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Projected Prevalence and Cost of Dementia: 2022 Update Highlights

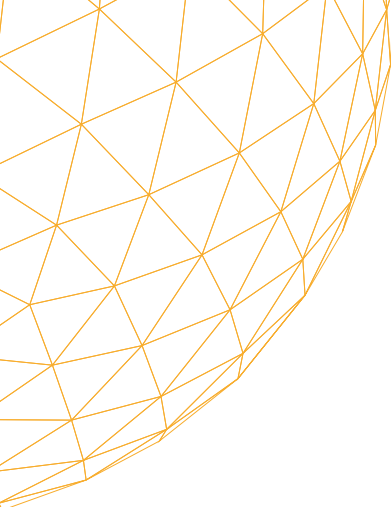
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Projected Prevalence and Cost of Dementia: 2022 Update Highlights

Decades of investment and research in Alzheimer's disease and related dementias (such as vascular dementia, frontotemporal dementia, and Lewy body dementia) are showing progress:

- The US Centers for Disease Control and Prevention recommends evidence-based ways to improve brain health and reduce dementia risk,¹ such as by getting regular physical activity, maintaining a healthy weight, preventing and managing high blood pressure, getting adequate sleep, preventing and correcting hearing loss, seeking mental health support for depression, and avoiding binge drinking and smoking.
- New biomarker tests, including noninvasive blood-based tests, are now available to aid in the diagnosis of Alzheimer's disease.
- In June 2021, the Food and Drug Administration approved the first disease-modifying therapy to treat mild cognitive impairment and early-stage Alzheimer's disease; as of January 2022, 143 therapeutics were in the development pipeline to prevent, delay the onset, slow progression, improve cognition, or reduce behavioral disturbances of Alzheimer's disease.²
- Researchers, medical practitioners, policymakers, and community-based organizations are working together to scale access to comprehensive models of care, which improve health outcomes, support caregivers, and reduce costs.³



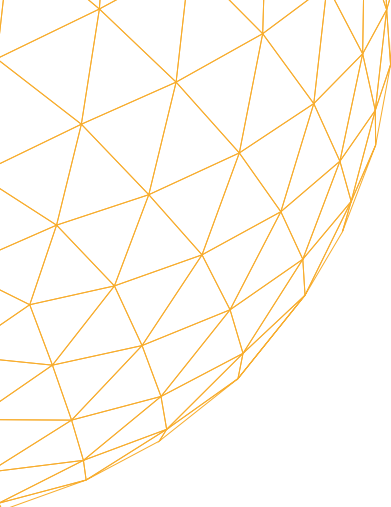
Despite this progress, an updated Milken Institute analysis using the latest (2015–2019) Medical Expenditure Panel Survey data shows that dementia prevalence and treatment prevalence (the number of people self-reporting being treated) continue to rise, and medical expenditures related to ADRD are increasing significantly compared to our [2019 report findings](#). Although some research indicates that new cases of dementia have been declining, the absolute number of people living with dementia will sharply increase with the aging of populations across the globe.⁴

These updated research findings highlight the continued challenges people living with dementia and their caregivers face when seeking help and managing care costs. The escalating cost projections for Medicare and Medicaid should compel policymakers, health systems, employers, and communities to provide more support to families caring for loved ones with dementia at home. The data also show how women continue to face an enormous burden of cost and prevalence compared to men.

The Milken Institute launched the Alliance to Improve Dementia Care (the “Alliance”) in 2020 to engage public-, private-, and nonprofit-sector leaders in improving outcomes, supporting caregivers, reducing costs, and narrowing disparities. Our multisector Alliance now has more than 100 organizations and leaders working together, creating consensus-built recommendations to improve the dementia-care continuum. Many of the Alliance’s recommendations address these updated research findings.

MILLIONS OF PEOPLE LIVE WITH UNDIAGNOSED ALZHEIMER’S DISEASE AND RELATED DEMENTIAS

Only 2.43 million people in the US are being treated for Alzheimer’s Disease and Related Dementias (ADRD), which is considerably fewer than the Alzheimer’s Association estimate of the number of Alzheimer’s disease-specific cases (6.5 million) and the Milken Institute’s estimate for *all* ADRD cases (8.1 million to 10.8 million). An estimated 62 to 78 percent of dementia cases may be undiagnosed or not reported, consistent with previous findings.⁵ The gap in treatment versus projected prevalence indicates that many Americans with dementia are unaware they have the disease, which suggests shortcomings in detecting, diagnosing, treating, and communicating a dementia diagnosis.



Consistent with other studies, the Milken Institute research update indicates that Black and Hispanic individuals not only have a higher prevalence of dementia, but they also are less likely to report receiving treatment compared to Whites. To address systemic inequities, measurement of treatment prevalence and costs is critical. The Alliance's report, "[Better Brain Health through Equity](#)," highlights how amid demographic trends showing a population growing older and more racially and ethnically diverse, the need to reduce health and economic disparities in dementia care in the US is increasingly urgent.

In the 2021 report on "[Building Dementia Workforce Capacity](#)," the Alliance highlighted multiple barriers to detecting and diagnosing dementia in its early stages, including physician reluctance, structural barriers, the complex diagnostic process, the shortage of dementia specialists, and stigma. Timely detection and diagnosis among adults at higher risk for dementia are critical to reducing risks and delaying onset. The report provides recommendations to increase awareness and improve training, coordination, and health-system and community infrastructure.

ADRD TREATMENT-RELATED EXPENSES ARE HIGH AND PROJECTED TO INCREASE SIGNIFICANTLY

The estimated 2022 expenditure for all treatments for people living with ADRD is \$34 billion, almost three times the direct spending on ADRD-only treatment (\$12.8 billion). There is a high probability of having multiple chronic conditions along with dementia. The graph below (Figure 1) compares the per-person medical expenditures for people living with and without ADRD. Total medical expenditures among people with ADRD are roughly 3.7 times higher than all ADRD-treatment expenditures, implying the coexistence of medical conditions in addition to ADRD among people ages 65 and older. When examined by health-service category, inpatient care (26 percent), home health (29 percent), and prescription drugs (20 percent) account for 75 percent of expenditures.

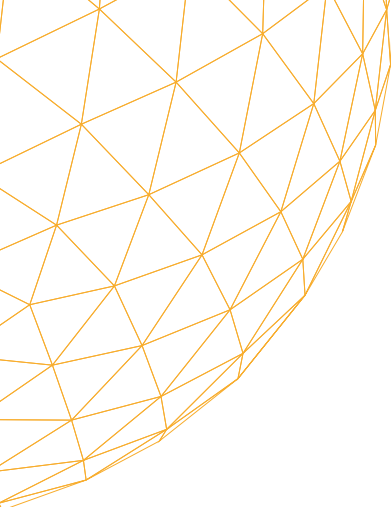
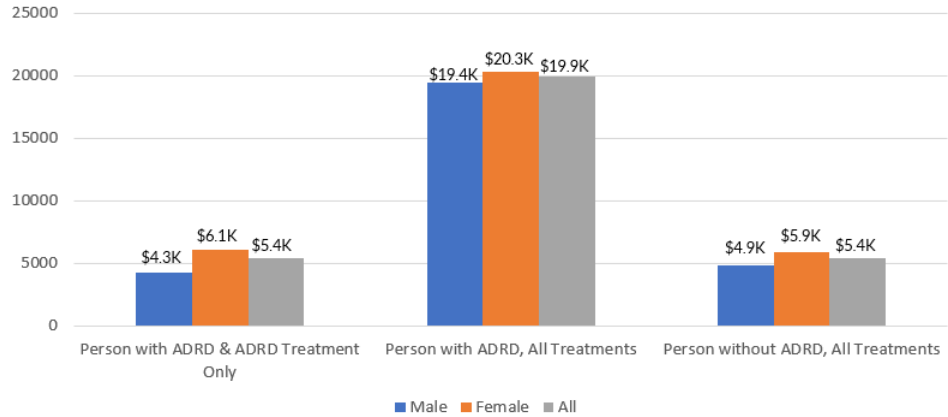


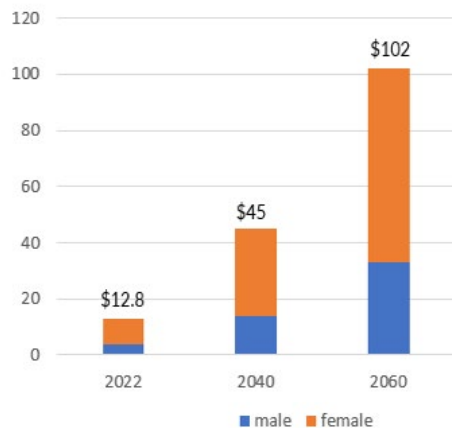
Figure 1. Per Person Expenditures (\$ thousands)



Source: Milken Institute (2022)

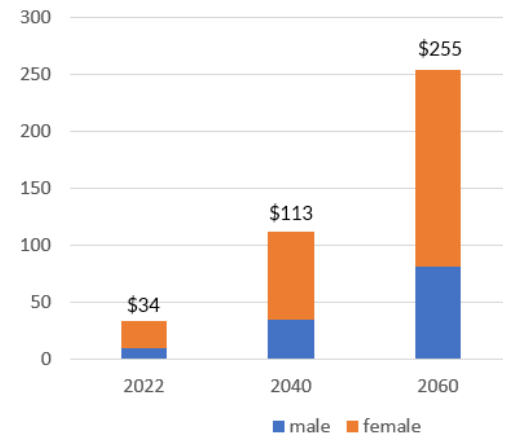
Projections show ADRD treatment expenditures tripling to \$45 billion by 2040 and more than doubling from there to \$102 billion by 2060 (Figure 2[a]). The current 2040 estimate of \$45 billion is due to the increased treatment prevalence, from 1.86 million in 2012 to 2.43 million in 2015–2019, and the use of the adjusted Consumer Pricing Index for medical services. When total expenses for all treatments for people with ADRD are examined, costs explode to \$113 billion by 2040 and \$255 billion by 2060 (Figure 2[b]). These projections do not account for any medical or disease modifying therapy innovations; many in the field share cautious optimism.

Figure 2(a). Total Treatment Expenditures Associated with ADRD (\$ billions)

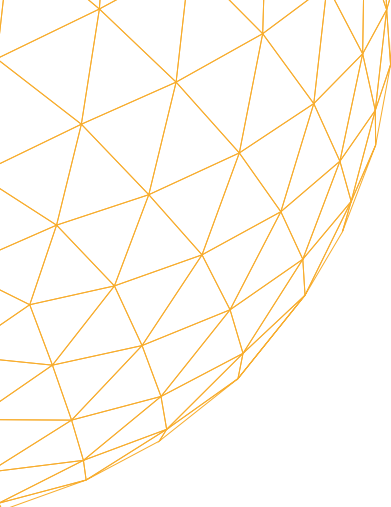


Source: Milken Institute (2022)

Figure 2(b). Total All-Treatment Expenditures for People with ADRD (\$ billions)



Source: Milken Institute (2022)

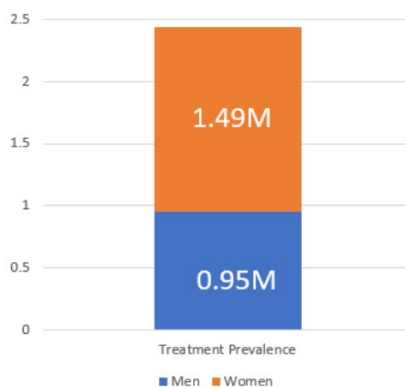


Alternative payment mechanisms to support comprehensive care models are needed to rein in ADRD expenditures and increase access to care. Appropriate reimbursement for nonmedical services (e.g., caregiver training, transportation, respite care) generally delivered by community-based organizations can improve care quality. They reduce the economic, physical, and emotional strain experienced by family caregivers, who are disproportionately women. The Alliance’s 2021 report, “[Scaling Comprehensive Dementia-Care Models](#),” provides recommendations around two themes: (1) developing a structured framework to test, implement, and scale comprehensive dementia-care models; and (2) implementing effective payment policies to incentivize adoption of and participation in comprehensive dementia-care models.

THE GENDER GAP IS WIDENING, AND ADRD TREATMENT COSTS FOR WOMEN OUTPACE THOSE FOR MEN

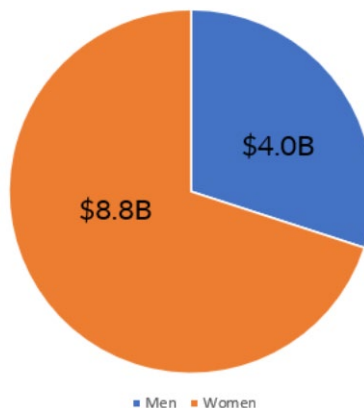
A person’s sex remains one of the best-established determinants for developing dementia, as nearly two-thirds of people living with dementia in the US are female. Women are disproportionately impacted not only by the disease itself but also by the costs associated with caring for people with dementia (Figure 3 [a-c]). The research updates show:

Figure 3(a). Total Treatment Prevalence



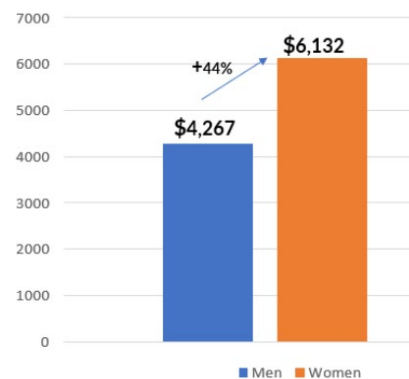
Source: Milken Institute (2022)

Figure 3(b). Total 2022 ADRD Treatment Expenditures



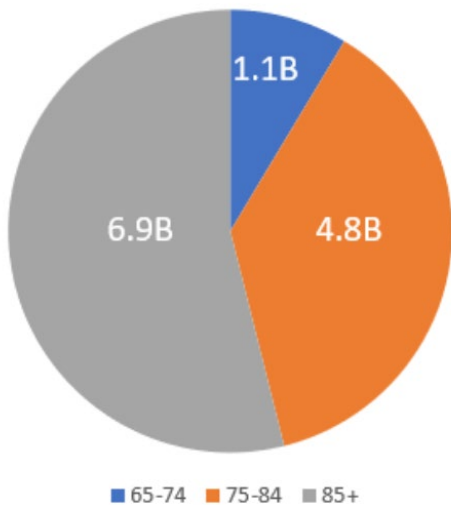
Source: Milken Institute (2022)

Figure 3(c). ADRD Annual Treatment Expenditures per Person



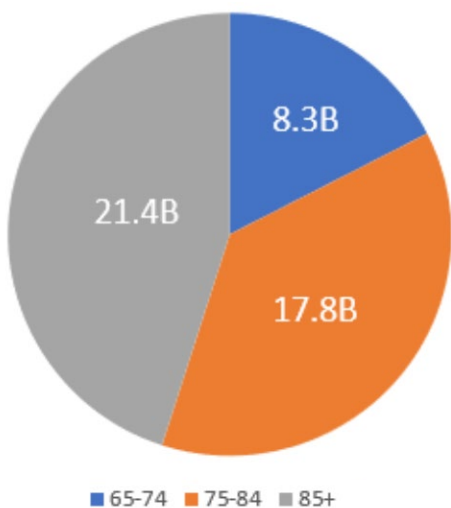
Source: Milken Institute (2022)

Figure 4(a). Total ADRD-Only Treatment Expenditures by Age



Source: Milken Institute (2022)

Figure 4(b). Total All-Treatment Expenditures for People with ADRD by Age



Source: Milken Institute (2022)

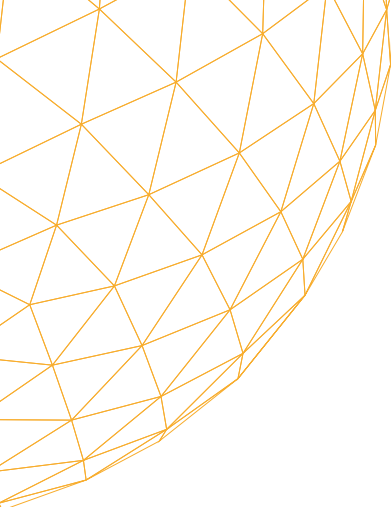
Women shoulder the lion’s share of unpaid caregiving in the US, including care for their spouses as well as for aging parents. They subsidize the care for men, often choosing between using their savings to pay for in-home care for loved ones or providing the care themselves—or some combination of the two. Women may spend down assets to qualify for Medicaid for their spouses, leaving themselves without savings and creating a higher cost for care when they eventually need it. Women are also more likely to be widowed and live in poverty when they have dementia.⁶

Paid family and medical leave for family caregivers is essential to ensure that caring for a loved one with dementia does not compound the gender gaps in financial security.⁷ With approximately two-thirds of dementia caregiving performed by women, too many have no choice but to leave the workforce as families grapple with affording paid care and navigating the fragmented care system.

AGE ACCOUNTS FOR THE MAJORITY OF ADRD EXPENDITURES AND WIDENS THE GENDER GAP

Most individuals (about 85 percent) treated for ADRD are older than 75. The Milken Institute’s analysis shows that this group accounts for 91 percent of ADRD-treatment expenditures (Figure 4[a]) and 83 percent of all medical spending (Figure 4[b]). Age remains the most significant risk factor for dementia, with a person’s risk roughly doubling every five years after age 65.⁸ The analysis found that individual patients’ annual ADRD-treatment expenditures increased 2.5 times between the age groups 65–74 years (\$2,753) and 85 and older (\$6,734).

In December 2021, the National Plan to Address Alzheimer’s disease (NAPA) [added a sixth goal to the plan](#), focused on funding for prevention research and



encouraging health behaviors that address known risk factors for dementia. Research indicates that a medical or pharmaceutical innovation that delayed AD onset by five years would translate to a 41 percent lower prevalence in 2050 among persons aged 70 and older than if onset were not delayed. Societal costs could decrease by about 40 percent.⁹

CONCLUSION

Today, the dementia community better understands how the brain works and its complex and dynamic relationship with the rest of the body. New tools, resources, and practices to support earlier detection, innovations in biomarkers, and a robust pipeline of disease-modifying therapies promise to change how we diagnose and treat dementia. However, many of the issues highlighted in our 2019 report, “[Reducing the Cost and Risk of Dementia](#),” including improving equitable access to dementia-care services and increasing detection and diagnosis rates, still require urgent attention.

The Alliance urges policymakers, researchers, product and service delivery innovators, and dementia-care leaders to continue finding ways to promote timely detection and accurate diagnosis equitably, and increase access to high-quality dementia-care services for everyone. The Alliance has issued a series of articles, op-eds, policy briefs, and reports centered around health and economic disparities, workforce development and capacity building, and comprehensive dementia care. For more background information, see the reports available on the [Alliance website](#).

Endnotes

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