

# **Dementia in Primary Care**

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# Why is dementia so hard?

- Lose cognitive ability slowly. Slowly lose what many point to as “who they are.”
- Paranoia, aggression, yelling can occur.
- Fear and shame are high.
- The diagnosis in early stages is uncertain.
- No disease-modifying treatments.

# Earlier Diagnosis → Better Care

- Align medical care - take into account dementia. Adjust preventive care, adjust communication, adjust decision-making.
- Get family in-loop: support + understanding.
- Advance Care Planning: DPOA + alternates
- Patient safety: retirement from driving, protect finances, avoid meds that harm cognition.

# Goals Today

Make a  
diagnosis of  
dementia

Managing  
retirement from  
driving

Treating  
behavioral  
symptoms

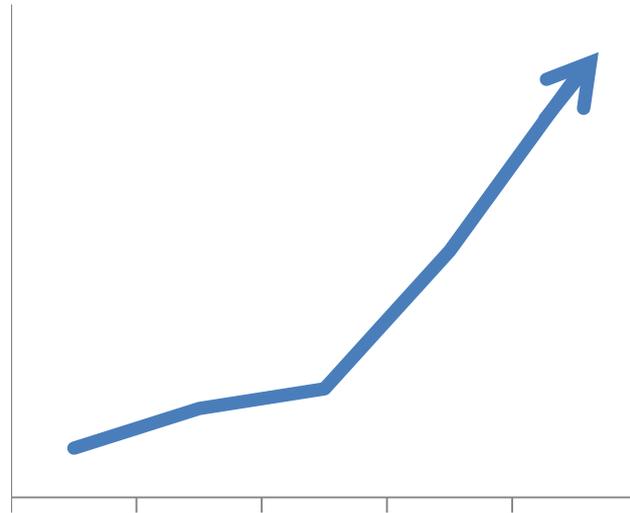
Golden key:  
advance care  
planning

# Problem Scope

- 5.8 million Americans have dementia
- Over age 65: 10% have dementia
- Over age 85: 32% have dementia

Alzheimer's Dementia 2019;15:321-387.

# The Shock Ahead



Numbers to increase by 40% in next 10 years

And will **triple** in the next 20 years ...

# Two Forces at Play

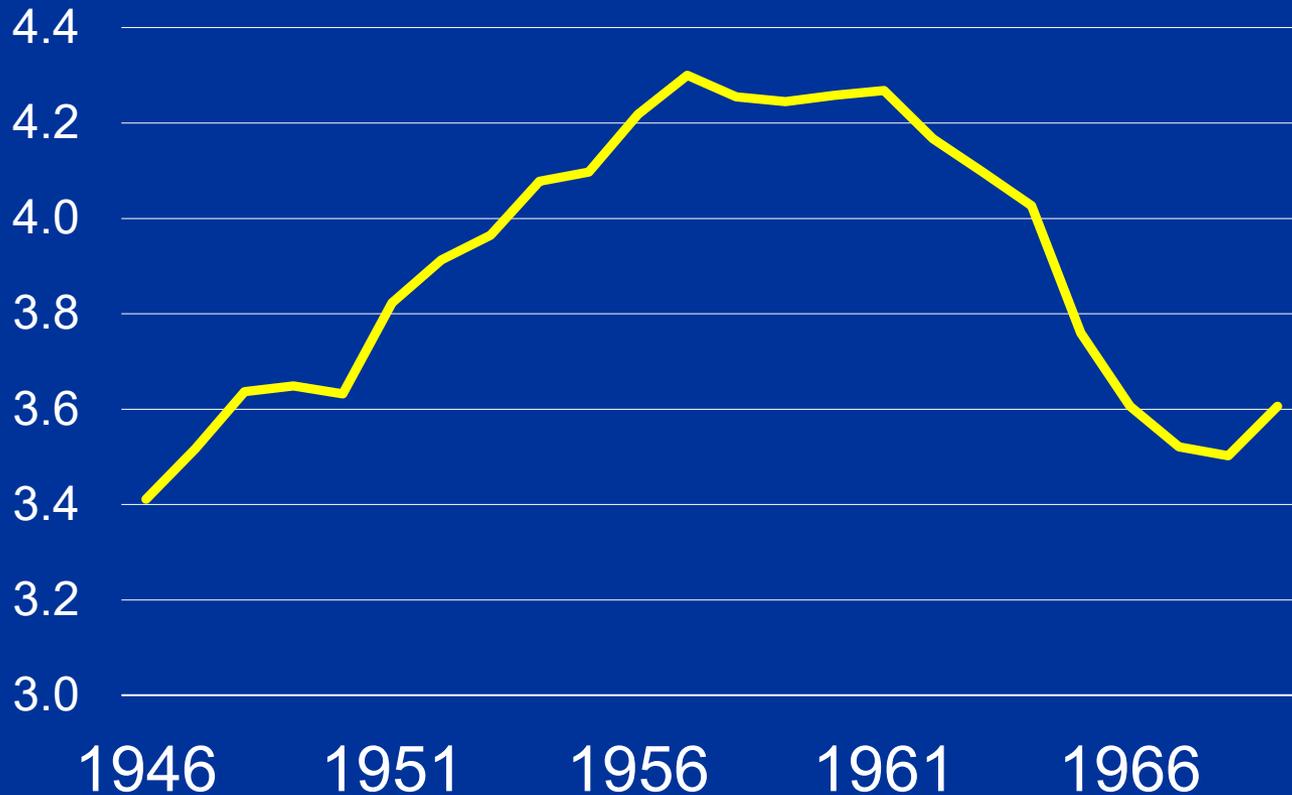
1. People are living longer
2. Baby Boom - Bubble



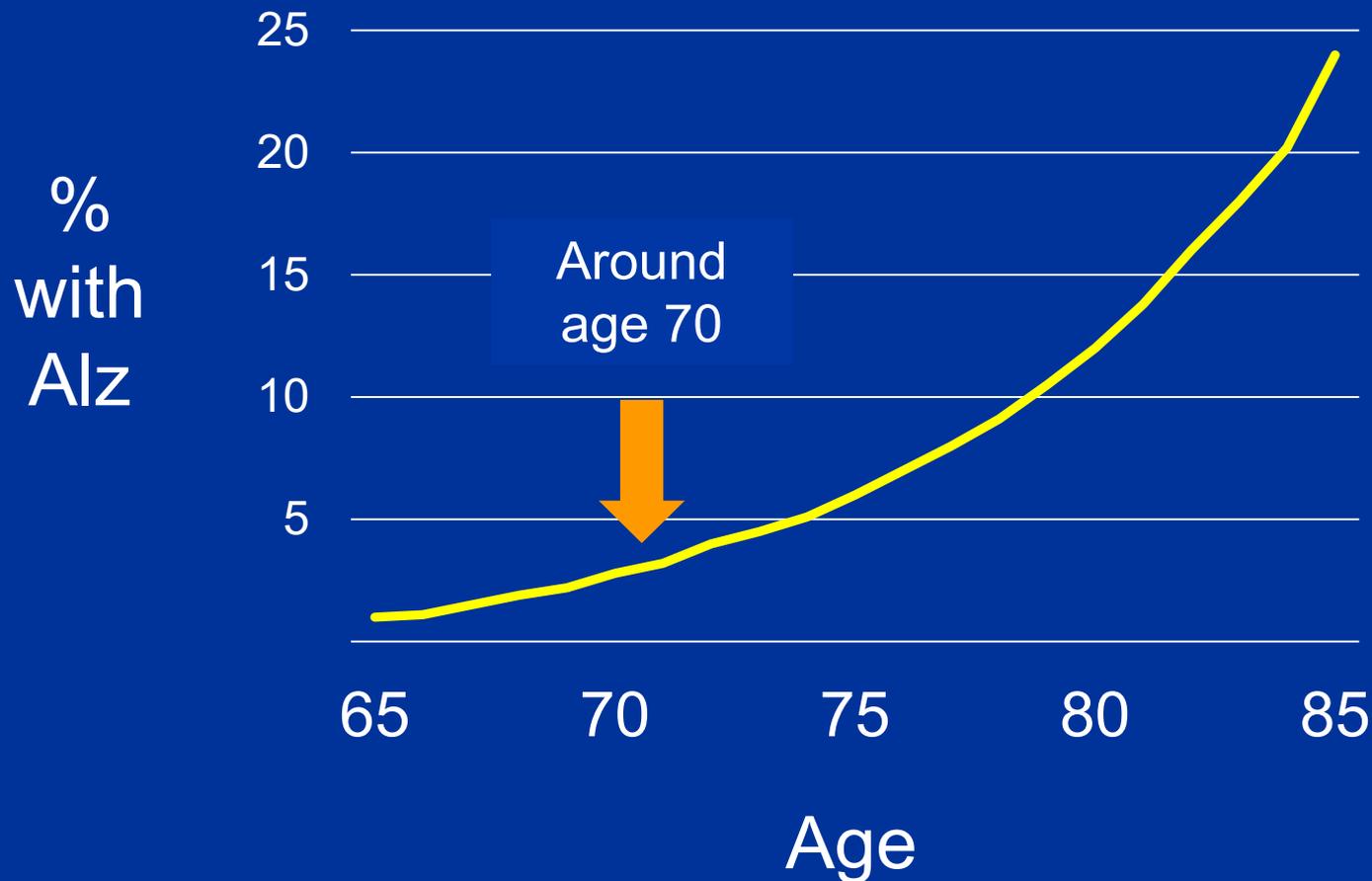
# The Baby Boom



U.S.  
births  
per  
year  
(mil)



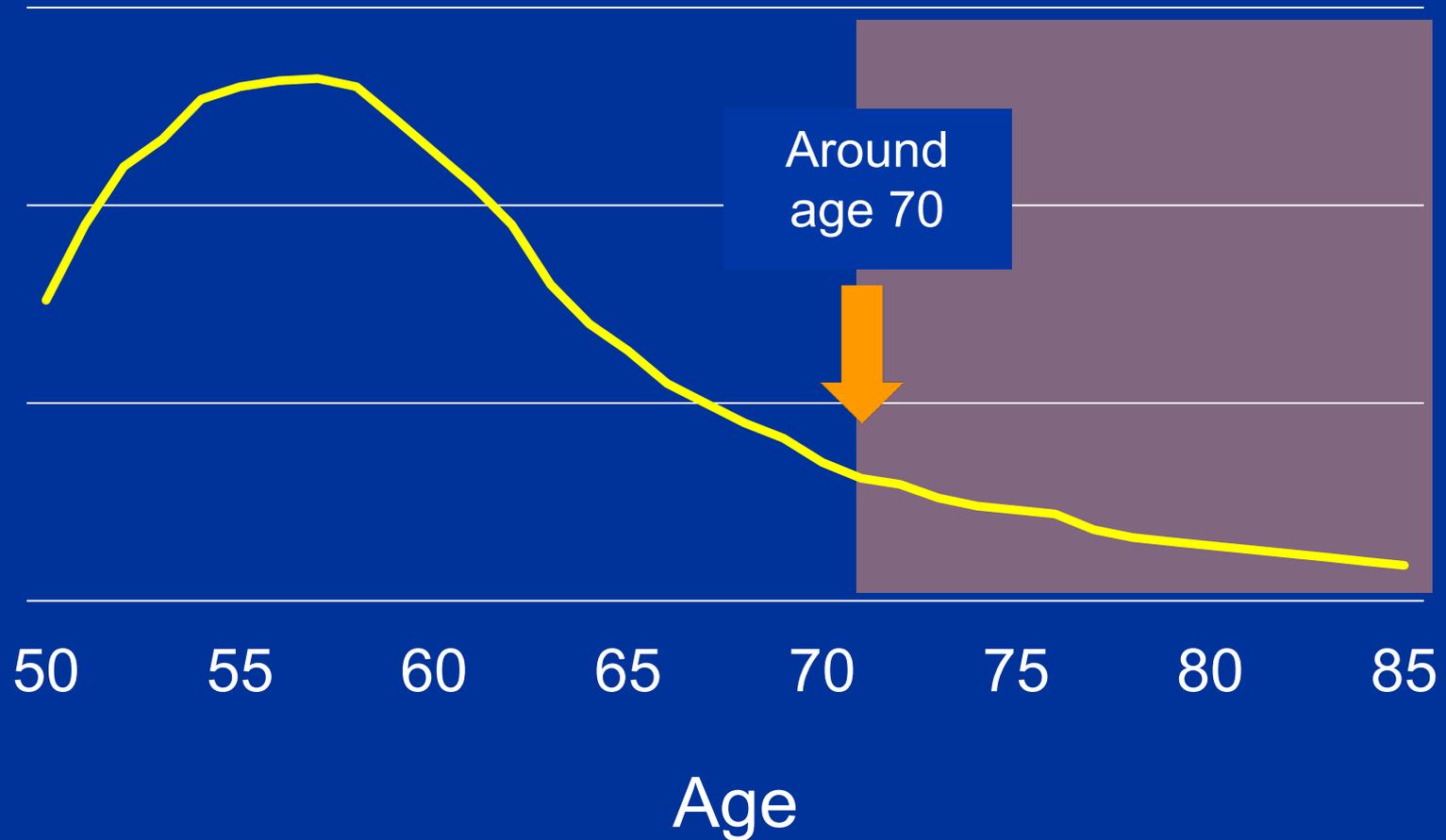
# At what age do people get Alzheimer's disease?



# Baby Boomers Today

➔ Today

Risk of Alz

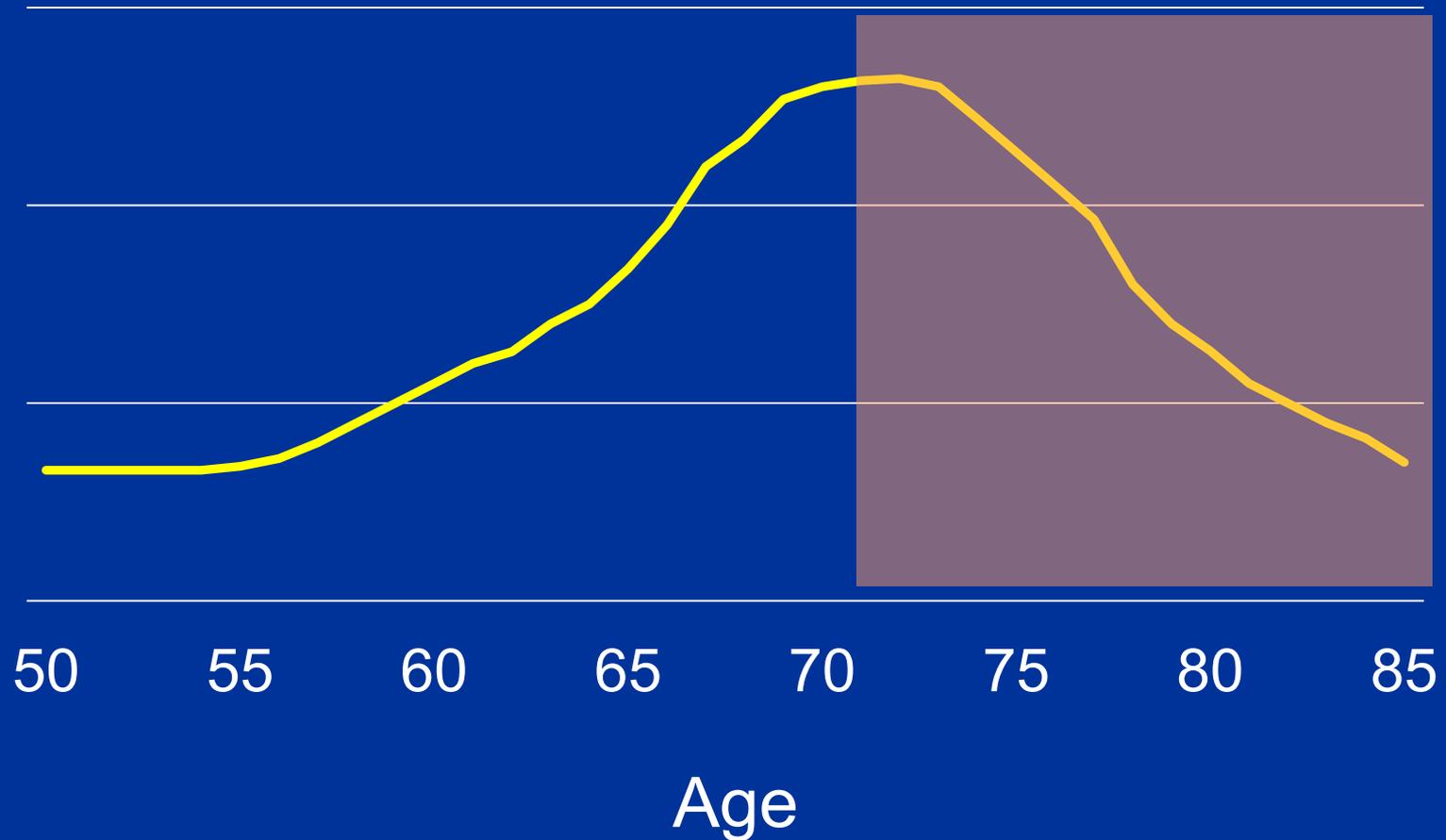


# Baby Boomers 12 years from now



12 yrs from now

Risk of Alz



# The #1 Disease Challenge We Face



# This is a primary care disease

- Not enough neurologists to see all of these patients. Especially not for long-term day to day management.
- People want the connection with their PCP who they know and trust most.
- We as PCP's can provide excellent dementia care.

82 year old man here for wellness visit.  
Generally very healthy.

Hypertension, osteoarthritis.

Medications: Losartan, rare ibuprofen, rare  
zolpidem.

He happens to mention, “I’ve been worried  
about my memory.”

## Should you:

- A. Reassure him. “Me too. Don’t worry, it’s normal to get more forgetful with age.”
- B. Refer him to a Memory Clinic.
- C. Do a 15 minute cognitive assessment right then and there (so that you’ll then be 15 minutes late.)
- D. Schedule him for a memory-eval, a longer follow-up visit (with *family member*).  
“Hmm, maybe worrisome, but I can help.”

# A Follow-up Visit for Memory

- For when patient or family report “worry about memory” or when you see patients forgetful, not keeping appts or not following care plans.
- Don’t miss the easy mimics: B12, TSH
- Screen for: heavy alcohol use + depression
- Side effects of: Benzos, zolpidem, oxybutynin
- Don’t forget: Sleep apnea and hearing loss.

# Office Eval of Cognitive Function

- It's not practical for patients or for specialists for us to turf these out for someone else to do.
- We as PCP's really can, and should, become comfortable evaluating this common scenario.

Making the assessment:    need to combine:

Family input    +    a 10-min cognitive eval

# Family Observer Input

- Questions to ask a family observer:
  - Repeating the same question 30 min later?
  - Losing ability to do complex tasks that patient once found easy?
  - Getting disoriented in familiar places?
- Not hard to get used to asking these questions.
- Or you may prefer a form, such as: the AD8



# MoCA Montreal Cognitive Assessment

- More sensitive than MMSE ... and no \$2 fee
- The MoCA takes 10 minutes to administer.
- Surprise in June 2019: “to access test from website” must now pay for online training.
- But: still legal to take a copy from me. And still legal for you to use it with your patients.
- Any malpractice risk? I’m not a lawyer. But risk seems very low. Training is so-so / OK.

# Evaluating a MoCA Score

- Patient gets a score on 0-30 point scale.
- Interpretation: 25 or less = abnormal.
- If score  $< 20$  and observer reports gradually worsening, then dementia is very likely.
- Tricky: specificity not great if score 23-25.
- Often, uncertainty is unavoidable.
- Neuropsych evals? Shared decision making

# Putting It Together

Assessment of cognitive function:

Family input + MoCA

If MoCA < 20 and family reports gradual change over time, then make a diagnosis of dementia.

If MoCA is 24-28 then: voice concern and voice some reassurance. Plan to repeat yearly.

Meanwhile: Address EtOH, consider PHQ-9.

Review med list. ? Sleep apnea ? Hearing aids

# What is “Mild Cognitive Impairment”?

- The textbooks say: you need progressive loss of i-ADLs to make a diagnosis of dementia.
- So, cognitive impairment (with preserved ADL's) is “Mild cognitive impairment” (MCI)
- Large majority of people with MCI (70-90%?) do progress to textbook dementia. Most with MCI: do have early stage Alzheimer's disease.
- But: some pt's with MCI (30%?) don't progress.

# Talking “MCI” vs “Early Alzheimers”

- Danger: false reassurance of “MCI” (People have never heard of it.) Be honest, be clear.
- Say “I’m worried of a high chance of **early Alzheimers**. Let’s watch closely, repeat 1 yr.”
- But also danger of over-fear of “dementia.”
- Say “Let’s look at changes to make” (EtOH, Ambien, hearing aids.) “And keep in mind: if this does get worse, it happens very slowly.”

# Who Needs a Referral to Neuro?

- It should be a shared decision with patients. Prep them up for it. Avoid pts' bad experiences.
- Most patients (at least initially) are reluctant to see a specialist. It's OK to hold off on a referral if no red flags. (e.g. odd neuro sx or age < 65)
- For many cases: it's OK to work up and follow, build trust with patient and family.
- But be aware of atypical dementia symptoms...

# Types of Dementia

Alzheimer's	70%	Memory is main symptom.
Lewy Body	20%	<b>Visual hallucinations.</b> Severe adverse reactions to antipsychotics. (They can cause severe Parkinsons.)
Frontotemporal	5%	<b>Very young onset (&gt;50% are below age 65)</b> <b>Personality changes (e.g. apathy, acting strangely.)</b> SSRI's are worth a try. Donepezil much less likely to work.
Vascular	5%	More often mixed with AD.

Questions?

10 minute break

# Communicating the diagnosis

- Reinforce that life continues for many good years beyond the diagnosis, that it's possible to live well for many years with dementia.
- “Maybe early dementia which may not get worse” is better messaging than “MCI”
- Prescribe engagement, exercise, healthy diet. Refer to community resources, help people stay connected to activities.

# Key messages to the newly diagnosed

**“You are not defined by your disease.** You have people who love you, you still have things you like to do.”

**“Living with memory loss is not easy, but there are ways to cope. By keeping lists and a healthy routine, by exercising,** you will feel better, think more clearly, and find ways to still enjoy life.”

**“You will not have to walk this path alone.** Your family, your friends, and me are with you as you move forward.”

# Guides for the Newly Diagnosed

- Dementia Road Map: A Guide for Family Members and Care Partners
  - On-line and contains an email to order copies.
- Living with Memory Loss: A Basic Guide (by UW Medicine)
  - Available on-line free. Search using above phrase.

# Medications to treat dementia

- In some pts may result in small improvements in cognition, might slow loss. Often hard to tell.
- They do not change course of disease.
- They do not work for early-stage memory loss (not a reason to screen.)
- They do not help with severe dementia. (Agents usually should be stopped.)

Annals Int Med. Jan 2018: 39-51.

# Donepezil dosing

- Start with 5mg once daily for 4 weeks
- Then 10mg once daily
- Cost is low (\$15 per month)
- Side effects occur in 20% of patients, e.g. diarrhea and nausea. Usually transient (for few days or weeks) usually mild, but discontinuation rate is high.

# Driving



# Driving: a stepwise approach

- Introduce the topic early. Gently: concerned, not threatening, let's "plan." (Safety of others, night restrictions, alternatives.)
- Voluntary on-the-road testing "to show everyone that you're able."
- WA-DOL: Consider reporting, form online, State then requires test for license renewal.
- Rare: Nuclear option: Change keys on car

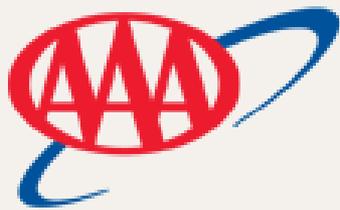
# Voluntary Road Testing

Voluntary road testing. On an annual basis.

\$150 screening evaluation might lead to a:

\$300 detailed assessment by an Occupational Therapist

Easy search: Senior Driving AAA



**SeniorDriving.AAA.com**

HELPING SENIORS DRIVE SAFER & LONGER

# Quick Google search: WA State Unsafe Drivers

Click here to START or CLEAR, then hit the TAB button



## Driver Evaluation Request

You can use this form to request we evaluate an individual's driving ability. You must provide specific information about their medical/visual conditions and/or driving ability. Age is not a consideration. Based on the information provided, we will investigate and take action as necessary. Insufficient information may result in no action. We are unable to divulge the outcome to you, however, **we will provide this form to the driver or their attorney upon written request.**

Additional witnesses must complete separate forms.

Return this form and any additional information or documents to:

**Driver Records, Department of Licensing, PO Box 9030, Olympia, WA 98507-9030**

*Based on my personal observation and knowledge, I request the Department evaluate this driver's qualifications.*

Name of driver (First, Middle, Last)		Date of birth	
Residence address			
City	State	ZIP code	Driver license number
Statement			
<i>I am concerned that this driver has one or more of the following conditions that may affect their ability to safely drive:</i>			
<input type="checkbox"/> Medical condition <input type="checkbox"/> Vision condition <input type="checkbox"/> Poor driving skills			
Details			

# Safety Kit for Families

Dementia Action Collaborative



**Info Kit**

Home safety, fall prevention, preventing elder abuse, financial exploitation, more.

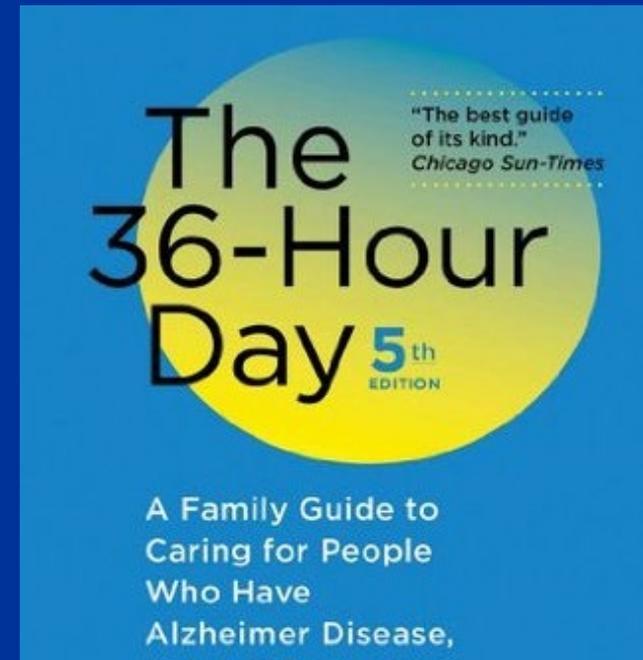
[www.dshs.wa.gov/altsa/dementia-action-collaborative](http://www.dshs.wa.gov/altsa/dementia-action-collaborative)

# Behavioral Problems

- The most troubling part of dementia.
- Agitation, paranoia, yelling, maybe hitting.
- 80% of patients at some point.
- Key intervention: stop oxybutynin, Ambien.
- Benzodiazepines: often can make sx much worse. Use extreme caution.

# Non Pharmacological Approaches

- Strategies that really do help.
- Best book for caregivers: “The 36-Hour Day.”
- Families usually need help implementing these approaches. Value of social workers, Care coordinators. Alz Assoc website can help.



# Referral to a Care Coordinator



**REASON FOR REFERRAL** (check all that apply)

- Orientation    Community resources    Respite providers    Care consultation    Safety concerns (wandering)
- Early memory loss programs    Care partner education    Support groups    Other



# Pharmacologic Approaches

- Antipsychotics work. Trial reasonable.
- But remember often behaviors stop on own. So schedule a taper to off at 6 months and 12 months. If symptoms recur, then restart.
- Why? Antipsychotics are sedating. Might worsen cognition. Plus polypharmacy concerns: SSRI's, valproic barely work. Pts on 3-4 drugs.
- But antipsychotics can be extremely useful, to quiet severely disturbing outbursts.

# Antipsychotic Dosing for Dementia

- Quetiapine (Seroquel) start 25 mg at bedtime  
Titrate slowly up to 75 mg twice daily
- Risperidone (Risperdal) start 0.5 mg at bedtime  
Titrate slowly up to 1 mg twice daily

# Lewy Body Dementia

- **WARNING:** beware antipsychotics. 50% have severe, potentially irreversible, parkinsonism.
- Visual hallucinations are the hallmark of LBD.
- Parkinsonism features at baseline more common (bradykinesia, rigidity, shuffling gait.)
- Higher benefit of referral to dementia specialist.

# Advance care planning for dementia

Aligning care with patient wishes.



## Standard Advance Directives

- Standard AD's provide almost no guidance about dementia. Main focus is: permanent coma or persistent vegetative state.
- Yet: the #1 cause of losing decision making capacity is dementia.
- But a large number of people have clear ideas what they'd want if they had dementia.

## Many People Have Clear Ideas

- Study done in Boston: 200 people over age 65 without signs of dementia.
- Shown video or given verbal narrative of people with severe dementia.
- 72% indicated that they would not want any life-prolonging care in such a state (comfort oriented care only.)

# Introducing → Dementia Directive

- As quality of life decreases from mild, moderate, to severe stages.....
- Most people would want gradually shifting goals for medical care, along the various stages.
- People with early dementia still have years of tremendously good quality of life.

# Dementia-directive.org



Mild  
Moderate  
Severe



Full code  
DNR / DN Intubate  
No ER or hospital  
Comfort-oriented care

My mom had Alzheimer's, she suffered for 8 years without being able to speak or understand. Having had this document would have helped our family so much.

I had to fly blind with my mom's dementia. I don't want the same thing to happen to my kids. I gave a copy of it to all my friends. Everyone should have it.

I've worked for many years with people with dementia. Your document distills the most important issues about it. It's simple and easy to use. Thank you!

## Best time for a dementia directive

- Before signs of dementia occur.
- Consider: for everyone at age 65-70.

[www.dementia-directive.org](http://www.dementia-directive.org)

## Benefits of a Dementia Directive

- Peace of mind from filling it out.
- Peace of mind later for families, that the decisions they make are guided by what their loved one would have wanted.
- Better aligned care: improving the likelihood that the care we give aligns with a patient's wishes.

# Advance Care Planning

- Once patients reach the moderate stage: gently start bringing up ACP. Talk about what their loved ones would have wanted.
- Broach the subject gently. Be kind, empathic. Emphasize the caring of comfort care.
- \* Fill out a POLST form \*
- It's a process. It's hard, but studies show it's what patients say they would want us to do.

# Having the Conversation

- Consider when is it that you think loved one looking down on themselves today would have said: “Please, just keep me comfortable.”
- Talk about the stress and the potential harms of frequent trips to the ER.
- Many patients would likely want comfort oriented care only, long before hospice benefit is allowed (“less than 6 months to live”)
- **[www.theconversationproject.org](http://www.theconversationproject.org)**

# What About Tube Feeding?



Feeding tubes in dementia do more harm than good.

Strong expert guidelines, based on good data-driven research.

Feeding tubes don't prolong life, they cause more pneumonia, they add to patient suffering.

# Billing for ACP at an AWW

- Since Jan 2016 Medicare pays for Advance Care Planning. It's easy.
- The RVU is 1.5 which doubles the RVU for an AWW ( $1.5 + 1.5 = 3$ ). For comparison, the RVU for an estab level 4 visit is 1.5 RVU.
- If ACP code is used as part of a Medicare AWW there's no-added-cost to patient. (No co-pay, no deductible.)

# Documentation to Bill for ACP

- Include in your note time spent discussing ACP (must be >15 min) (16 minutes or more.)
- Add to note what you learned about patient's preferences. Perfectly OK documentation is:
- Patient would like DPOA to be <spouse>. Patient preference if cardiac arrest then: <full code> <DNR>. Forms on file are: \*\*\*. I spent \*\*\* minutes (> 15 to bill) face to face with patient discussing preferences for future care. Dementia directive discussed.

- **Engage, learn, train.**
- **Stop averting our gaze. If warning signs appear, work them up.**
- **Explain the diagnosis to patients and families. Hard, but necessary.**
- **“Stay active” - Exercise, support groups.**
- **Engage family: plan finances, plan retiring from driving, gentle advance care planning.**

# Care planning



**Acceptance**

Let's talk about dementia.

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