



► Discover how significant losses in memory can appear normal in people with moderate dementia

PAGE 1



► “Caregiver Tips” offers practical suggestions for caring for people with Alzheimer’s disease

PAGE 2



► Learn more about about late-stage Alzheimer’s disease and the important role of caregivers

PAGE 3



► The “Trainer’s Corner” helps you relate the topic to caregivers’ personal experiences

PAGE 4



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

BEST PRACTICES IN RESIDENT-CENTERED CARE

○ VOLUME 3 | ○ 2008

Typical Strengths and Losses in Moderate Dementia

KEY POINTS

○ | People in the middle stage of Alzheimer’s disease are not safe to live independently. They often live in a past reality, believing they have long-gone work and family responsibilities. They have increased challenges with language, numbers, judgment, and visual-spatial issues.

○ | The strengths of early-stage AD — being helpful, social, and polite and showing pleasure, affection, and compassion — tend to remain throughout the middle stage, but may be expressed more through actions than language.

Many people with a loved one who develops Alzheimer’s As you learned in the previous issue of this newsletter, Alzheimer’s disease is marked by a progressive loss of abilities that is described in stages. In the last issue, we covered the early stage which is synonymous with stages 3 and 4 of Dr. Barry Reisberg’s Global Deterioration Scale. This issue will focus on Reisberg’s stages five and six, corresponding to middle-stage dementia, as well as stage seven, which is equivalent to late-stage dementia. Remember that while these stages represent typical patterns of progression, each person with AD remains a unique individual.

People in the early stage of Alzheimer’s disease are usually aware of changes in their memories and abilities, but they do their best to conceal or make excuses for those changes and continue to “get by” with relative independence. By the middle stage, however, they are no longer safe living alone. At this stage, some older adults continue to live with a spouse or an adult child, while others enter a residential care community. Some also spend their days at a respite or adult care center, where they can participate in structured activities.



People in the *early* middle stage of AD often appear “normal.” In actuality, however, they have significant losses in memory, judgment, and visual-spatial skills. For example, they:

- Have difficulty cooking for themselves, may accidentally start fires on the stove, or fail to recognize when food in the refrigerator is spoiled. Unable to operate stoves and microwave ovens, they may become malnourished.
- May forget to take medications or take them too often.
- Have lost their sense of time or float in and out of reality — so that they often see themselves as much younger, with responsibilities for work and family that ended decades ago. This is the stage when they are most at risk for walking away from home, often with the intent to meet perceived responsibilities, such as getting home to make dinner for the children or going to work on time.
- Cannot carry out multi-step tasks independently and, therefore, may lose the initiative to try.
- Lack the judgment, reaction time, and visual-spatial skills to drive safely.

CAREGIVER TIPS

BEING A MIRROR

There is an old saying, “Everyone you meet is your mirror.” If you greet others with a smile, they tend to respond with a smile. If you are rude, they tend to be rude in response, and so on. This is especially true for people with Alzheimer’s disease. They react to our anxiety or discomfort with the same emotions, and surprisingly, they tend to have excellent radar for fake cheerfulness. It’s as if they gain emotional intuition to offset losses in verbal skills.

To this end, we can either distance ourselves when we’re feeling unhappy or share our feelings and deepen our relationship with the person. Yet, people with AD are amazingly forgiving of our flaws and fumbles. They know they aren’t perfect, and they don’t expect us to be either. It’s one of their gifts to us.



Typical Strengths and Losses in Moderate Dementia

FROM PAGE ONE

In the *late* middle stage (Reisberg’s stage 6), people usually pay less attention to their appearance, and being comfortable becomes the priority. They require more assistance with dressing, grooming and bathing, so they often face these tasks reluctantly. While they should still be given choices about their preferences, they function best with simplified or limited options. For example, instead of asking an open-ended question — such as “What would you like to wear?” — an alternative such as “Do you want the blue dress or the flowered dress?” offers a more manageable choice.



Like those with early stage AD, people in the middle stage of AD retain their ability to:

- Be helpful and active
- Be social and polite
- Experience pleasure and enjoyment
- Show affection and compassion
- Express a full range of emotions
- Tap into their sense of humor

When they are loved and accepted unconditionally and treated with respect, many people with moderate-stage AD experience a

good quality of life. They often continue to enjoy social activities and may make gracious hosts at events; however, they may tire easily and need frequent periods of rest. Most love to be helpful, and progressive caregivers have found inventive ways for them to volunteer. Many tend to have a heightened sensitivity to the feelings of others and can be empathetic when, for instance, a caregiver is having a bad day. They enjoy humor and positive mental stimulation. Cameron Camp, Ph.D., director of the Myers Research Institute near Cleveland, has even had success in forming comedy clubs and reading groups with people with moderate AD.

KEEP IN MIND: AFFIRM, SLOW DOWN, AND SIMPLIFY

Many years ago, Virginia Bell, co-author of the “Best Friends” series of books on Alzheimer’s care, developed an unprecedented day program for people with Alzheimer’s disease that is still going strong. Certainly not everyone can replicate the one-on-one volunteer staff that is the program’s hallmark, but the atmosphere has three key elements that can enrich any setting:

- 1 Affirm
- 2 Slow down
- 3 Simplify

In Bell’s program, each person is accepted unconditionally. Everyone is cheerful and relaxed, and no one is rushed. Laughter abounds. Directions are simplified, but the atmosphere is

adult-level and stimulating. While the pace of activities is slowed and directions are given one at a time, activities are neither simple nor juvenile. For example, paper making, pottery classes, and charades were among the successful activities offered in Bell’s program.

Key Points:

One of the best things we can do for people with AD is something we hope they will do for us, too: accept them as they are, in spite of their imperfections.

Slowing the pace of activities and simplifying directions does not mean we have to offer simple activities. Don’t underestimate the abilities of people with AD.

Typical Strengths and Losses in Late-Stage AD

There is currently no cure for Alzheimer's disease, so, sadly, the late stage ends in death; however, caregivers have the power to bring pleasure and positive experiences to those living with AD every day.

People in the late stage have an abnormal appearance. Their expressions are blank, and gaining and holding their attention is difficult. Those still able to speak have a severely limited vocabulary or may only be able to produce unintelligible sounds. They have increasing problems with vision and proprioception, which means understanding where their body is in space. Thus, it is increasingly difficult for a person in late-stage AD to follow directions like "sit down" or "turn around," and simple tasks, such as trying to get a person into a car, can take 10 minutes or more. They are often unsure of their footing, in part because most tilt to one side when they walk, which creates balance problems. They may also walk about with a downward gaze, taking their cues from the floor. Because they retain little depth perception by this stage, they may interpret dark carpeting as a hole and refuse to walk over it. Eventually, most people become bedridden as they sleep for increasingly longer periods and their legs lose the strength to support their weight.

Consequently, people in the late stage of AD are totally dependent on others for virtually all aspects of their care. They cannot bathe or dress themselves, and they experience bladder and bowel incontinence. Eventually, they forget how to feed themselves and must be hand-fed. Death may result from swallowing difficulties, which precipitate the aspiration of food into the lungs; however most people with AD can experience a peaceful death, surrounded by a loving community. (See "Resources".)

It may seem odd to talk of joy in the late stage of AD, but joy appears amazingly possible. Roseann Kasayka, Ph.D., was a therapist in music and the healing arts who did a great deal of work related to end-of-life issues. Before her untimely death, she became fascinated by the fact that comparative brain scans of Buddhist monks in deep meditation and people in the late stage of AD were remarkably similar. Perhaps

some people with AD experience a peacefulness and tranquility we don't yet understand. Kasayaka's other work focused on the positive impact loving touches (hugs, hand massages) and music have on those with late-stage AD.



One explanation of how people with AD lose skills is the reverse of Piaget's theory of childhood development: People lose skills in the order reverse to how they acquired them. One of the first things a baby learns to do is smile, and one of the last things a person with AD loses is the ability to smile. Thankfully, many in the end stage of AD continue to know joy and to appreciate those who love them.

KEY POINTS

- | **People in the late stage of Alzheimer's disease are totally dependent on others for their care.**
- | **Their chief challenges are with language (speaking and comprehending) balance, vision, and proprioception (knowing where their body is in space).**
- | **Nevertheless, they still enjoy music, loving touches, and kindness. They can use a universal form of human interaction — smiling — until nearly the day they die.**

RESOURCES

To learn more about the stages of Alzheimer's disease and the remaining strengths in people who have it, try these:

www.alzheimer.ca/english/disease/progression-gdscale.htm

www.alz.org — go to the "Alzheimer's Disease" heading and look under "Stages." *Alzheimer's Basic Caregiving* by Kathy Laenhue (www.wisernow.com © 2006)

Reach Cameron Camp, Ph.D., through the Myers Research Institute's website (www.myersresearch.org) or by calling 888-693-7774.

Two excellent resources for learning more about end-of-life issues and helping people with AD to a peaceful death are:

The End-of-Life Namaste Care Program for People with Dementia by Joyce Simard © 2007. Available from Health Professions Press (www.healthpropress.com or 888-337-8808) or Amazon.

Hard Choices for Loving People by Hank Dunn (a former Hospice chaplain) is an inexpensive booklet available through his website www.hardchoices.com or by phone 571-333-0169.

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

Choose three of the following activities (or make up one of your own). What parts might someone with AD still enjoy? How could you simplify the activity so the person might still feel satisfaction in participating?

- | | |
|---|-------------|
| Bird watching/feeding birds | Bowling |
| Collecting antiques or classic cars | Cooking |
| Dancing | Painting |
| Playing the piano (or other instrument) | Woodworking |
| Word games | |



Let's talk

Jitka Zgola is an occupational therapist and the author of several books. *In Care That Works* (© 1999, page 177), she describes ways to engage people whose abilities are diminished. Among her recommendations for people with Alzheimer's disease are activities that use familiar movements, have a strong rhythmic component, and consist of one repetitive step. She also suggests a potential hierarchy of involvement according to abilities.

For example:

- An independent person who wanted to bake cookies could choose a recipe, shop for the ingredients, and bake the cookies.
- A less able person might be able to pour or stir the ingredients; another might put spoon-sized dollops of the mix on a cookie sheet.
- Someone who couldn't actively participate might announce when the oven timer went off or talk about a cookie-baking experience she had.
- Finally, at the very least, a highly disabled person could still give an opinion — Are the cookies tasty?

Using Jitka's guidelines, talk about participants' responses to the exercise from "Bringing the Lesson Home," and try to draw out as many more ideas as possible. Encourage them to practice this idea with aspects of dressing, bathing, and grooming.

Answer Key for Quiz on Page 5

1) c 2) d 3) d 4) a 5) a

QUIZ: The Stages of Alzheimer's Disease

PLEASE COPY AND DISTRIBUTE TO EACH PARTICIPANT

First Name

Last Name

Quiz Date

Supervisor's Signature

Date

**ALZHEIMER'S
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800.258.7030

703.319.9097 fax



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

1) By the time people are in the middle stage of Alzheimer's disease, they are no longer safe living independently. Which of the following is NOT likely to be a risk to their safety?

- a. Driving
- b. Cooking on a gas or electric stove
- c. Buying the wrong ingredients for a recipe
- d. Leaving home and getting lost
- e. Accidentally overdosing on prescription medications

2) In spite of the increasing disabilities that come with middle-stage Alzheimer's disease, with varying assistance, people can still participate in many activities. Which of the following are examples mentioned in this issue?

- a. Participating in a comedy club or reading group
- b. Being a host at an event
- c. Volunteering
- d. All of the above
- e. B and C only

3) People with late-stage Alzheimer's disease have problems with vision and proprioception, which means understanding where their body is in space. Which of the following would likely be challenges caused by this disability?

- a. Going from a standing to a sitting position (onto a chair or toilet seat, into a car)
- b. Differentiating shadows or dark spots on the carpet or tile from holes
- c. Maintaining one's balance on an uneven surface such as gravel
- d. All of the above
- e. A and B only

4) Even in the late stage of AD, people can find pleasure from hand massages, music and other comforting activities.

- a. True
- b. False

5) People with Alzheimer's disease often seem to have a heightened ability to recognize others' feelings.

- a. True
- b. False