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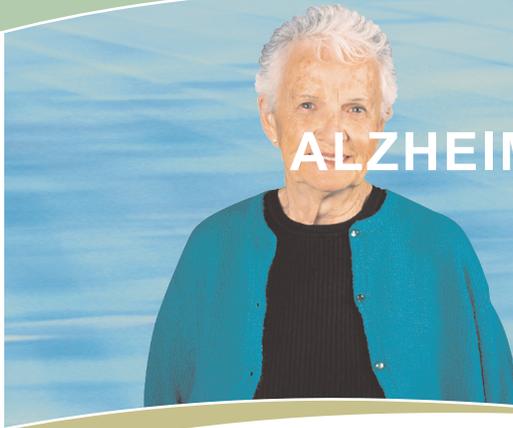
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ALZHEIMER’S *In-Service* M O N T H L Y

BEST PRACTICES IN RESIDENT-CENTERED CARE

○ VOLUME 8 | ○ 2009

Why is he doing that? Look at the situation.

KEY POINTS

- | Most behavior of those with AD is logical.
- | Their actions are often a reflection of their circumstances.
- | When a person with AD seems anxious, agitated, aggressive, or resistive, he may be alarmed, uncertain about his competency, living in a past reality, using adaptive paranoia or simply “at the end of his rope.” He may also misunderstand events or feel you are invading his personal space.

Graham Stokes is an English clinical psychologist who has written extensively about dementia (See *Resources*). He was an early convert to the idea that the behavior of people with Alzheimer’s disease has logical explanations that reflect what is happening around them. For example:

- **Defensive reaction to entering one’s personal space.** If you enter the room of a person with Alzheimer’s disease to help him get dressed, he may become agitated or even aggressive if he a) doesn’t recognize you, b) doesn’t see a need for a change of clothing, c) feels rushed, or d) is tired, afraid, or embarrassed. People with AD may also try to protect their personal space in crowded areas such as dining rooms and elevators. Calming defensive reactions requires slowing down, introducing yourself, and patiently explaining each step in the care process.
- **Alarm.** A person may also be surprised by someone who approaches unexpectedly from the side, from behind, or simply too rapidly. Remember that people with AD usually have a loss in peripheral vision and are often unsure of where they are. In addition, many older adults have vision and hearing losses that cause them to be easily startled.

- **Competency questions.** Sometimes, out of pride, people deny they need assistance even when they do. At other times, they know they can’t do what is being asked or fear that they won’t be able to. This can cause them to refuse to participate or say they aren’t interested. As one caregiver noted, “If she says, she doesn’t want to get out the dishes or make the coffee, I’ve learned to recognize that she probably knows she *can’t* do it.” When this happens, try not to challenge the person’s sense of competency.
- **Misunderstanding events.** A frail, confused person still living at home, for instance, may perceive a community nurse, even one who visits regularly, as an unwelcome intruder.



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CAREGIVER TIPS

BRIEF ADVICE

You may be a fabulous caregiver and still be surprised by a person's agitation or aggression. When this happens, try this:

- Stay calm in voice and body language.
- Back off. Respect the person's personal space. Offering regular opportunities to be outdoors often helps with this issue by creating a natural daily "cushion of air."
- Keep others away. Crowds — or feeling crowded — can increase agitation.
- Provide reassurance and a sense of safety.
- Ask the person directly what is troubling him. Try to identify the unmet need or the reason for his discomfort.
- Listen to his complaints; affirm the feelings behind his words or behavior.
- When possible, solve the problem.
- Provide alternatives or redirect attention. Remember the magician and the jester. What brings him pleasure? What will make him smile?



Why is he doing that? Look at the situation.

FROM PAGE ONE

- **Reality confrontation.** As their disease progresses, people with AD frequently live in a past reality and may perceive themselves as decades younger. A woman who believes she must return home before her children arrive from school will be understandably upset if you try to tell her that her children are long grown. At first she might ask, "Why don't you believe me?" If you persist in ignoring her concerns, she may become increasingly agitated. Anxiety and agitation are also likely to be provoked if a woman who believes she is a young bride is told that her husband has died.
- **Adaptive paranoia.** This is something we all do. When we find that our keys are not in the little tray on the entryway table where we usually leave them, the first thing we wonder is, "Who took my keys?" We perceive ourselves as reasonable, competent, orderly people, and if our keys are not where they "should" be, it is certainly someone *e/lse's* fault. It should be no surprise then when someone with AD accuses us of taking his money, wallet, or anything else he has misplaced.



- **The back-breaking straw.** We have all had the experience of absolutely "losing it" over some minor irritant after handling a dozen far more significant challenges earlier in the day. Everything a person with Alzheimer's disease does requires exhausting concentration, so an unexpected change in the routine, a forgotten name, or a shoe that won't tie properly can be enough to cause a surprising outburst that is entirely justified in their minds.

KEEP IN MIND: DON'T OVERLOOK PERSONALITY

Let's face it: "Be yourself" is not good advice for everyone. Some people have always been crotchety, and neither age nor Alzheimer's disease changes them. A person who had a life history of intolerance for particular groups of people may rudely voice her prejudices as her disease progresses. Another who has spent a lifetime being bitter may continue to complain. Some people resist every effort you make to please them, but the more you know about them, the more sense their reactions to a situation will make.

On the other hand, some people with AD really do experience personality changes. Sometimes they become anxious and easily

upset by the losses they experience early in the disease process, but later, as they forget what they have forgotten, they often become more easy-going.

Either way, never give up on kindness.

Key Points:

Some people have never had appealing personalities and never will. Be kind anyway.

Some people who are anxious early in the disease process may soften over time. They need kindness in all stages.

How do you know the real reason?

When a person with Alzheimer's disease and limited verbal skills has a problem, figuring out the cause can be challenging. In her book, *Individualized Dementia Care* (See Resources), Joanne Rader notes that caregivers must take on four roles: magician, detective, carpenter, and jester.

The *magician* turns herself into the person with AD. As we described in the previous issue, she learns to dance in the shoes of her care recipient by asking: Who is the *person* with the disease? What are his likes and dislikes? What comforts him? What upsets him? What is his life story? What were the significant influences on his life? Realizing a certain shirt feels itchy to him, that he dislikes asparagus, that he is unsteady on stairways, and that loud noises remind him of his wartime experiences makes it easier to determine potential causes of discomfort, as well as ways to prevent it from occurring in the first place. Knowing the person is often more important than understanding the disease.

When the cause isn't obvious, it can be useful to literally put yourself in the place of the person with AD. Joanne described a resident who wouldn't stay in bed at night and was having trouble sleeping. An aide lay down in the resident's place and discovered that a light from the hall shone directly into her eyes. When the light was removed, the resident slept fine. By lying in the resident's bed, the aide assumed the second role: *detective*. Think of the problem as a game of Clue or as a *CSI* mystery. If a resident has urinated in the plant in the library, what are the possible reasons? Was he having trouble



finding the bathroom? Does he have a urinary tract infection or increased confusion? Does he need clothing that is easier to manipulate or increased toileting assistance?

There are five basic questions detective caregivers answer to better understand why problems occur:

- **When** did it occur? (If it has happened more than once, how often? Is the timing consistent?)
- **Where** did it occur?
- **Who** was present?
- **What** happened immediately before? What was the context of the event?
- **Why** might it have occurred? (Have you noticed anything that either prevents or aggravates it?)

Note that answering these same questions when something positive has happened with a person with AD will help you to maximize the person's good experiences, thereby making caregiving more satisfying.

The role of the *carpenter* is to build a solution. All solutions may not be perfect, but using a variety of tools and teamwork, workable solutions can be achieved. If a solution falls short, be open to re-evaluation and adjustment.

The last role is *jester*. People with AD usually appreciate humor throughout the disease process. Think of ways to add fun to daily tasks. Joanne mentioned a nurse who wore a clown nose for greater success while distributing medications, another who made rounds with a parrot on her shoulder, and a third who used hand puppets to draw out a depressed resident. Fun fuels the brain, so gas up!

KEY POINTS

- | **When a person with AD has difficulty expressing his unmet needs, become a *magician* — put yourself in his shoes; learn all you can about him.**
- | **When faced with a specific challenge, become a *detective*: ask where, when, who, what, and why.**
- | **Become a *carpenter* and build a solution with your team. If the solution doesn't work perfectly, modify the blueprint.**
- | **Finally, become a *jester*. Look for ways to lighten the atmosphere.**

RESOURCES

The two books cited in this issue are:

- *Challenging Behavior in Dementia* by Graham Stokes (© 2000)
- *Individualized Dementia Care* by Joanne Rader (© 1995)

While Stokes has been an impressive leader in English dementia care, his book, intended for clinicians, is expensively priced and frequently unnecessarily complex. The information in this issue was adapted (and simplified) from a chapter called "Taxonomies of possible explanations."

Rader also writes for professionals, but is much more accessible and reader-friendly. She is especially well-known for her work related to bathing people with Alzheimer's disease, and she was a pioneer in promoting restraint-free care.

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

Let's try an exercise called "Be whacky" that taps into your jester role. Being whacky is a variation of brainstorming which asks you to come up with as many solutions to a problem as possible. To be whacky means to think up the craziest possible ideas, with the assumption that you are simply going to have fun and that none of your suggestions is likely to be a reasonable solution.

It may sound strange, but research has shown that there is a close connection between "ha-ha" (laughter) and "aha" (solutions). Being whacky is a way of having a good time along the road to real problem-solving. Start by thinking of whacky solutions to:

- A person who isn't eating well
- A person who takes things from another resident's room
- Any other challenges you would like to address



Let's talk

The "Be whacky" idea comes from Roger von Oeck, who is a well-known consultant in the field of creative thinking. It is based on the notion that by seeing the funny side of something, you must look at it from another angle. One new angle leads to others, and creative juices begin to flow.

Try the exercise above with your group and then talk about the results. In Joanne Rader's model, the role of jester comes last, but by putting it earlier in the problem-solving process, we can often become better detectives and carpenters. A person may have a dozen reasons why he won't do something we want him to do, yet he only needs one reason to change his mind. Tapping into that reason often requires making ordinary tasks fun, interesting, or pleasurable.

A person who isn't eating well, for example, may not like the atmosphere in the dining room, the people she is seated with, or the food she is offered. Being whacky might mean imagining transporting her to a sidewalk café in Rome where she is served by a gorgeous young Italian waiter who sings to her as he serves her exquisite linguini alfredo and tiramisu. While the entire fantasy is not possible, incorporating *parts* of it (Italian music, a plate of linguini, etc.), can transform a mundane task into an adventure.

Answer Key for Quiz on Page 5

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

QUIZ: Motivation — Part 2

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) People with AD may become anxious in a variety of specific situations. Which of these is NOT likely to be one?

- a. We are invading their sense of personal space.
- b. We have come upon them too quickly, from the side, or from behind, and they are startled by our sudden appearance.
- c. We have tried to bring them into our reality instead of accepting their reality.
- d. We are walking outdoors with them on a cloudy day.
- e. We have given them a task to do which they are not certain they can do alone

2) Many of the situations that produce anxiety in people with AD may also produce anxiety in us. Which of the following is LEAST likely to be a problem for most of us?

- a. The back-breaking straw (A minor incident that sends us "over the edge")
- b. Reality confrontation
- c. Adaptive paranoia
- d. Having our competency called into question
- e. Having our personal space invaded

3) The role of the magician is to put herself into the mindset of the person with AD. That requires first and foremost knowing the person (his life story, routines, preferences, etc.) Understanding Alzheimer's disease is secondary to knowing the person.

- a. True
- b. False

4) The role of the detective is to figure out what caused the person's discomfort and how to prevent that discomfort in the future. Assume that a person does not want to take a shower. Which of the following questions is LEAST likely to be relevant toward putting him at ease?

- a. Does he feel unsafe standing in the shower?
- b. Is the temperature of the room or water uncomfortable?
- c. Is he embarrassed accepting assistance from a female caregiver?
- d. Is he accustomed to only taking baths and only on Saturday nights?
- e. Does he like swimming?

5) One way to help people feel safe is to keep them indoors as much as possible.

- a. True
- b. False