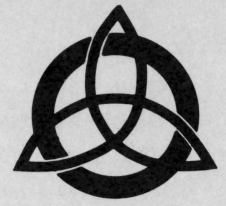


# HOME ECONOMICS GUIDE



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## The Disoriented Person CAREGIVER SUPPORTS

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The purpose of this guidesheet is to provide families with information about daily care of the intellectually impaired person with irreversible dementia. Over one-half of the 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. (Keep in mind that some kinds of dementia may be reversible. For information on this see Home Economics guidesheets 6871, "Approaches to the Disoriented person in your life," and 6872, "Relating Is Their Therapy.")

### When Dementia Is Progressive

Consider the problems of three aging parents.

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

Mary's mother has regressed more than Bill's father. She has great difficulty making decisions and plans, and has become more 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 check-book.

Tom's father is very 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 caregivers 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 function in that capacity, or a caregiver may retire early to care for a mate. Costs of long-term care may be prohibitive. 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 in the future 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 with this disease.

### Accepting the task as caregiver

Accepting the diagnosis and the inevitable progression of this illness are major tasks for all families. 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 see glimpses of the old personality they remember.

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

changes are common and distressing to most caregivers. Assuming responsibilities previously fulfilled by the ill family member often serve as painful reminders of the deterioration in the loved one. Other family members and friends may no longer visit because of their inability to cope emotionally with the illness.

Understanding the disease and the behavior of disoriented persons helps to ease caregiving. For example, it may help to know that 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 their feelings, concerns and problems with a trusted professional may help caregivers to deal more effectively with the caregiving role, clarify problems and make needed decisions. They should realize negative feelings are normal and talking about them will help.

## **Comprehending and explaining**

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

For some mates, 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 though the person cannot always remember names or follow a conversation.

Friends and neighbors may have difficulty accepting that the person is ill when they look 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 can't 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 being embarrassed by the person's odd behavior, not wanting the responsibility of caregiving, losing one's temper with the sick person, or considering nursing home placement. Recognize guilt feelings. Most important is not to let guilt guide your decisions. Do what is really 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 from family**

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

Everyone who has been close to this person will be affected by the illness and should be involved in responding to the condition. A caregiver should 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 parent's difficulties**

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

When the caregiver is the child, feelings about a parent can complicate matters. Observing a parent declining physically and intellectually can produce anxiety, fears and many other emotions. Accepting that a parent is no longer strong or having to assume responsibility for a parent with whom one has had a poor relationship is not easy. Balancing responsibilities to oneself, mate, children and aging parents may sometimes 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 mate. 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.

Caregivers can test their need for a break. Are they tired most of the time? Fatigue may be caused from 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 be able to 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 help locate community resources. Religious affiliations sometimes are able to 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.

When the caregivers are away, a written message should be provided for the patient to carry saying where they will be and when they will return. Writing such notes 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 of care? The need for 24-hour care, limited family support, lack of time for self, and sleep disturbances may make home care extremely difficult. With advancing disease a time may come when people are less important to the patient than the service that is given. Family members may not be recognized. The patient may even prefer to lie in bed undisturbed by people even though they may need 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 them?
- 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 offered a four-point 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."

## Self-Help Support Groups

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

The desperate needs of families stimulated in the late 1970s the development of support groups and a nationwide organization, The Association for Alzheimer's and Related Diseases. Self-help groups provide a strong sense of support with this problem. 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, 32 Broadway, New York, N.Y., 10004, telephone (212) 736-3670.

# 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 both 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. Limit the number of food choices and put only the utensil the patient will need at his place at mealtime. Divide activities into steps. Patients tend to have short attention spans—30 minutes or less.
- **Maintain a calm atmosphere.** Rushing the individual, becoming upset, or having a lot of activity in the house tends to confuse and frighten the intellectually impaired. Even small amounts of excitement can cause agitation. Avoid confrontation or overloading the individual with stimuli. Arguing and scolding usually will cause the patient to overreact.
- **Be consistent.** This includes consistency in behavior, routines, and the environment. Avoid changes. Keep household furnishings and objects in the same place at all times. 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 some 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 and give the names of family members and visitors. Labels on items may help the person to 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 that are relatively easy for the healthy person may be difficult for the intellectually impaired, such as bathing, dressing, and remembering to go to the bathroom.
- **Lower expectations.** Do not continue to hold the same expectations for the person with dementia 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 how to accomplish each step may be more successful. Psychological testing may be helpful. It can provide a realistic measure of how much to expect from the patient and identify the cognitive abilities still intact.
- **Make the environment safe.** Safety is a primary concern in activities and the environment. 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 severe 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 help to 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 a child, they are more likely to respond with child-like 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 of children, hobbies) in their past. Special holidays often motivate many people to remember. Old familiar songs may be particularly enjoyed.
- **Encourage recognition rather than recall.** It is easier to recognize rather 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 supplies suggestions for coping and resources for additional assistance.

## Managing Money

An inability to balance a checkbook often is the first noticeable symptom of mental decline. Eventually, a person's 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 be able to assist with the 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 are very resistive. A 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 a car,” to serve as a reminder. This avoids conflict between patient and family. A family lawyer also may be able to help. The Department of Motor Vehicles 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 that the patient cannot start the car.

## Wandering

Wandering behavior 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 and placing door locks near the bottom or top of the door where the person may not look for locks. Secure an identification necklace or bracelet on the patient which gives the person's name, address, telephone number, and the nature of the disease.

Exercise is important. Regular exercise often reduces wandering behavior, relieves tension, and helps the person to sleep better. Activities such as sweeping the floor or driveway may offer 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 prior to the illness.

Restraining devices are available, but usually make the 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 these activities. Again, bathing instructions written by a physician on a prescription pad, “bathe twice weekly,” may help to 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 Velcro tape. Wash-and-wear clothing provides the easiest care. Don't argue if the person wants to wear the same clothing every day or insists on sleeping with a hat on. This is not harmful.

## Mealtimes

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 doesn't interfere with overall nutrition and dietary restrictions. It is better the person eats what they want rather than not eat at all.

Sometimes the person may forget he ate and want to eat constantly. Setting out a small tray of nutritious snacks is sometimes a satisfactory solution.

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 big 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 the 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 patient stops eating or begins losing weight because these are possible symptoms of a complicating disease.

## Incontinence

As the disease progresses, loss of bladder and bowel control become more 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 two or three 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 they usually move their bowels. Sudden restlessness or picking at their clothes may also indicate a need to go to the bathroom.

Try to 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 help 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 the physician for additional aids available for urinal and fecal incontinence.

## 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 not used by the person. 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 difficult.

Touch can be soothing and an important means of communicating, particularly with the person who no longer comprehends speech. Holding hands, hugging, giving massages, or sitting together will communicate warmth and affection.

People communicate non-verbally with their bodies, facial expressions, eyes, and hands. Learn to use these

non-verbal communication methods in positive ways and to understand the non-verbal language of the patient. Brain-injured patients often are very sensitive to non-verbal messages.

No guidelines can cover all situations. But whatever the situation, open communication among all family members. A willingness to provide assistance is a key to successful management.

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