

Helping Home Caregivers of People with Alzheimer's Disease and Related Disorders

Home caregivers in the United States provide extensive care for their family members with Alzheimer's disease and related disorders (ARD). Caregiving for a loved one with ARD over a period of years is a difficult and challenging activity, and most caregivers have inadequate support and information to lighten their burden. The incidence of ARD and its impact on family caregivers is significant:

- Four million Americans have been diagnosed with ARD.
- ARD patients decline for an average of 8-10 years prior to death.
- Family members provide care for 80% of people with ARD.
- Spouses provide care for 60% of ARD patients, while children provide care for 20% of ARD patients.
- Caregivers provide an average of 17 hours of care per day.
- Dysfunctional behaviors occur in 70-90% of people with ARD.
- The main reason ARD patients are placed in nursing homes is caregiver stress due to behavioral symptoms.
- Caregivers often suffer from stress, depression, chronic illness, and burnout, which leads to institutionalization of the person with ARD.

A number of organizations and programs provide various methods of support and education to family members of people with ARD. However, due to geographic location, transportation, availability of respite care, educational level, financial resources, and other such factors, few caregivers receive the degree of assistance they need to carry the caregiving burden without compromising their own well being. This is particularly true regarding understanding, coping with, and successfully managing the behavioral problems that frequently occur in individuals with ARD.

There are typical behaviors that often occur in people with ARD. These behaviors are understandably very distressing to caregivers. Caregivers often do not understand the behavior, its triggers, or methods to minimize and cope with the behavior. Geriatric care consultants can be instrumental in helping caregivers anticipate behavior, interpret the behavior, and

provide techniques for minimizing and effectively managing the behavior.

Behaviors occurring in people with ARD can be grouped into two categories: (1) physical behaviors, and (2) non-physical behaviors. These types of behaviors usually occur simultaneously in most people with ARD, though some individuals have many behaviors over the course of their disease, while others have only a few. When certain triggers occur, a person with ARD may demonstrate many behaviors at one time and in significant degrees. This is termed a "catastrophic reaction" and may require professional assistance to resolve.

NON-PHYSICAL BEHAVIORS

■ Personality Changes

Personality changes that enhance negative personality characteristics are often one of the earliest signs of ARD, and can begin very subtly. Most often a person's more undesirable personality traits begin to become more apparent. For example, a former executive accustomed to issuing directives may show less social restraint and be overly aggressive towards a server in a restaurant.

Strategies: This symptom may be the first noted by family members of an individual developing ARD. If the person has not yet had medical and neurological evaluations, the caregiver should schedule an appointment with the primary care physician. It can be helpful to make written notes of the behavioral concerns to share with the physician, since patients usually don't recognize and actively deny their behavioral changes. When an individual is diagnosed with ARD, caregivers need to understand that the individual is less able to control these aspects of their personality. While negative words are usually directed at the caregiver, they are the result of physical changes in the brain and are not due to faults of the caregiver.

■ Depression

Changes in brain chemistry that occur with ARD often cause people to become biochemically depressed. In addition, in early stages of ARD, individuals have some level of awareness of their decreased abilities, which leads to situational depression. Some symptoms of depression include

withdrawal from others, changes in appetite and sleep (increased or decreased from normal), crying, anger, and lack of interest in formerly pleasurable activities.

Strategies: Because depression symptoms may be similar to dementia symptoms in older people, professional evaluation is necessary to determine the primary cause of symptoms and to decide on appropriate treatment. Caregivers should contact the physician who made the ADRD diagnosis and ask for evaluation for symptoms of depression. A psychiatrist or psychologist who specializes in geriatric mental health may conduct this evaluation. Medications may be prescribed and should be administered by the caregiver as ordered. The caregiver should monitor both the symptoms that stimulated the consultation as well as any possible side effects and beneficial effects from medication. It often takes two to four weeks for medication to have a positive effect. In early ADRD, psychotherapy or counseling may be helpful to the person in identifying and coping with perceived losses.

■ **Inflexibility**

The inability to be flexible is not usually noted until a change in routine occurs. For example, an overnight trip out of town requires staying in an unfamiliar environment and interacting with different people along the way. This disruption of normal routine can lead to confusion, agitation, and inability to carry out usual activities. Someone who normally sits at the kitchen table to eat meals is unable to sit down in the restaurant and instead insistently wanders throughout the room.

Strategies: Providing structure and routine are important for people with ADRD. Having a daily routine helps the person feel comfortable, while changing the routine often produces stress and undesirable behaviors. While in early stage ADRD individuals can tolerate some changes in routine such as celebrating a holiday at a daughter's home, it is often preferable to avoid major changes like taking a trip. It is also helpful for the caregiver to write down the daily routine in explicit detail in case someone needs to substitute for the primary caregiver. The less disruption in routine, the less likelihood there is of the individual with ADRD having a catastrophic reaction.

■ **Agitation**

Agitation can be defined as a mental state of extreme emotional disturbance, usually manifested in physical behaviors such as pacing, hand wringing, continual picking at something, weeping, and other repetitious movements. Agitation often occurs when there is a break in routine, when the person with ADRD is confronted with a new situation or person, when the primary caregiver is absent, or when the person has an unmet and unexpressed need. Agitation is a common symptom in people with ADRD, and caregivers need skills to discern the cause when possible and to provide effective care.

Strategies: Defining the cause of the agitation is the first step towards resolving the stimulus; although it is not always possible to determine what triggered the agitation. The caregiver should first check for issues of physical comfort—does the person need to be toileted, to be changed into clean clothes, to have food or liquids provided, or to add or remove clothing to maintain temperature. Is something causing pain somewhere in the body, which can range from abdominal pain due to constipation, to headache, to an open pin sticking the person. Any physical issue should be resolved promptly

and then the person should be observed to see if the agitation ceases. If there is no physical cause, emotional issues should be considered. Is something or someone in the environment new; or did seeing a photo, a mirror, or something on TV trigger an emotion.

The caregiver should provide comfort through speaking softly, offering a comforting beverage and/or item such as a soft afghan to stroke, turning on comforting music (comfort items should be identified in advance), and lastly by providing distraction from the triggering event. Going to a different room may help, as might releasing a pleasurable scent through a room atomizer. If the person with ADRD experiences frequent agitation, the physician can be consulted for medication to minimize the distress.

■ **Hallucinations**

Hallucinations are seeing, hearing, smelling, tasting, or feeling things that are not real. Most often hallucinations involve the senses of sight and hearing, with individuals seeing people or animals or hearing someone who isn't present talk to them. Sometimes hallucinations are called delusions or misperceptions. Some people with ADRD experience hallucinations, especially those with Lewy Body dementia. Hallucinations can be extremely real and often terribly frightening to the person experiencing them, although some individuals are not distressed by their hallucinations. In people with ADRD these inaccurate perceptions are caused by physical changes in brain, although they may be caused by adverse drug reactions.

Strategies: Caregivers are often very upset when their loved one first experiences hallucinations, especially if the person is insistent that someone or something is present when it isn't. Trying to reason with the person with ADRD about the reality of the situation is not usually effective. The caregiver should take necessary steps to ensure the physical safety of the person who is hallucinating. For example, if a man with ADRD is attempting to swat, push, hit, or remove an unseen adversary from the premises, the caregiver should remove objects that he could trip over and distract him with a previously identified comfort item.

The caregiver can tell the person to sit down and she will call 911, which she will need to do if distraction is not effective. Sometimes people with ADRD call 911 themselves because they think they smell smoke or hear someone breaking in. The caregiver can explain to the paramedics about the hallucination, and if needed, the person can be transported to the emergency department for assessment and treatment. Medication is available if people with ADRD experience frequent and/or upsetting misperceptions. However, if the delusions do not cause distress they can simply be tolerated. A 73-year-old highly religious man with Lewy Body dementia perceived that several "blue people" visited him daily. He gave them all pet names, like "Long Legs," and on occasion was noted by his spouse caregiver to be praying with them.

■ **Rejection of Assistance From All but Primary Caregiver**

People with ADRD become highly dependent on their primary caregiver, and may refuse to allow anyone else to help them with activities such as bathing, dressing, eating, etc. This obviously puts a great deal of stress on the primary caregiver to be "on duty" 24/7, and quickly leads to caregiver illness and burnout.

Strategies: The primary caregiver needs to write down a very detailed description of the person's daily routine and make it available to the backup caregiver. It is essential for a primary caregiver to have a backup plan in case of the caregiver's illness or injury and inability to provide care. The backup plan could include having a family member be a temporary caregiver, hiring a home care provider, or having the person with ADRD admitted to a facility for respite. In addition, if the person with ADRD is unable to initiate phone calls, the primary caregiver should have a signal arranged to indicate a crisis. Examples include calling the backup caregiver daily, or raising a curtain by a certain time each day so the neighbor knows the caregiver is up and well. It is desirable for any primary caregiver to have at least one day off per week from the beginning, and caregivers must understand that this will help them stay well and preserve their caregiving abilities. Introducing a respite caregiver in the earlier stages of ADRD will help the person accept other caregivers in the future. If another caregiver must be introduced without warning, the primary caregiver's prepared description of activities should be closely followed to minimize distress to the person with ADRD.

PHYSICAL BEHAVIORS

■ Aggression

People with ADRD sometimes engage in aggressive behavior that includes striking out physically at someone-often the caregiver-or damaging things in the environment. Aggression is often triggered by frustration, usually due to the inability to communicate one's wishes and needs.

Strategies: Caregivers of people with ADRD need to be aware that aggressive behavior can occur at any time, although it most often happens when providing personal care such as undressing or bathing. Individuals who have engaged in aggressive behavior are more likely to do so again, but even people who are generally cooperative and mild-mannered may become aggressive if something in their environment triggers a threat or they become frustrated. Caregivers can minimize the risk of injury from aggressive behavior by not getting into the "body space" or touching a person with ADRD without telling the person what to expect. For example, rather than just reaching out to wipe food from a spouse's face, the caregiver should say "George, you have something on your chin. I will wipe it off for you" and then approach in a way he can see the caregiver approaching. When helping a person undress, the caregiver should stand where they can be seen, use short phrases to explain what they will be doing, and then carefully approach the person. If the person does strike out, the caregiver should back off and take a brief time out. Redirecting or distracting the person may help diffuse his frustration and tendency to strike out. Aggressive behavior may sometimes be helped with medication prescribed by a skilled geriatric physician.

■ Wandering and Rearranging Household Items

One of the most difficult behaviors for caregivers to deal with is the person with ADRD's incessant wandering and "rearranging" (sometimes thought of as hiding) household items. Due to the underlying agitation experienced by a high number of people with ADRD, most of these anxious people are unable to sit calmly for activities such as watching TV, visiting with friends, or even eating. Instead they walk about in what appears to be an effort to find something they have lost, or simply to discharge nervous tension. Often in their

wanderings they go into rooms, open drawers, take something from a drawer, and then carry it to another place and deposit it. This behavior is often repetitious, so that the caregiver is unable to find needed items, which turn up in odd places-a hairbrush in the freezer, for example, or a coffee cup in a bottom dresser drawer. The most frustrating examples include moving the car keys, the checkbook, and other essential items.

Strategies: Caregivers can minimize the effect of the "rearranging" of household items by securing essential items in locked cupboards. Medications and cleaning supplies should always be locked securely in a home with a person with ADRD, including over-the-counter pills, creams, and any other potentially dangerous substances so they are not ingested inappropriately. Caregivers should maintain control of their checkbooks, wallets, keys, and other essentials by always putting them away in a secure location. Having backups of these essential items in another secure area can minimize frustration when they turn up missing.

Wandering itself is not considered harmful, and many experts believe that creating a safe area for people with ADRD to wander is appropriate. Ensuring safety may often include putting locks on doors so the person with ADRD doesn't leave the designated area or premises. It may be necessary to put loud alarms on doors as well, so if the person does get the door opened, the caregiver is alerted. Much wandering does occur at night, and the caregiver needs to be able to hear the alarms when sleeping without their own hearing aid. When it is time to use the toilet, eat a meal, go to an appointment, etc., the caregiver can begin to walk along with the person, explain what will happen next, link their arms together and lead them to the appropriate location. Both short verbal directions combined with the physical contact will help the person with ADRD pay attention to the next activity.

■ Disinhibition and Undressing Inappropriately

People with ADRD often experience a loss of inhibition or unrestrained behavior resulting from brain damage. This is often manifested by a lack of modesty like undressing in public; arguing, shouting, or using sexual talk in public; and behaving in a sexually inappropriate manner with a spouse or others.

Strategies: It is obviously distressing for a caregiver when their loved one is inappropriate about nudity and sex in public places or with other people. However, caregivers must realize that this behavior is due to brain damage and is not intended to humiliate the caregiver. Caregivers should maintain a calm attitude and assist the person in covering himself, which is often best accomplished through distraction rather than rational explanation. When the person with ADRD attempts to behave sexually with the spouse in a public place or in front of others, again the caregiver should be calm and matter-of-fact. Distracting the person with a previously identified comfort measure may be more effective than explaining the inappropriateness of his action. Backup and respite caregivers need to know that the person with ADRD may behave in a sexual manner so they will not be surprised if it occurs and they can be prepared to distract the person from the behavior.

■ Eating disorders

Eating problems in people with ADRD are generally one of three: (1) eating too much, (2) eating non-food items, and (3) eating too little. Eating too much usually occurs because the

person with ADRD doesn't remember having eaten, and signals regarding food intake are impaired by physical changes in the brain. Eating non-food items occurs because of brain damage also, and can involve eating items like buttons, coins, plants, dirt, dog or cat food, etc.

Strategies: Both eating too much and eating non-food items require similar strategies that involve securing inedible items as well as foods that should not be consumed from the person with ADRD. At times it is necessary to put locks on kitchen cabinets if the person seeks food, and to lock up or rid the premises of inedible items the person tries to eat. People who eat non-food items require very close supervision and prompt medical consultation if ingestion of a non-food item is suspected. In early and middle stage ADRD, people who eat too little do so because they are too agitated to sit and eat. Providing finger foods such as sandwiches cut into strips, cereal bars, pieces of fruit or vegetables, etc. allows the person to eat while pacing or wandering. It may be necessary to briefly stop the person from wandering to provide them with a beverage and encourage them to drink. In later stage ADRD, people may eat too little due to difficulty chewing and/or swallowing. At this stage, consultation with a speech therapist is helpful in determining the type of diet most easily consumed. In addition, discussion with the physician and family members about artificial feeding is appropriate at this time unless the issue has been previously decided.

■ **Sleep Disruption and Being up at Night**

Many people with ADRD become confused about time of day, sleeping too much during the day and too little during the night. They may have difficulty falling asleep, or they may wake up and wander about in the night. Their sleep disruption results in sleep disruption for the caregiver as well. Inadequate sleep makes the difficult task of caregiving nearly

impossible, so finding ways to ensure both people have enough sleep is essential.

Strategies: The first step is to identify the person with ADRD's sleep patterns and write them down in a log. A health care professional with experience managing dementia behaviors can assist in developing specific strategies to improve sleep patterns. Some of these techniques are avoiding naps during the day, including exercise in the daily routine-usually walking outdoors or in a mall, providing the larger meal at noon rather than evening to avoid gastric reflux and discomfort when going to bed, and avoiding excessive fluids after dinner to reduce the need to get up in the night to the bathroom. Some other techniques may include providing a dark, quiet bedroom, playing soothing music softly, and using relaxing scent like lavender in the room at bedtime. The physician can assist by considering the use of appropriate sleep medication if the nocturnal waking and wandering persist despite all these efforts. As a last resort, the caregiver can hire a companion to be awake with the person during the night so the caregiver can get eight hours of sleep.

Matrix has provided care coaching, care consulting, and health advocacy for people with ADRD and other disabilities and their families since 1987. To find out how a Care Consultant can help in your situation, call **763/560-1010** or **800/560-0961**. To receive future Issues on Aging by email, send a request to **matrix@visi.com** and include your email address.

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