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

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Alzheimer’s Conference: Preparing for the Future
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Preview

• Introduction: 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

- 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

Consumer Literacy Skills  
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, 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
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.mowasa.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.
Another example: Text and chart designed for fast, easy access

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 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.”

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