



► **Effective communication by caregivers is essential in helping those with Alzheimer's disease**

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# ALZHEIMER'S *In-Service* M O N T H L Y

BEST PRACTICES IN RESIDENT-CENTERED CARE

○ VOLUME 5 | ○ 2008

## How Can Caregivers Communicate Effectively With the Person Who Has Alzheimer's Disease?

### KEY POINTS

- | **People with Alzheimer's disease deserve our careful attention as much — perhaps, more — than anyone else.**
- | **The key to effective communication begins with common courtesy and active listening.**
- | **Anticipate the needs of people with AD; don't put them on the spot; do make them feel a part of your conversation.**

The opposite of listening isn't talking.  
The opposite of talking is waiting.  
— Fran Lebowitz

The first principle of good communication is common courtesy — to listen attentively to others, not just wait until it's your turn to respond. This is especially true when communicating with people who have Alzheimer's disease. In *Perspectives* (See Resources) Jan Mina Phillips wrote, "The reality is that when diagnosed with Alzheimer's, we are immediately discounted; our views are discredited because of the disease." (Vol. 6:1, Aug-Oct 2000) Unfortunately, Phillips' words are often true. A man who has always given excellent advice and shown wonderful insight into his fellow human beings is often seen as less trustworthy when he can no longer balance his checkbook or drive a car because of losses caused by AD. As caregivers, we must recognize and protect against these injustices.



The root of communication is to "commune" — to come together. In doing so, we show respect for one another and put each other at ease. Being

courteous to someone with Alzheimer's disease means applying the same rules of common courtesy you use with anyone else:

- Introduce yourself when you meet. (For someone with dementia, that means every time you meet.)
- Call the person by name.
- Make eye contact. (Sit beside the person or crouch down to wheelchair height to position yourself at the person's eye level.)
- Smile sincerely and keep your body language open and friendly.
- Say "please" and "thank you" regularly.
- Give the person your full attention. (Shuffling papers or otherwise attempting to "multi-task" while someone is speaking makes him feel unimportant, even invisible.)
- When others are present, be sure the person with Alzheimer's disease is not excluded from the conversation.
- Never speak in the third person about someone with AD when she is present. (For example, "Mrs. Smith doesn't like milk in her coffee.")
- Give the person with AD the opportunity to meaningfully contribute to the conversation by including him in discussions and asking for his opinion and advice.

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## CAREGIVER TIPS

### IT'S THE LITTLE THINGS THAT COUNT

Sometimes we worry too much about big issues. In her book, *Care That Works* (See Resources), Jitka Zgola notes that effective communication often depends on the little things. One highly stressed caregiver found that she was uplifted by strangers who said “Good morning” on her daily walk.

Similarly, Jitka noted the difference between two simple scenarios involving Mrs. Jones, a woman with AD, who is seated at a dining table and has finished drinking her coffee. In the first scenario, a caregiver removes the cup without acknowledging Mrs. Jones. In the second scenario, the caregiver asks, “Mrs. Jones, are you finished with your cup?” Mrs. Jones replies, “Em hm.” The caregiver then asks, “Would you hand it to me please?” and replies, “Thank you” when Mrs. Jones hands her the cup.

Such a simple exchange acknowledges, empowers, and respects the individual with AD.



## How Can Caregivers Communicate Effectively...

FROM PAGE ONE

The Golden Rule also applies: Treat others as you would want them to treat you under the same circumstances. Robert Simpson, a person with AD, who co-wrote the book, *Through the Wilderness of Alzheimer's: A Guide in Two Voices*, (See Resources) offered three valuable observations:



- 1 When you come up to me, especially if we are in a public place, move slowly and speak softly. Introduce yourself. Even if I know you, I may not be able to find your name and then we will both feel bad. Don't ask if I remember you! Let me save face. Say, “Hi, Bob, I'm \_\_\_\_\_.” Then I can say, “Of course you are! I'm glad to see you.”
  - 2 No one wants to talk to me . . . It's like I'm nothing. Oh, they'll say, “Hi, Bob,” but right away they start visiting with you [his wife] and I'll just stand there. . . I don't seem all that different to myself, but people treat me differently when they know I have Alzheimer's.
  - 3 Don't ask me — tell me! Then I don't feel pressure. If someone says, “Do you remember...?” or “Do you know who I am?” the pressure makes me panic.
- Perhaps Robert Simpson's most poignant plea in advising us how we could help people with AD was this: “I doubt if there is anything I can do as well as you, but I need you to help sing my song when I can't remember the words.”

## KEEP IN MIND: THE PERSON MAY HAVE VISION AND HEARING IMPAIRMENTS

As people age, the majority eventually have vision and hearing deficits. Consequently, communication challenges for a person with Alzheimer's disease may be influenced more by age-related sensory losses than by the disease itself. As these sensory deficits worsen, eyeglass prescriptions may no longer be appropriate and hearing aids may be seen as a bother (and, therefore, left behind), which can increase communication difficulties.

To help overcome these challenges, stand or sit directly in front of the person, making sure there is no glare behind you. Eliminate background noises, speak slowly and distinctly, and lower the

pitch of your voice. If you must speak louder, keep the emotional tone in your voice calm and natural, and give the person plenty of time to respond. Some people with AD are hypersensitive to noise and easily startled; speak softly to them.

### Key Points:

Many communication challenges are caused by vision and hearing impairments.

You are more likely to be understood if you face the person at eye level; speak slowly, calmly, and distinctly; and lower the pitch of your voice.

# Making Your Message Clear

Aphasia is the technical term for a loss of language skills. Expressive aphasia is the inability to speak coherently, and receptive aphasia is the inability to understand what is being said. With wide variations in individuals, both the ability to speak and understand deteriorate over time in Alzheimer's disease, but, as noted below, it is a mistake to jump to the conclusion that a person who is slow to respond to a comment or question has significant aphasia. Here are 10 basic strategies to guide you in communicating successfully with someone with AD:



- 1 Use short sentences that state what you want in positive terms. If someone says, "Don't think of pink elephants," the first thing that comes to mind is pink elephants, so always say what you want ("Please stay inside") instead of what you don't want. ("Please don't go outside.")
- 2 Be patient, and don't rush the person. One woman with AD creatively made up the word "flustrated" — a combination of flustered and frustrated — to describe how she felt when she was rushed.
- 3 Give directions one step at a time. Information overload happens quickly in people with AD, so simple directions are easier to follow successfully.
- 4 Give the person time to "tune in" to what you're saying. Many people have had the experience of calling to someone from another room and getting no response. It takes a person with AD longer to register the fact that he is being addressed, which is why standing in front of him, calling him by name, and making eye contact with him are key elements of effective communication.
- 5 Use the same words when you have to repeat a phrase. If you rephrase a question, a person with AD who is still puzzling over the last question will perceive your revised words as a new question, and find it "frustrating."
- 6 Use concrete words. "Put that over there," may be confusing to a person with AD. Instead, try, "Please put the newspaper on the coffee table."
- 7 As AD progresses, avoid open-ended questions. Early in the disease process, it is usually fine to use open-ended questions, such as, "Tell me about your family" or, "What are your favorite foods?" Later it is better to substitute questions that require only "yes," "no," or short phrase answers, such as, "Do you have any grandchildren?" or "Do you like Italian food?"
- 8 Limit choices. "Would you prefer the grilled cheese sandwich or the tuna sandwich?" is easier for people with dementia to answer than, "What would you like for lunch?"
- 9 Provide multi-sensory cues to increase the chances that a person will understand the meaning behind your words. For example, bringing a towel and soap into the person's room at bath time provides a cue about what's to come, even if the words "It's time for your bath" don't completely register.
- 10 As dementia progresses, avoid expressions you don't want taken literally ("It's time to hop into bed."), and recognize that metaphors may be confusing or distracting. ("It's so hot you could fry an egg on the sidewalk.")

Finally, in spite of all this advice, recognize that people with AD almost always comprehend much more than they can express. Don't say anything in front of them that you wouldn't want them to understand.

## KEY POINTS

- | **Expressive aphasia is the loss of the ability to speak coherently; receptive aphasia is the loss of the ability to understand what is being said. Processing of both speech and understanding slows down with AD.**
- | **People with AD tend to understand much more than they can express. Don't say anything you don't want them to understand.**

## RESOURCES

The following two resources were quoted in this issue for understanding Alzheimer's disease as seen through the eyes of people who have it:

*Perspectives* is published quarterly by the Shiley-Marcos Alzheimer's Research Center at the University of California, San Diego. Sign up for free online copies by sending an email to [adrc@ucsd.edu](mailto:adrc@ucsd.edu) and access past issues at <http://adrc.ucsd.edu/newsletter/newsl.htm>.

*Through the Wilderness of Alzheimer's: A Guide in Two Voices* by Robert and Ann Simpson, © 1999.

Here are two excellent resources for understanding in greater detail how to communicate effectively with people with AD:

*Care That Works: A Relationship Approach to Persons With Dementia* by Jitka Zgola © 1999.

*Navigating the Alzheimer's Journey* by Carol Bowlby Sifton © 2004.

# TRAINER'S CORNER

## IN-SERVICE GUIDE

*The "Trainer's Corner" helps you relate the topic to caregivers' personal experiences in order to make it relevant and memorable. With each issue, we will provide*

*discussion questions and an engaging exercise. A quiz is available on Page 5 to test participants' knowledge. (The answers appear on the bottom of this page.)*

### Bringing the lesson home

Most of us do not realize how complicated everyday activities are or how much we do automatically. People with Alzheimer's disease eventually need us to break down tasks into one-step directions, but that isn't easy. People with AD eventually forget the purpose of everyday objects and how to use them (the condition called apraxia), so following directions can be especially challenging.

Practice simplifying directions by finding a partner. Choose which one of you will be person A and who will be person B. Let A give B one-step directions for the first task below, and let B give A directions for the second task. The person performing the task should not speak but try to follow the directions precisely. Set up your props in advance.

- Make a peanut butter sandwich. (Start with getting the bread out of the bag.)
- Brush your teeth.

### Let's talk

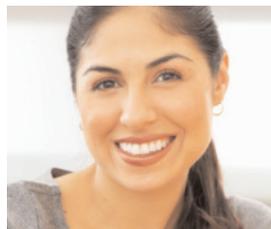
Try the exercise above with your group and then talk about the results.

One variation is for one person to give directions while facing away from the person who is following them. Groups who watch this exercise often find it both eye-opening and hilarious.

Most people forget crucial steps in these two sample exercises. For example, one direction-giver told the person to "Take two pieces of bread out of the bag." It was a simple straight-forward direction, but not precise enough. The plastic bread bag had been secured (as most are) with a twisty. The person following directions was not told to remove it, so she simply ripped open the bag, spilling the entire loaf. She got her two pieces of bread out, so technically she did as she was told.

The point is not to make either the person giving directions or the person following directions look foolish. The lessons to draw out are:

- Giving one-step directions is not as easy as we might think and takes practice.
- If we forget crucial steps, we can easily cause many miscommunications.
- When the person following directions makes a mistake, how can we help him or her to maintain dignity or "save face?"



### Answer Key for Quiz on Page 5

1) d   2) b   3) b   4) b   5) a

# QUIZ: Communication — Part 2

PLEASE COPY AND DISTRIBUTE TO EACH PARTICIPANT

\_\_\_\_\_

First Name

\_\_\_\_\_

Last Name

\_\_\_\_\_

Quiz Date

\_\_\_\_\_

Supervisor's Signature

\_\_\_\_\_

Date

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University with content  
contribution by Kathy  
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*Please answer the following questions based on the information on the previous pages.*

**1) Which of the following would NOT be a way to show common courtesy to someone with AD?**

- a. Introducing yourself by name
- b. Making eye contact and calling the person by name
- c. Smiling and keeping your body language open and friendly
- d. Continuing with what you are doing, so that the person doesn't need to worry if his words come slowly
- e. Including the person in your conversation when others are present

**2) Because of the damage to their brains, people with Alzheimer's disease are not usually embarrassed by their mistakes.**

- a. True
- b. False

**3) Aphasia is the technical term for loss of language skills. Expressive aphasia is the inability to understand what is being said and receptive aphasia is the inability to speak coherently.**

- a. True
- b. False

**4) This issue listed 10 basic guidelines for making messages clear to people with AD. Which of the following was NOT among them?**

- a. Providing multi-sensory cues
- b. When repeating a question, changing the wording slightly so that the repeated version will be clearer to the person
- c. Using short sentences and stating what you want in positive terms
- d. Using concrete words and avoiding expressions you don't want taken literally
- e. Being patient and giving the person time to "tune in" to what you are saying

**5) Vision and hearing impairment can contribute to challenges with communication. Which of the following is NOT recommended to try to overcome these challenges?**

- a. Stand or sit in front of a window so there is plenty of light.
- b. Try to eliminate background noises.
- c. Lower the pitch of your voice, especially if you are a woman.
- d. Keep your voice calm and natural, even if you need to speak louder.
- e. Speak slowly and distinctly.