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## Learning Resource Guide

### Coping With Alzheimer's Disease

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## ElderCare Online's Learning Resource Guide Coping With Alzheimer's Disease

### Table of Contents

|   |    |
|---|----|
| • Introduction                                  | 3  |
| • Chapter 1: Memory Changes in Normal Aging     | 4  |
| • Dementia and Alzheimer's Disease              | 4  |
| • The Importance of Medical Screening           | 5  |
| • Three Stages of Alzheimer's Disease           | 5  |
| • Stage One: Early                              | 5  |
| • Stage Two: Middle                             | 6  |
| • Stage Three: Late                             | 7  |
| • Chapter 2: Communication                      | 8  |
| • Nonverbal Communication                       | 8  |
| • Verbal Communication and Language Changes     | 9  |
| • Communication in Alzheimer's Disease          | 9  |
| • 11 Steps to Improved Communication            | 11 |
| • Chapter 3: Personal Care                      | 13 |
| • Common Difficulties                           | 13 |
| • General Suggestions                           | 13 |
| • Managing Behavior Problems                    | 14 |
| • Understanding Problem Behaviors               | 15 |
| • Guidelines for Dealing With Problem Behaviors | 16 |
| • Chapter 4: Activities                         | 17 |
| • The Benefits of Activities                    | 17 |
| • Types of Activities                           | 17 |
| • Exercise                                      | 17 |
| • Music   | 18 |
| • Games   | 18 |
| • Arts and Crafts                               | 18 |
| • Reminiscing                                   | 19 |
| • Pet Therapy                                   | 19 |
| • Spiritual Activities                          | 19 |
| • The Arts                                      | 19 |
| • Gardening                                     | 19 |
| • Tips and Techniques                           | 20 |
| • Chapter 5: Family Issues                      | 21 |
| • Common Family Issues                          | 21 |
| • Immature Promises                             | 21 |
| • Isolation                                     | 21 |
| • Family Conflicts                              | 22 |
| • Missing Skills                                | 22 |
| • Unrelated Problems                            | 22 |
| • Guilt   | 22 |
| • Acting Out Feelings                           | 22 |
| • Chapter 6: Resources and Support              | 23 |

## Reader Notice

This publication discusses tips and techniques for caregiver to understand and cope with the dilemmas of caring for an elder with Alzheimer's Disease. It is not a medical guide, even though it discusses a prevalent medical condition. For additional information, including diagnosis of Alzheimer's Disease, contact your physician or other qualified medical professional. This document is for educational purposes only.

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## Introduction

People who care for individuals with Alzheimer's Disease can find their work frustrating, lonely and thankless. The disease is confusing. Its symptoms can be quite different from person to person, and even from day to day. Caregivers may find themselves dealing with a person who is quite lucid in the morning, then confused, angry and scared in the afternoon. Just when a caregiver thinks she has a person figured out, he'll change, showing a different effect of the disease. The ability to both understand and use language begins to slip away, making communication difficult.

The frustration and confusion experienced by people with Alzheimer's Disease sometimes show up as problem behaviors such as wandering, rummaging, sleeplessness or hostility. Caring for an elder with Alzheimer's Disease requires patience and understanding, as well as the time and ability to listen.

## Chapter 1: Memory Changes in Normal Aging

For most people, aging brings with it some mild memory problems. The ability to store and recall information changes as we grow older. New information must be meaningful and important to be remembered easily. It becomes harder to learn bits of information or lists of words that have no context.

People as young as 45 or 50 can begin to feel their memories slipping. As people enter middle age, they need to focus on new information and link it to something meaningful if they want to recall it later. They may have trouble remembering names or appointments. Many people at this age begin to use tricks to help jog their memory. They link new information to a meaningful object, person or event. They may repeat the new information a few times. Some people begin keeping lists of appointments, or pick a single place to leave their keys and other important items.

Older people can help improve their memories if they:

- Take enough time;
- Think about the new information;
- Focus on the details of the new information;
- Repeat the new information out loud;
- Link new information to past memories;
- Practice using the stored information.

As people pass the age of 75, their metabolism seems to slow down. The process of storing and recalling information takes more time. For example, it can take more time to think things through to make a decision. This slowing down is normal and does not constitute Alzheimer's Disease. Normal memory problems can be described as "forgetfulness." They are mild, and the memory can be easily jogged. They do not get worse over time.

### *Dementia and Alzheimer's Disease*

The memory loss seen with Alzheimer's Disease and other forms of dementia is not simply forgetfulness and is not normal. Dementia is a medical term that describes a group of symptoms and behaviors shown by people with Alzheimer's Disease and a number of other disorders. A person with dementia has lost the ability to think, remember and reason to the point where he or she needs help with daily activities like cooking, dressing or bathing. Dementia also can lead to changes in mood, personality and behavior.

Alzheimer's Disease is the most common form of untreatable, irreversible dementia. It affects more than four million people in the United States and one out of every three families. Alzheimer's Disease is a degenerative disease that attacks the brain. It affects memory, thinking and behavior, and it gets worse with time. While the disease's beginning symptoms are different from person to person, it always causes a slow decline and eventually the need for long-term care.

Alzheimer's Disease causes physical damage to brain cells that make it harder for messages to be formed or sent from one brain cell to another. Alzheimer's Disease is: not normal to aging; not contagious; not caused by aluminum pots and pans. It is not simply forgetfulness. Forgetfulness does not get progressively worse and does not interfere with daily living.

The symptoms and progress of Alzheimer's Disease vary greatly from person to person. That's because the disease can affect different parts of the brain in each person and progress at different rates. This is further complicated by differences in each person's personality, education, cultural background, occupation and other medical problems.

Alzheimer's Disease is found in both sexes, all races and in people of every social, economic and environmental background. Alzheimer's Disease usually begins later in life, but people in their 40s and 50s – and even younger – have been diagnosed with Alzheimer's Disease.

### ***The Importance of Medical Screening***

Alzheimer's Disease is not the only cause of dementia. More than 100 causes of dementia have been identified and many of them are treatable. Ten to 15 percent of memory disorders are caused by changes in thyroid balance, a vitamin deficiency, inappropriate use of medicines, depressions or some other condition that can be medically treated. A careful medical evaluation with a series of tests must be conducted to find the precise cause.

Alzheimer's Disease is identified by excluding all other causes for the symptoms demonstrated. Testing will include:

- A medical and neurological evaluation to identify illness or infection that may cause dementia;
- A psychiatric evaluation to rule out depression or other stress that may interfere with normal function;
- Taking pictures of brain tissue using computer tomography (CT), magnetic resonance imaging (MRI), single positron emission computerized tomography (SPECT), an electroencephalogram (EEG), blood studies and urinalysis;
- An extensive psycho-social exam to look at family dynamics, employment and financial history, educational background, marital status, etc.

There is a great deal of research being done to determine the cause, treatment and prevention of Alzheimer's Disease, but at this point, science simply doesn't know what causes Alzheimer's Disease, or how to best treat or prevent it.

### ***Three Stages of Alzheimer's Disease***

Alzheimer's Disease is usually described as having early, middle and late stages. The rate at which a person will progress through the stages is unpredictable, and can take anywhere from two to 25 years. Stages very often overlap.

#### **Stage One: Early**

The afflicted person may or may not be aware that they are having difficulties. Lists and other reminders can help their changing ability to remember. A routine schedule and routine ways of doing tasks can also be helpful.

Often the person and caregiver do not realize there is a health problem at this point. They may feel that fatigue, extra stress, fickleness, stubbornness or laziness are causing the problems.

1. Memory Loss: The elder may begin to have problems recalling daily events, while long-term memory remains intact. S/he may repeat questions or recent comments, get lost in conversations and misplace things;
2. Disorientation: There is often a decline in the sense of direction. The elder may get lost in a familiar neighborhood or be unable to follow directions to the store. There may be a decline in the sense of time, such as being unable to remember appointments or the actual date;
3. Apraxia: The elder may forget how to use a tool or find it difficult to use tools or equipment, such as appliances, a toothbrush or eating utensils;
4. Anomia: The person may forget the right word or name of a person. The words may feel at the tip of the tongue, but the speaker is not able to say them;
5. Personality Changes: The person may seem different. S/he may be more withdrawn, frustrated, irritable, mellow, sensitive or inconsiderate of others;
6. Trouble With Routines: There is less ability to keep up with the daily routine at work or at home. S/he may forget what bills have been paid, or be able to handle office finances or telephone calls. At home, they may find it difficult to use a checkbook or prepare meals;
7. Decline in Grooming: There is a decline in grooming or personal hygiene. A previously well-groomed person may be untidy, unbathed or have uncombed hair.

### **Stage Two: Middle**

By Stage Two, it is obvious that “something is wrong” and that a medical evaluation is necessary. Sometimes the person with Alzheimer’s Disease may be unaware of the decline. Even the person who is aware of changes become less aware as time passes. The unpredictability of the decline and changing ability of the person to function from day to day can increase caregiver stress.

Symptoms become more severe in Stage Two and often include:

1. Poor Short-Term Memory: After completing a meal, the elder may ask, “When do we eat?:”
2. Disorientation to Person, Place or Time: A person in this stage may not know the name or relationship of a close relative or think that the current time is 10 to 30 years ago;
3. Inability to Perform Skilled Movements: The person may be unable to use eating utensils, tie shoelaces or operate the washer or stove;
4. Language Difficulties: It may take more effort to express ideas or needs with major word-finding problems; sentences may not make sense; speech may be slow;
5. Social Withdrawal: The elder may feel uncomfortable or awkward in new places or with groups of people, be socially dependent on caregivers and feel depressed;
6. More Spontaneity, Fewer Inhibitions: There may be inappropriate comments to friends, questions to strangers or an attempt to undress in a public place;
7. Agitation: An elder may exhibit anger or anxiety if unable to express needs or when faced with confusing situations. Frustration may lead to verbal or physical outbursts, such as yelling or throwing furniture;
8. Restlessness, Fidgeting, Pacing or Aimless Wandering: The person may feel restless in a chair and unable to sit for any length of time. S/he may wander around the house or pace the hallway;
9. Sleepiness: The person may be slow-moving and sleepy. S/he may sleep 10 hours at night and nap during the day. The person may even nap while sitting during a meal;

10. Severe Sleep Disturbances: Some people sleep 14 to 16 hours a day. Others sleep only two to four hours each night with or without daytime naps. Some mix up the day/night cycle;
11. Need for Assistance: Supervision and assistance with activities of daily living must be available, although it may not be needed constantly. For example, help may be needed with parts of dressing or just getting started at the task;
12. Sundowning: As the sun goes down, the confusion increases;
13. Hallucinations or Delusions: There may be evidence of hallucinations or delusions toward the end of the day, in the middle of the night or with some people at any time. The experience may be unpleasant or frightening;
14. Changes in Eating Habits: The person may experience erratic eating, weight loss or gain, for example.

### **Stage Three: Late**

Changes in the nervous system are seen through simple reflex actions. The person startles easily with sudden, loud noises; grasps onto objects or people and does not let go, especially during a handshake; and sucks on objects.

A person with Stage Three Alzheimer's Disease is totally dependent on the caregiver. The caregiver provides constant supervision and assistance with all activities of daily living: toileting, eating, dressing, bathing and mobility. It is absolutely essential that the caregiver have regular respite during this stage.

In this stage, a person will need constant supervision and assistance, Symptoms include:

1. Little to No Memory: Short- and long-term memory are severely impaired;
2. Great Difficulty Communicating With Others: The person may be unable to speak or understand words;
3. No Recognition of Family or Friends: The person may not recognize him or herself in the mirror. They may think that their spouse is a stranger or the person in the mirror is a stranger;
4. Need for Assistance: The person needs assistance with activities or interactions;
5. Difficulty Remembering How to Eat: The person may have difficulty coordinating the steps of biting, chewing, swallowing, etc. Despite good nutrition and meal supplements, typically there is weight loss;
6. Loss of Bowel and/or Bladder Control;
7. Difficulty With Coordinated Movements: The person may walk unsteadily. Fumble when grasping objects, to be unable to hold onto objects;
8. Increased Frailty: Muscles may weaken and people are susceptible to infections and other physical illnesses;
9. Upset Sleep Cycle: The person may be able to sleep only with the help of sleep medications.

## Chapter 2: Communication

Effective communication, both verbal and nonverbal, is essential to quality care. The breakdown in communication between a person with Alzheimer's Disease and his or her caregiver leads to frustration. For caregivers, living with a person who no longer remembers them and their relationship is painful. Understanding the language and communication problems that occur with Alzheimer's Disease can help caregivers develop realistic expectations and improve communication as the disease progresses.

People communicate both verbally and nonverbally. Verbal communication is an exchange of words or noises that express thoughts or emotions. Nonverbal communication consists of gestures, facial and body expressions, touch and tone of voice.

Memory disorders such as Alzheimer's Disease affect the ability to use and understand both nonverbal and verbal communication. People with Alzheimer's Disease do not understand information coming to them. While their sense of hearing and eyesight may be fine, the brain systems that make sense of incoming information may not be able to process it properly. What they hear, see or read may not make sense. Some information may get lost; other signals become confused. The end result is that people with Alzheimer's Disease often are unable to understand what is going on around them and may react in confused or inappropriate ways.

Effective communication requires speaking and being heard. It is important to listen carefully to people with Alzheimer's Disease, because what they say may not be easy to understand. Listen for key words and phrases which, taken alone, may not make sense, but in the context of the situation may have a great deal of meaning.

### ***Nonverbal Communication***

Nonverbal communication, often called body language, is an important part of how people communicate. Nonverbal messages are sent through gestures, body movements, facial expressions, touch, tone of voice and speed of words.

When people lose their word skills, nonverbal communication becomes critical. Sometimes people with Alzheimer's Disease who no longer understand spoken words depend on body language for their information. It is especially important that caregivers be aware of their own body language and the messages it sends. In addition, caregivers should learn to read the body language of people with Alzheimer's Disease to help figure out what their needs are and how they are feeling. Remember that a smile can help connect, reassure and calm a person with Alzheimer's Disease even after the ability to use and understand language is gone.

### ***Tips and Techniques***

1. Use all senses, such as vision, hearing, touch, smell and taste;
2. If a person seems to ignore you and is unreceptive, leave him or her alone for a few minutes. Tell the person that you understand that they want to be alone and that you will return;
3. Be sensitive to nonverbal messages. Be aware of your own nonverbal communication and use it to help calm, cheer or encourage;
4. Make nonverbal messages match your words. Smile when you greet someone and wave when you are saying goodbye;

5. Adopt positive, pleasant nonverbal behaviors to reassure and encourage. Look at facial expression and body posture to determine what is pleasurable or uncomfortable. Remember that you may be conveying emotions, such as sadness or irritation, through your actions more than through your words. If you are in a hurry, frowning or speak quickly and angrily, a person with Alzheimer's Disease will react to your emotions.

### ***Verbal Communication and Language Changes***

People with Alzheimer's Disease experience changes in their ability to use words. At first they may have a hard time finding the exact word to use in a sentence. Later, they may have a great deal of trouble finding most words and have to use many "filler" words to talk. In the latter stages of the disease, there may be very little language though they are trying hard to speak. They may use nonwords, speak gibberish and be unaware that they are not making sense.

It is important to recognize that communication is a two-way street. Effective communication requires both speaking and being heard. Caregivers must listen carefully to people with Alzheimer's Disease because what they say may not be easy to understand.

#### ***Tips and Techniques***

1. Use simple, short sentences. Organize your thoughts into the shortest sentences possible;
2. Say the person's name. Establish eye contact. Speak clearly, calmly and repeat as needed. Be aware of hearing difficulties;
3. Look for clues, such as eye contact or facial expression, that the person heard you. Does the person respond appropriately? Which of the person's words or actions are the actual response?;
4. Act out the message. Point to the object you are talking about;
5. Address the person by their familiar name or nickname.

### ***Communication and Alzheimer's Disease***

The steady loss of communication skills is one of the hallmarks of Alzheimer's Disease. The information presented in this section explains some of the behaviors and offers tips and techniques for making communication clearer during each stage of the disease.

Early in the disease, people with Alzheimer's Disease are often aware of gaps in their communication. If they are aware of language difficulties, they may try hard to cover them. They may make up stories, or act indignant, tough, stubborn, nervous or anxious. Or they may admit their difficulty coping with a particular task or problem. Many people withdraw and avoid troublesome situations that might reveal their problems with communication. They don't want others to see them fumble at a task they could once do easily.

Keep in mind that people with Alzheimer's Disease may have trouble with some tasks because they don't remember the purpose, task or instructions given to them. Sometimes all that is needed is gentle reminders.

### **Stage One: Early**

Closely related words are substituted for forgotten words. When you can't make out what a person with Alzheimer's Disease needs, point to the objects in question while asking questions like: "Do you want your purse? Your comb?" The person will have trouble understanding and following directions. Keep your sentences short and your directions clear. "Mother, fold the scarf." "Put the scarf in the drawer." "Close the drawer."

#### *Tips and Techniques*

1. Discuss important business during the morning when everyone is fresh;
2. Focus on one topic at a time;
3. Use specific words, names of people and objects;
4. Do not use pronouns or general language;
5. Words or events may be forgotten. Don't take it personally if birthdays or other special events are forgotten.

### **Stage Two: Middle**

At this stage, recall and word recognition decrease and attention span is shortened. A person with Alzheimer's Disease may change the subject often. You may need to repeat the same question or sentence many times and in different ways before it's understood.

#### *Tips and Techniques*

1. Give stimulation that can be sensed emotionally, like music and touch;
2. Present objects with the quality of moderate novelty. Things that are familiar enough so that they do not frighten or confuse, but unusual enough so that they interest;
3. Give touch in a systematic way. Stimulate the person's forehead, cheeks, ears, neck, shoulders, back, forearms, hands, feet and lower legs through small circular stroking movements. Use skin lotion to protect the skin;
4. Stimulate smell with bread, wood, soft soap, fur, camphor, yarn, etc.;
5. Comb the person's hair and give him or her the opportunity to look in the mirror;
6. Stimulate taste buds;
7. Elicit listening behavior and maintain attention by touching;
8. If the person speaks only in single words, then you should speak in single words. However, note that the person may be able to understand better than he/she can talk;

### **Stage Three: Late**

Toward the end, a person with Alzheimer's Disease loses almost all ability to communicate or understand. Both long- and short-term memory are severely impaired, and he or she is totally dependent on the caregiver.

1. Continue speaking warmly, quietly and with eye contact;
2. Pat or stroke the person. Touch with love;
3. Smile. After all else is lost, a smile can calm and bring joy.

### ***11 Steps to Improved Communication***

1. Get the Person's Attention; Use Eye Contact: Securing eye contact helps to get the individual's attention and gets them to focus on what you are saying. A gentle touch can also accomplish the same thing. Remember that your facial expressions help communicate your intention. Maintain contact and extend yourself to the person to convince him that you want to talk to and be with him. Look directly at

- the person to get undivided listening attention before you speak; identify yourself at the beginning of each interaction.
2. Speak Clearly, In Short, Direct Sentences; Use One-Step Commands: Keep it simple. Complex or abstract subjects will be difficult for them to follow. Talk about things that are seen, heard, touched or smelled. Be matter of fact; ask "yes" or "no" questions as much as possible.
    - a. Avoid open-ended questions;
    - b. Ask questions that include limited choices: "Would you like to go for a ride or take a walk?";
    - c. Be direct; say exactly what you mean. People with Alzheimer's Disease find it difficult to understand hints or suggestions. Instead of saying "Do I look like I have nothing to do?", say "I am busy now. I will come back.";
    - d. Be concrete. "We are going to have company today."
    - e. Be literal. Nonliteral terms are used frequently in conversation: "That dress is a knockout;" "This dessert is heavenly." People with Alzheimer's Disease find it increasingly difficult to understand nonliteral terms;
    - f. Present a limited number of choices and give positive direction (for example, "Now it is time to take a shower," not "Would you like to take a shower now?")
  3. Be Willing To Repeat And Rephrase:
    - a. Repeat yourself and restate critical facts several times. Restate and rephrase what is not understood: use simpler words to express your ideas and be brief. Remember that at some point, logical explanations will be meaningless and persistence in explaining leads only to frustration;
    - b. Use simple subject-verb sentence combinations;
    - c. Left-branching sentences ("Because Ben left the house without his coat, his mother was upset") are more difficult to process and require more memory than right-branching sentences ("His mother was upset because Ben left the house without his coat.");
  4. Don't Use Slang: Consistently use the same word for the same thing, and use the word most familiar to the person. ("It is time to go to the bathroom [or toilet], Frank.") However, vary the introduction of a topic, such as bathing, if it triggers resistance;
  5. Keep Your Tone Warm and Empathetic: Provide affectionate encouragement; use diversion and humor to overcome resistance;
  6. Ask Simple Questions: Closely related words are often used instead of forgotten words. When you can't make out what a person needs, point while asking simple questions: "Do you want your sweater? Your necklace?";
  7. Avoid Pronouns – Use Specific Words And Names For Clarity: Use names so it is clear who you are talking about. Don't say "he," "she" or "that group." Also be sure to call a person with Alzheimer's Disease by the name he or she is most comfortable with.
  8. Write Big, Clear Messages and Post Them: It may be helpful to have signs on room doors (such as bathrooms) or a "911" tag posted on the telephone;
  9. Use Your Nonverbal Skills:
    - a. Use illustration. Drawings and photographs give additional cues and jog the memory;
    - b. Enhance what you say with frequent gestures. Additional physical cues and emphasis increase the chance of successful communication;
    - c. Avoid environmental distractions. Noisy and busy surroundings are distracting. It is easier to get and keep someone's attention in a quiet environment;
    - d. If verbalizations do not make sense to you, search for important clues. Smile to connect with the person.

10. Praise and Encourage the Person; Show Affection: Be patient. If you or the person become frustrated, take a break and try again later. Remember that a person with Alzheimer's Disease will sense when you are tired, stressed or in a hurry, and may become upset or confused as a result. Although they are not able to comprehend the reasons for them, people with Alzheimer's Disease still seem to sense emotions such as frustration, anger and happiness. A quiet, soothing voice, gentle touch or a calm presence may reassure and calm someone who is confused or upset.
11. Be Patient!
  - a. Give the person time to respond. If a verbal or nonverbal response does not occur in one to two minutes, repeat the exact set of words and gestures;
  - b. Do not attempt to force a person to do anything. If he or she will not cooperate, leave for five or 10 minutes and then try again;
  - c. Do not assume that one set of behaviors, whether positive or negative, will stay the same. Simple changes in the environment, such as a different nurse or a room change in a nursing facility may cause behavior changes.

## Chapter 3: Personal Care

### *Common Difficulties*

Often people with Alzheimer's Disease begin to find it difficult to use objects. They may have difficulty putting on a shoe or blouse, or using a comb, toothbrush or spoon. They may hold an item in the wrong way or not remember its purpose. They may not be able to judge directions, such as up, down or behind. When someone tells them to hold up their sock, they may have forgotten what a sock is. Or they may know that a sock is clothing for feet, but forget how it is used and how to move their foot up toward the sock.

The problems faced by an individual with Alzheimer's Disease will be different depending on which brain cells are changing. Problems can vary day to day, or from hour to hour. Sometimes a person will be unable to do something in the morning, and then perfectly able to do it in the afternoon. The disease can cause confusing and often frustrating behaviors, and it affects every person differently.

Behaviors can include:

- Overeating or eating inappropriate things, such as buttons or art supplies;
- Not eating or drinking enough;
- Improper undressing;
- Refusing to undress;
- Refusing care;
- Inappropriate toileting, such as urinating in a potted plant;
- Sleep disorders;
- Lack of interest in activity.

### *General Suggestions*

People with Alzheimer's Disease and other memory disorders usually do best in organized, uncluttered settings with regular schedules for awakening, bathing, dressing, mealtime, activities and bedtime. The best routines balance a variety of activities with rest periods and quiet times.

Caregivers should remember to encourage people with Alzheimer's Disease to do as much as possible for themselves, especially personal care such as bathing or dressing. Caregivers should remind, guide and, when needed, help. If the task is too hard, a person may become frustrated and give up or act out in anger. If the demands are too few, a person may learn helplessness and feel worthless. Helping people do as much as possible for themselves provides them with a sense of control and a feeling of success.

A caregiver with a pleasant, smiling, gentle style will help keep people with Alzheimer's Disease in a positive mood. Detailed yet simple descriptions of what is currently happening will help them stay on track. For example, when helping someone dress, the caregiver could say, "Here are your clean socks. First put one on your right foot. Your toes go into the sock. Pull up the sock. Now the left foot..."

For activities of daily living, study the ElderCare Skill Builders™ available on ElderCare Online™ at <http://www.ec-online.net>. Topics include Bathing and Grooming, Dressing, Eating and Nutrition, and Sleep Disorders and Sexual Behaviors.

## ***Managing Behavior Problems***

Anyone who has an elder with Alzheimer's Disease knows that the hardest part of caring for the individual comes from the problem behaviors that can occur as a result of the disease. In some people, problems begin in the early stages of the disease and last until they die. Others seem to live in their own little world and are passive and easy to deal with. Sometimes "problem" behaviors are in the eye of the beholder. A behavior that may be problematic for one caregiver may not concern another. The key for dealing with behavior problems is for caregivers to have a positive attitude and be flexible.

Many of the techniques discussed in other chapters and the ElderCare Skill Builders will help stop behavior problems before they begin. This chapter focuses on reducing or eliminating problem behaviors once they occur.

Alzheimer's Disease is not just a disease of memory loss. People with Alzheimer's Disease also show symptoms of:

- Language problems;
- Problems with judgement, reasoning, sequencing and planning;
- Problems with perception;
- Loss of motor skills;
- Inability to carry out daily activities;
- Personality changes

All of these deficits lead to changes in behavior that can range from simple repetitive behaviors and lack of interest in past hobbies to extreme agitation and violence.

Some of the problem behaviors seen in people with Alzheimer's Disease include:

- Anxiety;
- Wandering;
- Stealing other's property;
- Pacing;
- Inability to remain quiet;
- Disorientation to time, place and/or person;
- Constant demand for attention;
- Repetitive speech and/or actions;
- Restlessness and fidgeting;
- Inappropriate toileting;
- Undressing;
- Feeding problems;
- Inappropriate sexual behavior;
- Emotional outbursts;
- Combativeness;
- Screaming;
- Cursing;
- Lack of interest in surroundings/activities;
- Disturbance of sleep/wake cycle;
- Sundowning;
- Hostility;
- Being uncooperative;
- Easy frustration;
- Hitting, kicking and biting;
- Paranoid ideas;
- Resisting care or refusing care;
- Sadness, hopelessness or despondency;

- Mood swings;
- Catastrophic reactions (when a demented person has an extreme reaction, often due to sensory overload);
- Hallucinations;
- Delusional ideas;
- Rummaging

### ***Understanding Problem Behaviors***

Difficult behaviors can be more easily understood if caregivers remember that:

1. All behavior has meaning: It is most important to remember that all behavior has meaning, even if it's sometimes hard to determine what that meaning is. Caregivers can't think like a person who has Alzheimer's Disease because caregivers are capable of logically thinking through their own behaviors. People with Alzheimer's Disease don't follow logic and can be very difficult to understand.
2. There is always a cause for a behavior and a result of the behavior: Behavior always has a cause and a result. For instance, a person may start to pace for multiple reasons. He may have a generalized feeling of anxiety or he may be searching for something. The behavior's result can be anything from a decrease in the feeling of anxiety to finding a way out of the house in order to search further.
3. Behavior does not occur in a vacuum: There are always outside influences that modify behavior. They can come from people or from the environment. For instance, a person with Alzheimer's Disease who is a resident of a nursing facility might become agitated when a message from a staff member is heard over the loudspeaker. Since these influences change from moment to moment, behavior also may change from moment to moment.

### **Stage One: Early**

Behavioral problems often occur early in the disease, before a caregiver is even aware that the person is afflicted. For instance, the person may become easily angered when a mistake is made due to memory loss. One person may lash out verbally at the caregiver when it is pointed out that she forgot to pay a bill. Another may become very angry when he asks why a favorite relative hasn't visited lately and is told she was just there the day before.

### **Stage Two: Middle**

As the disease progresses, behavioral problems may become more frequent and severe. Some people in Stage Two become very paranoid and suspicious, accusing their caregivers of stealing things or being unfaithful. Some people have sleep disturbances and begin to wander from home.

### **Stage Three: Late**

The person may scream or yell inappropriately and may resist a caregiver's attempts to help with bathing, dressing or other personal care.

### ***Guidelines for Dealing With Behavior Problems***

- Everything surrounding a person could contribute to the behavior problem;

- A thorough assessment of the elder, the environment and the caregiver by a trained professional is necessary in order to plan for intervention;
- Think ahead and plan for situations that could result in problem behaviors;
- Trying to argue or reason with a person who has Alzheimer's Disease only results in frustration for both the caregiver and the elder. It is not possible to win an argument with a person who has Alzheimer's Disease;
- Distract and divert whenever possible;
- Keep the routine the same. Changes in routine are upsetting to people with Alzheimer's Disease and can cause behavior problems;
- Promote a sense of security and comfort when problem behaviors occur. Problem behaviors often happen because a person is frightened and unable to make sense out of the environment;
- Use positive reinforcement such as food, smiles, a gentle touch, personal attention and lots of praise. These tools are more effective than negative reactions;
- Allow a person with Alzheimer's Disease some sense of control. Being able to save face is important even in a person who is very confused;
- Maintain a calm manner when confronted with threatening behaviors. This can defuse a very tense situation and help a person become less fearful;
- Keep things simple. Complex situations only cause frustration and can escalate behavior problems;
- If a caregiver becomes frustrated and angry, it is best to find someone else to handle the problem and have the caregiver leave the immediate area or take a break (respite). An angry caregiver will only intensify problem behaviors;
- Caregivers should practice ways to reduce stress when they become frustrated and angry. Deep breathing or talking to someone can be helpful. Remember that stress comes from many sources, including personal life;
- Behavioral problems result from the disease. Don't take things that the person says and does personally. It is the disease speaking;
- Be creative when seeking solutions to difficult behaviors;
- Use good common sense when attempting to solve problem behaviors;
- Keep a sense of humor even in the most difficult situations. Humor will help you cope with the frustrations of caring for a loved one with Alzheimer's Disease.

## Chapter 4: Activities

As the brain deteriorates, activities become more difficult. Memory begins to fade and your elder might find it difficult to move freely and see clearly. As a result, they are less able to begin activities on their own. They may become either withdrawn and appear lonely or empty, or hyperactive and restless.

In a nursing home or other extended care facility, activities are generally planned and led by an activity therapist at regularly scheduled times throughout the day. But activity therapists usually work only during daytime hours, Monday through Friday. This schedule leaves people with Alzheimer's Disease with a great deal of unstructured time, and it is during unstructured times that problem behaviors can occur. The same concept works for people who are caring for an elder in the home. While it may be unrealistic for the caregiver to be with their elder constantly throughout the day, you should realize that you must do whatever you can to keep your elder busy.

### *The Benefits of Activities*

Activities have a wide range of benefits. They ca:

1. Reduce violent behavior;
2. Increase physical well-being;
3. Decrease agitation and make people more comfortable;
4. Reduce wandering;
5. Decrease the need for psychotropic medications and restraints;
6. Help prevent or lessen disabilities;
7. Make people more compliant to overall direct care;
8. Make interactions more positive.

The activities suggested in this Learning Resource Guide may not be appropriate for everyone. Keep in mind that each person is an individual and will react differently in various situations. If any activity is poorly received or causes agitation, stop immediately. It is important to place the agitation/disruption in the context of who, what, where, when and why to prevent the situation from happening again.

### *Types of Activities*

People with Alzheimer's Disease can enjoy a wide range of activities. Here are some examples:

#### *Exercise*

Regularly scheduled exercise is very important to good health. Exercise can decrease constipation; increase appetite; help keep skin, muscles and bone healthy; decrease bedsores; and promote better sleep. It increases oxygen flow to the brain and blood flow to the entire body.

Exercise helps your elder practice motor skills and can lead to a decrease in disruptive behavior. It gives people a way to remain in control of their environment, and replaces restlessness with rhythmic motions. Because it decreases restlessness, exercise can also lessen the need for medications given for behavioral problems. Physical activity should be appropriate to the physical abilities and limitations of the individual. Exercise should be something that is familiar and comfortable.

Pacing is not always a disruptive behavior. In fact, it is often a good form of exercise. People who pace often have better appetites, more stamina, better overall health and less joint disease. Remember that people who pace need to drink plenty of fluids to avoid dehydration. Be sure that it is a safe and secure environment.

1. Dancing
2. Walking
3. Swimming or water exercise
4. Movement to music
5. Calisthenics
6. Chair or bed exercises

### *Music*

Music encourages people to talk, to move and sometimes to dance. It can bring back vivid memories and lead to storytelling. It's a wonderful way to encourage both verbal and nonverbal self-expression. Music with a distinct rhythm can be used during exercise to increase your elder's energy level. Be sure to play music that your elder likes. Ask family members or friends to join in.

1. Cassette tapes, CDs and records
2. Audio-visual tapes of dance instructions
3. Singing
4. Exercising to music
5. Radio, headphones

### *Games*

Games can encourage interaction with nursing facility staff, family and other people. They stimulate thinking and the sense of touch and can help people keep active and engaged

1. Sorting and separating different objects
2. A simplified version of "Concentration"
3. Alphabet or category games
4. Simplified jigsaw puzzle
5. Simplified "Trivial Pursuit"

### *Arts and Crafts*

Painting, coloring and clay work are simple, repetitious tasks that many people with Alzheimer's Disease can enjoy. Arts and crafts can encourage people to reminisce if the activity reminds them of childhood fun. Arts and crafts provide structure and routine, and give people a way to express themselves.

1. Working with nontoxic clay
2. Making collages
3. Painting with water colors
4. Stringing beads

### *Reminiscing*

Reminiscing can help provide a sense of self-esteem. It helps people retain their identities and stimulates both verbal and nonverbal communication. Remember that reminiscing can be painful for some people.

1. Scrapbooks and photo albums
2. Recall historical events using pictures
3. Recall past pleasant activities such as travel, food or entertainment
4. Develop a memory chain (Pick a particular topic, then ask each person in a small group to share a memory about that topic.)
5. Recall religious aspects of the elder's past
6. Do not use reminiscing therapy unless you know that your elder's background is comfortable and happy. Unpleasant events may resurface and cause emotional and physical distress.

### *Pet Therapy*

Pets allow people to interact lovingly, express emotions and feel loved in return. Be sure to check before introducing a pet, as some people may be frightened by certain animals or may have had bad experiences in the past.

1. Holding and stroking a dog, cat or rabbit
2. Watching a hamster or gerbil in its cage
3. Watching birds or squirrels at a feeder placed outside a window
4. Listening to a canary or parakeet
5. Caring for fish in an aquarium

### *Spiritual Activities*

Participating in church or temple services can bring back pleasant memories and have a calming influence

1. Attending religious services
2. Singing hymns or Christmas carols
3. Having Bible passages or other religious works read to them
4. Reminiscing about childhood experiences such as attending church or having Passover dinner with the family

### *The Arts*

People with Alzheimer's Disease may enjoy television programs and short films (generally 30 minutes or less). Avoid violent, suspenseful or scary movies, including some soap operas. Soap operas might include suspicious characters, cruelty or other negative images that the elder might find inappropriate and could cause emotional distress.

1. Travel films
2. Classic television shows
3. Wildlife shows

### *Gardening*

Both indoor and outdoor gardening allows the person with Alzheimer's Disease to see the results of their efforts and taps into past memories.

1. Planting small plants, bulbs or seeds in inside containers
2. Planting in outside planters, beds or a garden
3. Arranging cut flowers in vases or bowls

### *Tips and Techniques*

1. Activities for people with Alzheimer's Disease should be planned and scheduled so that everyone becomes adjusted to a routine. Use the same schedule every day. Keep it simple and predictable;
2. Give clear instructions one step at a time. Do not use abstract ideas. Visual instructions are much better than verbal. For example, point to an object or talk about something placed in the person's hand;
3. People with Alzheimer's Disease cannot learn new activities every day and will enjoy doing the same activity over and over. Sometimes the person will enjoy the activity one day but not the next;
4. Activities should draw on remaining abilities and knowledge. Do not assume that a person can do an activity;
5. "Busy work" can be appropriate. For instance, folding the same towels or sorting the same basket of clothes may appear to be busy work, but each provides a task that can be accomplished by many persons with Alzheimer's Disease;
6. Always look to what a person enjoyed in the past and then adapt those activities to their level of ability;
7. Avoid tasks that require paying attention to one thing for an extended period of time. Choose tasks that have very few steps and lead them through them, step by step;
8. Avoid activities that may be seen as childish. The satisfaction of doing something on his or her own may be one of their few remaining pleasures;
9. Give positive feedback. Encourage and praise them at each step;
10. If a person resists, do not argue or reason with him or her. Drop the activity or distract and try again in 15 minutes. End the activity when your elder becomes restless;
11. Organize the activity before you start;
12. Use humor. Make an activity fun. Humor is very therapeutic for everyone;
13. Listen carefully to your own voice and evaluate your body language. Nonverbal behavior can signal that you are bored, tense, agitated or in a hurry. Smile;

## Chapter 5: Family Issues

To meet the challenges of caregiving, it is important to be close to the person who has Alzheimer's Disease and at the same time distant from the disease itself and the changes it brings. Sometimes it is hard to separate the person from the illness. It helps to focus on the special characteristics of each individual. Enjoying the personality of your elder and keeping in mind their preferences can help you maintain a positive attitude.

Develop a healthy amount of emotional distance, remembering that the carereceiver is not responsible for the changes in his or her health. Emotional distance means being more objective, setting your personal needs and feeling briefly aside to focus on a specific task. Emotional distance is especially helpful during difficult tasks such as bathing and toileting.

Finding someone to listen after you have gone through a difficult experience will reaffirm that you have good skills, showed good judgement and overcame a difficult challenge. If you are the listener, remind the other person that he or she is a valued caregiver and an important person to the elder. Talking it out will reduce some of the built up stress and fatigue that go along with caregiving. Support from a sympathetic listener energizes both people.

Listen to your elder and try to involve them in conversations about their care, interests, objects in the room, anything or anyone nearby or their past memories. Share humor. Interacting with people while providing their care brightens and restores both the caregiver and the carereceiver.

### *Common Family Issues*

Most families want to keep their ill relative at home for as long as possible. They often view placement in a nursing home or other extended care facility as a "failure," and feel guilty because of it. Guilt makes them angry and embarrassed, and sometimes these feelings can affect their dealings with professional caregivers. The certified staff at a facility can help you find the support you need to feel more comfortable with your decision. A number of other factors can also come into play:

#### *Immature Promises*

Sometimes a married couple during their middle age years may promise each other that they will never put the other into a nursing home. Promises like these are usually made when they are young, strong and coping well with minor health problems such as an ulcer or slightly high blood pressure. These promises are unrealistic because they don't consider the breadth of demands involved in full-time caregiving. They need to be evaluated in terms of common sense and what is best for the whole family.

#### *Isolation*

Family members may feel trapped and alone in providing care. Sometimes handling their own household plus the additional expenses of caring for an ill person become overwhelming. Other relatives may stop visiting or telephoning to avoid facing the load of responsibility. It may be hard for relatives and friends to face deterioration in those whom they love, so they stay away. Take advantage of respite care options

offered by local Alzheimer's Associations, adult day care facilities, senior centers or religious organizations.

### *Family Conflicts*

There may be long-standing conflicts in the family, unresolved issues from years ago. These issues may carry strong feelings that ignite every interaction within the family. These intense feelings may also tinge interactions between the family and other people (such as professional caregivers at a facility or a home health aide).

### *Missing Skills*

Family members may never have learned how to work well together. They may not feel comfortable in each other's presence. Individuals may not know how to listen well and talk clearly to each other or know how to match communication strategies to the needs of different relatives. Or relatives may live far apart.

### *Unrelated Problems*

Individuals within a family may be dealing with difficult situations that are totally separate from the illness of their elder. Family members may be under stress or in crisis from a situation such as unemployment, impending divorce or treatment of some other degenerative disease or terminal illness.

### *Guilt*

Sometimes family members feel guilty about using volunteers or hiring helpers to assist at home. They feel even more guilty about relying on a residential care program, such as an adult congregate living facility or a nursing home, where their elder lives under the constant care and supervision of others.

Feelings of guilt in a family member may result from their own sense of failure. No matter how hard they worked and persistent they were in caring for their loved one, they could not slow down the decline or work a cure for Alzheimer's Disease.

### *Acting Out Feelings*

Sometimes family members act demanding or hostile toward those who are paid to care for their loved one. They may complain about small details, are never satisfied with any efforts and make humiliating remarks about everything in sight.

## Chapter 6: Resources and Support

### Respite Care

- Adult Day Care
- Institutional Respite
- In-Home Respite
- Short-Term Residential Care

### Health Care

- Memory Disorder Centers
- Geriatric Medical Centers
- Public Health Clinics
- Mental Health Association
- Veterans Medical Centers

### Legal and Financial

- County/State Legal Services
- American Association of Retired Persons
- Guardianship Programs
- Attorneys
- Private Case Managers
- Accountants

### Government Agencies

#### Local:

- City/County Elderly Services Division
- Area Agency on Aging
- Visiting Nurses Association
- Senior centers

#### State:

- Department of Elder Affairs
- Elder Issues Hotline

#### National:

- Social Security Administration
- Medicare/Medicaid
- Veterans Administration
- National Council on Aging

### Organizations

- Alzheimer's Association, Inc.
- Alzheimer's Disease Education and Referral Center
- Alzheimer's Resource Centers
- American Red Cross
- American Association of Retired Persons