WORLD ALZHEIMER REPORT REVEALS NEGATIVE PERCEPTIONS ABOUT PEOPLE WITH DEMENTIA

Alzheimer’s Association® Early-Stage Advisors Unveil Tips for Facing Stigma

CHICAGO, September 20, 2012 – Seventy-five (75) percent of people with dementia and 64 percent of caregivers believe there are negative associations for those diagnosed with dementia in their countries, according to survey fielded by Alzheimer’s Disease International and published today in the World Alzheimer Report 2012: Overcoming the Stigma of Dementia. The report was released on Alzheimer’s Action Day as part of World Alzheimer’s Month activities engaging people in the cause and raising awareness about the disease.

In response, Alzheimer’s Association® Early-Stage Advisors, men and women from across the U.S. living with the disease, and their caregivers developed tips on how to cope with the stigma surrounding Alzheimer’s based on their personal experiences.

“The Report reveals that people with dementia and their care partners often feel disconnected from society, and sometimes even by their own friends and family members,” said Beth Kallmyer, MSW, vice president of constituent services at the Alzheimer’s Association. “The misconceptions and stigma create unnecessary barriers to progress such as improving care and support services and increasing funding for research.”

In the current Report, nearly one in four people with dementia (24 percent) who responded to the survey said they hid or concealed their diagnosis, citing stigma as the main reason. They expressed concerns that their thoughts and opinions would be “discounted and dismissed,” and that they would be “treated more positively” if they did not reveal their diagnosis.

The authors noted that, social exclusion was a “major theme” with 40 percent of people with dementia in the survey reporting they have been avoided or treated differently because of their dementia. Respondents said their friends and family “say they don’t know how to behave ‘normally’ around me anymore,” and many have “drifted away.”

A survey respondent with dementia from the U.S. said: “It's very interesting to see how people close to me act. It's almost as if they are afraid of bringing up the subject. Being a cancer survivor, I know that I was constantly asked how I was doing while I was going through treatment. With Alzheimer’s, no one asks.”

The report found that when people with dementia are able to make new connections, it is often with people in similar circumstances. Sixty-six (66) percent of survey respondents who have dementia said that they have made friends who are connected to dementia, often finding each other through community-based support groups, online chat or bulletin boards, or through Alzheimer associations.
“People with dementia, especially in the early and middle stages, can take part in many everyday activities. They have the same needs as everyone else for social interaction and engagement in meaningful activities, even in the later stages of the disease. We encourage people living with Alzheimer’s or another dementia to be involved in making decisions that affect them for as long as they can, to help maintain their autonomy, dignity and self-esteem,” Kallmyer said.

Facing Stigma
In response to the Report and to honor of World Alzheimer’s Month, the Alzheimer’s Association is unveiling tips for coping with stigma created by people living with the disease. Current and former members of the Alzheimer’s Association National Early-Stage Advisory Group developed these tips based on their personal experiences:

- **Be open and direct.** Engage others in discussions about Alzheimer’s disease and the need for prevention, better treatment and an eventual cure.
- **Communicate the facts.** Sharing accurate information is key to dispelling misconceptions about the disease. Whether a pamphlet or link to online content, offer information to help people better understand Alzheimer’s disease.
- **Seek support and stay connected.** It is important to stay engaged in meaningful relationships and activities. Whether family, friends or a support group, a network is critical.
- **Don’t be discouraged.** Denial of the disease by others is not reflection of you. If people think that Alzheimer’s disease is normal aging, see it as an education opportunity.
- **Be a part of the solution.** Advocate for yourself and millions of others by speaking out and raising awareness.

The Alzheimer’s Association also recently launched ALZConnected (www.alzconnected.org), a social networking community designed specifically for people with Alzheimer’s disease and caregivers. After becoming a member (at no cost), ALZConnected users can connect and communicate with people who understand their challenges, pose questions and offer solutions to dementia-related issues and create public and private groups organized around a dedicated topic.

The Report released today includes 10 recommendations to enable governments and societies to tackle stigma, including encouraging greater public education. Nearly half of the survey respondents pointed to increasing education and raising awareness about Alzheimer’s and dementia as a much-needed, high priority action. Other recommendations are to provide more opportunities for people with dementia to share their experiences and ensure that they are included in everyday activities.

In addition to the survey results, the World Alzheimer Report 2012 includes essays by people with dementia, care and social science researchers, and legislators, and multiple examples of “best practice” programs from around the world, including:

- Alzheimer's Association National Early-Stage Advisory Group  
  [http://www.alz.org/about_us_early_stage_advisory_group.asp](http://www.alz.org/about_us_early_stage_advisory_group.asp)
- **Know The 10 Signs:** Early Detection Matters  
  [http://www.alz.org/Alzheimers_Disease_Know_the_10_Signs.asp](http://www.alz.org/Alzheimers_Disease_Know_the_10_Signs.asp)

**World Alzheimer’s Month 2012**
September is World Alzheimer’s Month, and the Alzheimer’s Association is encouraging everyone to “Go Purple.” Visit [www.alz.org/WAM](http://www.alz.org/WAM) to learn ways to “Go Purple,” including:
• Wear purple on Alzheimer’s Action Day, Friday, Sept. 21. Purple t-shirts, hooded sweatshirts and a limited-edition CJ Free bracelet benefiting the Alzheimer’s Association are available.
• Turn Facebook purple using an END ALZ graphic as your profile picture.

To learn more about Alzheimer’s disease and overcoming stigma, call 1-800-272-3900 or visit www.alz.org/WAM.

More about the ADI World Alzheimer Report Survey
ADI states, “the World Alzheimer Report 2012: Overcoming the Stigma of Dementia shares results from a worldwide survey conducted with people with dementia and [caregivers] on their personal experiences of stigma.” The anonymous online survey was conducted in June 2012 and completed by more than 2,500 people with dementia and caregivers from 78 countries. 2,068 responded in English; 519 responded to versions of the survey in Spanish (282), Greek (94) and Chinese (143).

According to ADI, of the 127 (6%) of respondents with dementia in the English language survey, most reported that diagnosis (or discovery of dementia) had occurred within the last five years (51%). Sixty-one percent (71) of respondents indicated they were female and 39% (46) male. Diagnoses included Alzheimer’s disease (55%), vascular dementia (12%), mild cognitive impairment (10%), and fronto-temporal dementia (7%). The largest group of respondents with dementia indicated they were between 63 and 72 years of age, with a little over half of the participants (56%) being at or over age 65. Individuals with dementia responded from 13 countries including Australia, Canada, Finland, United Kingdom and the United States, with the U.S. having the most at 55%.

ADI acknowledges that the survey respondents were not a representative sample noting, “results from the survey indicate that a majority of participants completed secondary education or above with nearly 50% of participants in the English, Chinese and Greek surveys completing college or graduate school. This indicates that survey respondents are a select group of people with dementia and informal carers with a mostly high level of education. In addition, over half of respondents in all four surveys also participate in programmes with Alzheimer’s organisations, societies, support groups or day centres.”

ADI, an international federation of 78 Alzheimer associations around the world, including the Alzheimer’s Association (U.S.), has produced an annual World Alzheimer Report since 2009, previously covering topics including global dementia prevalence and global cost of dementia care.

Alzheimer’s Association
The Alzheimer’s Association is the world’s leading voluntary health organization in Alzheimer care, support and research. Our mission is to eliminate Alzheimer’s disease through the advancement of research, to provide and enhance care and support for all affected, and to reduce the risk of dementia through the promotion of brain health. Our vision is a world without Alzheimer’s. Visit www.alz.org or call 800-272-3900.

# # #