

2024 Alzheimer's Disease Facts and Figures Report: Executive Summary

Since its 2007 inaugural release, the Alzheimer's Association annual *Facts and Figures* report has become the preeminent source on Alzheimer's issues and impact of Alzheimer's on individuals, families, government, and the nation's health care system. **The 2024 Alzheimer's Disease Facts and Figures report provides an in-depth look at the latest national and state-by-state statistics on Alzheimer's disease prevalence, mortality, caregiving, and costs of care.**

More Americans have Alzheimer's disease.

- An estimated 6.9 million Americans aged 65 and older have Alzheimer's dementia. It is estimated that approximately 200,000 Americans under the age of 65 have younger-onset Alzheimer's.

Deaths due to Alzheimer's disease are increasing.

- Between 2000 and 2021, the number of deaths from Alzheimer's disease in the U.S. as recorded on death certificates more than doubled, increasing 141%, while deaths from the number-one cause of death in the U.S. (heart disease) decreased 2.1%.
- Alzheimer's disease was the fifth-leading cause of death among individuals age 65 and older in 2021 (the most recent year for mortality data).

Alzheimer's is one of the most costly diseases for individuals, families, caregivers, and the government.

- The total cost for caring for people with Alzheimer's and other dementias in the United States is projected to reach \$360 billion in 2024. In addition, family and friends provided nearly \$350 billion (\$346.5) in unpaid caregiving in 2023.
- Without new treatments and advancements in care, the total cost for caring for people living with Alzheimer's and other dementias is projected to reach nearly \$1 trillion in 2050.

Caregiving time, costs of care continue to rise.

- In 2023, 11.475 million caregivers provided nearly 18.4 billion hours of unpaid care, a contribution to the nation valued at \$346.6 billion.
- The total lifetime cost of care for someone with dementia is estimated at almost \$400,000 (\$394,683) with 70% of these costs borne by family caregivers in the forms of unpaid caregiving and out-of-pocket expenses
- Sixty percent of caregivers of people with Alzheimer's or another dementia were employed in the past year. However, many of these caregivers had to make major changes to their work schedules because of caregiving responsibilities: 57% said they had to go in late, leave early or take time off and 16% had to take a leave of absence.

A shortage of dementia care specialists and direct care workers compromises care for people living with dementia.

- 55% of PCPs caring for people living with Alzheimer's report there are not enough dementia care specialists in their communities.
- Twenty U.S. states have been termed "dementia neurology deserts," meaning they are projected to have fewer than 10 neurologists per 10,000 people with dementia in 2025. (States include: AL, AR, DE, HI, IA, ID, KS, KY, ME, MS, MT, ND, NM, NV, OK, SC, SD, VT, WV, WY)
- Between 2012 and 2022, the number of direct care workers increased from 3.2 million to 4.8 million due to growing demand for long-term care. More than 1 million additional direct care workers are needed to meet future care demands between 2021 and 2031 — more new workers than in any other single occupation in the United States.
 - Twenty-one states expect to see a 30% to 40% increase in the size of this workforce, while two states — Arizona and Nevada — are expected to increase by more than 50%.
 - Although sizable, these employment projections fall short of true workforce demand.

An accompanying special report, *Mapping a Better Future for Dementia Care Navigation*, provides a comprehensive look into dementia care navigation surveying caregivers and health care workers on their experiences, challenges, awareness, and perceptions of care navigation in dementia care.

Dementia Caregivers

Dementia caregivers experience difficulty and stress interacting with the health care system.

- Seven in 10 dementia caregivers (70%) report coordinating care is stressful. More than half of these caregivers (53%) said navigating health care is difficult. Two thirds of dementia caregivers (66%) also have difficulty finding resources and support for their needs.

Cost and care coordination are top stressors for dementia caregivers.

- Two in 5 caregivers (42%) cite cost as a stressor in getting care for their recipient. More than 1 in 3 caregivers report coordinating care with multiple doctors (36%), securing appointments (35%) and getting help taking a break (35%) as leading stressors in navigating care for their recipient.
- Despite these and other stressors, only half of the caregivers (51%) report ever talking with a health care professional to help address their challenges.

Care navigation is an unfamiliar term for most dementia caregivers, although many receive help.

- Three in 4 dementia caregivers (75%) report little or no familiarity with the term “care navigator.” Yet half of these caregivers (50%) say they receive help with dementia health care, support and services for the care recipient from someone within their office or hospital.
- Nurses (42%) and social workers (35%) are the care team members most often providing navigation help to dementia caregivers.

Overwhelmingly, caregivers would welcome dementia care navigator support and believe it would benefit both the person living with dementia and the caregiver.

- More than 4 in 5 dementia caregivers (85%) say having access to a care navigator would influence their choice of dementia health care provider for the person they care for.
- Three in 5 dementia caregivers (61%) cite improvement in quality of life for their care recipient as a benefit of having a care navigator. Two in 5 caregivers (43%) believe access to a care navigator would improve the overall health of their care recipient.
- Three in 5 dementia caregivers say less stress (62%) and more peace of mind (62%) would be valuable outcomes of having a care navigator. More than half (56%) say having a care navigator could help them be better caregivers.

Top services that would be helpful to dementia caregivers include around-the-clock support, care coordination and help understanding their care recipient’s condition.

- Nearly 2 in 5 dementia caregivers (36%) say a 24/7 support or helpline is important in helping navigate care for someone living with Alzheimer’s or other dementia. Coordinating care and communication between different specialists (34%) and getting help in understanding their care recipient's condition (34%) are also valuable.
- Nearly 1 in 3 dementia caregivers say it would be helpful to have assistance with insurance or public benefits (32%), scheduling appointments (31%), caregiver training (31%), managing behavioral symptoms (31%), understanding the health care system (30%) and finding services to help with respite care (30%).
- The most helpful community-based resources cited to help dementia caregivers include local caregiver support groups (41%), respite programs (38%), and availability of financial resources in the community (37%).

Non-Physician Health Care Workforce

The findings below reflect the views of the non-physician health care workforce currently providing navigator-type services to patients and caregivers in addition to the other responsibilities of their role. The health care workers surveyed included medical professionals (nurse practitioners, physician assistants and registered nurses) and nonmedical professionals (health care social workers, community health workers and home health aides).

Health care workers say more can be done to help patients and families navigate dementia care but point out current barriers.

- Six in 10 survey respondents (60%) believe the U.S. health care system is not effectively helping patients and their families navigate dementia care.
- Nearly half (46%) say that their organizations do not have a clearly defined process for care coordination and clinical pathways for patients with mild cognitive impairment (MCI), Alzheimer's disease or other dementia.
- More than 3 in 4 (77%) identified a lack of community-based resources as a barrier, and 44% viewed it as the greatest barrier. Seven in 10 (70%) called out restrictions in current payment models as a barrier, with 41% saying this was the greatest barrier.
- Nearly 9 in 10 (87%) say developing alternative payment models is important in providing future care coordination for people diagnosed with dementia.

Most health care workers who provide navigator-type services are familiar with the concept of care navigation, even if that is not their focus.

- Three in 4 survey respondents (77%) are familiar with the term "care navigator." They spend roughly half their time providing navigator-type services, even if they do not refer to themselves as care navigators.
- Nearly 2 in 3 survey respondents (predominantly nonmedical professionals) (62%) help patients and caregivers understand the health care system, and more than 1 in 2 medical and nonmedical professionals (57%) say they coordinate care and communication with specialists.
- The most frequently provided navigator services are referrals to community support services and resources (75%), helping with emotional and cultural support (68%), and screening for safety needs (66%).

Most health care workers providing navigator-type services have experience in other medical specialties, with few working focusing exclusively on dementia.

- Four in 5 survey respondents (80%) have navigation experience in non-dementia medical specialties, and less than 1 in 10 (7%) focus primarily on providing navigator support and services to people living with dementia.
- Most (93%) feel at least somewhat knowledgeable about MCI (mild cognitive impairment), Alzheimer's disease, and other dementias. However, only 1 in 3 (36%) report they are very knowledgeable.
- Nearly 9 in 10 (86%) feel capable of directing dementia patients and caregivers to appropriate health care resources, but less than 1 in 3 (30%) feel very knowledgeable. Four in 5 navigators (82%) feel capable of directing dementia patients and caregivers to community resources, but only 31% say they are very knowledgeable.

Training in dementia care navigation is lacking and not standardized.

- Three in 4 non-physician health care professionals providing care navigation (75%) indicate they received no formal training in dementia care navigation.
- Those who did receive training were predominantly nonmedical professionals, receiving a median of 30 hours of formal training. Medical professionals who were trained received a median of 20 hours of formal training.

Nonmedical professionals are viewed as best suited to help people with dementia and their caregivers navigate care.

- Nine in 10 non-physician health care professionals providing care navigation (92%) say social workers, community health workers or home health aides are best suited to help people living with dementia and their caregivers navigate health care.