

CDC BRIEF

Addressing Stigma Associated with Alzheimer's Disease And Other Dementias: *Role of the Public Health and Aging Services Networks*

The Centers for Disease Control and Prevention (CDC) and the Alzheimer's Association have developed *The Healthy Brain Initiative: The Public Health Road Map for State and National Partnerships, 2013-2018*. This Road Map proposes 35 actions to increase the quality of life for people with cognitive impairment. Two action items in the "Educate and Empower the Nation" area are:

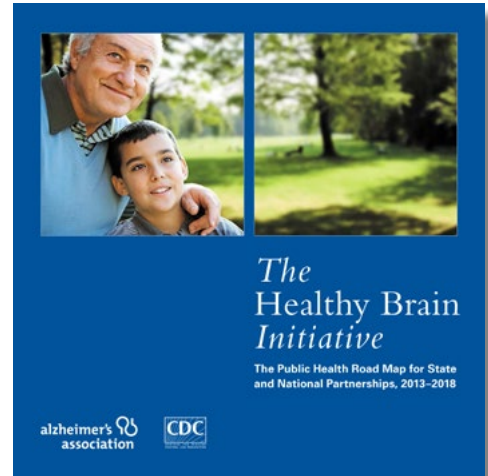
E-01. Identify and promote culturally appropriate strategies designed to increase public awareness about dementia, including Alzheimer's disease, to reduce conflicting messages, decrease stigma, and promote early diagnosis.

E-06. Identify and promote strategies for the public about how to communicate effectively and sensitively with people suffering from dementia, including Alzheimer's disease, and their families.

Also reflecting the need to address stigma, the 2014 Update to the *National Plan to Address Alzheimer's Disease* stated "Stigmas and misconceptions associated with Alzheimer's disease are widespread and profoundly impact the care provided to and the isolation felt by people with Alzheimer's disease and their families." The *2012 World Alzheimer Report* raised the importance of this issue by noting that "People with dementia are often isolated, or hidden, because of stigma or the possibility of negative reactions from neighbors and relatives to behavioral and psychological symptoms. The idea that nothing can be done to help people with dementia often leads to hopelessness and frustration."

*It is hard to describe, it is so subtle, the sense of being different.
Nuanced, subtle stigma. Anything makes you feel different.*

As with cancer and HIV, fear and stigma associated with Alzheimer's disease or related dementias may cause individuals to delay seeking a diagnosis and care. *The National Plan to Address Alzheimer's Disease* notes "Stigma associated with the diagnostic labels of dementia and mild cognitive impairment (MCI) can have a significant and negative impact on interpersonal relationships, interactions with the health care community, attitudes about service utilization, and participation in clinical research. The impact of stigma also extends to the family caregivers of individuals bearing such labels." Stigma may be even more profound for those who develop what is referred to as "younger onset" Alzheimer's disease (onset before the age of 65).



Stigma around Alzheimer's disease exists in part because of the lack of public awareness and understanding of the condition. Stigma may add to the burden of Alzheimer's disease as it can prevent individuals and their families from

- Talking with a health care provider when symptoms are present.
- Receiving an early diagnosis or any diagnosis.
- Benefitting from available treatments.
- Developing a support system.
- Living life to the fullest extent possible.
- Ensuring plans are in place for financial matters.
- Planning for future care, including plans for medical care, long-term care, and end-of-life care.
- Participating in research such as clinical trials.

You're stigmatized by your family. You're looked at differently. Friends provide stigma. My brother has just checked out. There's a lens that focuses immediately on you. I can feel it. It is the little things that affect you the most, at least at this stage. You're not driving so you have been accommodated.

Professionals in the public health and aging services networks can play important roles in reducing fear and stigma surrounding Alzheimer's disease. Among these roles are to

- Encourage individuals and their family members to talk with their health care provider about any concerns related to increased memory loss or confusion.
- In settings such as senior centers and adult day care programs, promote opportunities for individuals with Alzheimer's disease to stay as engaged and productive as possible, with an emphasis on their abilities, rather than on what they can no longer do.
- Consider their own thoughts and feelings about Alzheimer's disease and how their own fears or biases may influence their provision of care and services to people with Alzheimer's disease or their family members.
- Support and facilitate opportunities to enhance the public's knowledge and understanding of Alzheimer's disease (e.g., education sessions in public settings such as schools, libraries, community centers). To the extent possible, include individuals with Alzheimer's disease and their caregivers in speaking to the public about the disease, their experiences, and the impact of stigma.
- Promote incorporation of the principles of "wayfinding" into community settings. Wayfinding is the process whereby people use environmental information to locate and find their way within familiar and unfamiliar settings. Strategies based on wayfinding principles may assist individuals in navigating outdoor spaces and settings such as shopping venues, recreational areas, and office buildings.
- Include individuals with Alzheimer's disease and their family members in the planning and development of state and community policies, practices, and programs that affect individuals with dementia.

Millions of Americans and their family members are affected by Alzheimer's disease and related dementias and the impact will only grow as the US population ages. Scientific knowledge related to the causation and prevention of Alzheimer's disease is progressing, but is much less further along than for many other diseases such as cancer, cardiovascular disease, and diabetes.

While the science base is being built, public health and aging services professionals can be on the forefront in educating the public about Alzheimer's disease; facilitating conversations between individuals with Alzheimer's disease, their family members, and their health care providers; ensuring that the voices of individuals with Alzheimer's disease are part of community conversations; and helping to ensure that individuals with Alzheimer's disease are accorded the respect, dignity, and consideration that each of us wants and deserves.

The National Alzheimer's Project Act, passed unanimously by Congress and signed into law in 2011, called for the creation of a national strategic plan to address the challenges facing people with Alzheimer's disease and their families. Released in 2012, the National Alzheimer's Plan

- Recognizes Alzheimer's disease as a major public health issue.
- Provides a blueprint for coordinating Alzheimer's disease efforts across the federal government.
- Outlines concrete goals, strategies, and actions to help eliminate the burden of Alzheimer's disease for the American public.

In 2012, Alzheimer's Disease International conducted an anonymous online survey of people with dementia and family or informal care givers about their experiences of stigma. More than 2,500 individuals from 54 countries responded.

People living with dementia were asked the following. "In your opinion, do you think there are negative associations (i.e., stigma) about people who have dementia in the country where you live?" More than 75% of the respondents with dementia said "yes" and 42 people identified negative examples about people with dementia in their country. The most common negative association was the feeling of being discounted or marginalized by others (28%). The lack of understanding of what to do when having a conversation with a person with dementia or how to involve the person more was also a common theme (24%).

Citation: Nicole L Batsch, Mary S Mittelman. *World Alzheimer Report 2012. Overcoming the Stigma of Dementia*. Alzheimer's Disease International (ADI), London; 2012. Accessed May 5, 2015.

Resources

[Centers for Disease Control and Prevention \(CDC\)—Healthy Brain Initiative](#)

CDC's Healthy Brain Initiative provides national leadership for public health efforts to promote cognitive health, address cognitive impairment for individuals living in the community, and help meet the needs of caregivers by supporting states and communities and other partners.

[Administration for Community Living \(ACL\)](#)

ACL provides information for those who care for people with Alzheimer's disease and related dementias. Links are available to authoritative, [up-to-date information](#) from agencies and organizations with expertise in treatment options, planning, caring for someone, and addressing the challenges of Alzheimer's disease.

[Alzheimer's Disease Education and Referral Center](#) of the [National Institute on Aging](#)

The Alzheimer's Disease Education and Referral Center (ADEAR), a part of the National Institute on Aging at the National Institutes of Health, provides information on Alzheimer's disease to the general public, to individuals with the disease and their families, and to health professionals.

[Alzheimer's Association](#)

The Alzheimer's Association advances research to end Alzheimer's disease and dementia while enhancing care for those living with the disease.

[National Plan to Address Alzheimer's Disease —2014 Update](#)

First released in 2012, the National Plan to Address Alzheimer's Disease established the National Alzheimer's Project to address the many challenges facing people with Alzheimer's disease and their families. The 2014 Update of the Plan indicates "stigma and misconceptions associated with Alzheimer's disease" are among the five major challenges presented by the disease.

[Dementia: A Public Health Priority](#)

Developed by the World Health Organization (WHO) and Alzheimer's Disease International, this report is designed promote and advocate for action at international and national levels.

[World Alzheimer Report 2012: Overcoming the Stigma of Dementia](#)

Released by Alzheimer's Disease International, this report highlights the impact of stigma on individuals with Alzheimer's disease and calls for action to improve the understanding of dementia to reduce stigma.