Alzheimer's Disease: Support for Caregivers

What We Know

› The global prevalence of Alzheimer's disease (AD) is rapidly increasing. By 2010, there were an estimated 35.6 million people worldwide with dementia, a number projected to increase to over 115 million by the year 2050.\(^{37}\)
› Alzheimer's disease accounts for 60–80% of those with dementia. In 2015, the Alzheimer's Association estimated that 5.3 million people in the United States have AD, and over 15 million people, primarily family members, served as unpaid caregivers (CGs) for individuals with AD.\(^{22}\)
› In recognition that excessive CG burden can affect not only the individual receiving care but also the CGs' quality of life (QOL), increasing attention has been drawn to the needs of nonprofessional CGs, or individuals who care for disabled individuals.\(^{16,18,22}\)
› Care of individuals with AD often is provided in the home by their spouses/partners, grown children, other relatives, or friends. Individuals with AD often require extensive assistance, including help carrying out activities of daily living (e.g., managing household chores and finances, transportation, mobility, bathing, toileting, dressing, feeding); assistance with following treatment recommendations and medication regimens; supervision and management of behavioral manifestations (e.g., wandering, nighttime disturbances, aggression); and arranging for support groups, day programs, in-home care, and out-of-home placement. They also tend to receive care from their nonprofessional CG for a longer duration than older individuals with other conditions.\(^{32}\)
› The process of caring for individuals with AD is demanding, and the burden associated with caregiving may significantly impair the health of the CG, especially when both the CG and the individual with AD are older adults.\(^{1,7,9,11,12,13,14,17,18,19,25,26,30,32}\)
• A particularly difficult aspect of providing care to individuals with AD is the burden associated with the neuropsychiatric symptoms that occur during the course of the disease (e.g., agitation, delusions, hallucinations, depression, anxiety, irritability, aggression, sleep disorders). The behavioral and psychological symptoms tend to follow a trajectory of increasing severity over time, a feature they have in common with cognitive and functional decline.\(^{3,10,22,30}\)
  – The patient's cognitive decline increases the level of assistance required for activities of daily living and increases the burden on the CG.\(^{3,6,30}\)
• Spousal CGs may go from mourning the change in their marital relationship, sacrificing self-care, reclaiming self-care, and relinquishing the mindset of “couplehood” to learning to become a CG and accepting help from others while caring for their spouses/partners with AD.\(^{2}\)
  – Spousal CGs often forsake friendships and self-care activities (e.g., hobbies, exercise, healthcare appointments) to care for their spouse/partner with AD.
• The “sandwich generation” (those who must juggle the responsibility of meeting the needs of children and older parents) has difficulty balancing caregiver responsibilities with the demands and need for interaction with spouses and children, which often creates feelings of neglect and inequity in the home.\(^{2}\)
• The burden of caregiving varies between individuals. Investigators in an Italian study found that time restrictions and the physical toll of caregiving were greater concerns.
among older CGs, and unfulfilled goals and opportunities were a greater concern among female CGs.\(^{33}\)

- CGs of individuals with AD often experience worry, anxiety, frustration, depression, fatigue, and poor health associated with chronic stress.\(^{11,12,13,17,18,19,25,26}\)

  - Researchers in a study conducted in China found that higher educational levels were associated with better health-related QOL and fewer depression symptoms in CGs, while older CGs and those caring for individuals with more severe dementia had poorer health-related QOL.\(^{34}\)

  - Factors associated with an increase in CG burden, which can be emotional, physical, and/or financial, include difficulty obtaining a diagnosis, acting as an advocate for the individual with AD, perceived lack of social support, reduced ability to work, out-of-pocket expenditure (e.g., money for copays, household help, respite care), worries and uncertainties, exhaustion, balancing multiple demands, stresses of caring, loneliness, loss of freedom, and anxiety about one’s own aging. Admission of a spouse/partner to a skilled nursing facility (SNF) is associated with a decrease in CG burden.\(^{2,9,11,27,28}\)

  - Long-term placement of the individual with AD is associated with significant reduction in depression symptoms in CGs, which is attributed in part to having less restriction of social and recreational activities, and an increased sense of personal mastery.\(^{35}\)

  - The caregiving burden does not end with nursing home placement, however, as the CG continues with bill paying, insurance requirements, coordination of appointments, and ensuring proper care is being provided.\(^{8}\)

  - Factors associated with depression in CGs of individuals with AD include social embarrassment (i.e., embarrassment due to inappropriate behavior by the patient in social settings), perceived duty to provide care, poor health of the CG, anxiety about one’s own aging, low income, and caring for a person with severe AD-related behavioral problems.\(^{6,11,12,13,19,25}\)

  - CG depression typically improves after SNF admission or, if the patient was being cared for at home, death of the patient.\(^{9}\)

- Although CGs face numerous challenges in providing care and assistance to individuals with AD, there has been a great deal of research exploring which resources are most helpful for CGs.\(^{1}\)

  - Substitute care providers (e.g., respite care staff) can be helpful if CGs perceive them to be trustworthy.\(^{7}\)

  - Financial assistance for obtaining support services (e.g., respite care) has been shown to increase support service usage and support group attendance, as well as reduce CG depression.\(^{26}\)

  - Support group attendance provides emotional support and offers a sounding board and increased understanding of the signs and symptoms of the disease.\(^{29}\)

  - Multicomponent programs which utilize multiple interventions may have benefits for CGs as well as for individuals with AD.\(^{36}\)

  - Researchers studying the effects of a multicomponent program in the United States report that in addition to demonstrating positive outcomes for individuals with dementia, interventions such as exercise, behavior management, and education regarding dementia are linked with improved CG efficacy in providing care, and reduced physical health and relationship strain among CGs.

  - CG training has been shown to be helpful: the more skilled the CG and the higher the CG’s level of self-efficacy, the more effective he or she was in providing care to the person with AD and taking care of his or her own physical and emotional health.\(^{4,17,26,29}\)

  - Counseling in a variety of formats has been shown to be helpful.\(^{3,25}\)

  - Counseling and support group attendance by spousal CGs of a patient with AD continue to provide benefit after the patient’s death.

  - Researchers in a Brazilian study report that psychoeducational groups can reduce neuropsychiatric symptoms among CGs and that cognitive-behavioral group therapy (CBT) was associated with a reduction in physiological effects of stress.\(^{31}\)

### What We Can Do

- Learn about the specific or unique challenges faced by individual CGs in order to better evaluate their needs and provide support; share this information with our colleagues.

- Develop an awareness of our own cultural values, beliefs, and biases, and develop knowledge about the histories, traditions, and values of our clients. Adopt treatment methodologies that reflect the cultural needs of the client.\(^{15,21,23}\)
› Share knowledge and collaborate with CGs to develop goals and strategies for improving CG self-care, reducing the risk of depression, and providing resources for assistance in caring for the person with AD\(^5\)

› Develop a continuum of services for the CG at all stages of the disease, especially in the early stages when information and coping skills are most critical

› Assist CGs in addressing grief and loss feelings that arise with their loved one’s decline; be empathic and validate CG feelings\(^{20,24}\)

› Assess CGs’ stressors and dysfunctional coping strategies and tailor interventions to their individual needs\(^{33}\)

› Recognize the link between the well-being of CGs and care recipients. Assess CGs for depression and request a referral to a mental health clinician, if indicated\(^{18,26}\)

› Encourage CGs to find balance by setting limits on caregiving, creating routines for themselves and the care recipient, and setting aside time to get away and relax\(^{6,7}\)

› Encourage CGs to obtain more information about AD and provide them with a list of online resources\(^{1,26}\)
  • Alzheimer’s Association (http://www.alz.org)\(^{1,26}\)
  • Alzheimer’s and Dementia Caregiver Center (https://www.alz.org/care/alzheimers-dementia-support-groups.asp)
  • Alzheimer’s Disease International (http://www.alz.co.uk)
  • Alzheimer’s Society (http://www.alzheimers.org.uk)\(^1\)
  • Family Caregiver Alliance (http://www.caregiver.org)\(^1\)
  • National Institute on Aging (http://www.nia.nih.gov/alzheimers)\(^1\)
  • WebMD: Alzheimer’s Disease Health Center (http://www.webmd.com/alzheimers/guide/alzheimers-dementia)\(^1\)
References


