



2024 CAMPAIGN GUIDE

Leading in the Fight to End Alzheimer's and All Other Dementia



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Dear Candidate,

Alzheimer's isn't a red or blue issue — it affects everyone.

Over the past decade, thanks to bipartisan lawmakers at the state and federal level, our nation has made addressing the growing Alzheimer's and dementia crisis a priority. As a result we've entered a new era with Food and Drug Administration (FDA) approved treatments that treat the underlying course of the disease, a growing body of evidence on effective means of prevention, and rapid advancements in biomarkers that will enable diagnosis even before symptoms emerge.

Still, much work remains. More than 6 million Americans are living with Alzheimer's and another 11 million are providing unpaid care. One in 3 seniors dies with Alzheimer's or another dementia. It kills more than breast cancer and prostate cancer combined.

In the pages that follow, we outline the policy priorities of the Alzheimer's Association and the Alzheimer's Impact Movement (AIM), a 501(c)(4) separately incorporated advocacy affiliate of the Association, and our network of dedicated advocates. As you head out on the campaign trail, we encourage you to talk to your constituents, hear their stories about how dementia is impacting their lives and communities, and share your plan to address Alzheimer's and all dementia.

Best of luck in your election this year and we hope you'll continue to make Alzheimer's and all other dementia a priority in your state and our nation.

For statistics specific to your state we encourage you to visit [alz.org/facts](https://www.alz.org/facts).

Sincerely,

Robert Egge

Chief Public Policy Officer, Alzheimer's Association
Executive Director, AIM

2023 ALZHEIMER'S DISEASE FACTS AND FIGURES



More than
6 million Americans
are living with Alzheimer's

Over 11 million Americans

provide unpaid care for people with Alzheimer's or other dementias

These caregivers provided more than 18 billion hours valued at nearly

\$340 billion

1 in 3
seniors dies with Alzheimer's or another dementia

It kills more than
breast cancer
+
prostate cancer
combined

The lifetime risk for Alzheimer's at age 45 is

1 in 5 for women
+
1 in 10 for men

Between 2000 and 2019, deaths from heart disease has

decreased 7.3%

In 2023, Alzheimer's and other dementias will cost the nation

\$345 billion

By 2050, these costs could rise to nearly
\$1 trillion

while deaths from Alzheimer's disease have

increased 145%



While only 4 in 10 Americans talk to their doctor right away when experiencing early memory or cognitive loss,



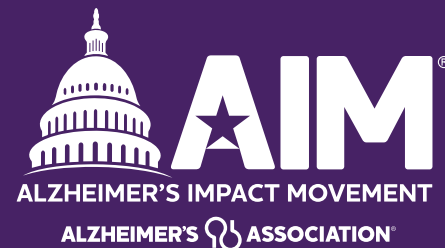
7 in 10 would want to know early if they have Alzheimer's disease if it could allow for earlier treatment.

For more information, visit alz.org/facts

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ALZHEIMER'S  ASSOCIATION®

2023 Federal Policy Priorities



Alzheimer's is a growing crisis for our families and the economy. The federal government must address the challenges the disease poses and take bold action to confront this crisis now.

Ensure access to FDA-approved treatment

Great progress has been made to advance research on Alzheimer's and dementia, providing hope to families in the midst of a terrible disease. And now that the Food and Drug Administration (FDA) has approved Alzheimer's treatments to slow the progression at an early stage, it's lifted that hope higher. The Centers for Medicare & Medicaid Services (CMS) coverage policy for these treatments must be implemented effectively to minimize clinician burden and maximize patient access. We are committed to working with the Administration, Congress, the physician community, our health system partners and other community partners to ensure access to FDA-approved treatments.

Continue to prioritize addressing Alzheimer's and other dementia

Prior to 2011, there was no cohesive national plan in the United States to address one of the country's most deadly diseases: Alzheimer's. The Alzheimer's Association and the Alzheimer's Impact Movement (AIM) recognized this shortcoming and began building a framework for a national plan that could change the trajectory of this devastating and fatal disease. Working with bipartisan leaders in Congress, the Alzheimer's Association and AIM developed the *National Alzheimer's Project Act (NAPA)* (P.L. 111-375), landmark legislation enacted into law in 2011 that required the creation of a national plan to address the escalating Alzheimer's crisis. Once the *National Plan to Address Alzheimer's Disease* was enacted, the Alzheimer's Association and AIM moved to develop and secure enactment of the *Alzheimer's Accountability Act*, legislation to ensure Congress hears directly from the scientists at the National Institutes of Health (NIH) on how much research funding is needed to fully pursue scientific opportunities needed to meet the first goal of preventing and effectively treating Alzheimer's.

- » The bipartisan *NAPA Reauthorization Act* (S. 133 / H.R. 619) will extend NAPA to build on the progress made in the fight against Alzheimer's and other dementia. The bill emphasizes the importance of healthy aging and risk reduction for Alzheimer's disease to reflect the new sixth goal of the *National Plan*. The legislation also adds new federal representatives to the NAPA Advisory Council from the Department of Justice (DoJ), the Federal Emergency Management Agency (FEMA), and the Social Security Administration (SSA). Additionally, the *NAPA Reauthorization Act* underscores and seeks to help address health disparities among underrepresented populations.
- » The bipartisan Alzheimer's Accountability and Investment Act (S. 134 / H.R. 620) would continue the Alzheimer's Accountability Act (AAA), and mark legislation enacted into law in 2014. The bill would continue the requirement for the National Institutes of Health (NIH) to submit an

Continue to prioritize addressing Alzheimer's and other dementia

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annual Professional Judgment Budget to Congress, ensuring members of Congress hear directly from scientists on what they will need to meet the nation's goal and equipping Congress with the best information to determine necessary Alzheimer's research funding levels each year.

Build a path to better dementia care

Caring for an individual with Alzheimer's or another dementia poses unique challenges. Comprehensive dementia care has been shown to reduce costs while providing better quality care. Unfortunately, dementia care management programs have not developed within the current Medicare fee-for-service system. The bipartisan *Comprehensive Care for Alzheimer's Act* (S. 626 / H.R. 1637) would ask the Center for Medicare and Medicaid Innovation (CMMI) to test a different payment structure for dementia care management. This important bill has the potential to streamline today's complicated health care maze for people living with dementia and their caregivers.

Increase the commitment to Alzheimer's research and public health response

More than 6 million Americans are living with Alzheimer's, and by mid-century, the number of people with the disease is set to nearly triple. Costs are estimated to reach \$345 billion in 2023, with nearly two-thirds paid by Medicare and Medicaid. These costs are projected to rise to nearly \$1 trillion by mid-century.

- » Consistent with the *National Plan to Address Alzheimer's Disease*, Congress has bolstered support for research funding at the National Institutes of Health (NIH). Nevertheless, current funding levels continue to fall short of the total funding scientists and the U.S. Advisory Council on Alzheimer's Research, Care, and Services believe is needed to meet the goal of finding a treatment or cure for Alzheimer's and other dementias. Congress must continue its commitment to the fight against Alzheimer's and other dementias by increasing funding for Alzheimer's research by an additional \$321 million in fiscal year 2024.
- » The bipartisan *Building Our Largest Dementia (BOLD) Infrastructure for Alzheimer's Act* (P.L. 115-406) directs the Centers for Disease Control and Prevention (CDC) to strengthen the public health infrastructure across the country by implementing effective Alzheimer's interventions focused on public health issues such as increasing early detection and diagnosis, reducing risk, meeting the needs of caregivers and addressing social determinants of health. The funding increases appropriated for BOLD's implementation over the years continue to be meaningful steps forward and have allowed CDC to award funding to three Public Health Centers of Excellence and 23 public health departments. Congress should appropriate \$35 million for FY24 BOLD implementation in order to have the meaningful impact that Congress intended and address Alzheimer's as a growing public health crisis.

Alzheimer's disease, the most common form of dementia, is a critical public health issue in America with more than 6 million Americans living with Alzheimer's disease today. By 2050, the number of people age 65 and older living with Alzheimer's is projected to reach 12.7 million, barring the development of medical breakthroughs to prevent or cure the disease. State governments are essential to reducing the long-term impact of dementia on state budgets and improve the lives of individuals living with dementia and their families.

1

Increase access to care, support and treatment

Dementia is one of the costliest conditions to society with the impact on state Medicaid budgets forecasted to top \$60 billion in 2022, while 70% of the total lifetime cost of caring for individuals living with dementia is still borne by families. The demand for direct care workers is projected to grow by more than 40% between 2016 and 2026, while their availability is expected to decline. This is particularly alarming as states across the nation are experiencing an unprecedented health care workforce shortage. Ensuring adequate access to home and community-based services (HCBS), improving care coordination, and streamlining the delivery of care for individuals living with dementia will mitigate the long-term impact on state budgets and improve the lives of those impacted by this devastating disease.

State actions :

- » Reduce health care barriers and increase access to residential and home and community-based services.
- » Ensure Medicaid programs provide appropriate coverage for FDA-approved treatments for Alzheimer's.
- » Create a statewide crisis response system that is sensitive to the changing behaviors of a person living with dementia.
- » Strengthen the health care workforce and address staffing shortages.
- » Establish or strengthen programs that support informal caregivers.

2

Improve quality of care

One in three seniors in America dies with Alzheimer's or another dementia. Between 2020 and 2025, every state across the country will have experienced an increase in the number of people with Alzheimer's. Yet 55% of primary care physicians caring for people living with Alzheimer's report there are not enough dementia care specialists in their communities to meet patient demand. Too often direct care providers and clinicians do not have sufficient dementia-specific knowledge to effectively support those living with dementia. Quality care delivered by trained providers leads to better health outcomes for individuals and caregivers, puts less strain on state health systems, and reduces care costs through decreased readmissions rates to hospitals.

State actions :

- » Increase dementia competency among health care providers so they can deliver person-centered care.
- » Improve residential and HCBS provider licensure requirements for dementia care.
- » Establish and implement quality measures that protect and enhance the lives of individuals living with dementia regardless of care setting.
- » Ensure that individuals living with dementia who are under court-ordered guardianship receive services.

3

Advance risk reduction, early detection and diagnosis

Alzheimer's disproportionately affects underserved and underrepresented populations, yet most states have not yet launched a coordinated effort to address health inequity and the impact of dementia on these communities. The need for greater awareness of the warning signs for a cognitive impairment which can lead to an Alzheimer's diagnosis is critical, particularly among underserved communities with a higher risk of developing dementia. Today, only half of those living with Alzheimer's have received an official diagnosis, with more than one-half of primary care providers indicating that they are not fully comfortable diagnosing a mild cognitive impairment due to Alzheimer's disease. An early and accurate diagnosis of Alzheimer's can improve access to care and support services, enhance quality of life and significantly reduce the financial impact of the disease.

State actions :

- » Expand access to resources in underserved communities to reduce stigma and increase early detection and diagnosis of dementia.
- » Incentivize care planning for individuals and families living with dementia.
- » Incentivize and advance dementia risk reduction strategies across provider and community settings.

4

Ensure a coordinated statewide response to Alzheimer's disease

As the number of Americans living with Alzheimer's continues to grow, so will the impact on state health systems, budgets and workforce. Numerous state agencies administer a variety of programs critical to people with dementia and their families. Efforts are often siloed with state agencies working separately from each other, leading to inaction and inertia. The lack of coordination hinders the ability of a state to evaluate the effectiveness of policy efforts across the spectrum of programs serving those with dementia and their families. Addressing this public health crisis requires a coordinated response.

State actions :

- » Improve the collection, availability and utilization of dementia-related data by relevant state agencies.
- » Establish a statewide Alzheimer's/Dementia task force that is administered by the state.
- » Develop, implement and regularly update a State Alzheimer's/Dementia Plan in collaboration with community stakeholders.
- » Establish a permanent, full-time Dementia Coordinator position and/or Dementia Unit within the relevant state agency to work across agencies in implementation of the State Alzheimer's/Dementia Plan.
- » Ensure all relevant statewide plans and assessments include the needs of individuals living with dementia and their families.

Engaging in the Fight to End Alzheimer's on the Campaign Trail

Throughout election season, the Alzheimer's Association, AIM and our nationwide network of dedicated advocates will be engaging candidates virtually at townhalls, debates and on social media. We hope you'll join us in elevating awareness of all those affected by Alzheimer's and all other dementia and share your plan to address this growing crisis.

Join the conversation. Follow us on social media at:



Twitter

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#ENDALZ
#Road2ENDALZ



Websites

alzimpact.org
alz.org/facts



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fb.com/alzimpact
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CANDIDATE QUESTION CARD

All Policymakers Need a Plan to Address the Alzheimer's Crisis



WHAT CANDIDATES SHOULD KNOW

- More than 6 million Americans are living with Alzheimer's, and more than 11 million provide unpaid care.
- 1 in 3 seniors dies with Alzheimer's or another dementia.
- It kills more than breast cancer and prostate cancer combined.