



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. Nearly 7 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,

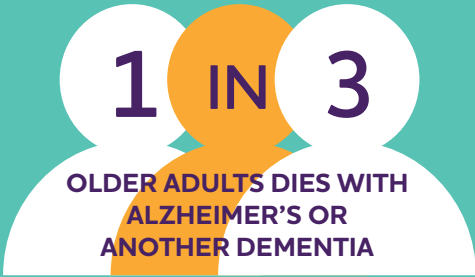
Robert Egge

Chief Public Policy Officer, Alzheimer's Association
President, AIM

2024 ALZHEIMER'S DISEASE FACTS AND FIGURES



NEARLY
7 MILLION
AMERICANS ARE LIVING
WITH ALZHEIMER'S



IT KILLS MORE THAN
BREAST CANCER AND
PROSTATE CANCER
+
COMBINED

OVER **11 MILLION**
AMERICANS PROVIDE
UNPAID CARE
FOR PEOPLE WITH ALZHEIMER'S
OR OTHER DEMENTIAS

BETWEEN 2000 AND 2021, DEATHS
FROM HEART DISEASE HAVE
DECREASED 2.1%



WHILE DEATHS FROM
ALZHEIMER'S DISEASE HAVE
INCREASED 141%

IN 2024, ALZHEIMER'S
AND OTHER DEMENTIAS WILL
COST THE NATION
\$360 BILLION
———— \$\$\$\$\$ ————

BY 2050, THESE COSTS
COULD RISE TO NEARLY
\$1 TRILLION



THESE CAREGIVERS
PROVIDED MORE THAN
18 BILLION HOURS
VALUED AT NEARLY
\$347 BILLION

THE LIFETIME RISK FOR
ALZHEIMER'S AT AGE 45 IS



70% OF DEMENTIA
CAREGIVERS
FEEL STRESSED WHEN
COORDINATING CARE

AND MORE
THAN HALF
OF CAREGIVERS
SAID NAVIGATING
HEALTH CARE IS
DIFFICULT



3 in 5 DEMENTIA
CAREGIVERS
SAY LESS STRESS AND MORE PEACE OF
MIND ARE POTENTIAL BENEFITS OF
HAVING A **CARE NAVIGATOR**

56% SAY IT COULD
HELP THEM BE
BETTER CAREGIVERS

For more information, visit alz.org/facts

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ALZHEIMER'S  ASSOCIATION®

2024 FEDERAL POLICY PRIORITIES

Alzheimer's and other dementia are 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.

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 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 Alzheimer's Disease to address the escalating Alzheimer's crisis. Once NAPA was enacted, the Alzheimer's Association and AIM moved to develop and secure enactment of the Alzheimer's Accountability Act (AAA) 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 prevent and effectively treat Alzheimer's and other dementia.

- » 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, Federal Emergency Management Agency, and Social Security Administration. 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 requirement for the NIH to submit an 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 dementia research funding levels each year.

STRENGTHEN THE DEMENTIA PUBLIC HEALTH INFRASTRUCTURE

Since the passage of the Building Our Largest Dementia (BOLD) Infrastructure for Alzheimer's Act (P.L.115-406) in 2018, public health departments have been creating and growing a public health infrastructure for dementia in communities throughout the nation. Because of BOLD, the Centers for Disease Control and Prevention (CDC) is able to provide funding to state, local and tribal public health departments. These departments utilize the funding to implement effective dementia interventions such as reducing risk, increasing early detection and diagnosis, and supporting the needs of caregivers. The bipartisan **BOLD Infrastructure for Alzheimer's Reauthorization Act (S. 3775 / H.R. 7218)** will strengthen the dementia public health infrastructure in communities throughout the nation by reauthorizing BOLD.

2024 FEDERAL POLICY PRIORITIES

Alzheimer's and other dementia are 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.

INCREASE THE COMMITMENT TO DEMENTIA RESEARCH AND PUBLIC HEALTH RESPONSE

Nearly 7 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 \$360 billion in 2024, 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 and the Alzheimer's Professional Judgment Budgets, Congress has bolstered support for research funding at the 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 dementia. Congress must continue its commitment to the fight against Alzheimer's and other dementia by **increasing funding for Alzheimer's research by an additional \$318 million in FY25.**
- » Since BOLD was signed into law in 2018, the CDC has made 66 awards to 45 state, local and tribal health departments. Congress should **appropriate \$35 million for FY25 BOLD implementation** in order to have the meaningful impact that Congress intended and address Alzheimer's and other dementia as a growing public health crisis.

ADVANCE DEMENTIA WORKFORCE PREPAREDNESS

Today, only half of those living with Alzheimer's disease are diagnosed, and of those, only half are told of their diagnosis. In 85% of cases, the initial diagnosis of Alzheimer's is made by primary care providers. But because they are not dementia specialists, most report they do not feel prepared to provide care for those diagnosed. Too often, overburdened primary care providers are unable to access the latest patient-centered dementia training.

Through the use of Project ECHO, the **Accelerating Access to Dementia and Alzheimer's Provider Training (AADAPT) Act (H.R. 7688 / S. 4276)** would provide virtual Alzheimer's and dementia education and training to more primary care providers to better understand detection, diagnosis, care, and treatment of Alzheimer's and other forms of dementia. Dementia ECHO programs connect dementia care experts with primary care providers using free, remote continuing education. ECHO's video-conference based program reaches rural and medically underserved areas where PCPs are especially strained. The AADAPT Act would expand the current ECHO program to provide grants specifically for Alzheimer's and dementia to address the knowledge gaps and workforce capacity issues primary care providers face.

Alzheimer's disease, the most common form of dementia, is a critical public health issue in America with nearly 7 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 \$68 billion in 2024, 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

@alzimpact
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#ENDALZ
#Road2ENDALZ



Websites

alzimpact.org
alz.org/facts



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alzassociation



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fb.com/alzimpact
fb.com/actionalz

CANDIDATE QUESTION CARD

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



WHAT CANDIDATES SHOULD KNOW

- Nearly 7 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.