

Understanding Early-onset Alzheimer's Disease

Alzheimer's disease is considered to be early in its onset, or starting point, if in 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.

This fact sheet presents some of the issues that early-onset individuals 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 families.

The local chapter of the Alzheimer's Association can provide information, support and referrals to families facing early-onset 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:

- Advocate with managed care for a comprehensive diagnostic evaluation.
- Encourage early-onset individuals and caregivers to write down symptoms and other experiences to share with health care professionals.
- If you have specific information that might be useful, send formal documentation describing your observations and concerns to the physician.

- Encourage caregivers to share information about Alzheimer's disease from the Internet with health care professionals 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 the 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 adviser or elder law attorney if funds are available to do so.
- Offer your assistance with completing the disability insurance application process.
- Arrange for the family to meet with social security consultants.

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Impact on children

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

- Fear of the gradual losses the parent experiences.
- Ashamed and may avoid inviting friends home.
- Anxious if he or she detects stress in the parents.
- Alone due to the well parent focusing his or her attention on the diagnosed parent.
- Awkward due to reversal of roles within 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 this website
<http://www.alz.org/Resources/TopicIndex/KidsTeens.asp>
- Assess the child's need for counseling and refer to a counselor who specializes in this area.
- Suggest the child's teachers be notified and provided with information about Alzheimer's.
- Help the caregiver find activities the child and the parent can do together.
- Assist the caregiver in making time to spend alone with the child.
- Encourage parent/child communication.
- Address fears related to heredity of early-onset Alzheimer's and fears of "catching or getting" it.

Finding 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 services and adult day programs with participants the same age as the early-onset individual.
- Locating 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 in a care facility.
- Assist the caregiver in finding residential care options before they are needed.
- Arrange for the caregiver to consult with an attorney or care manager to establish a financial plan for current and future needs.

How to Contact the Alzheimer's Association – Heart of America Chapter 1.800.272.3900 • alz.org/kansascity

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