 mg w/ placebo memantine
  - memantine 20 mg w/ placebo donepezil
  - memantine 20 mg and donepezil 10 mg
  - placebo of both drugs
- Approximately 75 patients per arm, for one year f/u
- Outcomes: MMSE scores and Bristol ADL score

DOMINO 2012: What does this all mean??

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

Scores on the SMMSE range from 0 to 30, with higher scores indicating better cognitive function. Scores on the BADLS range from 0 to 60, with higher scores indicating greater impairment. Shown are raw estimates of the mean score at each visit. Error bars denote the standard error.
The drugs were overall disappointing
Pts who stayed on donepezil did the best - cognitively (not ADLs)
Memantine helped little over placebo alone, and less than donepezil
Combination of donepezil and memantine not better than donepezil alone
Conclusions: - use one or the other drug in late disease, donepezil first choice
- if you take a patient off donepezil, consider tapering, even off the 5 mg dose
Vitamin E in Mild Alzheimer’s (with AchEI)

- Double blind placebo controlled trial of Vitamin E 2000 units, Memantine 20 mg, or both in veterans with mild to moderate Alzheimer’s (MMSE 12-26), on AchEI already.
- Mean f/u about a year in each arm
- Outcome is assessment of ADLs
- Results: Vitamin E arm alone did the best with delay in progression of functional decline 19% per year; Memantine showed no benefit, nor did combo of Vit E with Memantine.

Dysken et al. JAMA 2014. 311(1): 33-44
## FDA – Approved Drugs for Treating Alzheimer’s Disease

<table>
<thead>
<tr>
<th>Drug</th>
<th>Dosing</th>
<th>Stages Indicated</th>
<th>Side Effects</th>
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<tbody>
<tr>
<td>Donepezil (Aricept)</td>
<td>5 mg x 6 weeks, then increase to 10 mg (at bedtime)</td>
<td>mild, moderate, severe</td>
<td>nausea, diarrhea, dizziness, bradycardia, syncope, urinary retention</td>
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</table>
| Rivastigmine (Exelon) | **Oral:** 1.5 mg twice daily with food. Increase at 2 wk intervals to 3, 4.5, 6 mg  
**Patch:** 4.6 mg/24 hours. May increase to 9.5 mg after 4 weeks | mild, moderate | GI side effects especially, and as above per Donepezil                     |
| Galantamine (Razadyne) | Extended release capsule 8 mg x 4 wks, then may increase. Also in liquid. Always with food | mild, moderate | GI side effects plus anorexia, weight loss and per Donepezil                  |
| Memantine (Namenda) | 5 mg at bedtime x 1-2 wks, then 5 mg twice daily x 1 month if tolerated. May increase to 10/5, then 10 mg BID | moderate, severe (not mild) | Dizziness, confusion, falls, agitation, somnolence, headache, diarrhea        |

Clinical Geriatrics, 2012, edited
Goal is slowing disease, slowing time to leaving home

I have seen patients “slow down” or improve briefly (“track better”) on Donepezil

Families have testified to Namenda making a difference

I generally give all patients the option of a trial of Donepezil (any stage) or Namenda (mod-severe) for AD – and give them months on it before I make a decision to utility

I am thinking about high dose Vitamin E early in the course – have not adopted it yet.
90 year old woman with moderate AD recently moved from assisted living to foster home. In first week hitting caregiver, refusing care, refusing meds, spitting them out, and constantly wandering into other residents' rooms. You get desperate calls from family and from caregiver about her “agitation.” Caregiver is not sure she can keep your patient.
Behavioral and Psychological Symptoms in Dementia: BPSD

- Occur in 70-90% of patients over course of illness, more common later in disease
- Behavioral: pacing, yelling out, overdressing, wandering, resisting care, disrobing inappropriately, hitting, scratching, inappropriate sexual behaviors, sleep disturbances
- Psych Sx: delusions, hallucinations, depression, psychosis, anxiety
- Common Labels: “agitated,” “aggressive,” “disruptive”
Behavior = Expression of Unmet Need

What would you do if you could not tell somebody what you needed, why you were upset, or how you felt??????
Teach the Caregiver/Family This Framework

Ask them to think about underlying cause:

► Pain (constipation and urinary retention in addition to usual suspect of arthritis pain),
► Physical needs: hunger, thirst, fatigue, cold
► Emotional needs: anxiety, loneliness, fear
► Adverse reaction to med
► Other Triggers – family visit, staff/roommate reaction, driving in car, taking off diaper, shower/bathing
Non-Pharm Approach to BPSD

- Very few controlled, well-designed, powered studies
- Some suggested techniques:
  - caregiver education
  - sensory stimulation: hand massage, music, aroma-therapy
  - “validate, redirect, re-approach”
- Reality orientation increases frustration
Medication the answer for BPSD?

- Remember there is a RANGE of symptoms we are asked to treat – and you can’t think of them as all the same
- Data show some but minimal benefit for atypicals treating psychotic symptoms and aggression/physical harm – but adverse effects can outweigh benefit (CATIE-AD Trial, NEJM 2006; JAMA 2005; JAMA 2011)
- Haldol compared to risperidone has been equally effective (BMJ 2014)
- Risk for mortality is particularly increased after 90 days of use
- AKI risk increased for atypicals (Ann Intern Med 2014)
- AGS and Choose Wisely Campaign advocate against antipsychotic use for BPSD (JAGS 2013)
Citalopram for Agitation in Alzheimer’s

- 2014 study in JAMA – all the rage in geriatrics right now!
- RCT in 8 academic centers in US
- 186 patients randomized to psychological intervention plus citalopram 30 mg (n=94) or placebo for 9 weeks
- Results: 40% of citalopram patients had marked/mod improvement from baseline agitation vs 26% control (OR 2.13, p. 01)
- Worsening of cognition and QI prolongation in citalopram group: 30 mg dose is now against FDA guidelines in elderly

Anton P.  JAMA 2014. 311: 682-691
How To: What I do for BPSD/’Agitation’

- For patient with acute risk for harm to self or others (hitting, shoving, biting) – low dose risperidone 0.25 mg bid or haldol 0.5 mg bid
- For patient who is pacing, undressing, yelling – try to find cause (food, blanket, etc.), redirect, use massage
- For patient sundowning in afternoon, up at night – also redirect, but if necessary, use trazodone 50 mg or melatonin 3 mg
- I use depakote 125 mg sprinkles daily or BID in patients who won’t take pills and are hitting/shoving (anecdotal data only)
- I use antidepressants for anxiety, depression sx – esp citalopram
- Consider referral to Prov HH Mental HealthRN; Behavior Support Services
Dementia is undetected in many of our primary care patients.

Work to be more comfortable with diagnosing this disease and look for it in your patients – those who are less verbal, have family present who are doing more.

Do evaluation for dementia over multiple visits; normalize what you can (SLUMS, MMSE) as part of your usual care.

Disclose the diagnosis, ideally with family present; DOCUMENT.

Give them resources so they feel they have next steps.

Consider trial of Donezepil (early, middle, late) or Memantine (mid/late).

Look at behavior as expression of unmet need – figure out the need and consider meds as last resort.
Summitt Still Inspires, Often in Silence

By HARVEY ARATON  DEc. 11, 2011

Pat Summitt, longtime head coach of the Tennessee women's basketball team, revealed in August that she has early-onset Alzheimer's disease. Al Behrman/Associated Press