



# Cognitive Impairment & Alzheimer's Disease

## Alzheimer's Legislative Champion Applies Experience with her Father

Former Missouri Rep. Lana Baker's life has been colored by Alzheimer's disease since she was in college. That is when her father first showed signs of the disease. Since her mother was deceased, Lana became her father's primary caregiver, even as she was starting a career and family.

For several years after his diagnosis, Baker's father was able to live in his own home with some assistance. But as years passed and his health deteriorated, Baker was forced to consider alternatives. Because of her father's violent outbursts, Baker was hesitant to allow him to move into the house where Baker lived with her small children. Finally, in 1988, six years after his diagnosis, Baker made the tough choice to have him placed in a nursing home.

"It was the most difficult thing I ever did," she recalled. "It was like completely taking away his independence."

Baker's father died in 1994, just months before she was elected to the Missouri House. Baker was already a volunteer with the Alzheimer's Association, and her new role as a legislator gave her an opportunity to become a key player in continued research funding and to become a champion for issues related to Alzheimer's and nursing home quality. "It became the focus of my goals of what I wanted to accomplish when I was in office," she said.

During her eight years in office, Baker won passage of special care unit disclosure requirements mandating facilities and programs tell the state and families what they are doing that merits that designation. She also pushed legislation to protect a couple's financial assets when one is receiving Medicaid home- and community-based services. She was unable to win approval for that measure, however, before Missouri term limits forced her out of office. It still has not become law.

"I wish I had been able to do more," Baker recalled.

Today, she works as a lobbyist in Missouri. Although the Alzheimer's Association is not one of her clients, Baker said she never hesitates to lobby informally for legislation that will help Alzheimer's patients and their families.



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## Talking Points

### ☑ Why Should State Legislators Be Concerned?

- Age is the single greatest risk factor for Alzheimer's disease. Unless something is done to delay the onset or to intervene, researchers predict as many as 16 million Americans will have Alzheimer's disease by 2050.
- In 2008, Alzheimer's disease surpassed diabetes to become the sixth leading cause of death among U.S. adults age 18 or older.<sup>1</sup>
- Most states do not have a comprehensive strategy or plan to address the impact of Alzheimer's disease or other forms of cognitive impairment on individuals, families and communities in their state.
- Approximately 5.2 million Americans have Alzheimer's disease. Another 10 million adults age 18 or older suffer from other cognitive impairments.

### ☑ Alzheimer's Disease and Cognitive Impairment: What is Known

- Cognitive impairment is not caused by any one disease or condition, nor is it limited to a specific age group. Alzheimer's disease, the most common form of dementia, as well other dementias and conditions such as stroke, traumatic brain injury and developmental disabilities can all cause cognitive impairment.
- These conditions also can impact a person's ability to think, to make decisions, to remember, to communicate and to live a purposeful life.
- Dementia and Alzheimer's disease do not automatically occur with aging.
- There is no known cure for Alzheimer's disease.
- Active medical management can improve the quality of life for individuals with dementia and their caregivers.
- A growing body of evidence suggests cognitive function may be maintained by preventing or controlling risk factors, such as high blood pressure, high cholesterol and diabetes. Additional evidence points to a significant connection between regular physical activity and maintaining cognitive function.



### ☑ What are the Costs of Cognitive Impairment and Alzheimer's Disease?

- In 2005, people with Alzheimer's disease or other dementias incurred \$21 billion in state and federal Medicaid costs and \$91 billion in Medicare costs to cover nursing home care.
- At any one time, 70 percent of people with Alzheimer's disease or other dementias live at home and are frequent users of home- and community-based services.<sup>3</sup>
- People with Alzheimer's disease or other dementias constitute 25 percent of older adult home care users and about 50 percent of adult day center, assisted living, and nursing home services users.<sup>2</sup>
- Nearly 10 million Americans provide unpaid care for a person with Alzheimer's disease or other dementia. In 2007, they provided 8.4 billion hours of unpaid care, which is a contribution valued at \$89 billion.<sup>3</sup>
- American businesses suffered \$36.5 billion in indirect losses from lost productivity, missed work, and replacement expense of employees who are unpaid caregivers.<sup>3</sup>

### ☑ What Can State Legislators Do?

- Support the collection of information needed to assess the impact of cognitive impairment on individuals, families and communities in your state.
- Encourage your state to examine and monitor its brain health status through the Centers for Disease Control and Prevention's Behavioral Risk Factor Surveillance System ([www.cdc.gov/brfss](http://www.cdc.gov/brfss)). States can use the survey results to support policy changes and initiatives to meet health-related goals and measure their success.
- Encourage your state to incorporate new state questions for the surveillance system in 2010 to assess the impact of cognitive impairment. ([www.cdc.gov/aging](http://www.cdc.gov/aging))
- Support creation of a legislative task force to study Alzheimer's disease, dementia and cognitive impairment in your state.
- Support developing and implementing a state plan of action to address Alzheimer's disease, dementia and cognitive impairment in your state.
- Support proposals to create or increase training on care of patients with dementia training for all paid direct and indirect care staff in all care settings to ensure services are dementia-capable.
- Encourage your state health agencies to develop practical tools to help identify the needs of family caregivers.
- Consider incorporating caregiver assessments as part of your state Medicaid program.
- Partner with state agencies and the Alzheimer's Association to educate legislative staff on how to respond to constituent concerns regarding Alzheimer's disease and other dementias.

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## State Legislative Actions

- ☑ Several states are creating Alzheimer's disease plans and advancing policy solutions to implement the state plan recommendations.
  - To review completed state plans, see Kentucky (<http://chfs.ky.gov/dail/alzheimerscouncil.htm>) and Iowa (<http://www.state.ia.us/elderaffairs/living/AlzheimersDiseaseTaskForce.html>).
  - Tennessee legislation created a state plan task force (2007 Tennessee Chapter No. 566, S.B.8.26), which is included in CSG's *Suggested State Legislation*, Volume 68.
  - Iowa passed legislation implementing some of its state plan recommendations. (2008 Iowa S.F. 2341)
  - Other states with plans include California, Colorado, Georgia, Illinois, Iowa, Kentucky, Louisiana, New York, North Dakota, Oklahoma, South Carolina and Vermont.
  
- ☑ States have mandated dementia training as part of orientation and continuing education for workers in a variety of care settings:
  - 2001 Missouri S.B. 449, included in excerpted form in CSG's *Suggested State Legislation*, Volume 67
  - 2003 Florida Chapter No. 271 (H.B. 1527)

## Resources

### Alzheimer's Association

- [www.alz.org](http://www.alz.org)

### Centers for Disease Control and Prevention, Healthy Aging Program

- [www.cdc.gov/aging](http://www.cdc.gov/aging)

### Alzheimer's Disease Demonstration Grants to States (ADDGS)

- ADDGS provides funding to 22 states to increase diagnostic and support services for people with Alzheimer's disease, their families and caregivers.
- [www.aoa.gov/press/for\\_the\\_press/pr/archive/2008/September/9\\_29\\_08.aspx](http://www.aoa.gov/press/for_the_press/pr/archive/2008/September/9_29_08.aspx)

### California Alzheimer's disease management guidelines

- [http://www.caalz.org/PDF\\_files/Guideline-OnePage-CA.pdf](http://www.caalz.org/PDF_files/Guideline-OnePage-CA.pdf)

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### References

<sup>1</sup>Centers for Disease Control and Prevention. 2008. Deaths: Preliminary Data for 2006. National Vital Statistics Reports 56(16). [www.cdc.gov/nchs/pressroom/08newsreleases/mortality2006.htm](http://www.cdc.gov/nchs/pressroom/08newsreleases/mortality2006.htm). Retrieved August 28, 2008.

<sup>2</sup>Alzheimer's Association and National Alliance for Caregiving. Families Care: Alzheimer's Caregiving in the United States, 2004. Accessible at [http://www.alz.org/national/documents/report\\_familiescare.pdf](http://www.alz.org/national/documents/report_familiescare.pdf)

<sup>3</sup>2008 Alzheimer's Disease Facts and Figures. [http://www.alz.org/national/documents/report\\_alzfactsfigures2008.pdf](http://www.alz.org/national/documents/report_alzfactsfigures2008.pdf)

For more detail see the **Keeping the Aging Population Healthy** policy brief and talking points by visiting <http://healthystates.csg.org/Publications>.

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