



► Learn more about the verbal and communication challenges of

people with dementia

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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 4 | ○ 2008

What Is the Person With Dementia Trying to Express?

KEY POINTS

- | Communication skills diminish as Alzheimer’s disease progresses.
- | People with AD tend to have difficulty with nouns, names, and relationships.
- | It’s best to avoid asking questions related to short-term memory, numbers, and time.
- | Because people with AD frequently live in a past reality or float in and out of the present, caregivers need to join them where they are and offer support and reassurance.

Although people progress through Alzheimer’s disease at different rates, they experience several specific verbal and communication challenges:

- Word-finding problems, especially with names, nouns, and relationships
- Difficulty making conversation related to time or numbers
- Inability to store and retrieve short-term memories
- A tendency to revert back to a past reality, rather than living in the present

All of these challenges worsen over time, until eventually people may speak only a few words, and even these may not make much sense. We can facilitate the communication of those with AD more successfully by knowing them well, recognizing and anticipating their needs, and practicing patience at all times.



We all have word-finding difficulties now and then. When we say, “Hand me that thingamajig,” we are making up words (the process called creating a neologism).

Because we use made-up words so often, it is distressing that we don’t always show compassion and understanding when people with AD do the same. In the video *Inside, Looking Out*, a woman named Barb describes a time when she was talking to a neighbor and couldn’t think of a particular word she wanted to use. The neighbor made an impatient gesture with her hand that

Barb clearly read as, “C’m on, spit it out.” Barb says, “It destroyed me; it just destroyed me.”

In the film, Barb also explains that, in terms of her memory, she has good days and bad days. On a bad memory day, not only words elude her, but sometimes she doesn’t recognize her son, Michael. “On bad

days,” she says, “I have this thought, ‘I love this person, but I don’t know who the heck you are!’”

CAREGIVER TIPS

FIND BEAUTY

Lisa Snyder is the editor of *Perspectives*, (see Resources) a newsletter which features the often surprisingly uplifting writings of people with AD. Here is an excerpt from the newsletter, featuring the thoughts of writer E.L. Gorman: “Coping with Alzheimer’s disease at my age has not been that difficult. The early diagnosis has given me time to enjoy the life I have now. I also have the faculties to appreciate the simple things: a beautiful sunset; a tree in spring, summer, or autumn; a poem; music; the colors of a painting; a baby’s smile; a beautiful woman; the rising sun over the city. . . I realize that time is precious and not to be wasted on negative emotions . . .” (Vol. 6:4, May – July 2001).

The ability to find humor and beauty are two of the best weapons any caregiver or person with AD has against the disease.



What Is the Person With Dementia Trying to Express?

FROM PAGE ONE

As dementia progresses, the concept of time becomes more elusive. For example, one caregiver related the story of a good-natured woman with middle-stage AD in her 80s, who was asked, “How many years have you been married?” and answered, “I haven’t any idea. . . Go ask my mother.”



This example also illustrates another common challenge. As Alzheimer’s disease progresses, people often live in a past reality or float in and out of present reality. The woman just mentioned believed she was a young bride and that her mother was very much alive. Another woman who was asked how many children she had struggled for an answer. The problem was that she could not hang onto whether she was naming her siblings or her children because two generations had collided in her memory.

Vocabulary also diminishes with the progression of AD, and the names for relationships often get mixed up. A man with AD who is waiting for a ride

home from a day center may ask, “When is my mother coming to pick me up?” It can be hard to know if he has simply forgotten the word “daughter” and is using the universal word for his other closest female relationship — mother — or if he is actually living in a past reality. If he thinks he is a young man of 30 or less, it stands to reason that the woman in her 50s who comes to pick him up each day must be his mother.

In all of these situations, our role is not to attempt to bring people with AD back to our reality, but to accept their reality and to help them feel safe and secure in it.

KEEP IN MIND: HUMOR STILL WORKS

Cary Smith Henderson, who was featured in the book, *A Partial View*, said, “Laughing is absolutely wonderful. A sense of humor is probably the most important valuable thing you can have when you have Alzheimer’s.”

Although people with AD may have difficulty following a complex joke as dementia progresses, the universal language of smiles and laughter is often still understood throughout the disease process.

Caregivers should never make light of a person’s feelings, but they can help those with AD see the humor in everyday situations. Some people with AD do this instinctively. In the book *Painted Diaries*, Lou Howes, who has AD, watches her

granddaughter, Kate, play solitaire. When Kate gives up, saying, “I can’t. There’re only 50 cards. I don’t have a full deck,” Lou replies, “That’s okay, baby. I don’t either.”

Key Points:

Humor is a great communication tool for use with people living with AD.

Never make fun of a person’s feelings, but do look for ways to share the humor in everyday situations.

People with AD enjoy smiles and laughter throughout the disease process, often making their own jokes and witty comments.

Watch Out for Hidden Needs

Changes in speech patterns become more noticeable as Alzheimer's disease progresses. One such change is a tendency toward generalizations. People may use words such as "nice" to describe food, homes, husbands, and events. "It was very nice" is a common response for a multitude of situations. One caregiver relayed a story of a man who, when asked what



foreign countries he had visited, answered, "Oh, you name it; I guess I've been there." Another woman was asked about the jobs she had held: "What kind of work did you do?" She answered, "Anything I could get." Such vague responses provide ways for people with AD to interact with others without the pressure of trying to provide specific details that they cannot remember.

People with AD may also find that certain phrases allow them to seem both courteous and competent and will therefore use those phrases repeatedly. Usually it makes for pleasant conversation and isn't a problem. However, there are three scenarios in which it's easy to miss hidden needs.

First, a person who says, "No, thank you, dear; I'm fine," whenever you ask her if she would like a cup of tea, a sweater, a little outing, or any other question related to her well-being, is probably using a "pat phrase" (using virtually the same words to answer every question). These recurring phrases may work in social conversation, but their repeated use can mask real needs. If you know Mrs. Jones enjoys hot tea but refuses it whenever you ask, don't ask. Instead, bring her the tea you know she enjoys and say, "Mrs. Jones, I've brought you a cup of tea." If possible, sit with her while she drinks the tea, so she doesn't simply put it aside. Providing hydration

often means putting it in the person's hands, not simply asking the person if she is thirsty. Similarly, if a person's hands are cold, chances are he would feel better with a sweater on, so bring him the sweater and provide any help he may need to put it on. Similarly, if someone has been sitting a long time and needs a walk to improve circulation, digestion, and balance, invite her to accompany you on a walk. (Invitations are harder to say "no" to than questions.)

Second, a person asking repetitive questions, such as, "When's lunch?" really doesn't remember asking it 30 seconds ago. The man may be trying to engage in conversation, or he may be genuinely hungry. If possible, offer a snack. Older adults often need more frequent, smaller meals. Remember that a response such as "Lunch is at 11:45" is meaningless to a man who no longer has a concept of time, no matter how gently or frequently the response is given.

Third, it is common for people who are foreign-born to revert to their native languages as dementia progresses. When they lose the ability to ask for assistance in English, it is helpful if caregivers can learn some basic phrases ("Are you hungry? Do you need to go to the bathroom?") in the person's native language, as well as try to carefully "read" the person's tone of voice, facial expressions, and gestures when they speak in their native tongue.

KEY POINTS

- | **People who give "pat answers" may not be expressing their real needs. Caregivers must be clever and attentive to ensure those needs don't go unmet.**
- | **People who ask repetitive questions may be requesting help in a roundabout way.**
- | **Learning basic phrases in a person's native language, as well as watching for needs expressed in tone of voice, facial expressions, and gestures, can be helpful to caregivers of those who speak English as a second language.**

RESOURCES

Here are the resources quoted in this issue for understanding Alzheimer's disease, as seen through the eyes of those living with it:

Alzheimer's Disease: Inside, Looking Out is a 19-minute video featuring people with AD from the Cleveland Area Chapter of the Alzheimer's Association. Available through Terra Nova Films at 800-779-8491 or <http://www.terrano.org>.

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 and access past issues at <http://adrc.ucsd.edu/newsletter/newsl.htm>.

Painted Diaries: A Mother and Daughter's Experience Through Alzheimer's by Kim Howes Zabbia © 1996. Partial View, An Alzheimer's Journal by Cary Smith Henderson and Nancy Andrews © 1998.

The books are available used online, if not in stores.

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

While not everyone progresses through Alzheimer's disease in the same way, generally the verbal (and written) communication skills of people with AD diminish over time. In the early stage, they may feel frustrated when they can't think of a specific word. Eventually, they lose most of their language skills and caregivers have to rely on facial expressions, gestures, and tone of voice to determine the person's needs. Find a partner and try these two brief exercises to get a sense of what that is like.

- 1 How would you rearrange the letters in the phrase "new door" to make one word? There is only one correct answer.
- 2 Take turns playing charades. Try to express a need (hunger, thirst, being hot or cold, needing the bathroom, or another need of your own choosing) completely through gestures and facial expressions.



Let's talk

The answer to exercise 1 is "one word." It's a trick question. How many participants got it? If they didn't get it, did they feel frustrated? If they did get it, were they upset that it was a trick question and not a "real" problem? People with Alzheimer's disease often feel as if they are living in a world full of traps and tricks. Eventually, many stop worrying and go with the flow, but in the early stage, many people exhaust themselves trying to avoid stumbling. Caregivers can help them by removing as many obstacles to their success, as possible. Discuss ways of doing so. (This lesson continues in the next two issues.)

The charades exercise is intended to be fun. Most people can make their need to use the bathroom, for example, extremely clear, and likely in a way that is humorous. The point here is to be alert to subtle clues. A seated elderly woman with AD who has to go to the bathroom may be fidgety — folding and unfolding her hands, smoothing her dress, crossing and uncrossing her legs — wearing a slightly pained expression as she looks toward the door. Ask if participants have noted any particular gestures with meaning for specific people in their care.

Answer Key for Quiz on Page 5

1) d 2) b 3) a 4) d 5) e

QUIZ: Communication

PLEASE COPY AND DISTRIBUTE TO EACH PARTICIPANT

First Name

Last Name

Quiz Date

Supervisor's Signature

Date

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IN-SERVICE MONTHLY
IS PROVIDED BY
NOVARTIS
PHARMACEUTICALS
IN COOPERATION WITH
SENIOR LIVING
UNIVERSITY.**

**This publication has been
developed by Senior Living
University with content
contribution by Kathy
Laurenhue, WiserNow, Inc.,
(www.wisernow.com).**

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Please answer the following questions based on the information on the previous pages.

1) As Alzheimer's disease progresses, people tend to lose their verbal communication skills. All of the following are likely to be troublesome topics for conversation EXCEPT:

- a. Discussing what they ate for dinner last night
- b. Naming their friends
- c. Relating the number of years they worked at a career
- d. Talking about the joys of grandchildren
- e. Telling you the date of their next doctor's appointment

2) A neologism is a made-up word, usually used when we can't think of the word we want to say. This only shows up in people with Alzheimer's disease and is one sure sign of the disease.

- a. True
- b. False

3) People with Alzheimer's disease often talk in generalities or talk around a subject rather than providing a specific answer.

- a. True
- b. False

4) People who give a "pat answer" (using virtually the same words to answer every question) are at risk for failing to have their needs met. We can assure that their needs ARE met by:

- a. Paying close attention, so that we recognize from their body language when they might need to go the bathroom, for example.
- b. Issuing invitations ("Please join me in a cup of tea") instead of asking if they would like something.
- c. Bringing an item to them without asking ("I noticed your hands were cold; I thought you would like a sweater.")
- d. All of the above
- e. A and B only

5) People with Alzheimer's disease who ask repetitive questions often:

- a. Have an unmet need (such as for a snack) that they are trying to express
- b. Are purposely trying to annoy us and should be ignored
- c. Are trying to engage our attention by making conversation
- d. All of the above
- e. A and C only