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
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?

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.
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 regimes
– Their own health
– Shared decision making
– And?
Re-Defining Health Literacy

Strong Emotions

Consumer knowledge, skills, self-efficacy

Health Literacy Challenge

Complex Health Systems

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
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**
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-murt 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-tek) 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.
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.

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

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