
Effects of Alzheimer Disease on Patients and Their Family

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The diagnosis of Alzheimer disease (AD) affects not only the patient but the entire family and their supporting caregivers. Understanding the stressors that affect these individuals enables us to provide the support and care they need to remain happy and healthy despite living with the diagnosis of AD. This continuing education article examines the epidemic of AD in the United States today and its emotional, psychologic, and financial effects. It discusses ways that caregivers can reduce their own stress as they struggle to balance family responsibilities with caring for their loved one with AD. Although there is no cure for AD, research suggests there are ways to reduce the risk of developing AD; these will be explored here as well.

Key Words: Alzheimer disease; Alzheimer disease statistics; effects of Alzheimer disease on patient; Alzheimer disease caregivers

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Alzheimer disease (AD) was discovered on November 25, 1901, when Dr. Alois Alzheimer examined and observed a patient named Auguste Deter at the Frankfurt Asylum for the Insane and Epileptic. The 46-y-old patient had strange behavioral symptoms, including a loss of short-term memory. In April 1906, at the age of 51, Mrs. Deter died. Alzheimer had obtained her patient records, and her brain was brought to him in Munich. Along with 2 Italian physicians, Alzheimer used cell-staining techniques to identify amyloid plaques and neurofibrillary tangles within the cortical gray matter of the brain. On November 3, 1906, he gave the presentation that first linked these pathologic findings with the clinical symptoms of presenile dementia (1).

Today, over 110 y later, AD is a devastating disease that affects more than 46.8 million people worldwide. This

number is expected to double every 20 y, reaching 75 million in 2030 and 131.5 million in 2050 (2). AD currently affects over 5.7 million people in the United States and is expected to grow at a rate similar to the worldwide statistics mentioned above, nearly tripling by 2050 to a projected 14 million cases in people 65 y old or older (3). Currently, 5.5 million people are at least 65 y old—3.3 million women and 2 million men, and the prevalence of AD in people 65 y old or older is 1 in 10 (3). Among AD patients, 81% are 75 y old or older, 15% are 65–74 y old, and 4% are younger than 65 y (4). Approximately 200,000 individuals with AD are under the age of 65 y and have what is called younger-onset or early-onset AD (5). The statistics related to AD and its effect on the patient, family, and entire health-care system are staggering (5): AD is the sixth leading cause of death in the United States; 1 in 3 seniors die with AD, every 65 seconds someone in the United States develops AD, and AD kills more people than do breast cancer and prostate cancer combined. In 2018, more than 16.1 million caregivers will provide an estimated 18.4 billion hours of unpaid care, yet AD costs caregivers more than just their time. Some family members spend more than \$10,000 a year caring for someone with AD. For some families, caring for an AD patient means missing a vacation, but for others it may mean going hungry. In 2018, AD and other dementias will cost the nation \$277 billion.

Because our population is living longer—sometimes referred to as the Silver Tsunami (6)—the number of people with AD will continue to grow, putting increasingly more strain on family and caregivers emotionally and on the entire health-care system financially. New strategies, support groups, and even AD communities need to be created for patients and caregivers. The impact of the diagnosis on caregivers is multifaceted, ranging from economic concerns to concerns about having to alter their lifestyle to care for the patient. Being aware of their concerns, needs, and feelings allows the community to help them cope.

RISK FACTORS FOR DEVELOPING THE DISEASE

There are both controllable and uncontrollable risk factors for AD, with age being the leading known uncontrollable one (7). Most people are diagnosed at the age of 65 y or older (3).

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Another uncontrollable risk factor is family history. Individuals who have a first-degree relative (parent or sibling) with the disease are more likely to develop it than those who do not, and those who have more than one first-degree relative with the disease are at even higher risk (3). Genetics is also an uncontrollable risk factor, as there are 3 genes linked to early-onset AD and a fourth gene, apolipoprotein E, linked to late-onset AD (7). A final uncontrollable risk factor is sex, with more women than men having AD and other dementias. Almost two thirds of Americans with AD are women. Also, among people 71 y old or older, 16% of women have AD or other dementias, compared with 11% of men (3). There are several possible reasons why more women than men have AD and other dementias, the biggest being that women live longer than men, on average, and that older age is the greatest risk factor for AD (3).

Controllable risk factors for AD include high cholesterol levels, high blood pressure, lack of regular exercise, and lack of intellectually stimulating activities (7).

BENEFITS TO KNOWING A DIAGNOSIS

Knowledge of the diagnosis has value to both the patient and the family. According to a survey in 2011 (8), 84% of respondents would want to be told if their loved one had AD, 98% would want a family member exhibiting confusion and memory loss to see a doctor, and 89% would, themselves, want to know if they had AD. Cognitive impairment needs to be diagnosed as early as possible in the disease process. The value of knowing, especially in the early stages of the disease, is that the patient and family can plan for the future. The patient has more opportunities to be involved in decisions about current and future living arrangements, personal care, and financial and legal matters while still having the ability and the cognition to make such decisions (9). Early diagnosis also allows patients to receive the maximum benefit from treatment, in addition to being able to remain independent longer and have a better chance of participating in clinical trials, which can help stabilize, slow, or even reverse the amyloid plaque buildup in the cortical gray matter of the brain (10). An early and documented diagnosis leads to better outcomes for individuals with AD and their caregivers (10).

According to one author (11), “Dealing with legal and financial issues is a critical first step after a diagnosis of AD. Prompt action, before the patient becomes incapacitated, will help the family understand the patient’s wishes.” Choosing a lawyer, accountant, and financial planner can be helpful in addressing the many legal and financial issues to ensure the patient is cared for and protected. For example, these professionals can assist with setting up a trust or a living trust, planning how to finance long-term care, writing a will or a living will, allocating a guardian or a health-care proxy, setting up a medical or durable power of attorney, and planning the estate (11).

PAID AND UNPAID COSTS OF CARE

Payments by Medicare and Medicaid for health care, long-term care, and hospice for people with AD and other dementias were \$150 billion in 2014, \$236 billion in 2016, and are estimated to be \$277 billion in 2018 (3,4,12). Although these agencies and private insurers do cover some of these costs, Medicare does not cover the entire cost of chronic care. If an AD patient requires chronic care, the maximum coverage by Medicare is just 150 d and involves deductibles and copayment for which the patient is responsible (12). In 2017, Medicare beneficiaries aged 65 or older with AD and other dementias paid \$10,589 out of pocket, on average, for health-care and long-term care services not covered by other sources (3). AD patients also experience more hospitalizations than other people the same age, also increasing the financial burden to patients and family (4). People with AD or other dementias comprised 29.9% of individuals in adult day care in 2014, 39.6% of those living in residential care communities in 2014, 31.4% of those using the services of home health agencies in 2013, 44.7% of those in hospice in 2013, and 50.4% of those living in nursing homes in 2014 (13), all of which cost the patient and family a significant amount of money. A 2013 article claimed that AD is one of the costliest chronic diseases to society (14), and in 2014, the director of the Mayo Clinic Alzheimer’s Disease Research Center stated that “If we don’t get on top of [AD], it will bankrupt the health-care system” (15).

A 2016 report found that those who provide care are 28% more likely than those who do not to struggle with having enough money for proper meals (4). Another finding was that many family members and friends of people with AD or other dementias make great sacrifices to help provide care, such as spending money from their savings and retirement accounts, thus jeopardizing their own financial security. Startlingly, the report also revealed that many caregivers cut back on basic necessities such as food and medical care for themselves and their families and did not know, or had misconceptions about, which expenses Medicare and Medicaid cover, leaving them unprepared to handle the tremendous costs associated with the disease. Another finding was that caregivers spent an average of \$5,155 of their own money per year to take care of their relative or friend with AD or another dementia. The annual out-of-pocket costs ranged from less than \$1,000 to more than \$100,000, and it was the spouse or partner who incurred the highest expense—an average of over \$12,000 per year. Adult children spent an average of about \$4,800 per year, with some (16%) spending \$10,000 or more. The most common expenses were for groceries, followed by travel, medical supplies (e.g., adult diapers), medications, non-medical in-home care, and in-home health care (4).

An underlying financial burden relating to the care of AD patients is the hours of unpaid care and the economic value of caregiving. One report (12) found that in 2013, the 15.5

TABLE 1
Hours of Unpaid Care and Its Economic Value (3,4,12)

Parameter	2013	2015	2016
Number of family and other unpaid caregivers	15.5 million	15.9 million	15.9 million
Hours of unpaid care	17.7 billion	18.1 billion	18.2 billion
Hours of care per caregiver per week	21.9 h	21.9 h	21.9 h
Hours of care per caregiver per year	1,139 h	1,139 h	1,139 h
Hourly rate	\$12.45	\$12.25	\$12.65
Total cost	\$220.3 billion	\$221.3 billion	\$230 billion

million family members and other unpaid caregivers of people with AD or other dementias provided an estimated 17.7 billion hours of care. This number represents an average of 21.9 h per caregiver per week, or 1,139 h per caregiver per year. With this care valued at \$12.45 per hour, the estimated value of this unpaid care was \$220.3 billion (12). In 2015, 15.9 million unpaid caregivers provided an estimated 18.1 billion hours of care, averaging 21.9 h per caregiver per week, or 1,139 h per caregiver per year. At \$12.25 per hour, the estimated value of this unpaid care was \$221.3 billion. Thus, from 2013 to 2015, the cost of unpaid care increased by \$10 billion. In 2016, 15.9 million unpaid caregivers provided an estimated 18.2 billion hours of care valued at \$230 billion. In a newly released 2018 report, over 16 million unpaid caregivers provided an estimated 18.4 billion hours of care, which at \$12.61 per hour (a 2.9% increase over the 2015 hourly rate) is valued at \$232 billion, an increase of almost 5% from 2016 to 2018 and a total increase of over \$12 billion in 5 y (3,4,12). These numbers are staggering and have had a big impact on caregivers, their families, and the economy, and unfortunately the numbers continue to grow. Table 1 summarizes these data for 2013, 2015, and 2016.

SOURCES OF STRESS TO FAMILY CAREGIVERS

Demographic Stress

Figure 1 illustrates caregiver demographics (4). A 2014 report indicated that because of demographic changes in the U.S. population (i.e., parents of dependent minors are older than in the past, and the U.S. population is aging), we now have something called the sandwich-generation caregiver, or a middle-aged person who simultaneously cares for dependent minor children and aging parents (12). The report found that 30% of AD and dementia caregivers had children under 18 y old living with them and that 8%–13% of households in the United States had sandwich-generation caregivers. Such caregivers experience many challenges, such as limited time, energy, and financial resources, when balancing the care of both aging parents and dependent children. Because of these unique challenges, such caregivers may experience increased anxiety and depression and a decreased quality of life (12).

Work-Related Stress

Family caregivers also experience work-related stress, such as the need to adjust their work schedule to accommodate caring for their loved one. Reports show that 57% of

caregivers had to go in to work late, leave early, or take time off; that 16% had to take a leave of absence; and that 18% had to change from full-time to part-time work, a 5% increase in 2017 over 2016 data (3,4,12). Other work-related issues caregivers experienced were having to take a less demanding job (13%), having to give up working entirely (9%), receiving a warning about performance or attendance (7%), and having to retire early (6%) (3,8).

Time-Related Stress

Another stressful issue for families and caregivers is finding enough time to visit a loved one who is in a skilled care facility. If the loved one is cared for at home, the issue may be finding substitute caregivers when primary caregivers have other demands on their time. Issues may also arise with balancing the time needed to care for the patient with the time needed to care for self or other family members (12). According to one report (12), almost 23% of all caregivers are “on-duty” caregivers spending 24 h a day, 7 d a week, caring for the loved one. Interestingly, 59% of those who were not on-duty caregivers felt as if they were. The report also stated that women are 2.5 times more likely than men to provide on-duty care in the late stage of disease.

Caregiver intervention is an important area where more support is needed. If the health and well-being of caregivers are neglected, those they care for will suffer as well. The

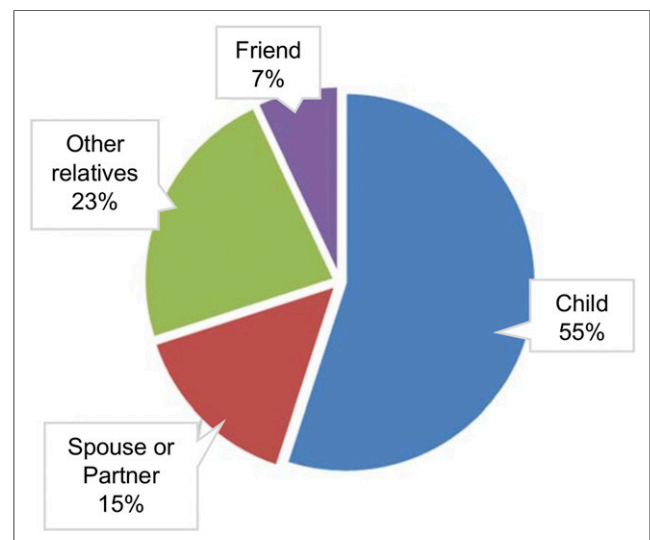


FIGURE 1. Caregiver demographics (8).

desired outcome of caregiver intervention is successful management of stress and depression, which in turn delays the need to admit the AD patient to a nursing home (4). Some examples of intervention include counseling, support groups, case management support, and respite care (4), all of which can help caregivers be their best for the patient.

Physical and Emotional Stress

Reports from 2014 and 2018 (3,4,12) cite both physical and emotional stress as being other burdens placed on families (Fig. 2); 47% of women and 24% of men considered their caregiving role to be physically stressful, and 62% of women and 52% of men considered their caregiving role to be emotionally stressful. Adding to the stress is that 51% of caregivers have no medical experience, creating difficulty with making decisions or knowing what to do next.

In a recent survey (Barbara J. Grabher, unpublished data, May 2017), the top 5 stressors for caregivers were found to be financial strain, fear that their loved one will get lost, effects on family vacations, caregiver stress of balancing all their family responsibilities with the responsibilities of taking care of their loved one, and reduced time with their family.

Three of the biggest issues family members face are a lack of privacy, sleep deprivation, and the lone-soldier syndrome—a sense that they have to bear the full burden of taking care of their loved one. A fourth issue is not anticipating what is coming next for their loved one, and a fifth is trying to manage the overwhelming task of taking care of their loved one (16). Incontinence, heavy lifting, and wandering behaviors in someone with AD are usually the most stressful issues; both urinary incontinence and fecal incontinence are among the leading causes of nursing-home placement (16).

Once a patient is diagnosed with AD, they too have stress related to their new diagnosis. The most common reasons patients give for increased stress are fears about forgetting their loved ones, becoming a burden to their family, losing their independence, and not being able to take care of themselves (12). In the early stages of disease, finances are the greatest cause of stress to patients, who may wonder whether they will have enough money to pay for their care.

Caring for AD patients creates emotional stress regardless of whether the care takes place at home or in a facility. Data from 2014 indicated that 76% of family caregivers for people with AD or other dementias agree—either somewhat or strongly—that it is neither right nor wrong for a family to decide to admit a family member to a nursing home. Yet many such caregivers feel guilt and emotional upheaval and have difficulty adapting to the admission (e.g., they have mixed emotions relating to what to do; their brain is telling them to place their loved one in an Alzheimer facility but their heart does not want to put their loved one in a nursing home facility) (12).

Family members of AD patients can experience many other types of feelings, including sadness, discouragement, aloneness, anger, and hope, as well as fatigue and depression (17). Different people handle stress and emotions differently, with some being able to express how they feel whereas others cannot. Emotions about the loved one with AD may be mixed. A family member may feel both love and dislike for the person at the same time or may want to care for the person at home while simultaneously wanting to hand over care to a facility. Embarrassment about how the patient behaves in public may also be a concern; however, this feeling might fade if the experience is shared with other family members, who can then share similar experiences of their own (17). Support groups are helpful in such situations by decreasing the feeling of being alone.

Two feelings that many family members have are helplessness and guilt. The feeling of helplessness may stem from having to take the loved one to multiple physicians before finally getting an accurate diagnosis of the cognitive impairment (17). Feelings of guilt may arise from many sources: family members may regret being impatient with the patient, losing their temper, or spending time with friends instead of with the patient. Other forms of guilt arise from wishing they did not have the responsibility of caring for their loved one, from considering placement in a facility, or from having to limit the patient's independence regarding driving, living alone, or finances (17).

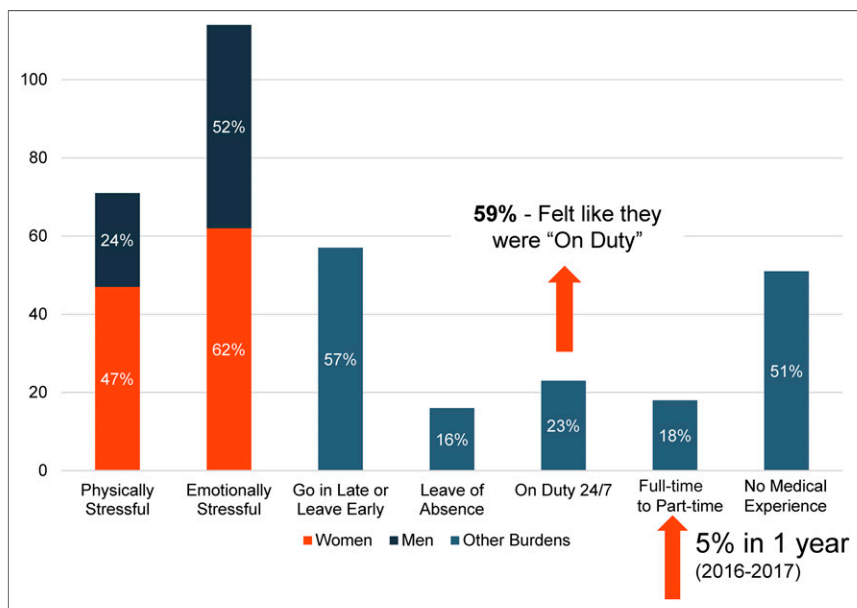


FIGURE 2. Physical and emotional burdens of AD caregivers and family members (3,4,12).

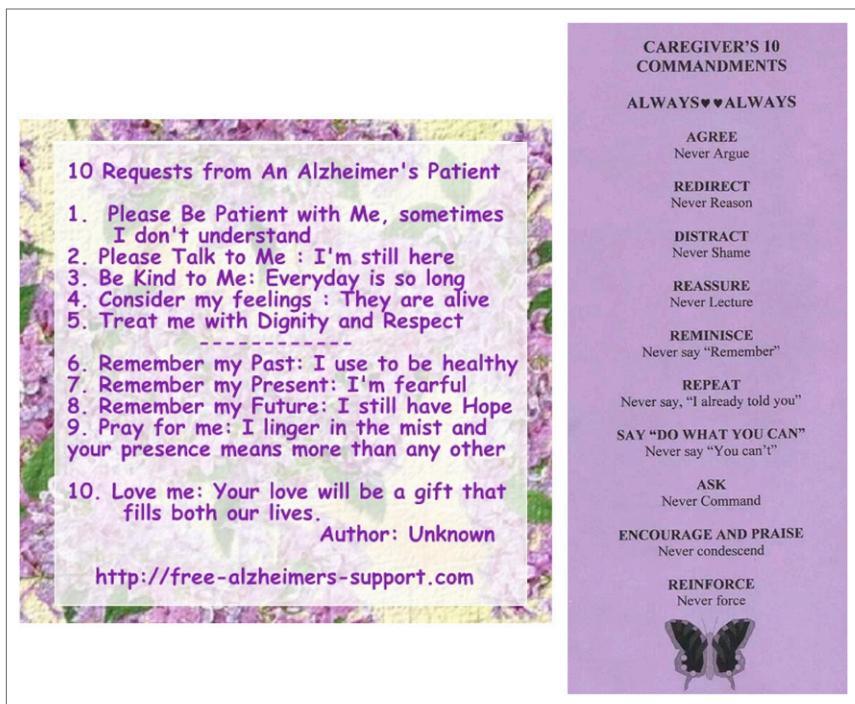


FIGURE 3. 10 Requests from an Alzheimer’s Patient (20) and Caregiver’s 10 Commandments (21).

ALTERNATIVE CARE

The United States needs to come up with more alternatives to family members and nursing homes for AD patient care. An example in The Netherlands is the tiny village of Hogewey, which includes tree-lined streets, shops, restaurants, a movie theater, a hairdresser, and 23 apartments carefully crafted to feel like home to the over 150 residents with AD. However, Hogewey is not a real village; it is a nursing home. The supermarket cashier, the restaurant manager, and the other village workers are all incognito nursing home staff, specially trained to care for people with dementia. Most of the residents think it is a real village (18).

The United States has AD facilities but nothing like Hogewey. Facilities such as AD villages serve several purposes: making the patients feel they are living a normal life, providing a safe environment, giving families peace of mind, and caring for patients in an environment different from the institutionalized atmosphere of a typical nursing home. Settings such as Hogewey have also been shown to reduce the need for medication and put patients more at ease and because they feel at home (18).

RECOMMENDATIONS FOR PATIENTS AND CAREGIVERS

Prevention of AD

Lifestyle modifications can help ward off AD (19). Such factors include maintaining a proper weight, blood pressure, blood glucose, and gut microbiome; getting daily exercise and sun exposure; socializing and engaging in mental activities; staying hydrated; avoiding aluminum,

mercury, and toxic chemicals; and practicing whole-body detoxification.

Dietary modifications are also important (19). Foods should be low in unhealthy fats, high in fiber, high in antioxidants, organic, and not genetically modified. Healthful oils that can reduce the risk of AD include coconut oil, cold-pressed extra virgin olive oil, flaxseed oil, avocado oil, hempseed oil, and macadamia nut oil. Fruits particularly helpful in preventing AD are red grapes, cherries, strawberries, blueberries, raspberries, pomegranates, oranges, and plums. Particularly helpful vegetables are spinach, kale, broccoli, beets, Brussels sprouts, peppers, alfalfa sprouts, leafy greens, and eggplant. Consuming fresh cold-water fish high in omega-3 fatty acids is beneficial, as is eating nuts high in vitamin E (almonds, pecans, and walnuts) and drinking herbal green tea. Sugar and wheat should be eliminated.

Finally, supplements such as vitamins B₁₂, C, E, and D₃, ginkgo biloba, magnesium, curcumin, resveratrol, silicon, acetyl-L-carnitine, docosahexaenoic acid, and a B-complex vitamin can help reduce the risk of AD.

Compassion

It is important to remember what the patient is going through, as well as what the caregiver is going through. Love and compassion by all are key to allowing those living with AD to remain happy and healthy. This disease is not easy for anyone involved—the patient, the caregiver, or the family.

Figure 3 provides compassionate reminders from the perspective of the AD patient and from the perspective of the AD caregiver. Carefully reading these reminders and allowing the words to sink in will help inspire compassion in those who are currently traveling the AD journey or who may someday embark on that journey.

CONCLUSION

AD is a growing, devastating disease that affects not just the patient but the entire family, as well as putting a large cost burden on the entire U.S. health-care system. The disease is a tremendous source of stress to caregivers, not only financial stress but physical, emotional, time-related, work-related, and demographic stress. We need to find a cure for AD, we need to increase education on its risk factors and on lifestyle modifications that may keep it at bay, and we need alternatives to the use of family members and nursing homes as care providers. But perhaps most important is that

we need to remember love and compassion toward those who travel the AD journey.

DISCLOSURE

Barbara Grabher is an employee of Life Molecular Imaging and is the chief consultant and president of Grabher Consulting and Specialty Services. No other potential conflict of interest relevant to this article was reported.

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