

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

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UNE Health Literacy Institute

Alzheimer's Conference: Preparing for the Future

# Disclosure

The speaker is an employee of the University of New England and is provided partial salary support through federal HRSA grant #UP4HP19207-03 to the UNE-Maine Geriatric Education Center. The speaker does not receive any extra compensation for this presentation and has no other financial or academic conflicts of interest to declare.

# Preview

- Introduction: 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.



## 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?

### Understanding Alzheimer's Disease

What you need to know



# Caregivers look to us for help



- Caregivers
  - Adult children
  - Spouses, partners
  - Community helpers
- Care providers communicate to:
  - Ask, diagnose
  - Explain
  - Teach
  - Plan
  - Recommend, refer

# 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



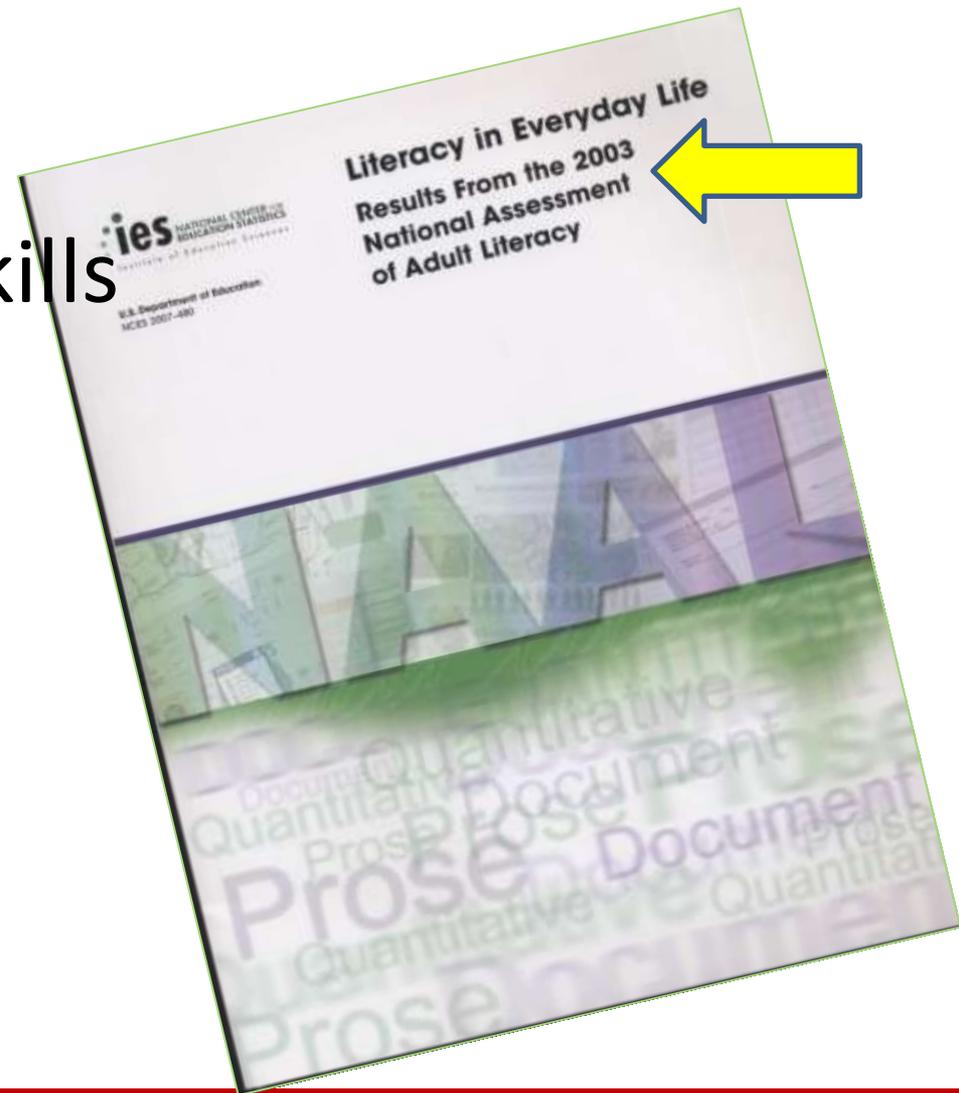
## Adult abilities to

- 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 affects... **everyone**



## Limited

- knowledge
- skills
- resilience

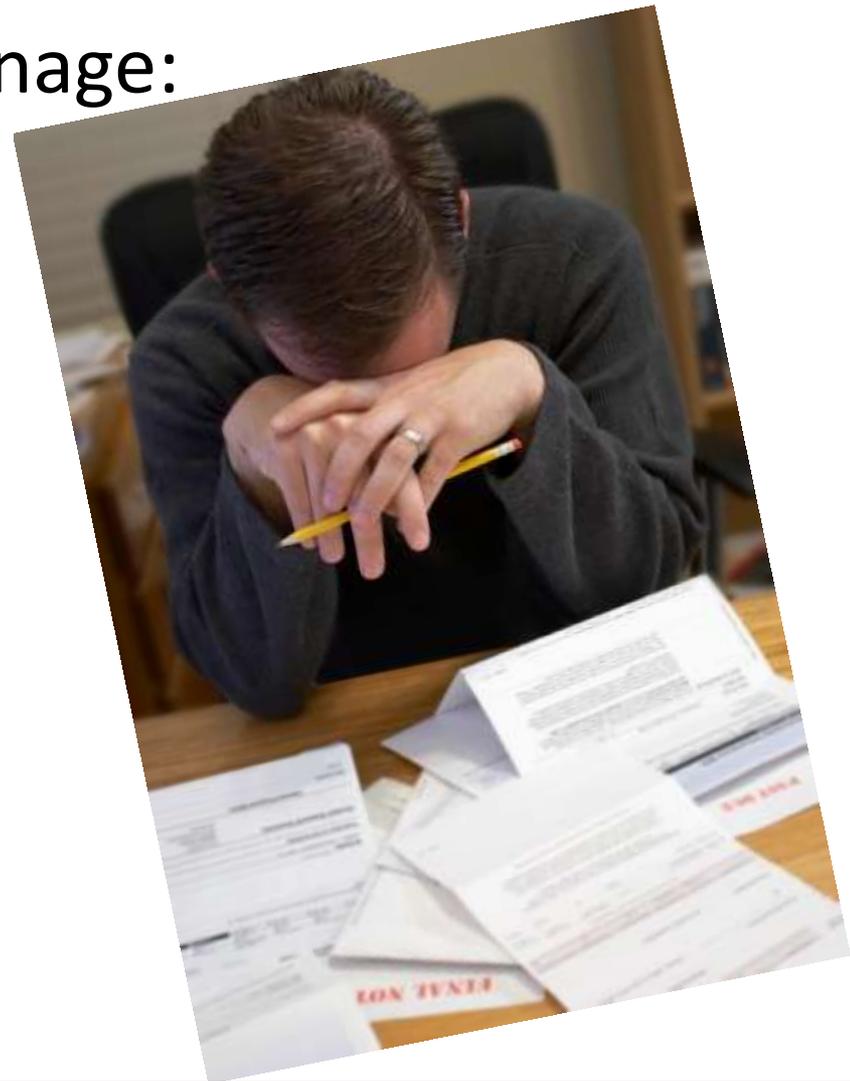
## Often, poor

- health
- vision or hearing
- support system

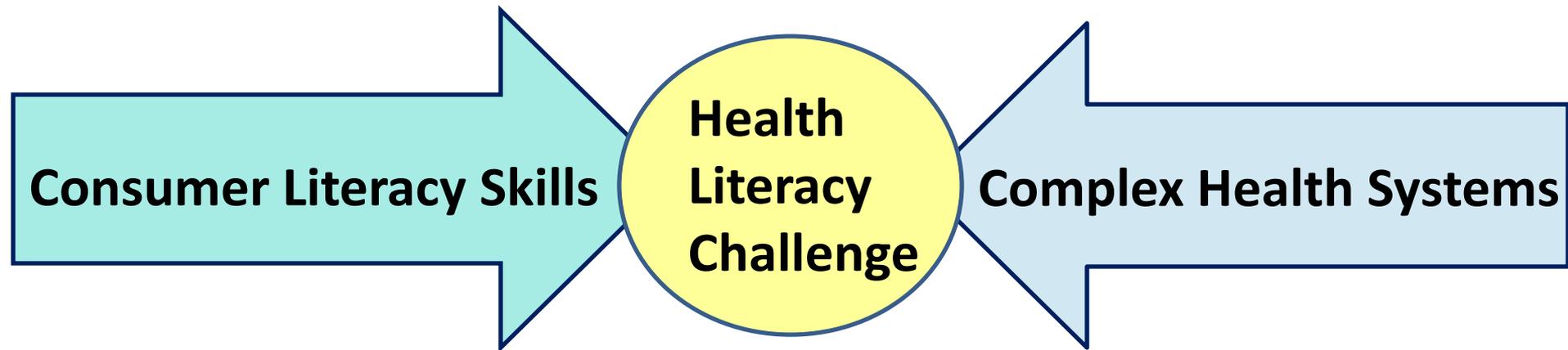
# What do health systems demand?

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



OOPS!!

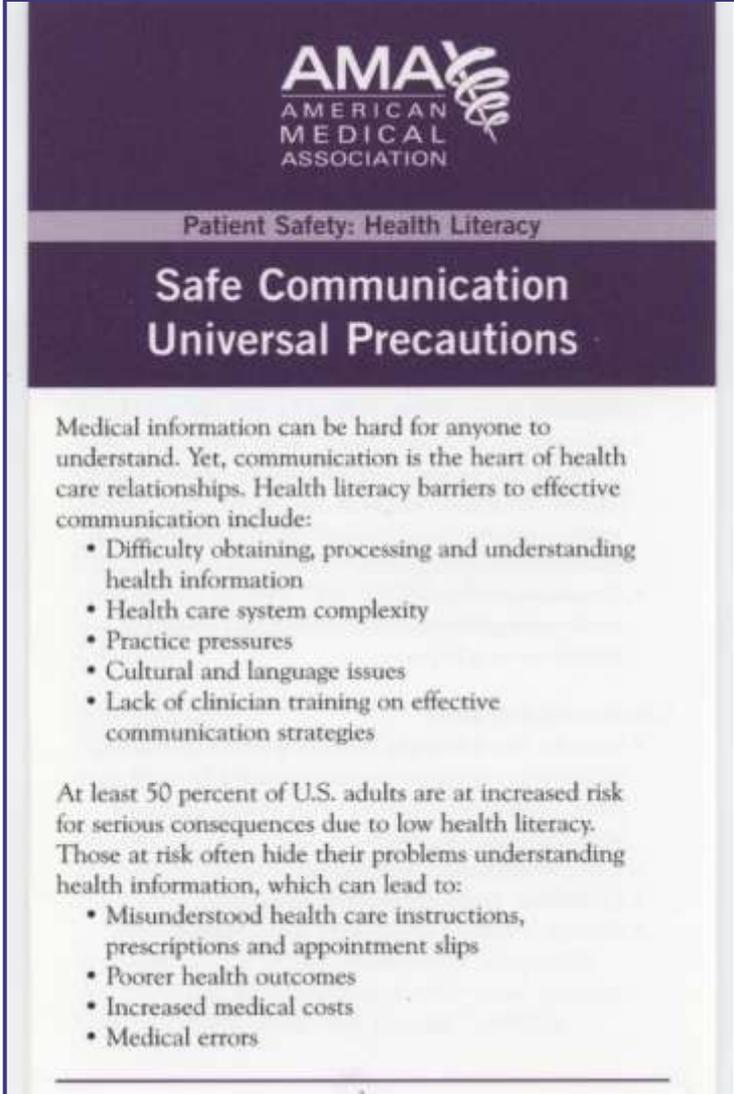
## Increased System Risk

- 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 several sections. At the top, the AMA logo is displayed, consisting of the letters "AMAA" in a large, bold font, with "AMERICAN MEDICAL ASSOCIATION" written in smaller text below it, and a caduceus symbol to the right. Below the logo, the text "Patient Safety: Health Literacy" is written in a smaller font. The main title of the poster is "Safe Communication Universal Precautions", which is written in a large, bold, white font on a dark purple background. Below the title, the text reads: "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:". This is followed by a bulleted list of five items: "• Difficulty obtaining, processing and understanding health information", "• Health care system complexity", "• Practice pressures", "• Cultural and language issues", and "• Lack of clinician training on effective communication strategies". Below this list, the text states: "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:". This is followed by another bulleted list of four items: "• Misunderstood health care instructions, prescriptions and appointment slips", "• Poorer health outcomes", "• Increased medical costs", and "• Medical errors". At the bottom of the poster, there is a small number "3" in the center.

**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

3

# Plain language: More than words

- **Content**  
Limited, reader-focused, culturally inclusive
- **Organization/structure**
  - Key actions (behaviors) up front
  - Information chunked and titled
- **Writing**  
Clear, using simple terms and proven techniques
- **Design**  
Effective in visually supporting key messages

## Helping children understand AD

When a family member has AD, it affects everyone in the family, including children and grandchildren. It's important to talk to them about what is happening. How much and what kind of information you share depends on the child's age. It also depends on his or her relationship to the person with AD.

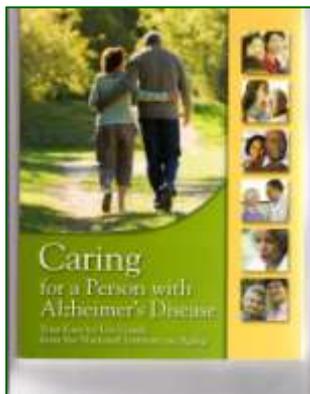
Give children information about AD that they can understand. There are good books about AD for children of all ages. Some are listed on the Alzheimer's Disease Education and Referral (ADEAR) Center website, [www.nia.nih.gov/Alzheimers](http://www.nia.nih.gov/Alzheimers).

Here are some other suggestions to help children understand what is happening:

- Answer their questions simply and honestly. For example, you might tell a young child, "Grandma has an illness that makes it hard for her to remember things."
- Know that their feelings of sadness and anger are normal.
- Comfort them. Tell them they didn't cause the disease. Young children may think they did something to hurt their grandparent.



# Text organized and visually structured for fast access



## Healthy eating

Eating healthy foods helps us stay well. It's even more important for people with AD. Here are some tips for healthy eating.

### When the person with AD lives with you:

- Buy healthy foods such as vegetables, fruits, and whole-grain products. Be sure to buy foods that the person likes and can eat.
- Buy food that is easy to prepare, such as pre-made salads and single food portions.
- Have someone else make meals if possible.
- Use a service such as Meals on Wheels, which will bring meals right to your home. For more information, check your local phone book, or contact the Meals on Wheels organization at 703-548-5558 ([www.mowaa.org](http://www.mowaa.org)). See page 79 for more information about this service.

### When a person with early-stage AD lives alone:

- Follow the steps above.
- Buy foods that the person doesn't need to cook.
- Call to remind him or her to eat.

In the early stage of AD, the person's eating habits usually don't change. When changes do occur, living alone may not be safe anymore.

### Look for these signs to see if living alone is no longer safe for the person with AD:

- The person forgets to eat.
- Food has burned because it was left on the stove.
- The oven isn't turned off.

For tips on helping someone with late-stage AD eat well, see page 114.



# Well designed charts and a thesaurus guide readers

Medicines Used to Treat AD and Its Symptoms	
Brand Name (how to say it) Generic Name (how to say it)	Medication Use • Things to Know About the Medicine
<b>Aricept®</b> (AIR-uh-sept) Donepezil (doe-NEP-uh-zil)	Used to <b>delay or slow the symptoms of AD</b> <ul style="list-style-type: none"> <li>• Loses its effect over time</li> <li>• Used for mild, moderate and severe AD</li> <li>• Does not prevent or cure AD</li> </ul>
<b>Celexa®</b> (Sa-LEKS-a) Citalopram (SYE-tal-oh-pram)	Used to <b>reduce depression and anxiety</b> <ul style="list-style-type: none"> <li>• May take 4 to 6 weeks to work</li> <li>• Sometimes used to help people get to sleep</li> </ul>
<b>Depakote®</b> (DEP-oh-cote) Sodium valproate (so-DEE-um VAL-pro-ate)	Used to <b>treat severe aggression</b> <ul style="list-style-type: none"> <li>• Also used to treat depression and anxiety</li> </ul>
<b>Exelon®</b> (EKS-uh-lawn) Rivastigmine (riv-uh-STIG-meen)	Used to <b>delay or slow the symptoms of AD</b> <ul style="list-style-type: none"> <li>• Loses its effect over time</li> <li>• Used for mild to moderate AD</li> <li>• Can get in pill form or as a skin patch</li> <li>• Does not prevent or cure AD</li> </ul>
<b>Namenda®</b> (nuh-MEN-duh) Memantine (MEH-man-teen)	Used to <b>delay or slow the symptoms of AD</b> <ul style="list-style-type: none"> <li>• Loses its effect over time</li> <li>• Used for moderate to severe AD</li> <li>• Sometimes given with Aricept®, Exelon®, or Razadyne®</li> <li>• Does not prevent or cure AD</li> </ul>
<b>Razadyne®</b> (RAZZ-uh-dine) Galantamine (gah-LAN-tuh-meen)	Used to <b>prevent or slow the symptoms of AD</b> <ul style="list-style-type: none"> <li>• Loses its effect over time</li> <li>• Used for mild to moderate AD</li> <li>• Can get in pill form or as a skin patch</li> <li>• Does not prevent or cure AD</li> </ul>
<b>Remeron®</b> (REM-er-on) Mirtazapine (MUR-taz-a-peen)	Used to <b>reduce depression and anxiety</b> <ul style="list-style-type: none"> <li>• May take 4 to 6 weeks to work</li> <li>• Sometimes used to help people get to sleep</li> </ul>
<b>Tegretol®</b> (TEG-ruh-tall) Carbamazepine (KAR-ba-maz-ee-peen)	Used to <b>treat severe aggression</b> <ul style="list-style-type: none"> <li>• Also used to treat depression and anxiety</li> </ul>
<b>Trileptal®</b> (tri-LEP-tall) Oxcarbazepine (oh-kar-BAZ-eh-peen)	Used to <b>treat severe aggression</b> <ul style="list-style-type: none"> <li>• Also used to treat depression and anxiety</li> </ul>
<b>Zoloft®</b> (ZO-loft) Sertraline (SUR-truh-leen)	Used to <b>reduce depression and anxiety</b> <ul style="list-style-type: none"> <li>• May take 4 to 6 weeks to work</li> <li>• Sometimes used to help people get to sleep</li> </ul>



## Words to Know

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

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

**Alzheimer's disease (AD)** (ALLZ-high-mer: dah-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.

**ADEAR Center**. Alzheimer's Disease Education and Referral Center. The ADEAR Center is an information clearinghouse on AD sponsored by the National Institute on Aging, one of the National Institutes of Health. To contact the ADEAR Center, call 1-800-438-4380 or go to [www.nia.nih.gov/Alzheimers](http://www.nia.nih.gov/Alzheimers) on the Internet.

**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.

## 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.

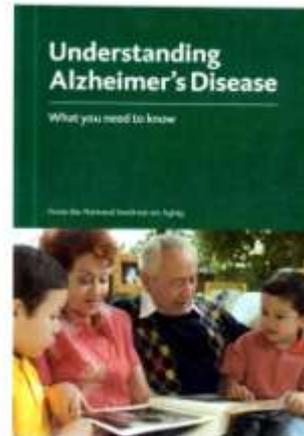
If you have MCI, it's important to see your doctor or specialist every 6 to 12 months. Ask him or her to check for changes in your memory and thinking.

### 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

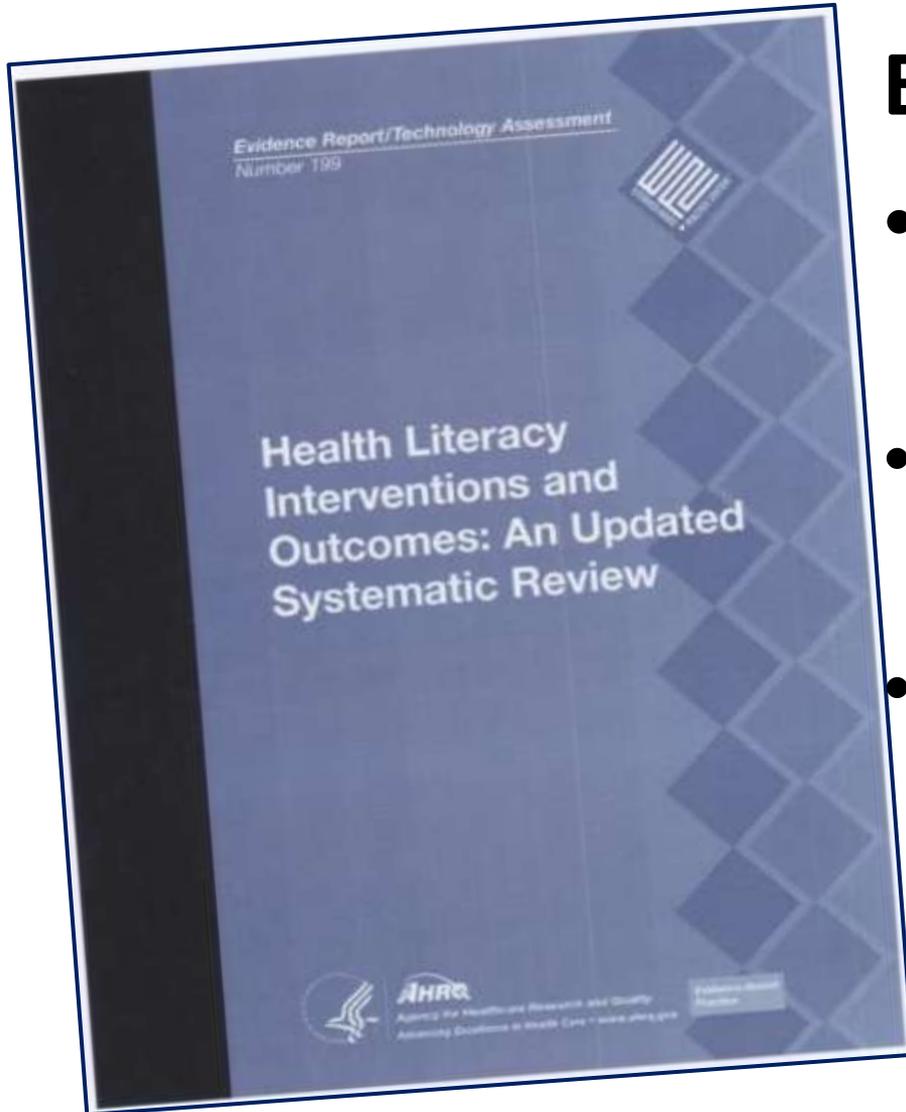
- Clinician or staff teaches
- Patient or caregiver tells or demonstrates
- Clinician re-teaches as needed

“Chunk - check - chunk”

“Show me”

“Teach to goal”

# 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