

ALZHEIMER'S DISEASE (AD)

CAREGIVING CHALLENGES

Some of the specific things that are challenging for patients with AD usually stem from the memory problems that are so predominant in this disease. The lack of memory for events or people can make the individual extremely anxious about daily life. This can be exhibited with asking questions and repeating information, preparing for appointments/day care well ahead of time, and use of notes and reminders endlessly. Apathy or a lack of initiative can be due to tasks that used to seem routine now being overwhelming. For example, the person who always enjoyed puzzles but no longer does them because they are too overwhelming and require skills he/she no longer possesses. Finally, agitation can occur often as people become less able to interpret the environment and control or express their feelings. This can be seen in people with dementia who may strike out when people are caring for them. These behaviors are very difficult for caregivers who are trying to provide care and understand the changes in their loved one.

STRATEGIES FOR COPING

The major strategy for coping is to keep the goal in mind. Often, caregivers trying to make everything all right, will end up exhausted and frustrated. The truth is they can't make everything all right and an adjustment of goals to be realistic and attainable may be helpful. Perhaps the goal is to be sure the patient is clean, comfortable and well fed and realizing that success might be 80%. Being comfortable with a less than perfectly groomed spouse or perfectly organized home is bound to be a difficult task but accepting this will allow you to perhaps enjoy time you might otherwise have spent fretting about hygiene issues.

Anticipate misinterpretation by the individual with dementia. They are often no longer able to accurately interpret verbal or non-verbal cues which can result in anxiety and frustration in both the individual and the caregiver. Try to be clear and concise in your communications – repeating things as needed using the same words or message. Reduce extraneous noise and distractions when trying to communicate. Do not use confusing pronouns (he, she, it) but rather names and specific titles. Try to imagine what someone MIGHT think you are trying to do or say if they were unable to think clearly.

Remember that all behavior has a purpose. Many experts believe that some of the behavioral symptoms that people with dementia exhibit such as shouting out or striking out are meaningful. Although the person does not generally intend to disrupt things or to hurt someone, they do intend to be noticed and perhaps communicate a need that is not being met. In addition, it is important to remember that while these behaviors are meaningful, they are not intentional and the individual is not doing this “on purpose” but more likely in an attempt to convey a message that they can longer explain in words. Slowing down, trying to see the world thru their eyes and trying to respond to the “feeling” behind the behavior rather than the behavior itself, may allow you to prevent an emotional crisis.

Many people with Alzheimer's disease remain physically fit and retain their ability to be comfortable and involved in social situations quite late in the disease. Therefore, **enjoy the good times** and continue to socialize, travel, be physically active and participate in activities that are enjoyable to both the person with Alzheimer's and the caregiver. Often, familiar activities that may be well memorized will continue to be enjoyable for the

person with Alzheimer's disease and should be encouraged. However, trying to learn new tasks or starting new hobbies may be frustrating or overwhelming.

Since memories from the distant past are not usually affected, **reminisce about the past** and encourage discussions about people and places that are familiar and evoke pleasant feelings for both of you. Watching family videos, looking at photographs or reviewing travels from the past can allow the person with Alzheimer's disease and the caregiver to continue to share experiences and feelings. Allow the person to share the history they remember with family members, grandchildren and friends. It can be fun for all involved and so satisfying for the person with dementia to continue to feel connected and to contribute.

Be flexible. The disease is progressive. The symptoms and needs will change over time. If strategies such as notes or reminders, are no longer working, don't use them! A successful intervention at one stage, can be a frustration and disaster at another. Seek help, ask for advice, learn from others who have had similar experiences. More challenging behavioral symptoms such as resisting care or being aggressive can be particularly difficult and often require a very individualized approach. Talk to your doctor about approaches, both pharmacological and non-pharmacological. Some strategies for specific behaviors are available at the links listed below:

For more detailed information:

- **Alzheimer's Association**
- **Family Caregiver Alliance**
- **Alzheimer's Caregivers' Manual**
Answers 4 Families

SAFETY

One of the priorities for caregivers is the safety of their loved one with dementia. As dementia progresses, the memory and judgment of the individual become impaired and he/she is often no longer able to anticipate or avoid dangerous situations. This can be an overwhelming responsibility for a caregiver and require some creative strategies for coping. The recommendations below are some areas to consider planning for in terms of safety.

Supervision

In the early stages, concerns about supervision may be minimal as the person with dementia is still able to make appropriate judgments about safety. However, the need for supervision usually increases as the person with dementia becomes more forgetful and their judgment becomes poorer. It is important at this stage to try to provide the appropriate level of supervision. This is often difficult to determine and involves evaluating the risk of the behavior actually or potentially occurring, the consequences should it occur and the ease/discomfort involved in protecting the person with dementia. Supervision can include simple reminder phone calls for medications, alarms on doors to prevent exiting, and actual personal supervision to prevent physical injury or harm. Some areas to review when considering level of supervision include the ability to handle emergencies when left unsupervised, ability to use appliances safely, and ability to safely answer the phone or door when left alone. Wandering often occurs in later stages when people may be confused about where they are or are trying to find a

familiar person or place. If there is a concern about this, enrolling in the Safe Return program should be considered. This program, which is administered by the Alzheimer's Association, provides national registration and identification of people with dementia to assist in locating them should they wander away or become lost.

For more detailed information:

- **Alzheimer's Association Safe Return**
Alzheimer's Association

ENVIRONMENT

Providing increasing supervision is a difficult and time-consuming task for many caregivers. If possible, modifying the environment to limit exposure to potentially dangerous situations can allow patients to continue to be independent and safe. Especially in the early stages, reminders and cues in the environment may be enough to keep the individual safe, for example, posting the steps involved in a task or labeling where things are kept. Later, strategies which limit the exposure to potentially dangerous situations may be considered. Removing stove handles when using the stove is anticipated to be a problem or using childproof handles on cupboards with dangerous materials in them. When more supervision is needed, it is best to assess each situation individually and gradually increase the amount of supervision needed to maintain as much independence and autonomy as possible in as safe a setting as can be provided. There are some resources that provide tips and products to modify the environment and protect the patient.

For more detailed information:

- **Alzheimer's Store**
Products and information for those caring for someone with Alzheimer's disease.
- **Careguide.net**