a call to states: make alzheimer’s a policy priority

the compassion to care, the leadership to conquer®
Alzheimer’s is a public health crisis.

One in eight Americans aged 65 and older have Alzheimer’s disease – and another American develops Alzheimer’s every 70 seconds. With the impending retirement of the Baby Boomers, this number is expected to explode in the future. By 2050, someone will develop Alzheimer’s every 33 seconds.

Alzheimer’s is a national crisis, affecting Americans across all walks of life and across all regions of the country. State policymakers cannot ignore this devastating disease.

- In 2010, state and federal governments spent a combined $30 billion in Medicaid costs to cover nursing home care for people with Alzheimer’s and other dementias.
- In 36 states in 2009, caregivers of people with Alzheimer’s and other dementias provided unpaid care valued at more than $1 billion per year. Unpaid caregiving in California, Florida, New York, Pennsylvania and Texas topped $6 billion per year in each state.
- Individuals with cognitive impairment, such as Alzheimer’s, who require help with daily living and receive paid services – often funded by state programs – require almost twice as many care hours each month as a person without cognitive impairment.
Prepare your state for the future of Alzheimer’s.

Estimated number of people with Alzheimer’s by state, 2025


Source: Alzheimer’s Association (www.alz.org)

For in-depth, state-specific information, see our Alzheimer’s Disease Facts and Figures report at alz.org/facts.
State policymakers cannot ignore Alzheimer’s.

Alzheimer’s disease is the most under-recognized public health crisis of the 21st century. Today, as many as 5.3 million Americans are living with Alzheimer’s disease – the most common form of dementia – and that number will rise to 16 million by 2050. While the number of deaths from heart disease, prostate cancer and stroke are declining, the number of deaths from Alzheimer’s are rising.

To achieve meaningful progress, every state must tackle Alzheimer’s not only as an aging issue, but also as a public health crisis. The disease steals a person’s memories, judgment and independence. It robs spouses of lifetime companions and children of parents and grandparents. It destroys the security of families and depletes millions of dollars annually from state budgets.

Alzheimer’s is a pivotal public health battle, and state governments stand on the front line. The Alzheimer’s Association calls on state policymakers to take bold action to confront this epidemic.

Participate in the BRFSS

Obtaining a more definitive picture of Alzheimer’s is essential to any successful local Alzheimer strategy. Recent work by the Centers for Disease Control and Prevention now enables states to collect information on the prevalence and impact of Alzheimer’s using the existing state Behavioral Risk Factor Surveillance System (BRFSS) survey. For more information on how your state can participate, contact Kate.Morrison@alz.org.
action 1 Develop a comprehensive state government Alzheimer’s disease plan.

Most states have a strategic plan to address cancer, diabetes or pandemic flu. But few states are prepared for the projected 50 percent increase in Alzheimer’s disease during the next 20 years. State Alzheimer’s Disease Plans create the infrastructure and accountability necessary to confront the sweeping economic and social impact of this disease.

By bringing together essential stakeholders – such as state agency officials, legislators, care providers, family caregivers and people with Alzheimer’s – the state planning process is able to identify critical issues, explore solutions and construct a roadmap to guide a state’s development into a dementia-capable state. Common recommendations include:

- Improved primary prevention and early diagnosis
- Delivery of community-based and residential dementia care services in a cost-effective manner

Even in the handful of states with completed Alzheimer’s Disease Plans, it is critical for policymakers to ensure that the plan’s recommendations are translated into actual policies. Only then will the burden on state budgets and families be reduced.
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action 2

Improve the quality of dementia care.

States provide and regulate many services that are used by people with Alzheimer’s across the spectrum of the disease. People with Alzheimer’s deserve to receive quality care throughout the course of the disease, in the setting they choose and from knowledgeable caregivers. To best serve those with Alzheimer’s, states should have a quality dementia care policy in place that includes the following key elements:

• Mandatory dementia training for direct care workers, regardless of care setting
• Disclosure by facilities of dementia care service options
• Home and community-based services that allow people with Alzheimer’s to remain at home
• Effective enforcement of dementia care regulations

States must also work to adopt policies on advance directives and care planning that reduce the complexity of end-of-life decision making, particularly with respect to the complicated adult guardianship issues that often occur when there is a failure to engage in end-of-life planning. One important action is to enact the budget-neutral Uniform Adult Guardianship and Protective Proceedings Jurisdiction Act (UAGPPJA), which establishes a framework for courts in different states to communicate about adult guardianship cases.
**action 3** Ensure access to Medicaid coverage for Alzheimer’s.

As the disease progresses, Alzheimer’s robs people of their financial security and ability to care for themselves. The average annual cost of nursing home care in 2009 was more than $70,000 – costs generally not covered by Medicare. As a result, Medicaid is critical for many people with Alzheimer’s who need long-stay nursing home care. In fact, 51 percent of nursing home residents with Alzheimer’s depend on Medicaid to help meet the costs.

While Medicaid spending constitutes one of the largest items in most state budgets – and while most states continue to face severe fiscal constraints – state policymakers must ensure that critical benefits are preserved. In addition, people with Alzheimer’s need a Medicaid system that:

- Evaluates cognitive functioning when determining eligibility for long-term care
- Offers home and community based services, such as adult day care, hospice and respite care
- Employs service providers and care coordinators who are trained to understand Alzheimer’s disease

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To learn more about how state policymakers can assist people with Alzheimer’s, please visit www.alz.org/join_the_cause_state_legislation.asp.

To reach Alzheimer’s policy experts in your state, please contact advocate@alz.org.

For more information on constituent services of the Alzheimer’s Association, such as our 24/7 Helpline and CareFinder™, please visit: www.alz.org.

The Alzheimer’s Association is the leading voluntary health organization in Alzheimer care, support and research. Our mission is to eliminate Alzheimer’s disease through the advancement of research; to provide and enhance care and support for all affected; and to reduce the risk of dementia through the promotion of brain health.