

CE I Case Management in Patients with Early-Onset Alzheimer's Disease

By Jennifer Voorlas, MSG, CMC

Introduction

One of the most difficult challenges facing case managers may be providing case management for individuals with early-onset Alzheimer's disease. Although some patients who are over age 65 may have some form of dementia (eg, memory loss, confusion, and difficulty with performing daily tasks), helping younger patients with early-onset Alzheimer's disease requires using a much wider lens to view our clients, their family support systems, and ultimately the resources and interventions that we will use.

Early-onset dementia is used to describe any form of dementia that is diagnosed before age 65, but the symptoms can begin affecting individuals in their 30s, 40s, and 50s. It is estimated that approximately 200,000 people in the United States have early-onset Alzheimer's disease, an illness that affects employment and intimate relationships, impairs judgment, and ultimately makes it difficult to take care of oneself.¹ Although early-onset Alzheimer's disease is thought to be rare, the number of cases is increasing every year as more accurate diagnostic tools are being developed and used. Thus, a case manager who works in a multitude of settings will undoubtedly come into contact with a patient with early-onset Alzheimer's disease who may not yet have been diagnosed or is in the early, middle, or end stages of the disease.

Impact of Cultural Stigma

The assumption that Alzheimer's disease is an illness that occurs exclusively in individuals over age 65 is a myth due to the lack of education about early-onset disease as well as cultural denial about who may be diagnosed with the disease. Case managers must be especially aware of how negative cultural attitudes impact individuals with early-onset Alzheimer's disease in terms of how individuals perceive their ability to fit into society and their ability

to use available resources. Moreover, growing bodies of research suggest that cultural stigmatization promotes social exclusion and the reluctance to seek help.² This is a challenge for the case manager because resources for individuals with early-onset Alzheimer's disease are still somewhat limited with regard to financial help, social opportunities, and appropriate housing.

Because of diminished functioning, many individuals with early-onset Alzheimer's disease who become unemployed experience changes in their social support system, which may breed isolation. It may also be challenging for an individual with early-onset Alzheimer's disease to establish new relationships because of the age gap of the new pool of available "peers". Most social service programs and assisted living and residential care facilities that cater to individuals with dementia are primarily occupied by patients who are well over age 65. If an individual with early-onset Alzheimer's disease is still able to live at home but needs care, it can be isolating if ample support systems and outlets for social, recreational, and mental stimulation are not provided.

Problems with Diagnosis

Another challenge for case managers is that symptoms of early-onset Alzheimer's disease are typically difficult to detect. If the disease is not detected, opportunities for treatment intervention may be lost as the disease progresses. Early-onset Alzheimer's disease may be misdiagnosed because some physicians may overlook the warning signs in young patients who don't present with medical issues. In fact, many patients with early-onset Alzheimer's disease undergo multiple evaluations and delays before a formal diagnosis is made. Research suggests these delays may in part be due to the fact that patients with early-onset Alzheimer's disease before age 60 have atypical symptoms: they present with more behavioral, vision, or language problems rather than with memory problems.³

Because of these particular challenges, the case manager must strive to:

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- Emphasize the importance of a good diagnostic work up: a baseline assessment is essential to providing a treatment plan and advanced planning for care
- Steer family members to competent specialists with knowledge, expertise, and interest in dementia
- Refer the patient to a well-respected neurologist if memory problems are suspected
- Support each family member in the way that makes sense. What is each member's role in the family system? What is their relationship to the individual with early-onset Alzheimer's disease? For example, support and resources will be different for a teenager than for a spouse.
- Locate top-rated university-based facilities devoted to research and treatment of early-onset Alzheimer's disease
- Advocate for proper medical care, including access to resources to pay for medical services.

Denial and Difficulty in the Family System

One of the most important things in working within a complex family system is that each family member's personal expression of grief is different. Some family members may be in disbelief, some members may be angry about their loved one's diagnosis, and other members may be accepting of the diagnosis and willing to be active in care planning. In addition, individuals with early-onset Alzheimer's disease may be aware of their diagnosis (especially in the beginning stages) but in denial about their capabilities. This may present challenges for case managers such as:

- Spouses with caregiver burden may still be in their 40s and 50s
- Grieving children who have a sick parent need support and education about Alzheimer's disease in language that they can understand
- Intense caregiver burden. The healthy spouse tries to care for everyone: the spouse with early-onset Alzheimer's disease, children, elderly parents, and in-laws.
- Minimization or refusal of home care services. This can range from the individual with early-onset Alzheimer's disease denying the need for help to feeling afraid about giving up control to concerns about cost of care.
- Minimization or refusing community resources, placement in a nursing home or institution, and or psychological support
- Intense grief/distress of family members
- Increased depression/agitation of the individual with early-onset Alzheimer's disease due to diagnosis and progression of the disease.
- Support groups for early-onset Alzheimer's disease may be difficult to locate, especially in rural areas
- Medicare may not cover medical benefits or social support programs for individuals with Alzheimer's disease who are under the age of 65

Comprehensive Planning

Although each patient with early-onset Alzheimer's disease is unique, the case manager's plan must be comprehensive enough to address immediate and possible future interventions but fluid enough to account for sudden changes in medical and or cognitive status. The case manager not only plays an integral role in assessing the independence level of the individual with early-onset Alzheimer's disease but also educates family members about next steps in care and advanced planning. It is important for the case manager to coordinate the patient's care with an array of professionals who can help complete the key pieces of the puzzle to develop an effective care plan.

If the individual with early-onset Alzheimer's disease still has mental capacity and is capable of making his or her own health care decisions, the case manager must walk a fine line by balancing the patient's safety versus his or her autonomy needs.

The case manager must use their skill set in the following areas:

- Help the healthy spouse adapt to his/her role of "decision-maker"
- Assess home and personal safety: Can the individual live at home? Are they a flight risk?
- Facilitate the preparation of legal documents such as advanced directives for medical treatment

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- Implement a legal care plan and provide referrals for legal and financial issues (eg, incapacity, power of attorney)
- Early detection of financial abuse: This is especially important when considering capacity issues and diminished executive functioning abilities. Conservatorships are often established because of financial abuse by family, friends, or healthcare providers.
 - Help the patient apply for disability benefits (eg, a patient may lose income due to unemployment or have reduced income due to cognitive impairment). Applications for disability are often denied and reapplications are necessary.
 - Manage behavioral issues: Progression of disease is often associated with behavioral issues. It is essential to know when to set up a referral to a neuropsychologist or geriatric psychiatrist.
 - Advocate and educate for using a “team” approach (eg, geriatric care manager, family, friends, and legal/medical professionals) to manage care
 - Empathize with and validate each family member's unique role in the family system. Provide structure for grief as well as hope.
 - Encourage the development of support systems by providing referrals to caregiver support groups and or individual counseling to bridge isolation
 - Disease management: Encourage medication adherence and changes in diet and exercise as well as a reduction in stress levels
 - Locate well-qualified caregivers who have been properly trained for dementia care
 - Encourage volunteering and mentoring roles to foster a sense of self-mastery and to enhance self-esteem
 - Provide educational resources on Alzheimer's disease that support community education as well as volunteer opportunities (eg, organizations/universities with healthy aging outreach programs such as the Alzheimer's Association)
 - Designate a residence or appropriate placement in the event of incapacitation, which may be challenging given the age gap between individuals with early-onset Alzheimer's and late-onset Alzheimer's disease in residential care facilities.

Conclusion

Although there is considerable research and information about early-onset Alzheimer's disease, there is still a lot that we don't know. Progression of disease occurs at a different rate in each individual with early-onset Alzheimer's disease, and individual cope with their disability differently. One person with early-onset Alzheimer's disease might decline rapidly and end up institutionalized whereas another person with the disease may be able to serve in a leadership role.

Regardless of the breadth of the case manager's role and the amount of time they spend managing a case, case managers working in different settings have a unique opportunity to serve patients with early-onset Alzheimer's disease by being their advocate and inspiration. Although the outcome for each individual with early-onset Alzheimer's disease is different, the case manager's involvement is of tremendous value in helping the individual assess a plan of action to meet the individual's needs and to thus support the individual's independence for as long as possible. **CE 1**

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