



When a Family Member Has Alzheimer's Disease

Family members play a crucial role in the care of many elderly individuals. When the elderly family member is demented, care can be especially demanding and stressful. Even the most dedicated and well-intentioned family caregivers can find themselves burdened by the frustrating, time-consuming and expensive prospect of providing care. Such a person's difficulties with basic activities of self-care, often accompanied by demanding or inappropriate behaviors, can be overwhelming. It is estimated that more than 70 percent of people with Alzheimer's disease (AD) are cared for at home, with almost 75 percent of that care provided by family and friends. The direct and indirect costs of home care constitute a huge financial burden for many families.

In addition to the needs of the AD family member, family needs must be addressed. Providing care can be more stressful than many people realize. Sixty-one percent of "intense" family caregivers (those providing at least 21 hours of care a week) have suffered from depression. Family psychotherapy, both with and without the demented patient, can help reduce some familial stress. The focus should be on issues of grief and loss as well as the practical issues involved in providing care. Many support groups for caregivers are available to help families cope with the stress of caring for a demented family member, a task that can continue for many years. Groups that are conveniently located can be identified with the help of the Alzheimer's Association (www.alz.org).

The importance of caregiver stress has been increasingly acknowledged, and several books are available as resources for caregivers. Mace and Rabins in their widely respected book, *The 36-hour Day: A Family Guide to Caring for Persons With Alzheimer Disease, Related Dementing Illnesses, and Memory Loss in Later Life*, offer clear and practical advice for caregivers. They advise that caregivers become knowledgeable about the patient's illness, address the most frustrating problems one at a time, make certain to get enough rest and support themselves, maintain a sense of humor and maximize freedom and activity within the patient's capacity. Their model of behavioral management focuses on the "Six Rs":

- Restrict inappropriate behavior when possible.
- Reassess the possible medical or environmental causes of the behavior.
- Reconsider the patient's motivation for seemingly irrational behavior by adopting an empathic stance.
- Rechannel potentially destructive behavior into more constructive activities.
- Reassure patients of your care and presence.
- Review periodically to see what can be learned from solved and persistent problems.

Family caregivers who learn behavioral-management techniques to target specific problem behaviors find relief in seeing improvement in the AD-affected member. A slower behavioral decline may be seen among demented individuals cared for by caregivers who have mastered such behavioral approaches. Manuals, training programs and peer-support groups are available for family caregivers. The Alzheimer's Association, which has both national and state presence, is a good source for educational materials and support groups.

In addition to appropriate training and support, caregivers should learn to draw on available resources for help in caring for a person with AD. Help at home may be all that is needed in the earlier stages of AD. Later, as increasingly more structure is needed, it may be appropriate to send the person with AD to an

adult day care program. Eventually, there will come a time when the family will not be able to provide sufficient monitoring and care for a person. For many families, the decision to seek placement in a long-term care facility is a difficult one that may require consultation, discussion and an honest appraisal of what can realistically be provided. It is believed that more people enter nursing homes because of caregiver burnout than an exacerbation of their own condition, so proper care of the caregivers can allow a person with AD to maintain independence as long as the progression of the AD allows.

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