DIAGNOSIS: ALZHEIMER’S

States are taking bipartisan action to combat one of the nation’s costliest diseases.

BY SAMANTHA SCOTTI

It wasn’t long ago that Scott Plakon thought of Alzheimer’s as that disease that causes you to forget things then eventually die.

But in 2014, the Florida Republican received the devastating news that his wife of 29 years, Susie, who was then 53 years old, had been diagnosed with Alzheimer’s. Between then and her death in July 2018, Plakon not only learned to recognize the disease for what it truly is, but also became a champion of the Alzheimer’s awareness movement: speaking at rallies, filing legislation and protecting and enhancing funding in his state's budget.

“It’s just become a life’s calling,” he says. “Before Susie’s diagnosis I didn’t know about myoclonic or grand mal seizures, the agitation, sundown syndrome, hospital stays from injuries from the seizure falls or wandering—I once found her in our neighborhood doing one of our neighbor’s dishes, and the sheriff was called.”

There were so many things, Plakon says, that “go along with Alzheimer’s and I didn’t know anything about it.”

“I didn’t know about being in the middle of a parking lot while she’s extremely agitated and wondering if people are calling the police because they think you’re taking some sort of aggressive action toward your wife because you’re trying to get her in the car,” he says. “So, I’ve tried to use the platform I’ve been given as a state legislator to bring greater awareness, and it seems to be working.”

Widespread and Increasing

Alzheimer’s disease, the most common form of dementia, is a progressive neurological illness that impairs the thinking and independence of millions of people worldwide. It’s usually diagnosed in people 65 and older, but it starts earlier with subtle neurological changes occurring years or even decades before symptoms...
An estimated 5.7 million Americans currently live with Alzheimer’s, and reports anticipate this number will more than double to 11.6 million by 2040.

To prepare for the increase, 49 states and territories have published a state Alzheimer’s plan. The reports examine the current effect of Alzheimer’s in each state and outline steps that could be taken over the next three to five years to support people with the disease and their families.

Included in nearly every state plan: recommendations for dementia training for health care and support workers. Most state plans also have provisions to improve the care received by those with the disease and to assist unpaid caregivers. Other areas of overlap among the plans include improving home and community-based services, public awareness and data collection.

Caregivers’ Burden

It’s not just those diagnosed who struggle with the disease. Most caregivers (66%) live with the person in their care, while one-quarter are members of the “sandwich generation”—caring for both an aging parent and children younger than 18—according to the nonprofit Alzheimer’s Association. Caregivers of people with dementia are twice as likely to report substantial emotional, physical and financial troubles as those caring for people without dementia.

Plakon, who has six children, says he was fortunate to have a large family to help with his wife’s round-the-clock care, which, he says, can be “absolutely brutal.” “I think of an elderly couple, where their kids live out of state and they don’t have financial resources—that can be a real hell-on-earth scenario,” he says. “Alzheimer’s requires 24-7 care, because sleep patterns are disrupted, they wake up in the middle of the night and may try to wander off. It requires a team of people to care for someone with Alzheimer’s.”

And the cost of care is sky-high. The approximate lifetime cost of caring for a person living with dementia in 2018 was $350,174, according to the Alzheimer’s Association. The national cost of Alzheimer’s and other dementias in 2019 is projected to reach $290 billion, including $195 billion in Medicare and Medicaid payments. If no treatment is discovered to slow, stop
or prevent the disease, estimates suggest that the price tag will grow to $1.1 trillion in 2050.

**What States Are Doing**

In response, state lawmakers are considering a variety of policy solutions. Some are broad in approach, such as strengthening payment and delivery systems for all long-term care or connecting unpaid family caregivers with the resources they need. Other policies are more narrowly targeted to individuals with the disease, and most of the work is bipartisan.

“Alzheimer’s doesn’t care what political party you are,” Plakon says, “if you’re male or female or, increasingly, even what age you are.” He notes a slogan he and Florida Representative Matt Willhite (D), with whom he has partnered on the issue, came up with a few years ago: “When you take red, the color of Republicans, and blue, the color of Democrats, and you mix them together, you get purple, the color of Alzheimer’s awareness.”

**Early Detection and Diagnosis.** A 2018 Virginia law directs the department of health to educate health care providers about the importance of early detection and timely diagnosis of cognitive impairment, and to increase awareness of the early warning signs of Alzheimer’s and dementia.

Virginia Senator Rosalyn Dance (D) hopes the bill will not only better inform health care providers about the disease, but also raise awareness of warning signs among communities of color, which are at greater risk of developing Alzheimer’s and dementia, she says.

“During the 2018 General Assembly session, I was honored to work with many stakeholders in the Alzheimer’s awareness community to sponsor legislation aimed at early detection awareness,” she says. “As a result of this legislation, I hope more people will have better access to resources and care to treat Alzheimer’s across the commonwealth.”

A 2018 Massachusetts law requires physicians to complete a onetime continuing education course on the diagnosis and treatment of patients with cognitive impairments. It also requires hospitals to develop and carry out a plan for recognizing and managing patients with dementia. The law allows doctors to share an Alzheimer’s diagnosis and treatment plan with a family member or legal representative according to existing federal and state privacy laws.

**Dementia Training for First Responders.** Dementia training is also needed for adult protective services officials, first responders and law enforcement. They frequently interact with people with Alzheimer’s and other dementias and are generally among the first to be contacted regarding emergencies, abuse or exploitation. In 2014, Connecticut established mandatory dementia training for a wide range of personnel, including emergency medical technicians, probate judges, paid conservators and protective services employees. The legislation requires that the refresher training EMTs take every three years for recertification.
Medicaid Costs and Alzheimer’s

Medicaid is the largest payer of long-term services and supports, covering more than half of those costs nationally. Medicaid payments for services related to Americans 65 and older living with Alzheimer’s or other dementias vary substantially by state. Payments totaled more than $46.5 billion in 2018, a number anticipated to increase 30% by 2025.

Below are the projected increases between 2018 and 2025 in Medicaid costs for Americans age 65 and older living with Alzheimer’s or other dementias.

**WHO’S AFFECTED BY ALZHEIMER’S**

5.7 million

Americans living with Alzheimer’s

2/3

Portion of patients who are women

2x

The rate at which older African Americans will get dementias compared with older whites

1.5x

The rate at which older Hispanics will get dementias compared with older whites

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In Florida, Plakon serves on the state’s Alzheimer’s Disease Advisory Committee. He has worked to fund memory disorder centers and has sponsored bills to require more regular reporting about the disease to the governor and to educate first responders who may be called to deal with situations such as when his wife was found in a neighbor’s home. Plakon says he’s also constantly trying to increase respite care funding.

“Here in Florida, we have 560,000 families affected by this,” he says. “And, with an aging baby boomer population, I’ve described it as a tsunami about to hit our state. We need to stay at the forefront on this in every different area, from policy to budget, so I’m trying to encourage my colleagues to get ahead of the tsunami before it hits the shore.”

**DISEASE DATA**

6th

Place Alzheimer’s holds in causes of death

1 in 3

Portion of those 75 or older who die of Alzheimer’s

4–8 years

Average lifespan of a person after a diagnosis of Alzheimer’s

includes instruction in Alzheimer’s and dementia symptoms and care.

**Alzheimer's and Dementia Task Forces.** Various states have created task forces to coordinate statewide efforts to ensure quality care for those living with Alzheimer’s or other dementias.

Wisconsin’s Task Force on Alzheimer’s and Dementia, formed by Assembly Speaker Robin Vos (R), developed the Wisconsin Cares Legislative Package. The Legislature enacted three of the bills the task force introduced in the 2015-16 session, including funding for caregiver respite, mobile crisis unit training and developing a pilot program to ensure that people with dementia who are experiencing a crisis are placed in an appropriate setting.

Samantha Scotti is a policy specialist in NCSL’s Health Program. Lesley Kennedy, NCSL’s manager of digital communications, contributed to this article.
ALZHEIMER’S IS A GROWING PUBLIC HEALTH CRISIS

Over 5 MILLION Americans are living with Alzheimer’s. 16 MILLION more are serving as unpaid caregivers.

The Alzheimer’s crisis requires bold action by state governments.

HERE’S HOW STATE OFFICIALS CAN HELP:

- Increase public awareness, early detection, and diagnosis
- Increase access to home and community-based services
- Build a dementia-capable workforce
- Enhance the quality of care in residential setting

alzimpact.org/state