

AID

FOR THE SILVER WAVE

States Find Ways to Help Alzheimer's Patients, Caregivers



Research is identifying best care practices for patients with Alzheimer's disease. Many states are working to improve the quality of life for patients with the disease, as well as for the people who care for them.

By Mary Branham Dusenberry



Sen. Martin Golden sees a silver wave coming, and he wants to be prepared.

Golden, chairman of the New York Senate Aging Committee, said 3 million senior citizens live in his state. That number will swell to 5.5 million over the next few years, and he estimates “a good third” of that number will be in their 80s in the next few years.

“A silver wave will be coming down on this state and nation and will impact them severely in the next 10 years,” Golden said. “We’re attempting to get in front of the silver wave.”

Golden has co-sponsored several bills this year to address the silver wave issues dealing with Alzheimer’s disease, which many seniors face as they age. The Alzheimer’s Association estimates the senior citizen population will increase to 70 million by 2030, and 7.7 million people could be affected by the disease.

New York isn’t alone in addressing the needs of Alzheimer’s patients and caregivers. Aging baby boomers, combined with a better understanding of the disease, have prompted many states to seek ways to serve this growing population.

“Alzheimer’s disease, we know, is already prevalent,” said Ashlen Anderson, a policy analyst with the Alzheimer’s Association in Washington, D.C. “We expect if there is no intervention with drugs or research advancements, the prevalence is going to triple by the middle of this century.”

The Alzheimer’s Association has a number of state policy objectives, chief among them state government Alzheimer’s disease plans.

“What we recommend is that states develop some kind of task force, either mandated by the state legislature or through executive directive that brings together people from all parts of the state that are affected ... to create a series of solutions, first to identify all of these problems that are specific to that particular state and analyze what they’ve already done,” Anderson said.

Many states are doing just that.

New York’s legislature approved a coordinating council and state plan “which will allow us to identify best practices for working with persons with Alzheimer’s and with caregivers,” Golden said.

Kentucky developed a state plan in the late 1990s that created a council on Alzheimer’s disease and related disorders, according to Phyllis Culp, acting staff assistant for the state’s Department for Aging and Independent Living. The legislature this year passed a resolution that calls for revisiting the plan.

The state plan over the years has generated several programs to serve patients and caregivers, one of which is funding for an Alzheimer’s respite program. Kentucky and other states have also developed services and programs for the Alzheimer’s community.

State Programs

States over the years have developed programs designed to improve the quality of life for Alzheimer’s patients and caregivers.

“The sheer numbers are forcing us to take a look and try to do more with that population,” said Bill Peterson, senior policy analyst with the Virginia Department for the Aging. “At least half of the people in nursing homes in Virginia have some form of dementia.”

Romaine Turyn, director of the Maine Alzheimer's Project, said the demographics are critical.

"If you look at the demographics in general for the older population and break that down to the people who are likely to have Alzheimer's disease ... it's definitely an issue that needs to be addressed," she said.

Many projects have been funded by Alzheimer's demonstration grants from the U.S. Administration on Aging.

"For a state like Maine, it's been an incredible opportunity to develop programs and see what works for people and what doesn't," said Turyn. "We've been able to try a number of different programs, some of which we've been able to maintain with state funds.

"As a result of these monies, there have been some best practices across the country that other states can replicate," she said.

Virginia Provides Virtual Support

Virginia's Alzheimer's Commission has developed a virtual Alzheimer's center, a Web site "that's an attempt to bring a lot of information in one place for families as well as researchers and practitioners in hopes of making Virginia a state where we can have research and bench to bedside services for people," said Peterson. (The Web site is www.alzpossible.net.)

"We're trying to create this virtual Alzheimer's center ... a center without walls to bring together intellectual resources as well as information for caregivers," he said.

Virginia has also used federal grants to fund respite services through the four Alzheimer's Association chapters in the state. The state has also used the grant to fund tool kits by the School of Nursing at James Madison University.

The Alzheimer's Commission is also working with the University of Virginia to develop a registry for families that have prevalence for the disease. Another project involves a telemedicine approach providing consultations to physicians in rural areas in the state.

Maine Helps Caregivers

In Maine, the state uses program funds to provide mental health counseling to Alzheimer's caregivers to reduce depression.

"We identified the fact that caregivers need support too," Turyn said. "It's draining and very stressful."

Most people prefer caring for Alzheimer's patients at home, and Maine recognized that requires an informal care system.

"We need to support family members because they're a critical component in keeping people at home," Turyn said.

Those people eligible for nursing home care can choose to have that care provided in their homes, as long as the costs are the same. Maine also has a state-funded program for people who are not Medicaid-eligible.

That's the latest in a series of projects the state has developed through the Alzheimer's demonstration grants, according to Turyn.

"We tried to start at the beginning and enhance systems as we went along to make them more responsive to the needs of people with dementia," she said.

Maine has received the federal grant since 1994, and has used the funds "to develop programs and made changes to make the systems more dementia friendly," Turyn said.

The state has used those funds to develop memory evaluation clinics, different models for respite and home care services, and methods for helping people with end-of-life care.

Washington Looks at Day Services

Washington state is using a demonstration grant to develop model Dementia Day Services. It's in the third year of the grant, according to Lynne Korte, program manager for the Washington State Aging and Disability Services Administration. This year, Korte said, the state will evaluate how the program has worked and whether it has been effective and can be sustained within the state system.

"Our current state models were not really designed to meet the specific needs of people with dementia," Korte said. "As a state, we've been moving in a direction of recognizing what the special needs are and modifying programs to meet the needs of people with dementia.

"There are things we can do to make a difference in the lives of people with dementia," she said.

Washington also offers a family caregiver counseling model to help caregivers deal with the stresses of taking care of an Alzheimer's patient, as well as a consultation service to educate them on caring for the patient.

The state also has a respite care program for caregivers that started in 1998.

Kentucky Assesses Training Effectiveness

Kentucky's Alzheimer's council is working with the University of North Carolina to assess the effectiveness of increased training for nursing home staff. The state is in the first year of the project, in which training is provided in nursing home facilities, according to Marnie Mountjoy, community opportunities branch manager for the state Department of Aging and Independent Living.

Kentucky also is working with advocacy groups and the nursing home industry to gather information about improving the quality of care, according to Deborah Anderson, commissioner for the Department of Aging and Independent Living.

Under a federal demonstration grant, Kentucky is using a faith-based approach to reach an underserved group.

"One of the things we recognized ... is that we don't really have a very effective outreach or relationship with minority populations," said Culp. "The basic program element was education to families and professionals about Alzheimer's disease."

Alzheimer's Disease Growth

The Alzheimer's Association expects the United States to see an average 44 percent increase in Alzheimer's disease by 2025, with the Western and Southeastern states to be hit the hardest.

The greatest increase in cases will occur in the West, and six states—Utah, Alaska, Colorado, Wyoming, Nevada and Idaho—will double the number of cases of Alzheimer's disease between 2000 and 2025 due to the low total population and high growth of older people, according to the association.

The three largest states—Texas, Florida and California—will continue to have the greatest total number of cases and will experience significant growth rates at 74 percent, 64 percent and 50 percent respectively.

The association predicts only Pennsylvania, Rhode Island and the District of Columbia will not have an increase in the prevalence of Alzheimer's disease. That's due in part to the slower growth rates of the older population in these areas.

For more information, visit www.alz.org.



Assessments have been provided in senior housing, senior citizens' centers and at health fairs. The University of Kentucky has developed a clinic in a northside Lexington neighborhood to serve the population "in a culturally sensitive way," said Culp.

"We've had three major conferences targeting the needs of the African-American community," she said. "The major focus has been building a relationship of trust with the communities."

Mountjoy said Kentucky also assists caregivers of people over age 60 with training and support groups.

Kentucky boasts one of the most successful programs developed for Alzheimer's care. The Best Friends Approach to Alzheimer's Care, an internationally recognized and utilized program, was developed in an adult day center in Lexington about 20 years ago.

State Laws

While programs have been and are being developed, states are also considering a multitude of laws addressing everything from quality of care to safety issues.

The Alzheimer's Association was pleased with the number of states considering laws to establish state plans, as well as addressing the other issues associated with the disease. The association has three priority issues in the states: the state plans, dementia-capable Medicaid coverage for long-term care, and quality care across the continuum of the Medicaid system, according to Anderson.

"When you realize that 85 percent of what we know about Alzheimer's disease has been generated in the last 15 years, it's time to get caught up," said Mike Splaine, director of State Policy and Advocacy Plans for the Alzheimer's Association.

Other issues of concern for the association include safe return programs for those Alzheimer's patients who wander and respite programs for caregivers, according to Splaine.

"I'd like to be in a situation in about two years where we could say 'this is a real Alzheimer's, dementia capable state,'" said Splaine.

No state is there yet, according to Splaine. But states are inching closer to that goal.

New York's Golden, for instance, was actively involved in getting several bills approved during this legislative session. He proposed a process to identify cognitive impairments of patients 60 and older prior to admission at a general hospital, and a tax credit for GPS locator systems for Alzheimer's patients.

"Being from New York City, there's not a day that goes by that one of the precincts doesn't put out a system alert looking for somebody who's missing, who's strayed away from the home or care center," said Golden, a former New York police officer. "It becomes a real safety issue, besides a quality of care issue."

Time for Action

The Alzheimer's Association believes it's imperative for states to address the growing concerns surrounding the disease.

"Alzheimer's disease affects multiple parts of government," said Anderson, "from public safety to long-term care to health care."

"There's a climate of concern out there," said Splaine. "It's a constructive tool that state governments can seize on and be proactive.

"Overall I think we're on the right trajectory," he said.

"There's a way for states to be strategic about this and really take a good long hard look about what is working, and really begin to weave the network of collaboration between the different parts of state government."

—Mary Branham Dusenberry is managing editor of State News.