



# Texas Agricultural Extension Service

*People Helping People*

Series on Aging

## Caring for the Disoriented Person

The purpose of this publication is to inform families about daily care of the intellectually impaired person with irreversible dementia. More than half of dementia cases are the irreversible Alzheimer's type and involve progressive intellectual decline. The individual increasingly loses the ability to remember, communicate, make judgments and act independently. (Some kinds of dementia may be reversible.)

### When Dementia Is Progressive

Consider the problems of three aging parents.

*Bill's father shuns unfamiliar places, sometimes forgets names, has less interest in his family and hobbies and angers easily. He is in the phase of dementia when no one is quite sure anything is wrong.*

*Mary's mother has regressed more than Bill's father. She has difficulty making decisions and plans, and has become self-absorbed and insensitive to the feelings of others. She functions satisfactorily in many daily activities but needs supervision in activities requiring the ability to calculate, such as balancing a checkbook.*

*Tom's father is disabled. His behavior has changed remarkably, and he has lost orientation to time and place. Directions must be repeated for him. He needs considerable help with simple daily activities. He has difficulty with bladder and bowel control, does not recognize family members and invents nonsense words.*

With irreversible dementia, the family must learn to live with an incurable, degenerative illness. As the person loses the ability to care for himself and experiences personality changes, family responsibilities and isolation usually intensify. There are financial difficulties. The wage earner may no longer be able to work, or a spouse may retire early to care for a mate. Long-term care may be expensive. As the judgment and reasoning of the ill person diminishes, legal matters require attention.

Rapid advances are now being made in the health sciences, and methods may be found to prevent or interrupt the progress of this disease. Until that time, much can be done to help the disoriented person and the family caregiver cope.

### Accepting the Task as Caregiver

Accepting the diagnosis and the inevitable progression of this illness are major tasks. Families often do not recognize the disease early because people in early stages of dementia do not look different. Many changes are difficult to see, particularly when family members still glimpse the old personality.

Coping with a chronic illness changes one's life. Role

changes are common and distressing. Assuming responsibilities previously fulfilled by the ill family member often serves as a painful reminder of the deterioration. Other family members and friends may no longer visit because of their inability to cope emotionally.

Understanding the disease and the behavior of disoriented persons eases caregiving. For example, the disoriented person often cannot control his behavior. Caregivers should know what they can realistically expect from the disoriented person and methods of dealing with difficult behavior.

Talking about feelings, concerns and problems with a trusted professional may help caregivers to deal more effectively with their caregiving role, clarify problems and make needed decisions. Negative feelings are normal, and talking about them will help.

### Explaining

Explaining the illness to the person afflicted with Alzheimers Disease, family, friends and neighbors is a difficult task.

For some spouses, a strong inclination is to hide their partner's dementia. The disoriented person may talk quite well socially, especially in the early phases of the disease. The casual observer may not notice signs of mental deterioration, even thought the person cannot always remember names or follow a conversation.

Friends and neighbors may have difficulty accepting that the person is ill when he looks fine. Explaining the disease helps them understand. People need to know that the disease causes gradual deterioration of the mind and is not contagious. Persons afflicted are not "crazy" but often cannot control their behavior.

### Understanding Your Thoughts and Feelings

Caregivers experience many powerful feelings. Some feel trapped and helpless. Common feelings include anger, guilt and grief.

*Anger* is a natural emotion. In one study, more than 90 percent of the families reported they felt angry at the situation, the patient, other family members or professionals.

*Guilt* may arise from embarrassment at the person's odd behavior, not wanting the responsibility, losing your temper with the sick person, or considering nursing home placement. Recognize guilt feelings. Never let guilt guide your decisions. Do what is best for you and your family.

*Grief.* Caregivers often grieve during the course of this disease. They grieve over the way their loved one used to be.

Loss often is most deeply felt when the person is no longer able to clearly speak or understand.

## Handling Criticisms

Caregivers sometimes feel other family members criticize too much or do not provide enough assistance. Rather than let resentment build, hold a family meeting to plan what each person can contribute. When family members do not share the day-to-day experiences with a person suffering from dementia, they are not aware of the stresses. Having the doctor talk with the family members about the disease often reduces tension.

Everyone who has been close to this person will be affected by the illness and should be involved. Do not try to provide total care. Even if other family members have problems of their own, they have a right to be involved in the patient's care.

## Feelings about Parents' Difficulties

Everyone has complex patterns of feelings toward parents, brothers and sisters. People are aware of many of these feelings, but may have repressed some. The crises of an illness can cause earlier, unresolved feelings to surface and severely strain relationships.

Feelings about a parent can complicate caregiving. Observing a parent declining physically and intellectually can produce anxiety, fears and many other emotions. Accepting that a parent is no longer strong or assuming responsibility for a parent with whom one has had a poor relationship is not easy. Balancing responsibilities to oneself, spouse, children and aging parents may seem impossible. Adult children over age 60 who are caring for aged parents may experience added stresses of adjusting to retirement, reduced income, changes in health or death of a spouse. Many caregivers benefit from outside help in making the necessary adjustments.

## Friendships and Time

Friends can be comforting and helpful. Getting away from the house if only for a brief time and meeting personal needs for friendship, recreation and pleasure makes a caregiver better able to love and care for the disoriented person.

## Respite Care

Getting away from caregiving takes effort and ingenuity, yet breaks are essential. Lack of relief and chronic fatigue are major sources of distress and can cause illnesses. The well-being of the disoriented person depends directly on the well-being of the caregiver.

Are you tired most of the time? Fatigue may be caused by exhaustion, depression, taking on new roles, or hidden anger. A rest may mean watching television, uninterrupted sleep through the night, taking a weekend off or having a vacation.

Getting needed rest may require frankness with family members and friends. Family members living at a distance may help pay for senior day care, an in-home respite

program, periodic hospitalization or temporary nursing home admission. Local offices on aging and information and referral can locate community resources. Religious affiliations can sometimes organize assistance with caregiving tasks and respite care. Some families find a responsible person to stay with the disoriented person for a scheduled time every week.

Before going away, a caregiver should write a message for the patient to carry saying where he will be and when he will return. Writing a note is also a good idea when the person is left in an unfamiliar place.

## Decisions about Institutionalization

How long should a family accept the responsibility for care? The need for 24-hour care, limited family support, lack of free time, and sleep disturbances may make home care extremely difficult. With advancing disease, people may become less important to the patient than the service. Family members may not be recognized. The patient may even prefer to lie in bed undisturbed even though he needs to be turned, bathed and cared for physically.

The Burke Rehabilitation Institute suggests caregivers ask themselves the following questions in deciding whether it would be best to maintain the person at home or seek institutional care:

- Is the situation manageable?
- Is the person safe in the home environment?
- Is the family physically and emotionally able to care for the person's needs and protect him?
- Is the patient able to function independently in the most basic ways?
- Is the cost of 24-hour supervision by paid personnel greater or less than the financial and human cost of the trauma (for both the family and the ill person) of institutional care?

The Alzheimer's Disease and Related Disorders Association offers four criteria for making this decision. "If patients wander, if they endanger themselves or others, if they are incontinent or spoil others' sleep, it is very hard to keep them at home, and placement is probably indicated."

## Support Groups

For every hour psychiatrists spend with elderly dementia patients, 3 hours should be spent with the patients' families, according to a noted psychiatrist, Dr. S. I. Finkel. Finkel believes family guidance and support is critical in managing older persons with dementia. Unfortunately, not all doctors are sensitive to the needs of families.

In the late 1970's, the desperate needs of families stimulated the development of support groups and a nationwide organization, The Association for Alzheimer's and Related Diseases. Patients' families have established volunteer organizations in many parts of the country. These organizations have established a national organization which will provide family support, education, advocacy, and encourage research and legislative action concerning dementia. More information can be obtained from Alzheimer's Disease and Related Disorders Association, (ARDA), 360 North Michigan Avenue, Suite 60, Chicago, Illinois 60601, telephone (312) 853-3060.



# Managing the Person at Home

*Managing a person with intellectual loss is not easy, but patience, understanding and skills will help. The following guidelines will reduce anxiety and improve the quality of life for the patient and the family.*

- **Simplify routines and reduce choices.** Keep daily routines simple and familiar. Tasks that were previously easy for the patient now may be too difficult. Limit choices. For example, remove seldom worn and out-of-season clothing from the closet. At mealtime, limit the number of food choices and put only the utensil and the patient will need at his place. Divide activities into steps. Patients tend to have short attention spans — 30 minutes or less.
- **Maintain a calm atmosphere.** Rushing, becoming upset, or having a lot of activity in the house confuses and frightens and the intellectually impaired. Even small amounts of excitement can cause overloading the individual with stimuli. Arguing and scolding usually will cause the patient to overreact.
- **Be consistent.** This includes behavior, routines and the environment. Avoid changes. Keep household furnishings and objects in the same place. Do things the same way at the same time each day. When changes must be made, prepare and support the person. Even minor changes can be traumatic.
- **Use repetition.** Sometimes the person will remember tasks and information from repetition. When repeating, do not remind the person that you have said this before.
- **Use memory aids.** Signs, clocks, calendars, seasonal decorations, and a schedule of the day's activities promote better orientation. Give cues. For example, name events, family members and visitors. Labels on items may help the person remember them. Mark off days on a calendar with a large felt pen so the person will see the current date. Pictures may help the patient to remember family members and close friends.
- **Reassure and praise.** The intellectually impaired also need a feeling of success. Provide praise for tasks accomplished. Tasks such as bathing, dressing, and remembering to go to the bathroom, that are relatively easy for the healthy person may be difficult for the intellectually impaired.
- **Lower expectations.** Do not hold the same expectations that you held when the individual was healthy. Know what you can realistically expect from the patient at each stage of the disease. Explanations may no longer be effective if the person no longer understands speech. Simplifying tasks, giving instructions one step at a time, and demonstrating each step may be more successful. Psychological testing can provide a realistic measure of how much to expect from the patient and identify cognitive abilities still intact.
- **Make the environment safe.** Family members continually need to be aware of sources of danger—high windows, stairs, power tools, appliances, knives, hot water, matches, cigarette lighters, firearms, poisons and scatter rugs. Lower the setting of the hot water heater to prevent burns. Check temperature and depth of bath water before the patient enters. Supervise smoking and the use of items such as alcohol, razors and hair dryers. Remove locks on bathroom and bedroom doors. Install

handrails and tub mats. Lock medications, poisons and other harmful substances out of the person's reach. Dispense the patient's medications. Utility companies can make stoves safe. Never leave the individual alone in a parked car.

- **Treat the person as an adult.** The intellectually impaired have feelings and do not like to be treated as children. If treated like children, they are more likely to respond with childlike behavior.
- **Use reminiscence.** People who seem to have little memory often respond to discussions about unique historical events (the Depression) and significant personal experience (weddings, births, hobbies) in their past. Special holidays often motivate people to remember. Old familiar songs may be particularly enjoyed.
- **Encourage recognition.** It is easier to recognize than to recall information. Limit the demands for recall of facts, names and schedules. For example, post a schedule of the day's activities. Avoid asking open-ended questions such as "What do you want to wear?" Instead ask, "Do you want to wear this blue dress or this red dress today?"
- **Maintain a sense of humor.** It can help a family deal with many situations and crises.

Families face some common daily tasks. This section suggests ideas for coping and resources for additional assistance.

## Managing Money

Inability to balance a checkbook often is the first noticeable symptom of mental decline. Eventually, financial matters may need to be transferred to another family member. This transfer is often difficult because of the independence, responsibility and freedom that money represents. Giving the person a small amount of spending money may help. Banks often can give advice on handling and transferring money. A lawyer may assist with legal concerns.

## Driving

Giving up driving a car is difficult for most people because of the mobility and independence it represents. While giving up driving may be a relief to some people, others resist. The family has a responsibility to intervene when the person's driving is no longer safe.

Ask the physician to tell the patient that he or she can no longer drive—and even write on a prescription pad, "no driving" to serve as a reminder. This prevents conflict between patient and family. A family lawyer also may help. The Department of Public Safety will investigate and sometimes suspend a license upon receiving information and the advice of a physician that the person's health makes driving unsafe.

Keys may need to be hidden and the distributor cap removed so the patient cannot start the car.

## Wandering

Wandering is common. For some, it increases at night. Patients sometimes find their way out of a house despite locked doors. Preventive measures include installing dead bolt locks near the bottom or top of the door where the person may not look for locks. Secure on the patient an

identification necklace or bracelet which gives the person's name, address, telephone number, and the nature of the disease.

Exercise is important. Regular exercise often reduces wandering, relieves tension and helps the person sleep better. Activities such as sweeping the floor or driveway may provide not only exercise, but also give a feeling of usefulness. A high fence with locked gates may allow the patient to wander and exercise freely outdoors. This is particularly important for the person who spent considerable time outdoors before the illness.

Restraining devices are available, but usually make a person angry and combative.

## Bathing and Grooming

A well-groomed appearance enhances self-esteem and behavior. However, some individuals resist bathing and changing clothes. Remind the patient, using simple explanations, about the necessity of grooming. Again, bathing instructions written by a physician on a prescription pad, "bathe twice weekly," may persuade the resistive person to bathe.

Simplify bathing and dressing. Arrange implements and clothing in the order of use. When necessary, show the person what to do.

Easy-dress garments help the patient to dress independently. Select slip-on shoes rather than those that tie. For the person who has difficulty with buttons or snaps, replace them with self-fastening tape. Wash-and-wear clothing is the easiest to care for. Do not argue if the person wants to wear the same clothing every day or insists on sleeping with a hat on. This is not harmful.

## Mealtime

Keep menus familiar. Sometimes patients will eat only one food several times a day or develop specific likes and dislikes. Accept the behavior if it does not interfere with overall nutrition and dietary restrictions. It is better that the person eats what he wants rather than does not eat at all.

Sometimes the person may forget he ate and want to eat constantly. If so, set out a small tray of nutritious snacks.

With increasing brain deterioration, table manners often decrease. Use finger foods when the person can no longer use utensils. Use a plastic cloth on the table, spill-proof containers, and smocks with the bottom edge turned up into a bib pocket to catch crumbs. Cut food into small pieces. Avoid foods the patient may not chew thoroughly.

Persons who have difficulty swallowing should sit up straight with their head tilted forward slightly, never back, and remain sitting at least 15 minutes after eating. Remind patients who begin stuffing too much food into their mouth to swallow. Learn the Heimlich method from a medical professional or the Red Cross. It can save the life of a choking person.

Contact the doctor if the patients stops eating or begins losing weight, because these could be symptoms of a complicating disease.

## Incontinence

As the disease progresses, loss of bladder and bowel

control become common. At first, this may occur only occasionally or during sleep. Later, the person may not respond to the body's signal to void, or forget where urine and feces are to be deposited.

You may need to remind the person at regular intervals—every 2 or 3 hours upon rising in the morning, after meals, and before bedtime—to go to the bathroom. Take the person to the bathroom at the time of day he usually moves his bowels. Sudden restlessness or picking at clothes may also indicate a need to go to the bathroom.

Limit fluid intake after the evening meal. Getting the patient up once during the night or placing a commode or urinal bottle near the bed may prevent accidents. Use night lights in the bedroom and bathroom.

Special clothing with disposable pads, protective bedding and disposable bed pads are available from surgical supply houses and some drug stores. Consult a physician for additional aids available.

## Hiding and Losing Things

Patients sometimes lose things, hide objects, or put them in a safe, but forgotten place. Items may not be returned to their customary place. Keep important and valued items away from the individual. Reduce hiding places by locking rooms or cupboards. Check the garbage cans before emptying if these become hiding places.

## Communication Problems

Persons with dementia may not speak sensibly or comprehend speech. The inability to communicate verbally with a family member can be particularly frustrating.

Touch can be soothing and an important means of communicating. Holding hands, hugging, giving massages, or sitting together will communicate warmth and affection.

People communicate nonverbally with their bodies, facial expressions, eyes and hands. Learn to use these nonverbal communication methods and to understand the nonverbal language of the patient. Brain-injured patients are often sensitive to nonverbal messages.

Whatever the situation, open communication among all family members. Willingness to assist is a key to successful management.

## For Additional Information

Mace, Nancy L. and Peter V. Rabins. *The 36-Hour Day: A Family Guide to Caring for Persons with Alzheimer's Disease, Related Dementing Illnesses, and Memory Loss in Later Life* (1982).

Powell, L.S. and K. Courtice, *Alzheimers: A Guide for Families* (1982)

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