

The Alzheimer's Disease Caregiver

There are an estimated four million Americans with Alzheimer's disease. That number is expected to grow dramatically in the coming decades, with an equal increase in the number of individuals who will become their caregivers. While researchers continue to search for ways to reverse and cure Alzheimer's disease, we must provide caregivers with the same love, compassion and support that they give to their Alzheimer's patients.

Q . **What effect can Alzheimer's disease have on a caregiver?**

A . Alzheimer's disease affects more than just the person who has been diagnosed. In most cases, it also impacts the family members and friends who become caregivers. Caring for an Alzheimer's patient can cause emotional, psychological, and physical problems. As the disease progresses, caregivers often find themselves cut off from friends and regular social activities. Further, even the most dedicated caregivers will struggle with guilt over feelings of resentment or frustration that arise as they cope with a loved one's difficult behavioral changes. Alzheimer's disease frequently poses financial problems for caregivers as well. Studies on the economic impact of the disease have found that the average caregiver with a full-time job will miss more than three weeks of work a year, and that one fifth will quit their jobs altogether to provide full time care.

Q . **How important is early detection and diagnosis of Alzheimer's disease?**

A . Of all the things that caregivers can be taught, the first and perhaps most important is to identify Alzheimer's disease as early as possible. Early warning signs include: Gradual loss of short-term memory

- Mood or personality changes
- Problems finding or speaking the right word
- Inability to recognize objects
- Forgetting how to use simple, ordinary things, such as a pencil
- Forgetting to turn off the stove, close windows, or lock doors

When Alzheimer's disease is diagnosed in its earliest stages, patients can still contribute to their own caregiving strategy (e.g., address financial matters, draw up a will or appoint powers of attorney, decide about participating in experimental therapies). Early detection and diagnosis of Alzheimer's disease can substantially lighten a caregiver's burden.

Q . **Can Alzheimer's patients be cared for at home?**

A . Most Alzheimer's patients-particularly those in the early and middle stages of the illness- can be cared for at home instead of at nursing homes or other facilities. More than half of all diagnosed Alzheimer's patients continue to live in home settings, and 80 to 90 percent of these rely on family and friends for care.

Q . Is training important for an Alzheimer's caregiver?

A . A major obstacle to quality home care is a lack of adequate training for caregivers. The challenges posed by a patient with Alzheimer's disease, such as personality and behavioral changes, can baffle the unprepared caregiver. As caregivers learn about Alzheimer's disease and adapt to the afflicted person's behavior, they will learn how to customize a patient's living environment, thereby making the caregiving experience less difficult and stressful.

Q . Are caregiver support services helpful?

A . Caregivers who take advantage of programs such as support groups, adult day care and respite care (a temporary nursing home-like service where patients may stay for a limited number of days) keep their Alzheimer's patient at home longer than those who do not. They also tend to feel healthier and find caregiving more rewarding than those who do not use support services.

Q . What can a caregiver do when home care is no longer enough?

A . At some point, most caregivers confront the possibility of no longer being able to provide home care for a person with Alzheimer's disease. Residential options for these patients fall into three broad categories:

- Independent living facilities
- Assisted living facilities
- Nursing homes

Another housing choice for Alzheimer's patients is the Continuing Care Retirement Community. These comprehensive facilities offer all of the above residential options "under one roof."

Q . Are caregivers being recognized for their work?

A . There is no doubt that caregivers are receiving increased attention, support and recognition, and a growing number of researchers and organizations are realizing that caregivers have much to offer the larger society. One suggestion is that former caregivers be incorporated into the health care network, so they can share their hard-earned skills and expertise with those who are new to the disease.

Q . Where can I go for more information?

A . The Alzheimer's Association, a national organization with chapters across the country, can be reached at 800-272-3900, or on the Internet at www.alz.org. The Alzheimer's Disease Education and Referral Center can be reached at 800-438-4380. Two additional resources are:

The Family Caregivers Alliance (800-445-8106; website: www.caregiver.org) and the National Family Caregivers Association (800-896-3650; website: www.nfcacares.org).



Perform a MEDLINE search on Alzheimer's Disease Caregivers

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For information regarding dementia or delirium, you can ask your doctor, or refer to The American Geriatrics Society's Complete Guide to Aging & Health. (To obtain a copy, check your local library, or call 800-677-9944, for a 35% discount through the AGS.)

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