Dementia: A How-To Approach for PCPs

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MARIAN HODGES, MD, MPH
REGIONAL MEDICAL DIRECTOR, GERIATRICS, PROVIDENCE - OREGON

Statistics from Alzheimer Assn

Quick Facts

- More than 5 million Americans are living with the disease.
- Every 67 seconds someone in the United States develops Alzheimer's.
- Alzheimer's disease is the 6th leading cause of death in the United States.
- There are approximately 500,000 people dying each year because they have Alzheimer's.
- 1 in 3 seniors dies with Alzheimer's or another dementia.
- In 2013, 15.5 million caregivers provided an estimated 17.7 billion hours of unpaid care valued at more than $220 billion.
Alzheimer’s in Oregon

**Oregon Alzheimer’s Statistics**

<table>
<thead>
<tr>
<th>Year</th>
<th>65-74</th>
<th>75-04</th>
<th>85+</th>
<th>TOTAL</th>
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<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:
- 2015-2020: 15.0%
- 2015-2025: 40.0%

Causes of Death in Oregon: 2012 statistics

1. Cancer
2. Heart disease
3. COPD
4. Stroke
5. Accidental Death
6. Alzheimer’s dementia
Evidence of Poor Quality and Poor Value of Care

- Less than 50% are informed of diagnosis
- More than 25% are prescribed unsafe drugs
- Too many receive care that is unwanted
- Too many have adverse effects from care
- High cost care doesn't equate to improved quality of life, quality of death, or outcomes

Mitchell SL et al. NEJM 2009; Arling G et al. Med Care 2013

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: Refer to Providence resources
- How to: Assess for caregiver burden
- 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; 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**
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."

Detection in the Office Practice:

Opportunities to suspect:
- Hospital stay complicated by delirium, change in mental status
- Family reaching out with concerns – in hallways, on phone, out of earshot
- Patients who consistently show up on wrong day or wrong time for appointment
- Family members begin to accompany patient to appt when they came alone before
Detection in the Office Practice

Overlooked cases rate – 35-90% in primary care

To detect, look for:

- 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 depression, paranoia)
- Has functional decline – can’t navigate world independently

Valcour, Arch Intern Med. 2000; 160: 2964-2968
CLINICAL PROVIDER ROADMAP

COGNITIVE IMPAIRMENT SCREENING

**Annual Exam**
- Mini Screen may be performed by trained assistant

**Tools**
- Mini-Cog or GDS-15
- Family Questionnaire (if family makes available)

- Normal
  - if
  - Follow up in one year

- Score falls outside of normal range

**Cognitive Assessment**
(same day or new visit)
- Include family

**Tools**
- One of the following:
  - SLUMS or MoCA may be performed by trained assistant
  - Family Questionnaire, e.g. AD8
  - Screening Interview of Alzheimer’s Association Family Questionnaire

- Normal
  - if
  - Follow up in one year

- Score falls outside of normal range

**Proceed to Dementia Workup**
(page 2)

- Determine the continuity of care plan
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
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 pt says – 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. Review ADLs, IADLs
    - med review, including OTC, alcohol use
    - Detailed review of cognitive deficits, onset, course, behaviors (from family usually -sometimes can’t be said in front of patient) – AD8 helps
  - ROS – assess for depression, anxiety, irritability

AD 8}

AD 8 Dementia Screening Interview

<table>
<thead>
<tr>
<th>Behavior</th>
<th>Yes</th>
<th>No</th>
<th>N/A</th>
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<tbody>
<tr>
<td>1. Problems with judgment (e.g., problems making decisions, poor financial decisions, problems with timing)</td>
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<td>2. Loss interest in hobbies/activities</td>
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<td>3. Repeats the same things over and over (e.g., stories, stores, or destinations)</td>
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<td>4. Trouble learning how to use a new appliance, or gadget (e.g., VCR, computer, telephone, remote control)</td>
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<td>5. Forgets current 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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<tr>
<td>7. Trouble remembering appointments</td>
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<tr>
<td>8. Daily problems with thinking or memory</td>
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TOTAL AD8 Score
Medicines that interfere with cognition

- Benzodiazepines
- Anticholinergics
- Opioids, Benadryl and antihistamines, antipsychotics, antispasmodics (incontinence medicines); antiemetics; tricyclic antidepressants
- Sedatives/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?
Gait abnormalities?
**Cognitive Testing:** SLUMS or MOCA
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

SLUMS or MOCA?

- MMSE: proprietary, ie licensed, longer, not useful for MCI
- SLUMS: helps differentiate MCI vs dementia, scored by educational level
- MOCA: longer, more useful for the less common dementias
  - Available in ~ 20 languages
- No significant difference between MOCA and SLUMS for detection MCI and dementia in Veterans study

CBC, CMP, thyroid, B12, Vitamin D. No RPR unless concern. Consider HIV test.

- Noncontrast CT or MRI recommended unless pt is very advanced
- Brain imaging especially important if these concerns:
  - Neuro exam focality
  - Younger presentation
  - More acute progression of symptoms
  - History of head trauma
- Patients with FAST stage 5-7 symptoms with normal neuro exam, age >80, need no imaging
- Biomarkers and PET scans are advocated for routine use
What if you are not sure it’s dementia?

- Outpatient OT evaluation for Allen Cognitive Level – helps to understand practical planning for independent living OR NOT. Insurance covers.
- Neuropsych evaluation – can give more data if dx is in doubt, but not always conclusive for diagnosis
- Cognitive Assessment Clinic (CAC); Providence St Vincent Brain and Spine Institute.
- Dr Ho-Yann Jong, neurologist specializing in dementia, starts in CAC 8/2016; Christine Bloom ANP supports CAC.

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. |
**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
- Advance care planning

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**Disclosure: Separate Visit**

- Suggest patient return with family after labs done
- Be straightforward and direct, but compassionate, about diagnosis. It is like telling bad news. Find out how much they want to hear. Find out about their attitudes to dx/stigma.
- “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.”
- Emotional support: “I will support you and your family on your journey”
- Give them tangible resources
### Dementia: Brain Failure

- **Healthy brain**
- **Advanced Alzheimer's**

### 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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</thead>
</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 |
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](http://www.dementiahelpishere.org); proceeds go to Providence Foundation)
- Providence brochure: **Services for Older Adults**
- Referrals to clinic Care Manager for social supports, caregiver support groups through PMG
- Referral to Alzheimer Association for support groups, education

Resources: Family needs! At time of diagnosis

- Referral to outpatient OT driving assessment (out of pocket cost) – Anita Dunsmoor OT at PMG Northeast /Erin Breyer OT
- Elder law attorney
- Family members may need individual counselling or support
- Aging and Disability Resource Connection of Oregon: [www.helpforaltz.org](http://www.helpforaltz.org)
- [www.oregoncarepartners.com](http://www.oregoncarepartners.com) – free online and in-person training for caregivers
- **FUTURE:** Dementia Care Pathway at Providence
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.
When you are dealing with dementia in the room, who is the real patient??

Stories

- Jack, the husband caregiver of a 67 year old wife in a private home
- Mark, the son of Bob, the husband caregiver for his 80 year old wife in independent living
Palliative Care and Dementia

- Disease is with the patient
- Suffering is with the caregiver

Caregiver Burden

“The extent to which caregivers perceive that caregiving has had an adverse effect on their emotional, social, financial, physical and spiritual functioning.”

In USA, 2013:

- 15.5 million family and friends for persons with dementia
- 17.7 billion hours provided of unpaid care
- $220 billion value
Risk Factors for Caregiver Burden in Dementia

- Decline in patient’s ability to perform ADLs and IADLs
- Caregiver’s age, relationship (spouse at greater risk), living in the same household
- Number of hours devoted to caregiving


What Does the Burden Look Like?

![Graph showing stress levels in caregivers](image-url)

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

<table>
<thead>
<tr>
<th>Percentage</th>
<th>High to very high</th>
<th>Not high to somewhat high</th>
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<tbody>
<tr>
<td>Stress</td>
<td>Emotional stress of caregiving</td>
<td>Physical stress of caregiving</td>
</tr>
<tr>
<td>0</td>
<td>59%</td>
<td>62%</td>
</tr>
<tr>
<td>20</td>
<td>41%</td>
<td>38%</td>
</tr>
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</table>

Created from data from the Alzheimer’s Association.
A Disproportionate Share of Dementia Care Is Funded by Families


How do we help the family or friend with caregiver burden?

- Identify the primary and additional caregivers – in the chart, in your office visit notes
- Improve caregivers’ understanding of their role and teach them the skills necessary to carry out the tasks of caregiving (team up with your office care manager)
- Recognize the need for longitudinal, periodic assessment of care outcomes for the care recipient and family caregiver
This may be the most important thing

▶ You can’t cure the patient of his dementia

BUT.....

▶ You can help heal the caregiver

Case: “Agitation”

▶ 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”

J Am Med Dir Assoc 2007

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 brief, shower/bathing

*Ann Long Term Care, 2012*

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**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

*Ann Long Term Care 2012*
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.
- AGS and Choose Wisely Campaign advocate against antipsychotic use for BPSD (JAGS 2013); 2015 Beers criteria also advocate against unless nonpharm options have failed and pt is risk of harm to self or others.

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 QT prolongation in citalopram group: 30 mg dose is now against FDA guidelines in elderly.

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 halodol 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 1-3 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

End of Life Care and Dementia

- It is a FATAL Illness
- Most patients die within 4-8 years of diagnosis
- Many die of infection (aspiration pneumonia, UTI with sepsis, decubitus with sepsis)
- Infection risk increases with weight loss, which happens as they near end of life and lose appetite
- Artificial nutrition does not improve survival or comfort or outcomes
American Geriatrics Society Feeding Tubes in Advanced Dementia Position Statement 2014

- Feeding tubes are not recommended...Careful hand feeding should be offered.
- Efforts to enhance oral feeding....should be usual care.
- Tube feeding is a medical therapy that an individual’s surrogate decision maker can decline or accept in accordance with patient’s wishes.
- It is the responsibility of the long term care residence to understand the wishes of the patient...
- Institutions...should not exert pressure on individuals or providers to insert tube feeding.

Concluding Takeaways

- 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, MOCA) as part of your usual care.
- Disclose the diagnosis, ideally with family present; DOCUMENT.
- Give them resources so they feel they have next steps.
- Worry about caregiver burden and assess it.
- Look at behavior as expression of unmet need – figure out the need and consider meds as last resort.
Alzheimer’s Association App

Interactive Tools

Annual Wellness Visit

- NO
- YES

B. Conduct brief structured assessment

- Patient Assessment
- Informant Assessment of Patient

Brief assessment triggers concerns: Patient: 71; Informant: 79. Skilled and caring for 5 yrs. Informant indicates a 3.0 on a 5-point scale with patient scoring a 5.

- NO
- YES

Additional Geriatric Apps

Geriatrics At Your Fingertips

- Geriatric Criteria
- Gerontology Navigator
- Ger/Psyh Consult
- Guide to Common Immunizations
- Management of Atrial Fibrillation
- Prevention of Falls Guidelines