



► People with Alzheimer's disease...tend to speak through their

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# ALZHEIMER'S *In-Service*

## M O N T H L Y

BEST PRACTICES IN RESIDENT-CENTERED CARE

○ VOLUME 7 | ○ 2008

## Why Is He Doing That? There's a Logical Reason.

### KEY POINTS

- | People with AD often "speak" through their behavior.
- | They always make sense to themselves, but caregivers must sometimes work to decipher the meaning of certain behaviors.
- | When a person with AD seems anxious, agitated, or aggressive, or is resisting care, first consider whether he might be tired, frustrated, fearful, confused, or physically uncomfortable.

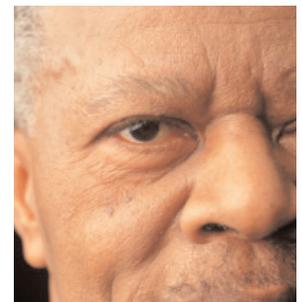
As people with Alzheimer's disease lose their verbal abilities, they tend to "speak" through their behavior. All behavior has meaning, but it is not always easy for caregivers to decipher that meaning. As a result, people with AD are often labeled as "a problem" when what they are trying to tell you is that they HAVE a problem. Remember, the person with Alzheimer's disease always makes sense to himself. You can often understand his message if you look first at these four possibilities:

### The Big Four

Whenever you are confronted with a person with AD who seems anxious, agitated, or aggressive or who is resisting the care you are trying to give, consider the "Big Four." These things affect all of us:

- **Fatigue.** When we're tired, we are all irritable and find it hard to "think straight." Most of us have a time of day when we are most alert, (for people with Alzheimer's disease, it tends to be morning), and when that time passes, we are no longer at our best. We may have trouble remembering the items we want to pick up at the grocery store on our way home from work, or we may be more impatient drivers. Tasks take more effort, and we tend to be irritated at having to *make* that effort. People with AD have the same reaction. The difference is that they tend to tire more easily and more often and can't always tell us they need to rest.

- **Frustration.** As we age into our older adult years, staying fit takes more work, hearing deteriorates, and vision loses acuity. It's harder to thread a needle or read fine print. Even when we come to accept our aging bodies, most of us are frustrated at times that we can no longer move as effortlessly or hear and see as well as we once could. People with AD must deal with both normal aging and disease-related changes. Something as ordinary as putting on a pair of pants becomes an insurmountable challenge, and what's worse, people with AD are often unable to express their frustration coherently. Furthermore, because those with AD have trouble with some tasks, others are frequently mistrustful of their knowledge and skills in *everything*. They may be kept from doing things they could accomplish independently and successfully, such as chopping vegetables or clipping coupons because others fear for their safety or assume they are incapable.



## CAREGIVER TIPS

### LEARNING THE DANCE

People with a chronic illness often talk of “battling” their condition, but when a person has Alzheimer’s disease, a better metaphor is “learning the dance.” When we dance well, we say we are “attuned” to the music, in harmony with it. Our footwork flows.

As AD progresses, people lose many of their abilities, but, surprisingly, many can literally dance better than they can walk. We can learn to dance alongside by:

- Recognizing how frustrating it is to misunderstand others and to be misunderstood
- Imagining the exasperation caused by being unable to accomplish what was once easy and being kept from doing things that you still believe you can do
- Realizing how frightening it is to face procedures, expectations, and an entire world that no longer makes sense

Remaining attuned takes fancy footwork, but you and the person with AD can still make beautiful music together.



## Why Is He Doing That? There’s a Logical Reason.

FROM PAGE ONE

- **Fear and Confusion.** Think of your first day learning a new task, such as cooking, passing out medications, or riding a bike. You were probably excited but also afraid of making a mistake. If you had a good teacher, you might have felt more confident, but what if you were left alone and weren’t sure what was expected of you? When we are confused by directions we don’t understand, or when we are afraid of making a mistake or fear for our safety, we will resist that activity or hesitate to act. So will the person with AD.
- **Pain, discomfort, and other physical causes.** This category covers a wide variety of possibilities. Some are easily solvable. Is the person hungry? Provide a snack. Does he need to go to the bathroom? Take him. Is she cold? Bring her a sweater. Are her legs stiff? Help her to take a walk. Other causes are more complex and may require more careful examination. They are discussed elsewhere in this issue.



## KEEP IN MIND: VIOLENCE IS NOT A SYMPTOM OF ALZHEIMER’S DISEASE

When we hear that someone has kicked a vending machine or thrown a computer out the window, most of us are sympathetic, not shocked. We understand the frustration behind the action. Yet, we often fail to show the same concern for those with AD.

Years ago it was commonly thought that most people with Alzheimer’s disease would eventually become violent. Now we know that — barring a history of alcoholism or psychosis or a medication side-effect — people with AD who become verbally or physically combative are essentially saying “No!” to whatever it is we are trying to get them to do. Chances are, we have been pushing them to take a shower or

get dressed without paying attention to their confusion, fear, or discomfort. Lashing out is their way of getting us to stop and take notice of their needs.

### Key Points:

Violence is not a symptom of Alzheimer’s disease. Violence in someone with AD always has an external cause, and often we’re it.

Resistive behavior is a coping mechanism.

People with AD who “resist care” are most often feeling frightened, confused, or uncomfortable. It is up to us to put them at ease before continuing.

# Physical Discomfort Can Have Many Causes

As noted previously, many causes of physical discomfort are easily discernable even when the person can't fully verbalize the problem. Fidgeting can indicate the need to use the bathroom; cold hands are a sign of being chilled. Other conditions, however, can be trickier. As their condition progresses, people with Alzheimer's disease have trouble "self-reporting" their discomfort, and are dependent on our vigilance at detecting the following:



- **Pain.** Although saying "My stomach aches" may seem simple, in reality, people with AD usually express pain non-verbally. Watch for changes in behavior, such as withdrawal from activities or decreased mobility. Pay attention to self-protective behavior, like a person holding her arms close to her stomach or holding her hand on her head. Also watch for clenched fists or jaws, glazed eyes, and increased sensitivity to noise or light.
  - **Effects of medication.** Although drugs can have huge benefits, all older adults need periodic reviews and re-evaluations of their medicines because many signs of discomfort (including anxiety, agitation, and aggression) can be attributed to inappropriate drugs, dosages, or combinations of medications. Side-effects, prolonged use, and allergic reactions may be culprits, as well.
  - **Impaired vision or hearing.** Most older adults have some hearing and vision loss, and a great many either do not have hearing aids or glasses, or are using those that are ill-suited to their current needs. Thus, many older adults misunderstand directions and misinterpret visual clues. For those living with AD, this can cause frustration, fear, and confusion.
- **Acute illnesses.** A person with a fever, diarrhea, or vomiting is easily noticed, and (we hope) quickly treated. Yet many people with less obvious conditions — ear, bladder, and urinary tract infections, for example — may only be diagnosed as irritable or "having a bad day." Watch, too, for uncharacteristic fatigue and a sudden onset of symptoms.
  - **Chronic illness,** often accompanied by chronic pain, is also usually expressed by irritability. People with conditions such as arthritis are expected to ask for a pain reliever when it is needed; people with Alzheimer's disease may be unable to say, "I need a pill for my arthritis pain" — or ulcer, restless legs, or any other condition.
  - **Dehydration** is a common problem among people with AD because they may forget to drink, not recognize the sensation of thirst, not know how to pour a glass of water, or not know how to ask for a drink. People are especially at risk outdoors in hot weather and indoors in cold weather (because of the dry heat produced by most furnaces).
  - **Constipation.** Not only does constipation discomfort produce irritability; it can also have many other side effects if left untreated. Furthermore, bowel impaction can contribute to delusional behavior.
  - **Depression.** Many people with AD, particularly early in the disease process when they are aware of their losses and concerned about the future, are mildly or clinically depressed and could benefit from anti-depressants. Later, when their self-awareness diminishes, if they are valued and well cared for, they often have a surprisingly cheerful outlook and a sense of well-being.

The bottom line is that caregivers need to be constant advocates for people with AD, looking for stressors in all possible forms.

## KEY POINTS

- | People with AD tend to have difficulty "self-reporting" as their condition progresses.
- | They are dependent on us to notice signs of pain, acute and chronic illnesses, dehydration, constipation, and depression.
- | We must also be vigilant in noticing hearing and vision difficulties and behavior that could indicate an adverse reaction to the medications they are taking.

## RESOURCES

In understanding what motivates behavior, the best sources are the people who have AD. To this end, we have previously noted books by Cary Smith Henderson, Larry Rose, Ann and Robert Simpson, Lisa Snyder, and Kim Howes Zabbia, along with the video *Inside Looking Out*.

One of the earliest — and still best — books of this genre is *My Journey into Alzheimer's Disease*, by Robert Davis (© 1988). Davis was a successful minister diagnosed with AD at age 53. His book has a strong Christian focus, which may not appeal to all readers, but his chapter 7, "The Abnormal Changes So Far," is unsurpassed in clearly describing his experiences.

# 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

This exercise requires the following props:

- Old sunglasses or prescription glasses with dirty lenses (Add your fingerprints or dip them in salted water and let them air-dry.)
- Ear plugs
- Ace bandages
- Empty boxes of cold medicine
- Belts or blouses with tiny buttons

Give each person a pair of glasses and earplugs to wear. Immobilize the dominant arm and hand (including fingers) of each participant with an ace bandage. Speaking in a soft voice, give all participants a series of tasks to complete, such as reading the fine print on the cold medicine package, buttoning the blouse while it is on the table, or putting on and buckling the belt. Add other tasks or variations that come to mind. Keep participants handicapped and busy for at least 10 minutes, so that they begin to feel distressed.



### Let's talk

Try the exercise above with your group and discuss the results. The goal is to help participants experience physical disabilities that might give them empathy into the frustrations, confusion, and pain of older adults — including those without dementia. The goal is NOT to overcome these difficulties — someone always proudly will — but to feel their everyday challenge.

Anyone who is forced to wear prescription glasses not suited to her eyes will usually start to develop a headache within 10 minutes. While this is perhaps the easiest way to experience discomfort, the point is that people with AD frequently have eyeglasses that are dirty or prescription lenses that no longer suit them, and they may not be able to tell us. Even with the right prescription, they may have trouble reading (and understanding) the tiny print often found on medicine packaging.

If you speak softly, and the participants cannot see you clearly while they are wearing earplugs, they are likely to have trouble following directions. Additionally, putting on a belt or buttoning a blouse is often too difficult to do with one hand.

Draw out the *feelings* of participants, and note that what brought discomfort for them in 10 minutes is a constant reality for many older adults.

### Answer Key for Quiz on Page 5

1) b   2) e   3) a   4) e   5) b

# QUIZ: Motivation — Part 1

PLEASE COPY AND DISTRIBUTE TO EACH PARTICIPANT

\_\_\_\_\_

First Name

\_\_\_\_\_

Last Name

\_\_\_\_\_

Quiz Date

\_\_\_\_\_

Supervisor's Signature

\_\_\_\_\_

Date

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

**1) Which of the following statements about *fatigue* in people with AD is NOT true?**

- a. It may be related to physical illness.
- b. It is usually more of a problem in the morning.
- c. It can cause irritability.
- d. It interferes with the person's ability to think clearly.
- e. People with AD tend to tire more easily and more often as their disease progresses.

**2) Which of the following is LEAST likely to be *frustrating* to a person with AD?**

- a. Being unable to do something he once could do easily, such as get dressed
- b. Being kept from doing something he thinks he is perfectly capable of doing
- c. Not being able to see clearly enough to do things she once enjoyed, such as reading
- d. Not being able to hear and understand directions
- e. Working together with someone on a task he enjoys

**3) *Fear and confusion* are linked in this issue because a person who is confused about what is expected of him is likely to fear making a mistake and may therefore resist doing anything.**

- a. True
- b. False

**4) All of the following are examples of *physical discomfort* to watch out for in people with AD except:**

- a. Acute or chronic illnesses
- b. Being hungry or cold
- c. Depression or emotional pain
- d. Medication issues (side-effects, wrong dosage, allergic reaction, adverse interaction of multiple medications)
- e. All are valid

**5) *Violence* is a common symptom in people with Alzheimer's disease.**

- a. True
- b. False