In 2015, more than 1 million people in the 11-state Midwest were living with Alzheimer’s disease — the sixth-leading cause of death among adults in the United States. And minus a cure, this common form of dementia will touch and take even more lives in the decades ahead.

In most of the region’s states, for example, the number of Alzheimer’s cases is expected to increase by close to 20 percent or more between now and 2025 due to rises in the number of people 65 or older (see table). By the middle of this century, the number of Americans with the disease could triple.

The heavy toll that Alzheimer’s takes on individuals and families is well known, but the disease also has high costs for state health care systems. According to the Alzheimer’s Association, the average Medicaid costs for a senior with this disease and other dementias are 19 times higher than those for other seniors.

“The impact on state budgets and state resources to assist people with the disease is going to be tremendous,” says Randi Chapman, the association’s state affairs director. “It’s an issue that states need to think about, comprehensively.”

That means addressing a host of policy challenges — for example, coordinating care and services, helping caregivers, and training law enforcement and health care providers. But a first step for many states (usually as the result of legislation) has been to develop, and then regularly update, wide-ranging Alzheimer’s plans.

“The real reason for the need for these plans is for the states to engage with community partners, with business partners, with legal partners and with the law-enforcement community to engage comprehensively and collaboratively to address what is a quintessential health issue of our time,” Chapman says.

**Alzheimer’s plans in Midwest**

Most states in this region have created Alzheimer’s task forces and plans. In Illinois, for example, these plans are updated every three years (the first one was created nearly 30 years ago) to examine the impact of Alzheimer’s and to recommend new state policies.

In Wisconsin, partly as the result of a state Supreme Court ruling and subsequent legislative proposals, the state has now embarked on a redesign of its system for providing dementia care. This new strategy includes enhancing staff training at health care facilities, developing new statewide standards for dementia care, and improving data collection on the quality of care being delivered.

Nebraska’s first-ever statewide Alzheimer’s plan, meanwhile, is now in the works — the result of a task force on aging formed by the Unicameral Legislature in 2014 and a bill (LB 405 [2]) passed the following year. The Cornhusker State’s increased emphasis on aging policies and related diseases coincides with a major demographic shift occurring there: During this decade, the percentage of Nebraskans 65 and older (the time of life when most people are diagnosed with Alzheimer’s) is expected to increase by more than 30 percent.

Some parts of Nebraska are aging even faster, says Sen. Al Davis, who represents one of those areas — a large, sparsely populated district in the northwest portion of the state.

“A lot of the places where the needs are [the greatest] are parts of the state where there aren’t many services,” says
Davis, the sponsor of LB 405.  

One objective of the new state plan (expected to be released sometime in 2016) is to begin addressing these gaps in services. Another goal, he adds, is to find ways for the state's health care system to be less reliant on institutional care for people with Alzheimer's.  

“If at all possible, [we want] to keep people in their homes,” Davis says.  

For the state, that can mean less-expensive care; for an individual with Alzheimer's disease, that can mean an improved quality of life. But for this shift to occur in Nebraska, as in other states, new policies are often required to enhance the availability of home health assistance, adult day care and other services.  

**More support for families, caregivers**  

About 70 percent of people with Alzheimer's disease live at home with a family member or other caregiver.  

“Alzheimer's patients may be physically healthy,” North Dakota Sen. Dick Dever says, “but in need of around the clock care.” For the loved one/caregiver, he adds, providing that type of intensive, long-term care can take a heavy toll.  

About a decade ago, Dever served as the chair of an interim legislative committee in North Dakota that became the catalyst for new state policies that are now lending a hand to these family members and caregivers.  

Lawmakers established the Dementia Care Service Program in 2009 (HB 1043), and one of its central goals is to help caregivers by providing them with individualized consultations, training and support. With a biennial legislative appropriation of $1.2 billion, the state contracts with the Alzheimer’s Association to provide these services. Almost 60 percent of those served are from rural areas.  

Through the individualized care consultation, the needs of both the person with dementia and his or her caregiver are assessed. This information is then used to provide resources, develop (or update) care plans, and, when necessary, refer the family for additional services.  

Between January 2010 and June 2015, North Dakota’s Dementia Care Service Program served 3,441 caregivers and 1,723 individuals with dementia. For a vast majority of them (95 percent or more, according to a survey of the program), these consultations have improved participants’ understanding about dementia and support services. Caregivers also reported feeling less stressed.  

“Those reports have been positive,” Dever says. “Funding has continued in each biennium since the program’s inception. “Most importantly, families have talked about the difference it has made for their loved ones and for their families.”  

Along with individualized care consultations, the program has sponsored hundreds of dementia-related community and professional education classes.  

In 2014, Michigan began funding an in-home care pilot program of its own that is modeled after North Dakota’s.  

“The ultimate goal of this project is to help people get the resources they need at home, so they can get the best possible care and, at the same time, save the state money,” says Lindsay Brieske of the Michigan chapter of the Alzheimer’s Association.  

As part of the pilot project, university researchers are studying its efficacy. For example, are these newly funded support services delaying the need for residential long-term care? If so, what are the potential cost savings? According to Brieske, researchers are also evaluating whether the program helps reduce the frequency of 911 calls or unnecessary trips to the emergency room.  

“These are things people rely on when they don’t have the tools they need to care for someone,” she says.
Training for health care providers

Staying at home may be the first and best option for many Alzheimer’s patients, but for others, some type of residential care is needed. According to the Alzheimer’s Association, 64 percent of seniors in nursing homes have Alzheimer’s disease or a related dementia. Forty-two percent of seniors in assisted-living facilities and one-third of those in adult day-care facilities suffer from some form of dementia.

These statistics, Chapman says, underscore the importance of state legislators addressing the quality of care being delivered to Alzheimer’s patients. One response has been to establish new or more-stringent requirements for professionals who work with Alzheimer’s patients and their loved ones.

“Are professional caregivers effectively trained in dementia care? Do they know how to communicate with someone who has the disease? Do they know how to communicate with the family? That is where states need to focus their energy, so that families have the resources and the choices they need to ensure that loved ones are receiving the best care possible as they go through this disease,” Chapman says.

According to a recent Justice in Aging report:

- Fewer than half of U.S. states require dementia-services training for nursing-home staff;
- Nineteen states require dementia-specific training for staff at adult day-care facilities; and
- Forty-four states require dementia training for the staff at assisted-living facilities (see map for the status of training-requirement laws in the 11-state Midwest).

In this region, Illinois is one of the few states that require dementia-services training at all three types of residential facilities. For example, staff at assisted-living facilities must receive instruction on:

- the nature of the disease,
- minimizing challenging behaviors,
- minimizing safety risks,
- communication techniques, and
- residents’ rights.

Starting this year in Minnesota, as the result of legislation passed two years ago (HF 2402), all staff members at assisted-living facilities are required to meet new dementia-specific training-hour requirements.

For direct-care workers and their supervisors at facilities with special programs or care units, eight hours of initial training and two hours of yearly instruction are now mandatory. For other personnel, four hours of initial training and two hours of yearly instruction is required.

Changes may soon be coming to Iowa as well. Last year, legislators established an Interagency Dementia Proficient Workforce Task Force (SF 505). This group’s policy recommendations, released in December, include a requirement that all direct-care workers in the state get training on:

- how to keep dementia patients safe,
- understanding progression of the disease,
- learning behavioral symptoms and how to address them, and
- implementing a “person-centered” approach to patient care.

Under the Iowa task force’s proposal, each worker would receive a certificate of completion for this competency training. The certificate would be “portable” for workers who move from one setting to another.

Statewide alert systems aid in search for missing, at-risk adults

One of the more common — and frightening — concerns for the family members of someone with dementia is “wandering”: a loved one losing his or her way from a care setting and, as a result, being put at risk of serious injury or death.

In response, many states have created Silver Alert programs (usually through state legislation). Though modeled after Amber Alerts for missing children, successful state programs recognize the differences between looking for a child who may have been kidnapped and a person with dementia who has “wandered,” says Randi Chapman, state
affairs director for the Alzheimer’s Association.

“The search area is going to be smaller, the search team should start sooner, [and] law enforcement needs to be trained on how to work with people who have dementia,” she says.

As of August 2015, 42 states had established some type of alert system for missing adults with cognitive impairments.

“We wanted to make sure immediate help would be given once people are aware that a person [with Alzheimer’s or dementia] is no longer under their eye,” says Wisconsin Rep. Ken Skowronski, the sponsor of the bill (AB 710) creating Silver Alert in his state.

“We had to make a law in order to have our Justice Department put that notice out and cover the area immediately, in order to make sure there was almost no harm that would come, especially during the inclement winter.”

Under the original language of AB 710, Silver Alert only would have applied to missing persons 65 or older. But that wording was changed to include an “adult at risk.” “We realized that people younger than age 65 could be afflicted with Alzheimer’s and dementia,” Skowronski says.

Wisconsin’s Silver Alert uses the state’s pre-existing Crime Alert Network to quickly broadcast information about missing at-risk adults; during the program’s first year, 49 Silver Alerts were issued, and all but five searches ended successfully.

In 2015, Illinois lawmakers strengthened their alert system (known as Silver Search) with passage of SB 1846. “In practice, law enforcement officers were getting calls and not knowing what to do,” says Illinois Sen. Daniel Biss, the bill’s author.

The new law requires training for law enforcement personnel as well as written guidelines for how to handle missing-person cases that qualify for the Silver Search (it applies to anyone 21 or older believed to have Alzheimer’s disease or other dementia). A statewide awareness program and toolkit for law enforcement will be developed by July 1.

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Attachment

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