



2020 CAMPAIGN GUIDE

Leading in the Fight to End Alzheimer's

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Dear Candidate,

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

Now more than ever in the midst of the COVID-19 pandemic we've seen the importance of protecting our nation's most vulnerable, and how essential medical research is to the nation's health and economic security.

Today, more than 5 million Americans are living with Alzheimer's, and another 16 million are providing unpaid care. A devastating disease for the individual and their caregivers, the pandemic has put a spotlight on these challenges, hitting the Alzheimer's and dementia community particularly hard.

As our nation flattens the curve and gets the pandemic under control, the need to address the country's most vulnerable — including those with Alzheimer's and other dementia — remains.

The cost of care for Americans with Alzheimer's disease is an estimated \$305 billion in 2020 — including \$206 billion in Medicare and Medicaid payments. Nearly 1 in 5 Medicare dollars is spent on people with Alzheimer's or another dementia, and as baby boomers continue to age this will grow to 1 in every 3 dollars by 2050.

And, we also know that voters care about Alzheimer's when considering their choices at the ballot box. Recent polls have shown there are more than 73 million American voters who have known someone with Alzheimer's or another dementia, including 37.8 million who have served as a caregiver for someone with dementia. Additionally, compared with other diseases tested, voters say Alzheimer's poses the greatest risk to their retirement.

With voters saying they are more likely to vote for a candidate who makes fighting Alzheimer's disease a campaign priority by an 8 to 1 margin, candidates would be wise to talk to voters about their plans to fight Alzheimer's and policies that can help families living with the disease.

The following outlines the policy priorities of AIM, a 501 (c)(4) separately incorporated advocacy affiliate of the Alzheimer's Association, and its network of dedicated advocates. We encourage all candidates running for office — at the federal, state, and local level — to talk about 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 a priority in your state and our nation.

For statistics specific to your state we encourage you to visit alz.org/facts or contact your local Alzheimer's Association chapter.

Sincerely,

John Funderburk

Vice President of Advocacy
Alzheimer's Impact Movement

2020 Alzheimer's Disease Facts and Figures



Alzheimer's disease is the leading cause of death in the United States

50%

of primary care physicians believe the medical profession is not ready for the growing number of people with Alzheimer's or other dementias



More than
5 million
Americans
are living with
Alzheimer's



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

It kills more
than breast
cancer and
prostate
cancer
combined



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

These caregivers provided
an estimated 18.6 billion
hours valued at nearly

\$244 billion



In 2020, Alzheimer's and other
dementias will cost the nation
\$305 billion — By 2050, these
costs could rise as high as
\$1.1 trillion

Between 2000 and
2018 deaths from heart
disease have decreased

7.8%↓

while deaths from
Alzheimer's disease
have increased

146%↑



Improving the State and Federal Response to COVID-19 in Long-Term Care Settings

Alzheimer's Association Policy Recommendations

The COVID-19 pandemic continues to create additional challenges for people living with dementia, their families and caregivers. These challenges are particularly being felt in long-term care settings. Indeed, nursing homes and assisted living communities are on the frontlines of the COVID-19 crisis, where 48% of nursing home residents are living with dementia, and 42% of residents in residential care facilities, including assisted living communities, have Alzheimer's or another dementia.

Residents with dementia are particularly susceptible to COVID-19 due to their typical age, their significantly increased likelihood of coexisting chronic conditions, and the community nature of these settings.

Our nation has not done enough to support these communities. Across the country these facilities, their staff, and their residents are experiencing a crisis due to a lack of transparency, an inability to access the necessary testing, inaccurate reporting and more. As of early May, it was estimated that more than 20,000 of COVID-19 related deaths were traced back to nursing homes around the country.

The Alzheimer's Association is urging state and federal policymakers to implement new policy solutions which will address the immediate and long term issues impacting care facilities during the COVID-19 pandemic.

TESTING: Each nursing home and assisted living community must have the onsite capability to verify that all residents, staff and visitors are free of COVID-19 infection, whether or not they are symptomatic. In short, access to testing should be the "White House Standard." Government support is needed to ensure accelerated production and delivery of testing, with rapid turnaround testing staffed by trained personnel.

- » Establish and implement a protocol to use testing to verify, as a baseline, that residents and staff of each facility are free of infection.
- » As an essential component of establishing a baseline assessment, immediately prioritize access to testing supplies for nursing homes and assisted living communities and require that all residents and staff be tested.
- » Purchase, deliver and provide training in the proper use of commercially available, rapid point of care COVID-19 testing.
- » Thereafter, implement daily testing for all new individuals who come onsite, and retesting for returning individuals who enter the facility, in accordance with local guidance.

REPORTING: All cases of COVID-19 at nursing homes and assisted living communities need to be reported immediately and accurately. Additionally, these reports should be updated upon remission, death, transfer or other appropriate status update. With all appropriate privacy safeguards for individuals, this reported data should be freely and immediately accessible to all down to the facility level.

- » Require all nursing homes and assisted living communities to report positive diagnoses to public health authorities immediately (never later than same day), update previously reported cases upon significant changes in status, and proactively notify family and/or designated persons of changes.
- » Protect the privacy of individuals, but do not tolerate this as an excuse to delay implementation of this expectation. These issues can be reasonably addressed.
- » Create a central, publicly accessible web platform that is searchable down to the facility level to make deidentified data available immediately upon reporting. No lag between reporting and publication is needed or tolerable.

SURGE ACTIVATION: As “hot spots” occur, they must be dealt with urgently and effectively. Any reported cases should trigger careful, ongoing monitoring and, if conditions warrant, “strike teams” will be employed to the facility to provide needed support until the outbreak is appropriately contained and eliminated.

- » Designate state Long-Term Care Ombudsman and state and federal CMS Surveyors as “essential,” ensure they have priority access to PPE, and authorize them to visit long-term care communities.
- » Establish a protocol for what steps nursing homes and assisted living communities must take once a resident or staff member tests positive for COVID-19 and require that this protocol is implemented by the care provider.
- » Require nursing homes and assisted living communities to implement a care coordination protocol that ensures a smooth transition between care settings if a resident must be moved to another care setting.
- » Activate statewide strike teams to help nursing homes and assisted living communities that are identified as “hot spots” and in need of additional support.

PROVIDING SUPPORT: All nursing homes and assisted living communities must have full access to all needed PPE, testing equipment, training and external support to keep them COVID-19 free.

- » Immediately prioritize access to PPE for all staff in nursing homes and assisted living communities. These facilities should be given access to an adequate, ongoing supply.
- » Require dissemination of essential dementia care standards to aid provisional staff in the delivery of person-centered dementia care.
- » Require the use of personal information forms for each resident to allow all staff to quickly identify essential information about the person to help maintain a stable and comforting environment.
- » Require nursing homes and assisted living communities to address social isolation and ensure people with dementia are able to communicate with designated family/friends.
- » Direct the state department of health to establish and administer a Statewide Long-Term Care Emergency Response Task Force to coordinate with all key stakeholders to identify pressing issues and implement solutions.

Federal Policies to Lead on Alzheimer's Disease

Alzheimer's is a growing crisis for our families and the economy, and American voters overwhelmingly want the federal government to do more to address the challenges the disease poses and take bold action to confront this crisis now. The following policies are endorsed by the Alzheimer's Association and the Alzheimer's Impact Movement.

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

More than 5 million Americans are living with Alzheimer's, and by mid-century, the number of people with the disease is set to nearly triple. Already the most expensive disease in America with costs reaching an estimated \$305 billion in 2020, these costs are projected to more than quadruple to \$1.1 trillion by mid-century, with two-thirds paid by Medicare and Medicaid.

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 by 2025. Congress must continue its commitment to the fight against Alzheimer's and other dementias by increasing funding for Alzheimer's research by an additional \$354 million in fiscal year 2021.

As scientists continue to explore new areas of research for prevention, treatment, and a cure, public health plays a critical role in promoting cognitive function and reducing the risk of cognitive decline. 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, and preventing avoidable hospitalizations. The BOLD Infrastructure for Alzheimer's Act will accomplish this by establishing Alzheimer's and Related Dementias Public Health Centers of Excellence; providing funding to state, local, and tribal public health departments; and increasing data analysis and timely reporting. To ensure the law's successful implementation, Congress must fully fund the \$20 million authorized in the law for CDC in fiscal year 2021.

Protect individuals living with Alzheimer's and other dementias

The bipartisan Promoting Alzheimer's Awareness to Prevent Elder Abuse Act (S. 3703/H.R. 6813) would require the Elder Justice Initiative of the Department of Justice (DOJ) to incorporate training with respect to elderly individuals with Alzheimer's disease and related dementias. The Promoting Alzheimer's Awareness to Prevent Elder Abuse Act would require DOJ to develop best practices materials to assist victims of abuse living with Alzheimer's and other dementias. These materials would be designed for law enforcement officers, prosecutors, judges, medical personnel, victims services personnel, and others who encounter and support individuals living with Alzheimer's and related dementias. The legislation would also require DOJ to report annually on the dissemination and use of the materials to Congress and the Advisory Council on Alzheimer's Research, Care, and Services.

Support education and outreach on Alzheimer's and dementia care planning services covered under Medicare

For individuals living with Alzheimer's and their caregivers, care planning is essential to learning about medical and non-medical treatments, clinical trials, and support services available in their community. As of January 2017, Medicare reimburses providers for care planning. However, too few providers and patients are aware of this benefit. The Improving HOPE for Alzheimer's Act (S. 880/H.R. 1873) would increase education and outreach to providers about Alzheimer's and dementia care planning services through Medicare and give clinicians the knowledge and the tools to better help their patients and families living with dementia.

State Policies to Lead on Alzheimer's Disease

Alzheimer's is a growing public health crisis and state governments must take bold action. Effectively implementing and updating State Alzheimer's Plans and supporting other policies will reduce the long-term impact of the disease on state budgets, and improve the lives of individuals living with dementia and their family caregivers. The follow policies are endorsed by the Alzheimer's Association and the Alzheimer's Impact Movement.

Increase public awareness, early detection and diagnosis

Most people who have been diagnosed with Alzheimer's disease are not aware of their diagnosis, and only about half of those with Alzheimer's have been diagnosed. Diagnosis — and disclosure of that diagnosis — is necessary for care planning, which is critical to improving outcomes for the individual. State officials must work to educate health care providers and the public about the importance of early detection and diagnosis, and improve access to and awareness of resources such as the Medicare Annual Wellness visit. Through public health campaigns and data collection via the Behavioral Risk Factor Surveillance System (BRFSS) state governments can further address Alzheimer's in their states.

Build a dementia-capable workforce

As our nation ages more people will develop Alzheimer's and need quality care, however a shortage of qualified health care workers could jeopardize care for individuals living with Alzheimer's and other dementias. State governments need to implement policies that will create incentives and career pathways to recruit and retain health care professionals, require competency-based dementia training for all involved in the delivery of care, and require training of adult protective services workers and law enforcement about how to recognize and interact with individuals living with dementia.

Increase access to home and community-based services

People living with dementia and their caregivers often prefer to keep the individual living in the home for as long as is manageable. In fact, 70 percent of people with Alzheimer's live in the community. State governments can reduce long-term costs and increase access to person-centered care in home and community settings including respite and adult day care, regardless of age or financial status through Medicaid and other state-supported programs.

Enhance the quality of care in residential settings

Alzheimer's requires a wide range of evolving care and services, and as the disease advances individuals often need to move into residential settings for more specialized care. In fact, among individuals with Alzheimer's, 75 percent will be admitted to a nursing home by the age of 80. It is important that state governments have in place laws to protect people with dementia from improper displacement in residential settings. State governments must also increase Medicaid reimbursement rates to reflect the higher cost of care for individuals living with Alzheimer's and other dementias to ensure residential care settings remain accessible to the population and their needs.

Public Health Policies to Lead on Alzheimer's Disease

Mitigating the future impacts of Alzheimer's and other dementias requires state and local governmental public health agencies to robustly promote risk reduction of cognitive decline, improve care for people with cognitive impairment, and strengthen support for caregivers as recommended in the Healthy Brain Initiative's State and Local Public Health Partnerships to Address Dementia: The 2018-2023 Road Map. The following policies are endorsed by the Alzheimer's Association and the Alzheimer's Impact Movement.

Increase early diagnosis of Alzheimer's

Only about half of all people who have been diagnosed with Alzheimer's disease, or their caregivers, are aware of the diagnosis. Early detection and diagnosis — and knowing the diagnosis — are essential to enhancing medical care for people living with dementia. Diagnoses also enable all affected to access information, services, and other support in the community and make plans for the future. State and local governmental public health agencies must ensure health care professionals have the competencies needed to effectively discuss memory issues and use validated cognitive assessment tools. Agencies also must directly educate the public about cognitive changes that should be discussed with a provider as well as the benefits of early diagnosis. State health improvement plans should include goals regarding early diagnoses.

Promote risk reduction of cognitive decline

Healthy behaviors — which research has shown to prevent cancer, diabetes, and cardiovascular disease — also may reduce risk for cognitive decline and possibly dementia. With budget allocations from state legislatures, governmental public health agencies must advance awareness about the interplay between cognitive health and physical health through culturally competent health education campaigns, especially for diverse communities. Public health agencies can also improve access to interventions and services that support cognitive and heart health and establish policies that ensure people living with dementia and their caregivers have safe, supportive communities with opportunities to stay engaged and live as independently as possible.

Increase attention to dementia caregivers

The challenges of caring for persons with Alzheimer's and other dementias can become difficult and overwhelming, especially when intensive care is needed for long periods of time. State and local governmental public health agencies can set continuing education standards for health care professionals on how to involve caregivers throughout the decision-making and health management process. Agencies must also use their leadership to increase delivery of care planning services, including caregiver assessments and referrals. An additional priority is for these agencies to expand access to affordable services, programs, and other community support for caregivers to reduce stress, protect their health and improve caregiving skills.

Build a dementia-capable workforce

As the nation ages, more people will develop Alzheimer's and other dementias and need high quality, compassionate care. State and local governmental public health agencies must strengthen competencies of professionals, especially physicians and primary care clinicians, who deliver health care and other care services to people with dementia. Agencies can also assure academic programs, professional associations, and accreditation and certification entities incorporate the best available science into training for the current and future health care and public health workforces. Finally, these agencies also can evaluate professional dementia training and caregiving support programs to identify ways to improve impact.

Enhance nationwide, state, and local surveillance

Surveillance is a fundamental and essential public health tool to understanding the prevalence of disease, health risk factors, preventive health behaviors and burden. State and local governmental public health agencies can enhance data collection and timely analysis of cognitive health issues, workforce capacities, and dementia caregiving. Two specific priorities are implementing the Cognitive Decline and Caregiver Modules of the Behavioral Risk Factor Surveillance System (BRFSS) and estimating the gap between workforce capacity and anticipated demand for services to support people with dementia and their caregivers.

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

Throughout 2020, the Alzheimer's Impact Movement 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 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
alzimpact.org/2020
alz.org/facts



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ALZHEIMER'S AFFECTS EVERYBODY



Alzheimer's is America's most expensive disease, costing the nation **\$305 billion in 2020**. Medicare and Medicaid will cover more than two-thirds of those costs.



More than **5 million Americans** are living with Alzheimer's and more than **16 million** provide unpaid care.

1 in 5 Medicare dollars is spent caring for someone with Alzheimer's.

