



► *Personal preferences are frequently overlooked*

because of memory loss

PAGE 1



► *“Caregiver Tips” offers practical suggestions for caring for people*

with Alzheimer’s disease

PAGE 2



► *Explore the progression of Alzheimer’s disease and how it*

is often measured in stages

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

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Strengths and Losses in Alzheimer’s Disease: Emphasize the Positive

KEY POINTS

- | **Caregivers can best support persons with AD by focusing on their remaining abilities, rather than defining them by their losses.**
- | **Persons in the early and middle stages of AD often maintain the ability and desire to remain helpful and social, to show affection, and to appreciate humor.**
- | **Especially in the early stage of AD, those with the disease are aware of their increasing problems and often feel frightened, frustrated, and embarrassed.**

Think for a moment about your best qualities — the things about you that make you a uniquely likeable individual. Maybe you’re wildly creative and artistic. Maybe you have endless patience and a calming influence on others. Maybe you’re fiercely loyal to those you love. Maybe you have an extraordinary sense of humor and a contagious laugh. Or maybe you’re the best cook in your family.

Now, imagine that you were to unexpectedly receive a diagnosis of Alzheimer’s disease. Imagine that suddenly people close to you stopped concentrating on all of your terrific qualities, instead describing you simply as a person with Alzheimer’s disease.

Unfortunately, when people are diagnosed with Alzheimer’s disease (AD) or another form of dementia, their personalities, life experiences, and preferences are frequently overlooked because of their memory loss. Even family members, friends, and other caregivers with the best of intentions often disregard or misinterpret the communication of people with AD, assuming that it is misguided or meaningless.

Although dementia is progressive, which means it gets worse over time, people in the early and middle stages of Alzheimer’s disease are quite capable of actively participating in — and enjoying — their lives.

For instance, a person with early-stage



Alzheimer’s disease may have trouble balancing her check book, but she may still be able to make a grocery list. Another person may become confused when trying to operate a washing machine but still be able to fold and put away his own clean clothes.

When people are tested for Alzheimer’s disease, they are frequently asked to name the day and date, draw the face of a clock, and count backwards by 7s from 100. Often they can’t do any of those things. Yet they may be able to remember the words to a song they learned as a child, to savor a really delicious piece of chocolate cake, or to appreciate the beauty of a classic automobile.

CAREGIVER TIPS

Whenever talk turns to the early signs of Alzheimer's disease, many of us start looking for it in ourselves. We might wonder whether misplacing our keys, forgetting the name of an acquaintance, or accidentally leaving the refrigerator door open could be signs that we are developing Alzheimer's disease. In asking these questions, it is important to understand:

1. Our forgetfulness is probably caused by stress.
2. Alzheimer's disease causes serious forgetfulness. People with AD will open the refrigerator door, forget their desire, and walk away, leaving the door open. We close the door, start to walk away, and remember within seconds what we were looking for.
3. People with AD may be offended when we make light of their illness with phrases like, "senior moment" or "old timer's disease." Those living with AD need to know that we take their feelings and concerns seriously.



Strengths and Losses in Alzheimer's Disease

FROM PAGE ONE

In other words, while the brains of people with AD are being continually damaged by the disease, and they need more and more help with their daily routines — eating, dressing, bathing, and so on — caregivers can protect their dignity by recognizing the distinctive personalities and drawing out the best qualities of those in their care.

Tom Kitwood is widely recognized as the originator of the idea of "person-centered care," the commonly accepted standard of quality care for people with Alzheimer's disease. He wrote that people with dementia are able to do all of the following until late in the disease process:

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

Frequently, people with AD, especially in the early stage, are aware of their increasing problems and



often feel frightened, frustrated, and embarrassed. All of us are afraid of making mistakes, but people with Alzheimer's disease have more reasons to be fearful than the rest of us.

As caregivers, we need to focus on supporting the best qualities of people with AD, rather than concentrating only on the tasks they cannot accomplish. In doing so, we enrich our own lives, as well as the lives of those for whom we care.

KEEP IN MIND: PRESERVING DIGNITY

People with Alzheimer's disease, especially in the early stage, are often very good at covering up their losses. Rather than admitting a need for assistance, those with early-stage AD may choose instead to withdraw from certain activities altogether. In an attempt to preserve their dignity, they frequently offer excuses such as, "I'm just not interested anymore."

We can help maintain the dignity of people with early-stage AD by doing the following:

- Labeling drawers and cabinets

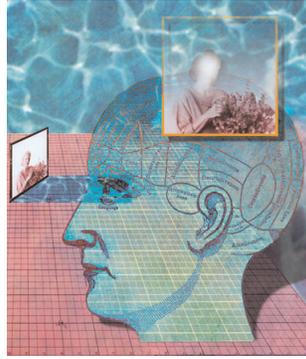
- Helping them find lost or misplaced objects
- Simplifying complex tasks into manageable steps
- Providing concrete way-finding cues ("The dining room is next to the grandfather clock," rather than, "It's the third doorway on the left.")
- Matching our speech and movement pace to theirs
- Providing opportunities to feel successful by using intact skills
- Being patient and respectful

PATTERNS OF PROGRESSION

The progression of Alzheimer's disease is often measured in stages. For many years these were simply called early, middle, and late stages, but now the National Alzheimer's Association uses "Reisberg's Global Deterioration Scale," which consists of seven stages.

Reisberg's first two stages are considered normal aging. Stages three and four are equivalent to

early-stage dementia. Stages five and six represent middle-stage dementia, and stage seven is equivalent to late-stage dementia. (Barry Reisberg, M.D., is a respected neurologist and researcher at New York University.)



with AD because it was an "overlearned" skill — something they did daily almost without thinking. Overlearned skills tend to remain intact, even as a person progresses into the middle and sometimes later stages of AD. For most of us, making a bed, washing dishes, folding laundry, and dusting are examples of overlearned skills.

Many people may also begin to experience challenges with vision, spatial relations, and finding their way early in the disease. That's why using a map or driving to the store may pose a problem. On the other hand, retired bus or taxi drivers may not experience these losses.

Similarly, people in the early stage often have trouble remembering names of people, places, and objects. Conversely, someone who has led a public life or pursued a career working with words may be able to recall names with relative ease.

Understanding typical patterns related to AD symptoms can make us more alert to changes, but they don't necessarily indicate a progression to the next stage of the disease. For example, if a person is having increasing difficulty dressing on her own, it may be a sign that she is progressing to a later stage, or she may just be having an "off" day. Similarly, sometimes people with AD are able to perform certain tasks relatively independently in the morning, but by evening, they are simply too tired to do so. A sudden change in a person's ability to perform tasks could also indicate a medical condition, such as a urinary tract infection, that needs treatment.

Although some typical patterns and symptoms exist in early stage Alzheimer's disease, it is important to remember that AD affects each person differently. Throughout the disease process, it's important to treat each person as a unique individual and to offer patience, understanding, and companionship.

A person in the early stage of Alzheimer's disease usually looks and sounds "normal" to the rest of us and may be able to hide his illness so well that we might think he is just being stubborn when he can't do something we ask. A person in the middle stage of the disease may have challenges communicating her thoughts clearly and need a great deal of cueing as well as some physical assistance to perform routine daily activities. By the later stage of the disease, the person is severely impaired. She may be unable to speak, walk, or feed herself. She is completely dependent on others.

The Early Stage

In this issue, we'll be focusing on the early stage of dementia, corresponding to Reisberg's stages three and four.

In the early stage of AD, many people experience challenges related to time and numbers, such as:

- Reading a clock
- Knowing the day and date
- Balancing a checkbook
- Making change
- Adding up a golf score (or keeping track of points in any game)
- Playing bingo

Accountants and bank tellers, however, may retain their number skills longer than other people

KEY POINTS

- | Typical losses in the early stage of Alzheimer's disease include word-finding and way-finding difficulties and trouble with time and numbers.
- | Although there are typical patterns of progression in AD, everyone remains a unique individual.
- | Knowing each individual with AD — their unique skills and interests, strengths and weaknesses — is essential.

RESOURCES

There are a number of places you can go to learn more about the stages of Alzheimer's disease and the remaining strengths in people who have it. Here are a few resources:

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 Laurenhue (www.wisernow.com © 2006)

Alzheimer's Early Stages by Daniel Kuhn (Hunter House Publishers, Alameda, CA © 2003)

Dementia Reconsidered by Tom Kitwood (Open University Press, Philadelphia © 1997)

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

Give participants the following list, and ask them to put two X's (XX) next to the item if it is very important, one X (X) if it is somewhat important, and no X's marks if it is not important at all.

When I am 80, I want to be viewed as someone who:

- | | |
|--|---|
| <input type="checkbox"/> can dress and groom her/himself | <input type="checkbox"/> has a good sense of humor |
| <input type="checkbox"/> can draw the face of a clock | <input type="checkbox"/> is kind |
| <input type="checkbox"/> can go to the bathroom independently | <input type="checkbox"/> is well-loved |
| <input type="checkbox"/> can play bingo without help | <input type="checkbox"/> loves life |
| <input type="checkbox"/> knows how to follow a recipe or a map | <input type="checkbox"/> is still going and growing |
| <input type="checkbox"/> can cook a meal and feed him/herself | <input type="checkbox"/> is still making new friends and keeping old ones |

What else do you want to be known for? _____



Let's talk

1. Try the fill-in-the-blank exercise above, and then discuss your group's answers. What is really important in your lives? (Most of us fear losing our independence, but for many, it is harder to lose friends than to accept assistance with ADLs.)
2. Think about someone you care for. What do you value most about them? How would you introduce them to someone new? (Most of us are not used to thinking of people with AD in terms of their qualities but can name them, when asked.)
3. What strengths and losses have you noticed in the people with AD you care for? (As we mentioned before, it is vital to recognize both their abilities AND where they need help.)
4. Have you noticed differences in how well a person functions depending on the time of day? Talk about it. (Have you noticed it in yourself, too?)
5. Think of a time when your patience really paid off during a caregiving situation. Think of a time when you wish you had been more patient. Share your experiences with others.
6. Think of someone you care for who has AD. In two minutes, write down everything you know about that person's life, his or her family and friends, career, hobbies, likes and dislikes, and any other personal information you know.

Answer Key for Quiz

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

QUIZ: Strengths and Losses in Alzheimer's Disease

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) Alzheimer's disease is a progressive disease that gets worse over time.

- a. True
- b. False

2) In the early stage of Alzheimer's disease, people often have problems with:

- a. Telling time
- b. Tasks involving numbers
- c. Remembering names of people, places, and objects
- d. All of the above
- e. A and B only

3) People with Alzheimer's disease frequently retain many strengths. Among them are the abilities to:

- a. Be social, polite
- b. Show affection and compassion
- c. Memorize sequences
- d. All of the above
- e. A and B only

4) Which of the following is NOT good advice for someone who is caring for someone with AD?

- a. Let the person with AD set the pace of conversation and activities
- b. Make light of the disease ("Senior moments happen to all of us.")
- c. Be patient
- d. Know the person as an individual, including both his or her strengths and weaknesses
- e. Strive to bring out the person's best qualities

5) Protecting the dignity of people with AD is important only in the early stage because that's when they are most embarrassed and frustrated by their losses.

- a. True
- b. False