

# RESEARCH & PRACTICE

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Practical Information for Health Care Professionals on Alzheimer's Disease and Related Disorders Published by: **ALZHEIMER'S ASSOCIATION**

## CARING FOR THE CAREGIVERS OF YOUR ALZHEIMER PATIENTS

From the moment a patient receives a diagnosis of Alzheimer's disease, a spouse, daughter, son, or other family member will embark on a new, perhaps unfamiliar journey as he or she gradually assumes the role of caregiver for his or her loved one.



Caregivers all too often sacrifice their own health and well-being to ensure their loved one is receiving the best possible care.

Unfortunately many caregivers and health care professionals fail to realize that the diagnosis is only the beginning of what lies ahead. Throughout the disease process, patients and

their caregivers will turn to you, the health care professional, for guidance.

### *The Alzheimer Caregiver*

As Alzheimer's disease progresses, it robs its victims of memory, judgment, and the ability to reason until they *cannot* care for themselves any longer or engage in normal daily activities such as cooking, dressing, or bathing. Alzheimer's disease forces once independent individuals to depend on someone else for their care.

According to a 1996 survey conducted by the Alzheimer's Association, an estimated 70 percent of the 4 million Americans with Alzheimer's disease are cared for at home. Most caregivers of Alzheimer patients are spouses or adult children who spend an average of 69–100 hours per week caring for their loved ones. Fifty percent of all caregivers live with their loved ones and assume responsibility for care 24 hours a day.

Although caring for a loved one with Alzheimer's disease reaches and often surpasses the equivalent of two full-time jobs, 96 percent of caregivers surveyed agreed that caring for a family member who has Alzheimer's disease is a "labor of love."

In nearly all cases, a caregiver's primary concern is providing a good quality of life for the affected loved one. Caregivers all too often sacrifice their own health and well-being to ensure their loved one is receiving the best possible care; many do not recognize or attend to their own personal needs and often do not know where to turn for help.

The first point of contact for patients and their caregivers is a visit to the doctor's office that ends with a diagnosis of Alzheimer's disease. Sadly, they are all too frequently sent home with little guidance and left feeling hopeless — with the sense that not much can be done about Alzheimer's disease.

Since the patient's primary caregiver will become your partner in care for the duration of the disease, it is important for you as a health care provider to equip him or her for the journey that lies ahead. Alzheimer's disease can last anywhere from 3 to 20 years, with an average duration of 8 years. Throughout that period, the health and well-being of the caregiver will affect the health and well-being of your patient.

Although caring for a patient with Alzheimer's is indeed a "labor of love," it can be emotionally,

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physically, and financially draining. More than 80 percent of Alzheimer caregivers report they frequently experience high levels of stress, and 75 percent are depressed, at least occasionally. Among the many causes of stress and depression among caregivers are feelings of guilt, anger, and resentment toward a loved one who no longer comprehends the world around him, as well as concerns about future care and finances. The level of stress caregivers experience often escalates as the disease progresses and their loved one becomes increasingly more dependent on them for daily care.

The best way to provide care for your patient's caregiver is to recognize the warning signs of caregiver stress (see

sidebar) and *listen* to what the caregiver is saying. Often caregivers just need the opportunity to ask for advice on how to cope with changes in their loved one.

You can help alleviate caregivers' stress by letting them know of resources available in your community. The Alzheimer's Association is a valuable source throughout the disease process of educational information, referrals to care services, and support groups for the patient and caregiver. Also advise caregivers not to be afraid to ask for help from family and friends, and let them know that they should be realistic about what they can handle alone and not feel guilty about taking time to care for themselves.

### *Planning for the Future*

Patients and their caregivers require comprehensive information about Alzheimer's and what to expect as the disease progresses *immediately* after the diagnosis is made. It is important to tell family members that they need to start planning for the future as soon as possible, while the patient is still capable of participating in the planning process.

Planning for a future in which the patient can no longer function independently should include preparing documents that authorize another person to make health care and financial decisions for the Alzheimer patient. Involving the patient in his or her future care alleviates stress and feelings of guilt for the caregiver, who would otherwise have to make very difficult decisions about the loved one's care without knowing the patient's original wishes. Direct your patient and his or her caregiver to an attorney who practices in the area of elder law; obtaining

### *Warning signs of caregiver stress*

Too much stress can be damaging to caregivers and the person for whom they are caring. Keep an eye on your patient's primary caregiver during regular visits and note the following signs of caregiver stress:

- Denial
- Anger
- Social withdrawal
- Anxiety
- Depression
- Exhaustion
- Insomnia
- Irritability
- Difficulty concentrating
- Health problems

### *For your waiting room...*

The Alzheimer's Association can provide you with educational and support materials for your patients and their families. You can request any of these brochures by calling (800) 272-3900 or contacting your local chapter.

- *Safe Return: For Their Safety, For Your Peace of Mind*
- *Steps to Enhancing Communication: Interacting with Persons with Alzheimer's Disease*
- *Steps to Enhancing Your Home: Modifying the Environment*
- *Steps to Planning Activities: Structuring the Day at Home*
- *Steps to Understanding Challenging Behaviors: Responding to Persons with Alzheimer's Disease*
- *Steps to Understanding Legal Issues: Planning for the Future*
- *You Can Make a Difference: 10 Ways to Help an Alzheimer Family*

legal advice about finances and future care options can be very helpful. Your local chapter of the Alzheimer's Association can assist you in finding elder law attorneys in your area.

Throughout the disease process, your patients and their caregivers will seek advice from you about a myriad of symptoms — agitation, aggression, wandering, and insomnia, among others. Take the time to analyze how your patients' behaviors are affecting their caregivers and treat both individuals accordingly. When you are unsure of what type of advice to give, refer them to the Alzheimer's Association, where they can talk to other families who are also living with Alzheimer's disease. To find a chapter of the Alzheimer's Association near you, please call (800) 272-3900. ●