

Understanding Early-Stage Alzheimer's Disease:

Alzheimer's Association

A Guide for Health Care Professionals

As diagnostic procedures become more sophisticated and the public's awareness grows, more individuals are being diagnosed earlier in the course of Alzheimer's disease. In the beginning stage of Alzheimer's, called **early-stage**, individuals have special needs that may be overlooked.

This fact sheet identifies some of those needs and provides suggestions to assist early-stage individuals and their caregivers. The local chapter of the Alzheimer's Association can provide information, support and referrals to families facing the following issues.

Common Symptoms in Early-Stage Alzheimer's Disease

Symptoms are usually mild in the early stage of the disease, allowing most individuals to continue to do simple daily routines. Many are aware of the changes that are taking place, including difficulty with:

- ▶ *Recalling recent events*
- ▶ *Making decisions and judgments*
- ▶ *Managing routine chores*
- ▶ *Expressing thoughts and feelings*
- ▶ *Processing what was said by others*
- ▶ *Handling complex tasks such as balancing a checkbook*

A person recently diagnosed is not necessarily in the early stage of Alzheimer's as individuals may be more advanced at the time of the actual diagnosis.

Reactions to a Diagnosis

Noticeable changes in mental functioning affect both the diagnosed individual and the caregiver. Reactions may include:

- ▶ *Depression*
- ▶ *Denial*
- ▶ *Anxiety and fear*
- ▶ *Isolation and loneliness*
- ▶ *Embarrassment and shame*
- ▶ *Feelings of loss*

Tips for Addressing Reactions to the Diagnosis:

- Acknowledge feelings and provide an opportunity to talk and ask questions. Refer the individual and their family to an Alzheimer's Association support group
- Assess for depression and/or suicidal thoughts. Short term counseling and medications may be helpful in some cases
- Refer families to a physician knowledgeable in dementia for evaluation and treatment
- Encourage the diagnosed individual and the caregiver to take care of his or her physical and mental health

Changes in Relationships

Alzheimer's disease can cause stress in relationships between diagnosed individuals, caregivers, family, friends and colleagues.

Early-stage individuals may experience:

- ▶ *Feelings of people trying to help too much or too little*
- ▶ *Role changes in relationships with family and friends*
- ▶ *Anxiety over whom to tell about the diagnosis*
- ▶ *Increased or decreased sexual desire*
- ▶ *Feelings of not being understood by others*

- ▶ *Problems trusting their own decisions*
- ▶ *Family and friends withdrawing or avoiding them*
- ▶ *Difficulty interacting in social settings*
- ▶ *Increased anxiety over legal and financial issues*

Caregivers may experience:

- ▶ *Role changes within the relationship*
- ▶ *Anxiety over whom to tell about the diagnosis*
- ▶ *Changes in the sexual relationship*
- ▶ *Feeling misunderstood by friends and family, which may lead to isolation*

Tips for Addressing Relationship Issues:

- Help families talk about the changes they are experiencing and how they feel
- Refer the individual and their family to support groups to share feelings and develop new supportive relationships
- Include the individual with Alzheimer's in the decision-making process as much as possible
- Encourage openness with friends and family about the changes that are taking place

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Changes in Lifestyle

The daily routine for Alzheimer families will likely be modified in response to the progression of the disease.

Individuals with Alzheimer's may experience:

- ▶ *Increased or decreased concern about safety*
- ▶ *Difficulty performing daily routines without assistance*
- ▶ *Frustration due to need for assistance with meals, medications, finances, and self care*
- ▶ *Anger and grief due to loss of independence, such as driving*

Caregivers may experience:

- ▶ *Difficulty assessing the individual's capacity to manage personal care and other activities*
- ▶ *Loss of independence due to added caregiving responsibilities*
- ▶ *A need for seeking socialization with others*

Tips for Addressing Lifestyle Challenges:

- Focus on the remaining abilities of the individual and develop strategies to compensate for declining abilities
- Have a home safety evaluation conducted and make modifications to address safety issues
- Suggest families enroll in the Alzheimer's Association *Safe Return* Program

- Encourage caregivers to keep a journal as a way of acknowledging feelings
- Help caregivers determine when the diagnosed individual should stop driving and assist with finding alternate means of transportation
- Establish a daily routine for families that provides structure, consistency and mental stimulation
- Incorporate physical exercise into daily routines
- Refer families to home care, adult day services, social clubs, and support groups
- Help families determine when it is no longer appropriate for the individual to live alone or remain at home alone for any period of time
- Create a list of practical things others can do to assist caregivers and tips on how caregivers can ask for help

Plan for the Future

Early-stage individuals can play an active role in making decisions about treatment options, housing preferences, financial and legal issues. Planning for the future facilitates decision making for the caregiver and assures the individual's wishes are known.

Alzheimer families may not initiate planning due to denial and depression. It may be difficult for some families to discuss these issues based on their history of communication, status of relationship and fears about the future.

Tips for Helping Families Plan for the Future:

- Refer families to an elder law attorney for counsel on issues they may face as the disease progresses and options for addressing them
- Encourage completion of a durable power of attorney and advance directives for health care and financial planning as soon as possible
- Refer families to a care manager to learn about programs and services available in the community
- Discuss and explore alternative housing options such as assisted living and nursing homes before they are needed
- Offer information about participating in a research study and the option of having a brain autopsy performed to confirm the diagnosis

Challenges for Those Who Live Alone

Not all individuals with early-stage Alzheimer's have a caregiver living with them. These individuals will need more frequent safety assessments and medical monitoring. Watch for changes that would indicate the need for additional supervision. Talk with colleagues about confidentiality issues and mandated reporting laws in order to be prepared to respond to different situations that may arise.

To receive a reading list on early-stage Alzheimer's disease, call the Alzheimer's Association Benjamin Green-Field Library at: (312) 335-9602.

The Alzheimer's Association is the only national voluntary health organization dedicated to conquering Alzheimer's disease through research and to

providing information and support to people with Alzheimer's disease, families, and caregivers. For more information or to locate the chapter nearest you call:

(800) 272-3900

or visit our Web site at:

www.alz.org

Alzheimer's Association

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