

Dementia-capable States and Communities: the Basics

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Introduction

Dementia, including Alzheimer's disease, touches almost everyone's life. People may have dementia or know or care for someone who has it. Others may fear getting it as they age. Many of us interact with people who have dementia or their families as we provide services, or meet them socially. We may not even know that a person has it.

If a person has some type of dementia, the person has a loss of brain function that leads to problems in at least two areas that are severe enough to affect daily life. For example, a person may have memory and language problems.

People with dementia experience losses over time, which may involve cognitive problems like difficulty with learning, thinking, and remembering. People also can have physical symptoms such as difficulty walking, talking, and eating. Some dementias involve troubling behavior changes. All of these problems interfere with their normal activities and relationships and generally get worse over time. The result is dependence on others.

Certain brain diseases and conditions cause dementia. Alzheimer's disease, which is progressive and fatal, is the most common form of dementia. Alzheimer's is only one type of dementia. A few causes of dementia are reversible, such as normal pressure hydrocephalus and cerebral vasculitis.¹ Symptoms of other conditions, such as depression, delirium, alcohol misuse, and brain tumors, can resemble dementia. So can the effects of certain drugs and medicine interactions.

As dementia progresses, people depend more on others for help with activities ranging from managing finances to the most personal tasks such as eating and bathing. At some point, people cannot manage their lives on their own. Caregivers, who are family or friends, generally help without pay out of a feeling of love or duty. Eventually, the demands of caring for someone with dementia may become more than caregivers can manage without help. Then, people with dementia and their families rely on paid caregivers in the home and community, or in institutions like nursing homes.

The Secretary of Health and Human Services (HHS) leads the *National Plan to Address Alzheimer's Disease*, which deals with many of these issues. The Plan provides a national strategy for strengthening research, medical care, and long-term services and supports for those living with dementia, including Alzheimer's disease. It contains actions for federal agencies, states, and communities related to dealing with the unique needs of people with dementia, and their families. The Plan, which the 2011 National Alzheimer's Project Act requires, has 5 goals:

1. Prevent and effectively treat Alzheimer's disease by 2025.
2. Optimize care quality and efficiency.
3. Expand supports for people with Alzheimer's disease and their families.
4. Enhance public awareness and engagement.
5. Track progress and drive improvement.

Using these goals as guidance, we discuss how states and communities can become *dementia-capable*, that is, able to help people with dementia and their caregivers. To show how this can be done, we provide examples from the United States and some other countries. We begin by explaining why dementia-capability is so important for families, their communities, states, and the nation.

The Impact of Dementia

Individuals, their families, communities, and states face a number of challenges in dealing with dementia. These include the impact of the diseases that cause dementia on individuals and families, the number of people with the condition, and the cost of care.

While dementia results from the loss of brain cells and the connections among cells, symptoms can vary by type of dementia. For example, in frontotemporal disorders, dementia symptoms can include changes in personality, behavior, language, and movement. Symptoms in the early stages of Alzheimer's disease include a declining memory and difficulty managing finances and health care. People with Alzheimer's may also have behavioral symptoms,² such as agitation and depression. Wandering away from home is a common and serious safety issue. As dementia progresses, people typically need help with bathing, dressing, eating, and other basic daily activities. In the final stages of dementia, people can barely communicate, fail to recognize family members, and need constant care. Given these losses, it is surprising that among people 71 years and older, 17 percent of people with severe dementia and 25 percent of people with moderate dementia live alone.³

In addition to relying more on family, people with dementia can lose their savings when they lose their jobs or need to pay for additional services. Another risk is that people with dementia are vulnerable to elder abuse, including financial exploitation. As a result, many people end up relying on Medicaid and other public programs to help finance their services and supports.

As dementia progresses, caregivers can experience more stress as they provide more services and supports, such as supervision and personal care.⁴ Caring for people with dementia is particularly difficult because of the way it affects abilities and behavior. Caregivers of people with dementia are more likely than caregivers of other older people to help with all daily activities, including getting out of bed, using the toilet and eating.⁵ The resulting strain causes many caregivers to have high levels of stress, become depressed, and have financial worries. These worries may come from time lost at work or even job loss as caregiving time increases.^{6 7}

Estimates of the number of people with dementia vary, but studies suggest that as many as 5 million Americans 65 years and older and about 200,000 individuals under age 65 may have the disease.⁸ Since age is a major risk factor for dementia, researchers expect that the number of people with the condition will grow as the U.S. population ages. States that use the cognitive impairment module of the Behavioral Risk Factor Surveillance System (BRFSS) from the Centers for Disease Control and Prevention can develop their own estimates of the number of people with cognitive disabilities. Information about the BRFSS can be found at: <http://www.cdc.gov/aging/healthybrain/surveillance.htm>.

Estimates of the number of caregivers for people with dementia vary. An analysis of the 2011 National Health and Aging Trends Survey of Medicare beneficiaries 65 years and older shows that 5.8 million caregivers are helping people who probably have dementia.⁹ The number of caregivers of people with dementia is also likely to grow with the aging of the population.

Use of Medical and Long-term Services and Supports

Dementia complicates managing medical care. Those with the condition often have other chronic diseases, such as heart disease, diabetes, and arthritis¹⁰ and are more likely to have them compared to those without dementia.¹¹ Cognitive problems can lead to poor management of other diseases and increased risk of falls.^{12 13} For example, on average, people with dementia have three times as many hospital stays and three times the average Medicare expenditure of other older people.¹⁴ Recent studies of coordinated care designed to help people with cognitive disability and their caregivers move from medical settings to home appear to better meet their needs than usual care.¹⁵

Many people who need long-term services and supports (LTSS) have cognitive problems, which often come from dementia. Fifteen percent of older adults living in the community with at least one limitation in a daily activity have a cognitive disability and the percentage increases with severity of disability.¹⁶ As a result, people with dementia form a large percentage of people using LTSS. Over 40 percent of nursing home residents have a diagnosis of dementia; most often they have Alzheimer's disease.¹⁷ The percentage is higher among nursing home residents who are eligible for both Medicare and Medicaid. Not surprisingly, people with cognitive disabilities are high users of home and community services. Approximately 24 percent of people of all ages who receive Medicare or Medicaid-funded home health care have moderate to severe cognitive disability.¹⁸ Similarly, more than a quarter of Medicare-Medicaid dual eligibles who receive home and community-based services through Medicaid waiver programs have Alzheimer's disease or other types of dementia.¹⁹

The large number of people with dementia makes it a costly condition for individuals, families, and the nation. Researchers estimate that dementia care for people 70 years and older in the U.S. cost between \$159 billion and \$215 billion in 2010, depending on how informal care costs are calculated.²⁰ Costs stem from supports and services, and from loss of paid employment for caregivers, among other causes. Costs would be even higher if people under age 70 were included in these estimates.

State and Community Dementia-Capability

States and communities have many people at risk of or living with dementia. They live alone or with family and they use all service systems, public and private. People with dementia rely on their families and faith communities, grocery stores and banks, and medical, health, and LTSS, among other services. The long, slow progress of most dementias means that the needs of people with the condition and their caregivers change and become more intense over time.

Below we describe a model dementia-capable system. Given the impact of the condition on people and communities, service systems that wish to be dementia-capable should consider adopting key aspects of the model that apply to their mission. We developed this model based on two sets of information: research on dementia progression and supportive services, and an evaluation of Administration for Community Living (ACL) grantee experience in developing dementia-capable systems.

A model system would:

1. Educate the public about brain health. This would include information about the risk factors associated with developing dementia, first signs of cognitive problems,

management of symptoms if individuals have dementia, support programs, and opportunities to participate in research.

2. Identify people with possible dementia and recommend that they see a physician for a timely, accurate diagnosis and to rule out reversible causes of dementia or conditions that resemble it.
3. Ensure that program eligibility and resource allocation take into account the impact of cognitive disabilities.
4. Ensure that staff communicate effectively with people with dementia and their caregivers and provide services that:
 - a) Are person- and family-centered
 - b) Offer self-direction of services
 - c) Are culturally appropriate
5. Educate workers to identify possible dementia, and understand the symptoms of dementia and appropriate services.
6. Implement quality assurance systems that measure how effectively providers serve people with dementia and their caregivers.
7. Encourage development of dementia-friendly communities, which include key parts of dementia-capability.