



Midnight Sun Home Care
First In Care For The Last Frontier

DEMENTIA TIPS FOR EMPLOYEES, CLIENTS AND FAMILIES

These tips are helpful for any one suffering from or dealing with Dementia and Alzheimer's disease.

Table of Contents

Page 1: Symptoms of Denial
Page 2: The Role of the Caregiver
Page 3: Basic Principles for Understanding and Caring for a Person with Dementia/Alzheimer's disease
Page 4: Communication with Persons with Dementia/ A.D.
Page 5: Practical Answers to Common Questions
Page 6: Safety Concerns
Page 7: Handling Daily Activities
Page 8: Coping with Behavior Problems
Page 9: Coping with Behavior Problems, continued
Page 10: Ideas for Activities
Page 11: Words of Advice from Individuals with Dementia/A.D.

SYMPTOMS OF DENIAL

Many people with dementia do not recognize or acknowledge their condition or deterioration. This is part of the disease. Some of their reactions are:

1. Anger over issues of control and loss.
2. Defensive responses when confronted with facts of memory loss or functional problems.
3. Refusal to make or keep doctor's appointments.
4. Gradual withdrawal from social situations.
5. Less participation in activities once enjoyed.
6. Unusual or unreasonable fears of people or situations.
7. Excuses for changes in behavior, i.e. "I'm Tired."
8. Insistence on continuing activities that are unhealthy or even dangerous, such as driving.

The caregiver may wish to share the following with the person in early stage dementia.

IF YOU HAVE DEMENTIA...

1. Take your time. Don't let others rush you.
2. Explain to people that you have a memory problem and ask them to repeat if you feel this is necessary.
3. If you lose a thought, don't panic. It may come back later-relax. You may ask a person with whom you are talking to tell you what you said last.
4. Focus on what you can do, not what you cannot do.
5. Try to keep on a schedule for meals, medications, exercise, and bedtime.
6. Ask for help with sorting out and choosing clothing.
7. Write yourself notes and leave them in visible places, i.e. "turn off stove".
8. Consider buying a pocket sized voice memo recorder to jog your memory.
9. If someone comes to your door that you do not recognize, do not let him or her in. Ask for a name and number and give them to family or friend.
10. If you live alone, ask a friend or relative to call you each day and make sure they have a key to your house.
11. Arrange for someone you trust to pay your bills and balance your checkbook.
12. Take someone along whenever you go out.
13. Write important things down in a "memory book" that you keep with you.
14. Label things around your house with their contents, i.e. "Sock Drawer".
15. Make a list of the things you want to do each day.
16. Keep a calendar of your appointments and commitments in a very visible place. Mark off the days each night before going to bed.
17. Don't hesitate to ask for help.

THE ROLE OF THE CAREGIVER/CAREGIVER TIPS

Everyone with A.D. at some point will need help from a caregiver. Often a family member will meet this need. The caregiver will need to make many adjustments from the time the diagnosis is given. Fear of what will happen and how they will be able to manage the manifestations of the disease is very common. Thus, the best thing that the caregiver can do is to gain understanding of the disease.

Caregivers must be ready to:

1. Provide adequate supervision
2. Ensure the patient's medical well being
3. Provide for the patient's financial security
4. Assist with the daily chores
5. Assist with personal care
6. Provide companionship and psychological support
7. Educate other family members and friends about the illness and teach them that the patient's behavior is not intentional even when it is repetitious, difficult, or abrasive.

Adapter from Managing Alzheimer's Disease, Pfizer Pharmaceuticals 1997

CAREGIVER TIPS

1. Get enough sleep. It is vital to take care of oneself. Exhaustion makes it harder to cope with the patient's demands.
2. Eat well and pay attention to nutrition.
3. Keep medical appointments and follow your doctor's orders.
4. Set aside some personal time just for you.
5. Find ways to put enjoyment and relaxation into each day.
6. JOIN A SUPPORT GROUP. Make friends with others in similar situations and share your concerns and helpful hints.
7. Cultivate patience. Becoming angry and frustrated will only make the situation worse.
8. Let family and friends help. Ask them for help if they do not offer. Do not let yourself become isolated, as no one can do this alone.
9. Learn about community resources and make use of community support.
10. Plan ahead for emergencies and the future. Consider an elder law attorney.
11. Consider utilizing private or subsidized in-home respite care, individual counseling, and day care programs.
12. Be realistic. Feeling guilty about what you cannot do may keep you from doing what you can.

**BASIC PRINCIPALS
FOR UNDERSTANDING AND CARING FOR A PERSON WITH A.D.**

- 1) Treat the person with respect and dignity.
 - a) Do not treat the person as if he/she were not there
 - b) Do not joke about inappropriate speech or behavior. Humor can be very good if used at an appropriate time.

- 2) Simplify tasks.
 - a) Break down each task and activity into easy steps.
 - b) Limit choices.
 - c) Allow time for slower processing of messages.
 - d) Reassure the person with each step i.e., “You are doing great”.

- 3) Maintain a calm, soothing environment.
 - a) Soft sounds and voices are the best. Music can be comforting.
 - b) Give a reassuring touch when appropriate.
 - c) Avoid surprises or abrupt movements.
 - d) Keep environment as consistent as possible. Even slight changes can be upsetting.

- 4) Know what to do if the person becomes agitated.
 - a) Try to figure out the source of the upset. Does he/she need to use the bathroom? Is he/she ill or in pain?
 - b) Change the subject if it appears to bother the person.
 - c) Distract and try to involve them in a different activity.

- 5) Use your patient’s view of reality.
 - a) Reality orientation (except sometimes for time and place) is not effective with those who suffer with severe memory loss.
 - b) Remember that their reality is different from yours. Whenever possible, just go along with the person and “be in their world”. Don’t argue, as it will not be productive.
 - c) Practice reminiscence (recalling past events). Focus on pleasant experiences and achievements.

- 6) Remember that patience is essential.
 - a) The A.D. person may have no or little control over strange verbal, physical, or sexual behavior.
 - b) The person often cannot remember enough about their past reasoning or behavior patterns to always respond appropriately.
 - c) Understand that what can seem like manipulative behavior is just the disease.

COMMUNICATION WITH PERSONS WITH ALZHEIMER'S DISEASE

1. If you really need to be heard, make sure that you have the person's attention by saying their name and making eye contact.
2. Remember that the functioning level may vary from day to day, time of day, location, and conversational topic.
3. Limit the number of people in a conversation.
4. Use short simple words and sentences with minimal information.
5. Reduce distractions and extraneous noise when trying to communicate.
6. Use more than words to communicate. Body language, gestures, and facial expressions also communicate meaning.
7. Encourage the person to express thoughts even if having difficulty. Be careful not to interrupt.
8. Demonstrate tasks in easy to understand steps, one step at a time.
9. Use recognition rather than recall questions. Instead of, "Don't you remember Sally from last summer?" Try, "This is Sally who we met last summer".
10. Expect that the person may ask the same question over and over again. Try to be reassuring and move on.
11. Be patient. Ask one question at a time. If asking a question wait for a response. Sometimes there may not be a response. Gently move on.
12. Avoid criticizing, correcting, and arguing.



UNIVERSAL REASONS

PRACTICAL ANSWERS TO COMMON QUESTIONS

Often people with A.D. believe they are at a different stage of life than they actually are. This leads them to think that they should be fulfilling previous roles and tasks. To answer their repeated questions, give them a universal reason “why” – something that they will believe. The following are questions that might be asked repeatedly:

1. Where are my children?
Answer: Your kids are in school. Your kids are taking a nap. Your kids are at _____'s house.
2. I have to go to work.
Answer: It's a holiday or weekend. The boss called and said he does not need you today.
3. I have to go to school.
Answer: It's vacation time. It is supposed to storm, so school is closed.
4. Where is my Mom?
Answer: She is doing errands, shopping for groceries, over at _____'s house. She went for a walk.
5. Where is my husband?
Answer: He is at work, out of town, drinking coffee with the guys, at the hardware store.

A difficult situation is when the person asks where their spouse is and their spouse has already passed away. This person would not be asking where their spouse is if he/she did not think their spouse was alive. Imagine what grief and pain you would go through if someone told you today your spouse was dead. If you were told that news every day it could affect your health and cause depression, and decrease functioning ability. It is not recommended that you tell the person their spouse is dead. If there is more than one care provider, make sure you all have the same story. When the person gets different answers to their questions he/she will possibly become suspicious and the story will not be worth much.

SAFETY CONCERNS

Safety is a major concern. A thorough inspection of all areas of the home is necessary in order to determine if there are any safety hazards for the person with a memory disorder. From the beginning, the caregiver must keep a watchful eye. Was the stove left on? Can the patient safely go out alone? Should the person still be driving? Recognize that the A.D. patient loses his/her sense of danger. Simply explaining to them that they must be careful will not work.

- ❖ Reduce clutter; put small knick-knacks away.
- ❖ Supervise the taking of medications. Lock all medications in a safe place.
- ❖ Clear all pathways of unnecessary objects.
- ❖ Keep things in the same place and in the same order.
- ❖ Secure dangerous items, i.e. poisons, hazardous substances, and sharp knives.
- ❖ Supervise any smoking.
- ❖ Keep a spare key hidden outside the house.
- ❖ Put a bell or buzzer alarm on any door that leads outside.
- ❖ Obtain an identification/*Safe Return* bracelet for person in your care.
- ❖ Make sure that smoke detectors are in working order. Check them regularly.
- ❖ Have a list of emergency numbers on hand.
- ❖ Avoid things in the home that can cause falling such as scatter rugs and extension cords.
- ❖ Disconnect small appliances. Put away mixers and blenders.
- ❖ Consider installing an intercom system.
- ❖ Install grab bars or handrails in the bathroom.
- ❖ Pad sharp edges of furniture.
- ❖ Get rid of any poisonous plants.
- ❖ Turn the water heater down to about 110 degrees.
- ❖ Pull the knobs off the stove when not in use.
- ❖ If necessary, disable the car, hide the keys, or if the car is not being used keep it out of sight.

HANDLING DAILY ACTIVITIES

Bathing- It is important to respect the person's privacy and dignity as much as possible. Simplify the task by having everything ready and doing one task at a time. Keep portions of the body covered while bathing if this is an issue. Be calm and gentle and do not hurry the person. If the bath is refused, don't force the issue, as this will cause agitation. Try again later. Check the temperature of the water and only use a few inches. Use safety devices such as rubber mats, grab bars, and safety seats.

Oral Hygiene- Sometimes the A.D. person will not brush his/her teeth or allow anyone else to do so. Stop the activity and try again later. A diluted hydrogen peroxide solution for rinsing may have to be used instead. Encourage foods like apples, which help clean the teeth. Demonstrate the brushing steps one at a time. Some medications cause mouth dryness. Rinses and hard candy can help.

Dressing and Grooming- The self-esteem of the patient is still very important. Consider past grooming habits and social customs. Make it easy for the person to select their clothes, but avoid forcing decisions on them. Remove seldom used clothes or ones they dislike. Use simple garments such as sweat suits that have few buttons and do not have to pull over the head. A person who undresses in public can be dressed in difficult to remove clothing. Encourage the people to dress themselves, but help with step-by-step instructions. Do not rush the process.

Mealtime and Nutrition- Confused persons may not be able to remember whether they have eaten or how to use utensils. Use step-by-step instructions. Limit the number of choices that the person has to make. Try to maintain a relaxed atmosphere. Allow the person enough time to eat and encourage him/her to help to the extent possible. Giving the person a spoon to use and providing finger foods may make mealtimes easier. Remind the person to eat slowly and chew thoroughly.

Toileting- Set a regular schedule for going to the bathroom, but watch out for signals, such as restlessness, that will alert the need to use the toilet. Always respect the person's privacy. An elevated toilet seat and/or grab bars may help to prevent a fall. Easy to manage clothing will make toileting easier.

Exercise and Leisure Activities- Encourage daily exercise such as walking. This and other activities can improve energy levels, circulation, mood and sleep. Suggest activities that the person can do well and will enjoy.

COPING WITH BEHAVIOR PROBLEMS

Common behavior triggers are: fatigue, change, overwhelming stimuli, loss of meaningful activities, an over demanding caregiver and illness.

1. Wandering – A person may wander because they are trying to find something familiar, need to go to the bathroom, are anxious, restless, or hungry. Objects or pictures on doors can help the person to locate a room. To keep a person inside the house, place locks on doors and use childproof or removable doorknobs. It is essential to purchase a *Safe Return* bracelet or provide a wallet or purse card with the person's name, address, and phone numbers handy in case the A.D. person leaves the house. People with Alzheimer's have traveled great distance by car, train, airplane and public transportation.

2. New Situations – These increase confusion and place great stress on the A.D. person's adaptive abilities. It will help if they are given frequent reassurances. Expect that troublesome behavior might result from new situations, but will probably settle down when they become comfortable.

3. Sundowning – An increase in confusion in the late afternoon or early evening is common with Alzheimer's disease. The person might be tired and thus, does not handle the stress well. It can help to rearrange the schedule so that few major activities take place at these times. Daily routines that require a person's cooperation, such as bathing, may best be done earlier in the day.

4. Losing and Hiding Items – Limit the number of places that the individual can use to hide things. Lock closets, drawers, and even rooms that are not needed during the day. Valuable items should not be left out. Have extra eyeglasses, dentures, keys, and other essential items.

5. Offensive Behavior – Inappropriate behavior that is purposeful is rare. Rather it is caused by lack of awareness and loss of understanding of social rules and manners. An example of this is a person who undresses in public. It is important not to overreact to improper behavior, but instead to stay calm and try to distract the person. The person should be removed from the scene if they become hostile or abusive. The A.D. person may be expressing hostility due to fear or anxiety. It will not help to reason with or contradict the person. Remember, offensive behavior should not be taken personally.

Coping with Behavior Problems (continued)

6. Sleep Disturbances – Sleeplessness and changes in patterns of sleep are a frequent occurrence. It helps if a consistent bedtime is maintained and naps eliminated if they are causing nighttime wakefulness. See that the person gets some exercise each day. Avoid fluids after dinner and encourage the person to use the bathroom before going to bed. For night safety use a nightlight and have the bathroom clearly marked.

7. Restlessness and Anxiety - As Alzheimer's progresses the individual may become more anxious and less able to remain still. Reassure the person, involve him/her in activities, and find outlets for their excess energy.

8. Dangerous Behavior – The person with A.D. may walk in to traffic, drop a lighted cigarette, eat inappropriate things, start a fire, or play with dangerous tools. The caregiver needs to understand this and prevent dangerous situations from occurring. Secure the environment and remove all possible hazardous objects. Avoid restraining, arguing, or explaining. Try to understand the person's behavior in the context of the illness.

9. Hallucinations and Delusions – Alzheimer's disease sometimes causes a person to see or hear things that are not there or to develop suspicions about people. If the behavior is not harmful, ignore it. Do not argue or explain that what they are seeing or hearing is not real. You can reassure the person without agreeing with them. Check with the doctor if this happens frequently as hallucinations can be caused by certain medications.

Caring for an Alzheimer's patient is stressful, demanding, and frustrating. In order to deal with these situations and behaviors the realities of coping with the disease must be accepted. If behaviors are particularly troubling or unsafe, talk with a neurologist, geriatric psychiatrist, or geriatrician about appropriate medications to control behaviors.

IDEAS FOR ACTIVITIES

Keeping the mind and the body active and busy is important for everyone, but especially for the person with Alzheimer's disease. Activities should focus on the person's abilities, not their limitations. Activities should be safe, with enjoyment, not achievement being the intent. Recognize that the A.D. person's interests can change from day to day and hour to hour. Activities that provide mental stimulation is best done in the morning, while soothing or calming ones are best done in the late day or evening. Realize that the attention span is likely to be short and the person may not be able to initiate activities but may be able to do them once the caregiver starts.

Following are some ideas for useful and interesting activities:

- ❖ Helping with chores gives the person a feeling that they are still a part of the household. Examples include: setting the table, folding the laundry, sweeping the floor, and sorting the silverware.
- ❖ Exercise can release tension, meet physical needs, and provide a feeling of accomplishment. A stationary bicycle or easy video can be used effectively.
- ❖ Gardening – simple tasks under supervision can provide satisfaction as the person “watches their garden grow”.
- ❖ Arts and Crafts – i.e. making pencil holders or vases from tin cans, trivets with glued tile pieces, painting shells and stringing beads for jewelry.
- ❖ Games appropriate to the individual's level of function can be stimulating.
- ❖ Building with wooden blocks or Lincoln logs.
- ❖ Sorting buttons, cards, coins, keys, or socks. *This is a good activity for the lower functioning individual.*
- ❖ Drives can be calming and life enhancing. A trip to the zoo or a botanical garden is fun and provides the basis for positive communication.
- ❖ Reading aloud and using visual aids to share stories, poems, and pictures about days gone by. It is not a good idea if the person becomes upset.
- ❖ Use of a VCR – old movies can bring back pleasant memories. Nature and travel films move more slowly and are easier to follow.
- ❖ Scrapbooks to put in favorite or treasured small items or pictures.
- ❖ Busy Boxes and Reminiscence Boxes can include everything from kitchen gadgets to sports equipment, sewing supplies, or cosmetics depending on the person interests and the safety of the objects.
- ❖ Music the person enjoys can be soothing or stimulating. This includes everything from active listening to sing-a-longs.

Activities (continued)

These are just some of the many activities that can be modified to the functioning of the individual. Most of the time the caregiver should start and organize the activity. Keeping busy can reduce agitation and wandering. Meaningful activities can give the A.D. person a feeling that they are making a worthwhile contribution and thus enhance their self-esteem. Some positive ways to introduce an activity are: “ Can you help me with . . . ,” “Could you show me how you do” “It would be nice if you would make this for me.” It is not a good idea to ask the person to do a simplified version of an activity or craft in which they once excelled, as this could be upsetting. Above all, the A.D. person needs to feel a sense of accomplishment, satisfaction, and involvement from the activities presented.



WORDS OF ADVICE FROM INDIVIDUALS WITH A.D.

Collected during an early diagnosis support group meeting.

1. Acknowledge my disease – don't pretend there is no problem.
2. Don't treat me like a child.
3. Learn all you can about this disease.
4. Take time to listen to me – take me seriously.
5. Give me some space and time to do things on my own.
6. Let me continue to do the things I still can do.
7. Understand that I will get upset or frustrated when I cannot do things I used to do.
8. Finally: “Remember Me!”