

# **Communicating with Caregivers: Health Literacy, Plain Language, and Teachback**

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Alzheimer's Conference: Preparing for the Future

# Disclosure

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# What's Ahead

- Communication– Patients, caregivers, and care providers
- Literacy and Health literacy
- Plain language
- Teachback
- Why it all matters



## John's story



My neighbor's mom has Alzheimer's disease. I never thought it would happen to someone in my family. I was upset and worried when I found out my father had the disease. I had so many questions. What is Alzheimer's disease? Can it be treated? How is the disease going to affect my father? Will I be able to care for him? Where can I go for help? In time, I found information on the Internet and by calling Alzheimer's groups.

### Understanding Alzheimer's Disease

What you need to know

From the National Institute on Aging



## Questions this story raises

- What is Alzheimer's?
- Can it be treated?
- How is the disease going to affect my father?
- Will I be able to care for him?
- Where can I go for help?

# Caregivers look to us for help

- Who are caregivers?
- Purposes of communication?



# Medical and public health language can overwhelm caregivers

- Do you use these words?
  - Dementia
  - Cognitive decline
  - Risk factor
  - Progressive disease
  - Degenerative disorder
  - Neurotransmitter
  - Beta-amyloid plaque



# Keep health literacy in mind



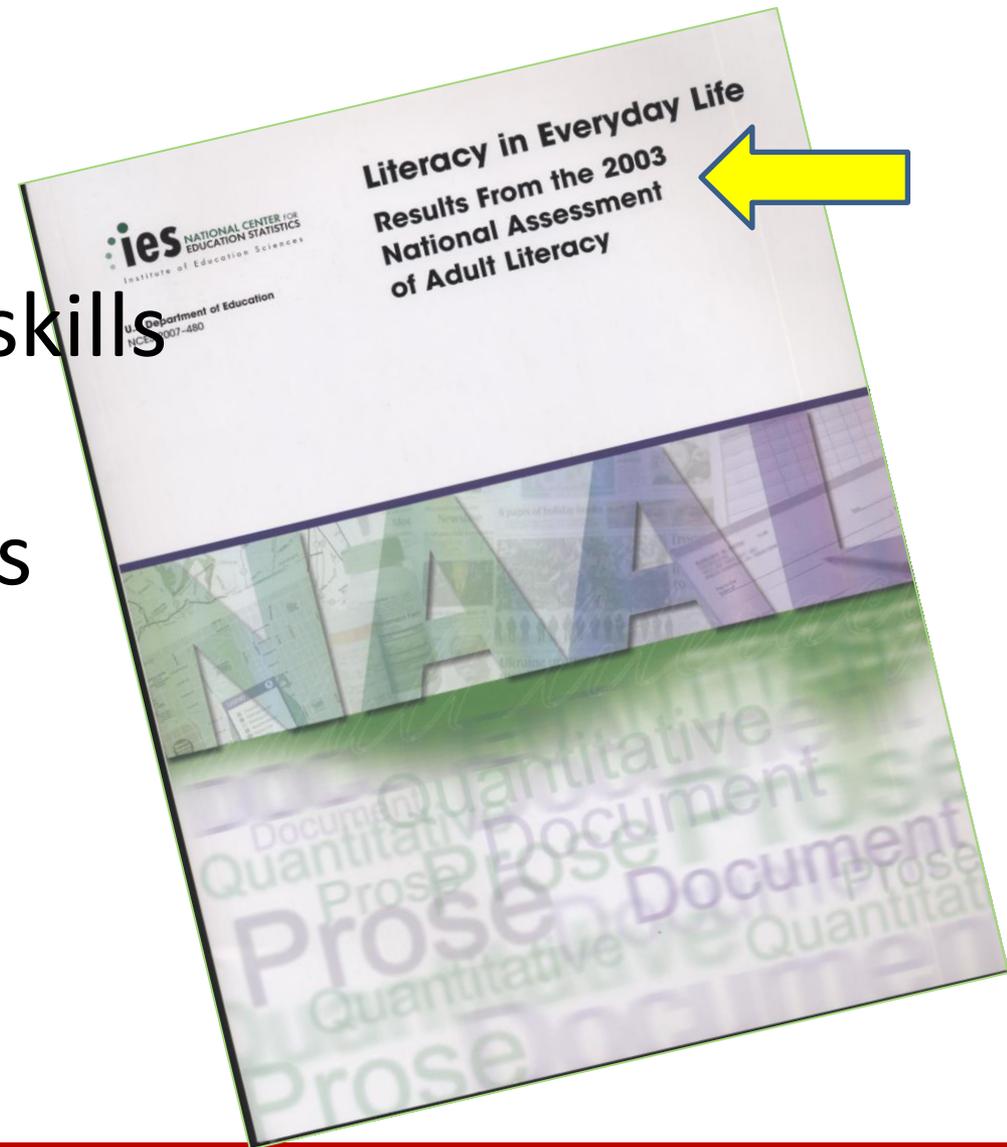
## Adult abilities to

- Read
- Write
- Compute
- Understand
- Communicate
- Use health information

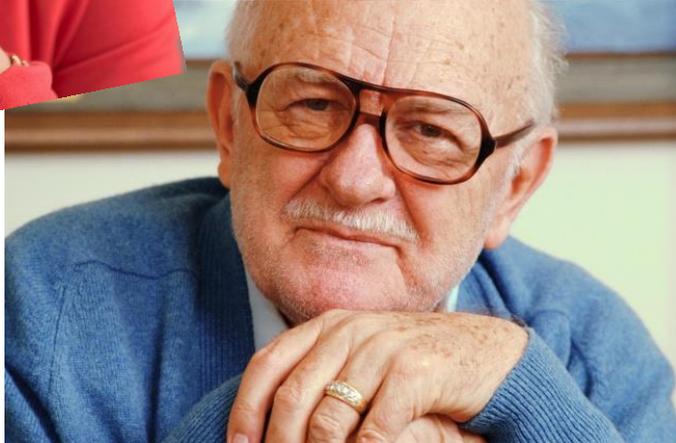
# Literacy skills of American adults

- 43% Basic or below basic **prose** literacy skills
- 55% Basic or below basic **numeracy** skills

**Health** literacy skills:  
Only 12% Proficient



# Most vulnerable population groups



## Adults who are:

- Older (esp. ages 65+)
- Hispanic/Latino
- Immigrants
- Poor
- Managing a chronic physical or mental health condition

# Health literacy challenges ... **everyone**



## Limited

- knowledge
- skills
- time
- resilience

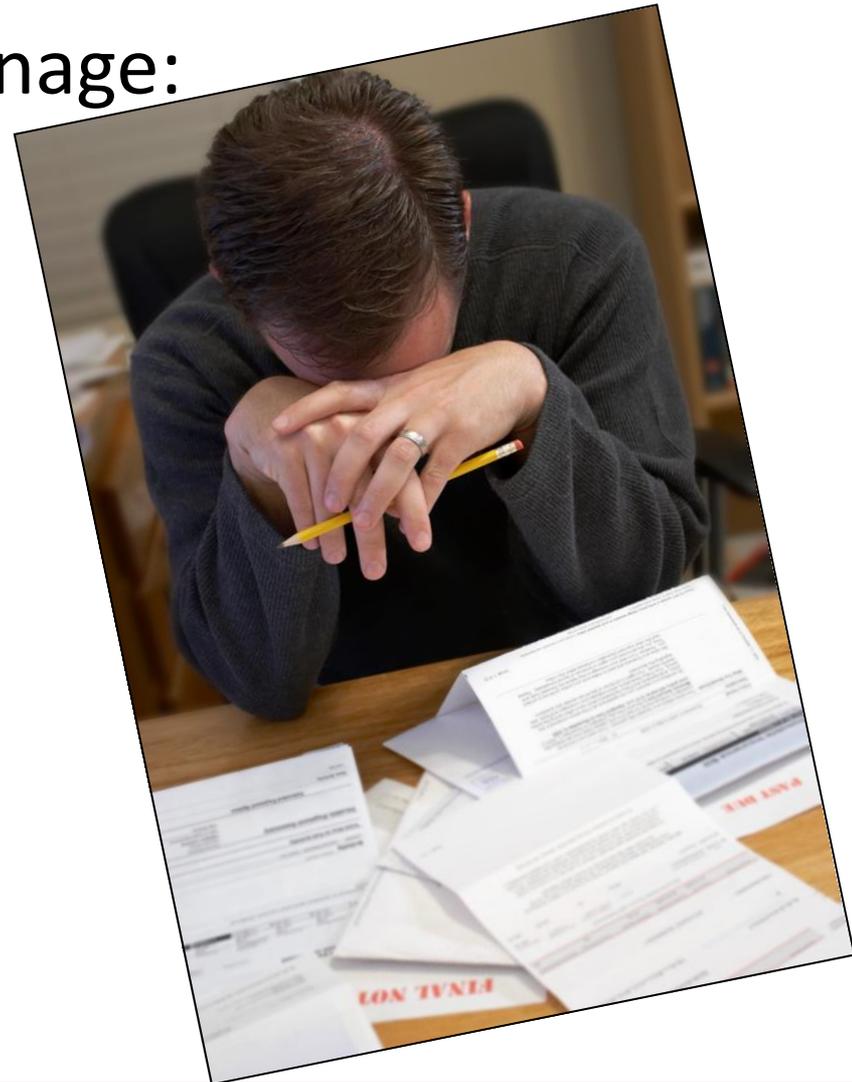
## Often, poor

- health
- vision or hearing
- mobility
- support system

# What do health systems demand?

Caregivers expected to manage:

- Insurance
- System navigation
- Medical appointments
- Treatment regimens
- Their own health
- Shared decision making
- And?



# Re-Defining Health Literacy



Adapted from IOM conceptual framework in  
*"Health Literacy: A Prescription to End Confusion"*, 2003

# The Communication “Gap”

## Consumer Skills vs System Demands

Average literacy skills  
about grade 7/8

Most health information  
at reading level 10 +

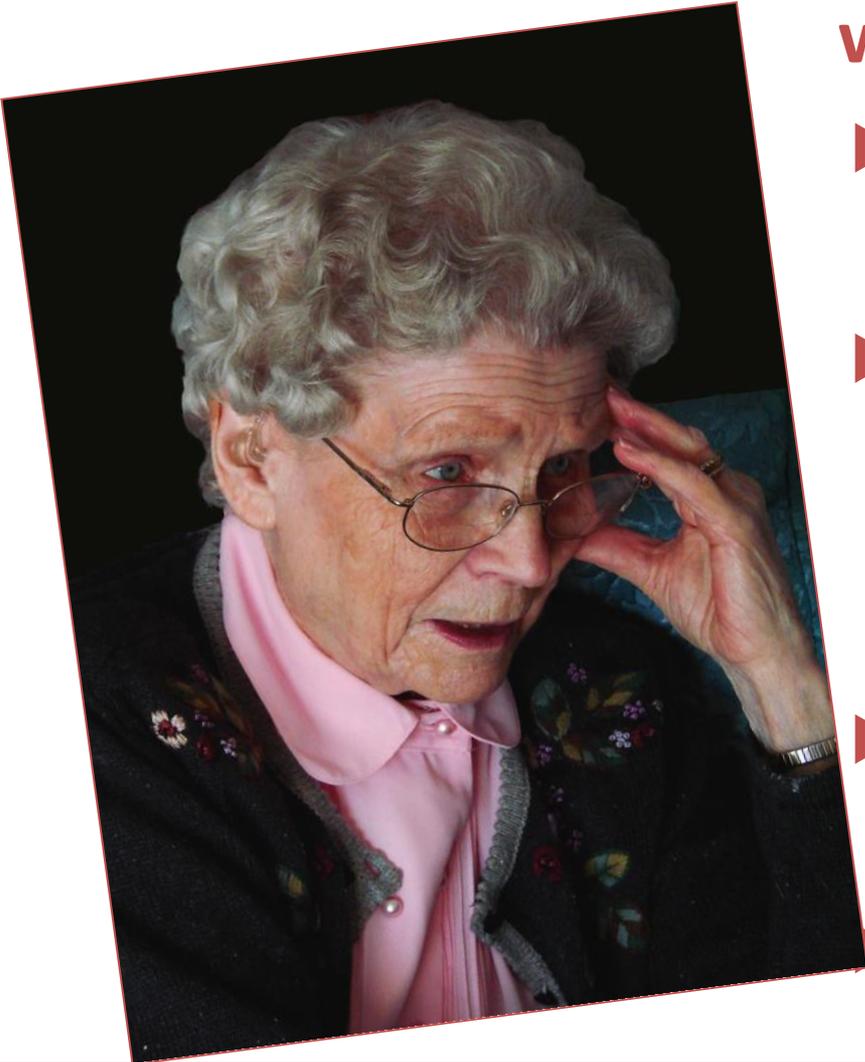
Verbal teaching too fast  
in a “foreign language”



# Impact: Serious for patients

## Research studies — Patients with limited literacy skills:

- ▶ Low understanding of health information
- ▶ ↓ Knowledge and uneven adherence in managing chronic conditions → poor outcomes
- ▶ ↓ Knowledge and likelihood of getting preventive care
- ▶ ↑ Hospitalizations, costs, and deaths



# Impact: Serious for systems



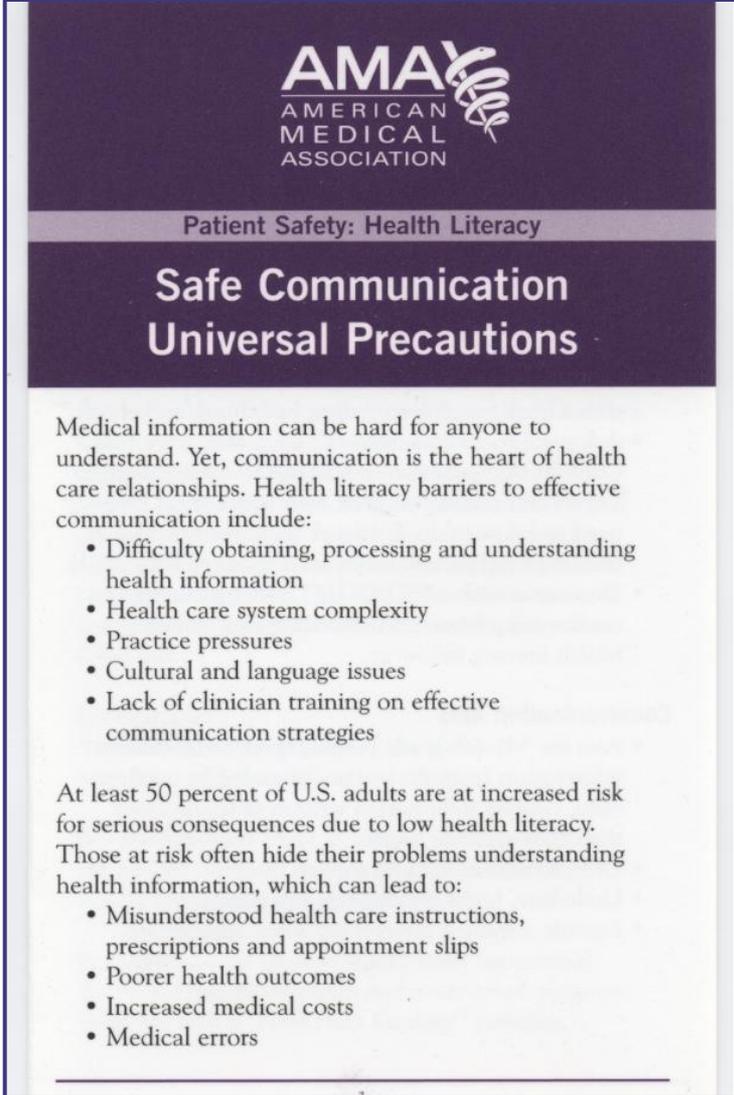
## Increased System Risk

- Missed appointments; cancelled procedures
- Callbacks/Time to repeat instructions
- Medicare refusal to pay
- Missed prevention opportunities

# What works to address the problem?

## 2 evidence-based solutions

- ✓ Plain language
- ✓ Teachback



The image shows a poster from the American Medical Association (AMA) titled "Patient Safety: Health Literacy". The poster is divided into sections. The top section features the AMA logo and the text "AMERICAN MEDICAL ASSOCIATION". Below this is a purple banner with the text "Patient Safety: Health Literacy". The main title of the poster is "Safe Communication Universal Precautions". The text on the poster discusses the challenges of health literacy and provides a list of barriers and consequences.

**AMAA**  
AMERICAN  
MEDICAL  
ASSOCIATION

Patient Safety: Health Literacy

### Safe Communication Universal Precautions

Medical information can be hard for anyone to understand. Yet, communication is the heart of health care relationships. Health literacy barriers to effective communication include:

- Difficulty obtaining, processing and understanding health information
- Health care system complexity
- Practice pressures
- Cultural and language issues
- Lack of clinician training on effective communication strategies

At least 50 percent of U.S. adults are at increased risk for serious consequences due to low health literacy. Those at risk often hide their problems understanding health information, which can lead to:

- Misunderstood health care instructions, prescriptions and appointment slips
- Poorer health outcomes
- Increased medical costs
- Medical errors

# Plain language: More than words

- **Content**  
Limited, reader-focused
- **Organization/structure**
  - Key actions up front
  - Text visually structured
- **Writing**  
Clear, brief, conversational
- **Design**  
Supports key messages
- **Culturally inclusive**



**Providing Everyday Care for People with AD**

**Activity and exercise**

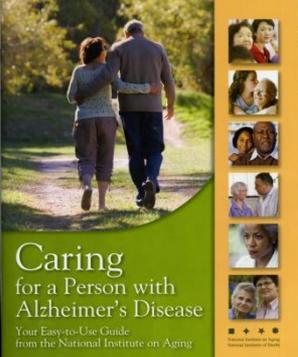
Being active and getting exercise helps people with AD feel better. Exercise helps keep their muscles, joints, and heart in good shape. It also helps people stay at a healthy weight and have regular toilet and sleep habits. You can exercise together to make it more fun.

You want someone with AD to do as much as possible for himself or herself. At the same time, you also need to make sure that the person is safe when active.

Here are some tips for helping the person with AD stay active:

- Take a walk together each day. Exercise is good for caregivers, too!
- Make sure the person with AD has an ID bracelet with your phone number if he or she walks alone.
- Check your local TV guide to see if there is a program to help older adults exercise.
- Add music to the exercises if it helps the person with AD. Dance to the music if possible.
- Watch exercise videos/DVDs made for older people. Try exercising together.
- Make sure he or she wears comfortable clothes and shoes that fit well and are made for exercise.
- Make sure the person drinks water or juice after exercise.
- For more information on exercise and p activity, visit [www.nia.nih.gov/Go4Life](http://www.nia.nih.gov/Go4Life) call 1-800-222-2225.

**Caring for a Person with Alzheimer's Disease**  
Your Easy-to-Use Guide from the National Institute on Aging



Text organized and visually structured for fast access

## Caring for Yourself

Taking care of yourself is one of the most important things you can do as a caregiver. This could mean asking family members and friends to help out, doing things you enjoy, using adult day care services, or getting help from a local home health care agency. Taking these actions can bring you some relief. It also may help keep you from getting ill or depressed.

### How to Take Care of Yourself

Here are some ways you can take care of yourself:

- Ask for help when you need it.
- Join a caregiver's support group.
- Take breaks each day.
- Spend time with friends.
- Keep up with your hobbies and interests.
- Eat healthy foods.
- Get exercise as often as you can.
- See your doctor on a regular basis.
- Keep your health, legal, and financial information up-to-date.



# Words to Know

**Aggression** (uh-GRESH-un). When a person lashes out verbally or tries to hit or hurt someone.

**Agitation** (aj-uh-TAY-shun). Restlessness and worry that some people with AD feel. Agitation may cause pacing, sleeplessness, or aggression.

**Alzheimer's disease (AD)** (ALLZ-high-merz duh-ZEEZ). Disease that causes large numbers of nerve cells in the brain to die. People with AD lose the ability to remember, think, and make good judgments. At some point, they will need full-time care.

**Anti-anxiety** (an-tye-ang-ZYE-eh-tee) **drugs**. Drugs used to treat agitation and extreme worry. Some can cause sleepiness, falls, and confusion. These drugs should be taken with caution.

**Anticholinergic** (an-tye-KOL-in-er-gik) **drugs**. Drugs used to treat stomach cramps, incontinence, asthma, motion sickness, and muscle spasms. **These drugs should not be given to people with AD.**

**Anticonvulsants** (an-tye-kon-VUL-sunts). Drugs sometimes used to treat severe aggression.

**Antidepressants** (an-tye-dee-PRESS-unts). Drugs used to reduce depression and worry.

**Antipsychotics** (an-tye-sye-KOT-iks). Drugs used to treat paranoia, hallucinations, sleeplessness, agitation, aggression, and other personality and behavior disorders. These drugs should be taken with caution.

**Assisted living facility**. Type of living facility that provides rooms or apartments for people who can handle most of their own care, but may need some help.



A clear, easy to use thesaurus guides readers

## Mild cognitive impairment

Some older people have a condition called **mild cognitive impairment**, or MCI. It can be an early sign of Alzheimer's. But, not everyone with MCI will develop Alzheimer's disease. People with MCI can still take care of themselves and do their normal activities. MCI memory problems may include:

- losing things often
- forgetting to go to events or appointments
- having more trouble coming up with words than other people the same age.

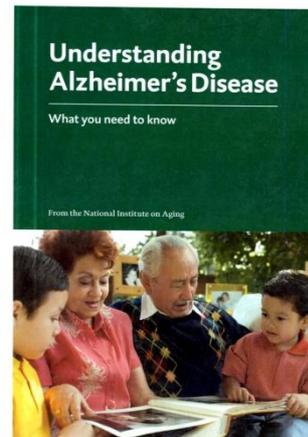
**If you have MCI, it's important to see your doctor or specialist every 6 to 12 months.** Ask him or her to check for changes in your memory and thinking.

### Differences between Alzheimer's disease and normal aging

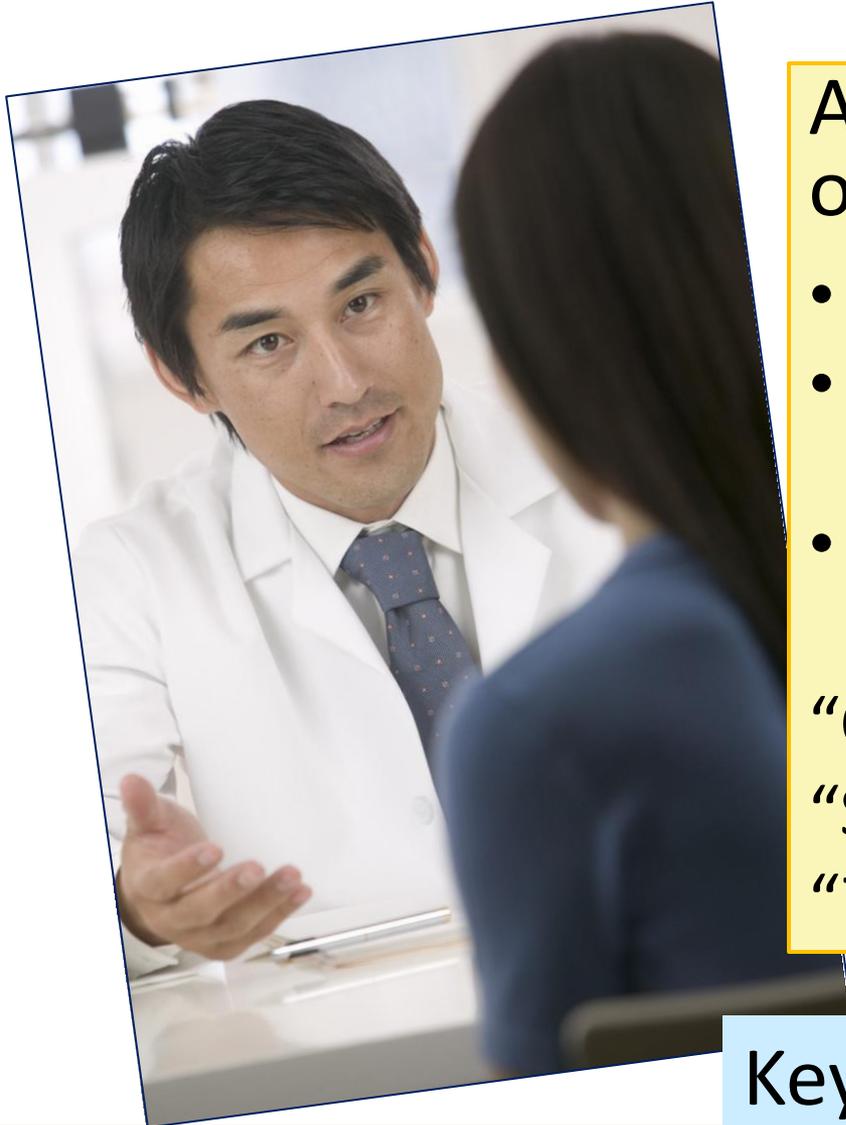
Use the chart below to help you understand the differences between Alzheimer's disease and the normal signs of aging.

Alzheimer's disease	Normal aging
Making poor judgments and decisions a lot of the time	Making a bad decision once in a while
Problems taking care of monthly bills	Missing a monthly payment
Losing track of the date or time of year	Forgetting which day it is and remembering it later
Trouble having a conversation	Sometimes forgetting which word to use
Misplacing things often and being unable to find them	Losing things from time to time

# Another example: Text and chart designed for fast, easy access



# Solution 2: Teachback or 'Guided Imagery'



Assures understanding of verbal teaching

- Clinician or others teach
- Patient or caregiver tells or demonstrates
- Clinician re-teaches as needed

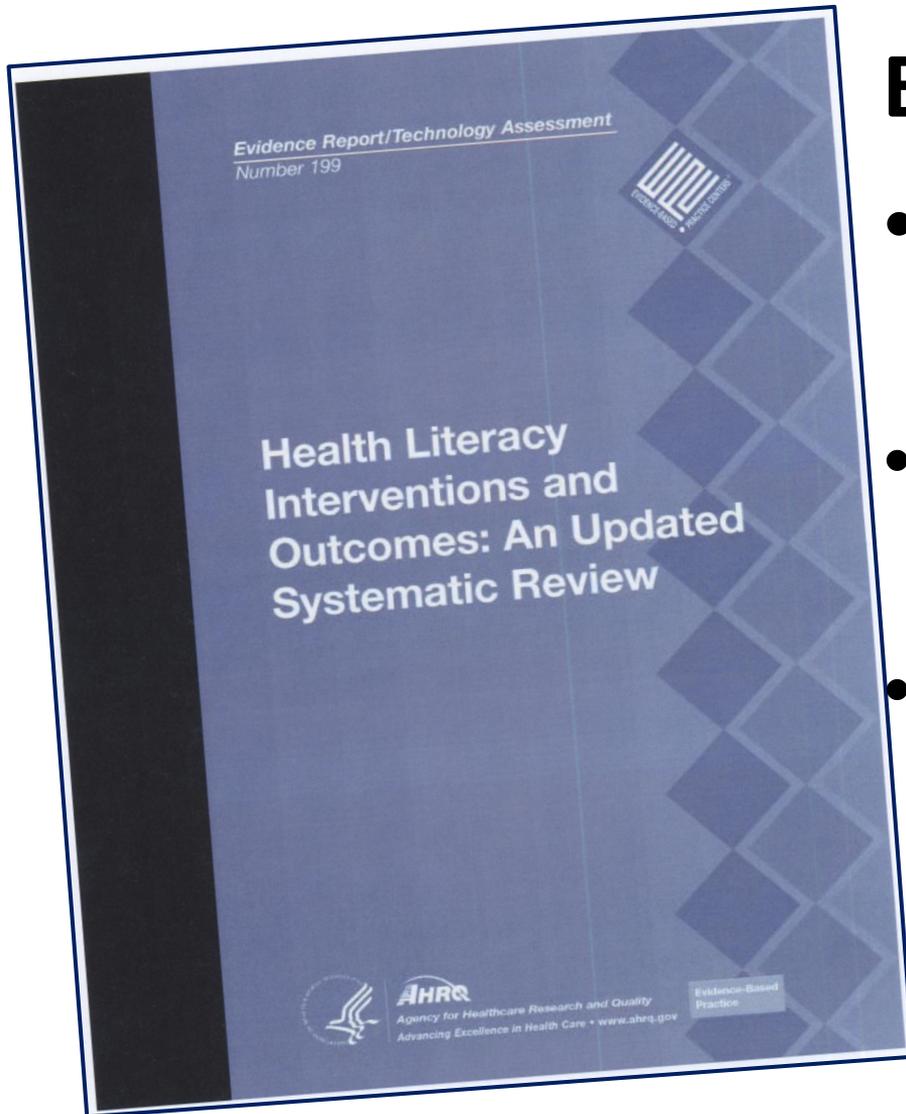
“Chunk - check - chunk”

“Show me”

“Teach to goal”

Key: Not “grilling” or intimidating

# Do “solutions” work?



## Evidence says yes...but

- Understanding ↑ with better material design
- Understanding ↑ with professional support
- More research needed

# Myths and Truths

Myth: We'll “dumb everything down.”

**Fact:** Our **tone** determines how we sound.

Myth: Plain language will insult adults.

**Fact:** Most adults want quick, clear help.

Myth: Plain language creates legal risk.

**Fact:** Plain language protects organizations.

Myth: Plain language is just common sense.

**Fact:** Plain language takes skill and practice.

# A Model of Success



→ Bottle flat for reading ease

→ Drug name big and bold

→ Directions right away

→ Key info stays with bottle

→ Cap color coded by family member

# Worth the effort?

## Consider:

- Population trends
- Alzheimer's trends
- Health delivery trends
- Accreditation requirements
- Safety and quality of care
- Costs



## Final Words: Richard Carmona, M.D.

“The poor state of health literacy in America is a crisis...Without addressing health literacy, we will not be able to respond adequately to such health concerns as obesity, diabetes, heart disease, and cancer...We need to reach beyond the walls of our iatroculture and drop the medical jargon. We can communicate in plain simple terms and take the time to confirm comprehension.”

J Gen Intern Med 2006