

Understanding Early-Onset Alzheimer's Disease:

Guide for Health Care Professionals

As diagnostic procedures become more sophisticated and the public's awareness grows, more individuals will be accurately diagnosed at a younger age and an earlier stage of the disease. Alzheimer's disease is considered to be early in its onset, or starting point, if an individual is age 65 or younger when symptoms first appear. Early-onset individuals may not necessarily be in the early stage of Alzheimer's when diagnosed.

Individuals will experience similar symptoms as early-stage Alzheimer's disease (see Understanding Early-Stage Alzheimer's Disease.) This fact sheet presents some of the additional issues that early-onset individuals may experience due to their younger age (e.g., children living at home, employment issues) and offers suggestions on ways professionals can assist early-onset Alzheimer's families.

The local chapter of the Alzheimer's Association can provide information, support, and referrals to families facing the following issues.

Difficulty Obtaining a Diagnosis

Early-onset individuals may have a difficult time obtaining an accurate diagnosis due to:

- ▶ *Younger age and healthy appearance ruling out Alzheimer's disease*
- ▶ *Attributing the early symptoms to stress*
- ▶ *Diagnosis of depression or another psychiatric illness*
- ▶ *Conflicting diagnosis from different health care professionals*

Tips for Helping Individuals Obtain a Diagnostic Assessment:

- Call the Alzheimer's Association for diagnostic protocol information and referral to a specialist
- Advocate with managed care and HMOs for a comprehensive diagnostic evaluation
- Encourage early-onset individuals and caregivers to write down symptoms and other experiences to share with health care professionals
- Refer caregivers to the Alzheimer's Association Web site at www.alz.org
- Encourage caregivers to access and share information about Alzheimer's disease on the Internet with his or her health care professional to confirm accuracy of information

Financial Challenges

Due to the relatively young age of early-onset individuals, insurance and other benefits may be more difficult to obtain and there may be more expenses to consider. Financial challenges may include the following:

- ▶ *Loss of income and insurance coverage when no longer employed*
- ▶ *Reduction or loss of retirement benefits due to early retirement*
- ▶ *Delay in eligibility for Medicare or disability*
- ▶ *Increase in family expenses due to treatment and care for diagnosed individual*
- ▶ *Spouse may need to work or increase hours to help support the family*

Tips for Addressing Financial Challenges:

- Investigate early retirement or other financial planning options if the early-onset individual is still working
- Refer to a skilled financial consultant or elder law attorney
- Offer your assistance with completing the disability insurance application process
- Arrange for the family to meet with social security consultants

(Continued on back page)

(Continued from front page)

Impact on Children at Home

Children of a parent diagnosed with early-onset Alzheimer's disease

► may feel:

Fear and grief at the gradual losses

► *the parent experiences*

Ashamed and may avoid inviting

► *friends home*

Anxious if he or she detects stress in

► *the parents' relationship*

Alone due to the well parent

focusing his or her attention on the

► *ill parent*

Awkward due to a reversal of roles

► *withing the family*

Frustrated due to changes in lifestyle

► *Frightened about his or her own future and the chances of getting Alzheimer's disease*

Tips for Helping Children Cope:

- Refer to the Alzheimer's Association for resources for children and adolescents
- Assess the child's need for counseling and refer to a counselor who specializes in this area
- Refer the child to a support group to express his or her feelings
- Suggest the child's teachers to be notified and provided with information about Alzheimer's disease
- Help the caregiver find activities the child and parent can do together
- Assist the caregiver in making time to spend alone with the child
- Encourage open communication between parent and child
- Address fears related to heredity of early-onset Alzheimer's
- Refer to the Alzheimer's Association for education about the limits of genetic testing

Finding Appropriate Support Services

Early-onset individuals may need additional support services to supplement help from family and friends. Challenges you may face include finding a home care agency that understands how to meet the specific needs of individuals with early onset Alzheimer's. Locating respite and adult day programs with participants in the same age group as the early-onset individual is difficult. It also may be hard to locate a residential care setting with younger residents.

Tips for Helping Families Arrange Support Services

- Inform families about the type of programs available in the community (e.g., respite care, home care, adult day programs) and link them to the needed resources
- Contact the Alzheimer's Association for community programs that specialize in Alzheimer care
- Work with the family to discuss their issues regarding placement
- Assist the caregiver in finding residential care setting options before they are needed
- Arrange for the caregiver to consult with an attorney and care manager to establish a manageable financial plan for current and future needs

Alzheimer's Association

To receive a reading list on early-onset Alzheimer's disease, call the Alzheimer's Association Benjamin Green-Field Library at: 312.335.9602.

Through its nationwide network of chapters, the Association offers a broad range of programs and services for people with the disease, their families, and caregivers. These services include support groups, telephone helplines, educational seminars, advocacy programs, and a variety of print and on-line resources on the disease, caregiving approaches, and current research.

Research into the causes, treatment, and prevention of Alzheimer's disease will create new options for treatment and care. The Alzheimer's Association, the largest private funded of Alzheimer research, is dedicated to supporting scientists who are making advances toward conquering this disease.

For more information or to locate the chapter nearest you call: 800.272.3900.

Alzheimer's Association

National Office
225 North Michigan Ave., Fl. 17
Chicago, IL 60601-7633

800.272.3900 **phone**
312.335.3900 **TDD**
info@alz.org **e-mail**

www.alz.org

ED432G

©1999 Alzheimer's Disease and Related Disorders Association, Inc.
All Rights Reserved Reprinted 2004