Early Diagnosis: The Value of Knowing

Americans view Alzheimer’s as a major health threat.

- Alzheimer’s disease is the second most feared disease – behind only cancer. Nearly 22 percent of Americans rate Alzheimer’s as the disease they are most afraid of getting.

- This fear is even prevalent among younger adults. More than one in seven Americans aged 18-34 fear getting Alzheimer’s more than any other disease. And one in 10 Americans in this younger age group are very worried that they will get Alzheimer’s themselves.

- Nearly three-quarters of Americans know or have known someone with Alzheimer’s; 42 percent of Americans have or have had a family member with the disease.

Most Americans want to know if they have Alzheimer’s disease.

- Nearly 89 percent of Americans say that if they were exhibiting confusion and memory loss, they would want to know if the cause of the symptoms was Alzheimer’s disease.

- Of those aged 60 and over, 95 percent say they would want to know.

- Over 97 percent say that if they had a family member exhibiting problems with memory loss, they would want them to see a doctor to determine if the cause was Alzheimer’s.

But, half or more of Americans with Alzheimer’s do not know they have the disease.

- The convergence of evidence from numerous sources indicates that as many as half of people with dementia have never received a diagnosis.

- Some evidence suggests that it could be more than 50 percent.

Poll data come from a survey of public perceptions and awareness of Alzheimer’s disease conducted by the Harvard School of Public Health. The poll was commissioned by Alzheimer Europe through a grant provided by Bayer.
An early and documented diagnosis leads to better outcomes for individuals with Alzheimer’s and their caregivers.

- A formal diagnosis allows individuals and their caregivers to have access to available treatments, build a care team, participate in support services and enroll in clinical trials.

- Participating in planning early in the disease process allows individuals with Alzheimer’s to create advance directives regarding their care and finances – so that their wishes can be carried out when they are no longer cognitively able to make such decisions.

- Early diagnosis also allows individuals with the disease and their caregivers to better manage medications, receive counseling, and address driving and safety issues in advance.

- Undertaking the diagnostic process early potentially allows cognitive impairment to be reversed in some people. Research suggests that the cognitive impairment in 9 percent of individuals experiencing dementia-like symptoms is due to a potentially reversible cause, such as depression or a vitamin B12 deficiency.

Federal legislation – the HOPE for Alzheimer’s Act (S. 709 / H.R. 1507) – would increase the diagnosis of Alzheimer’s, thereby closing the gap between those who want to know they have the disease and those who actually do know. Consistent with the recommendations of the National Plan to Address Alzheimer’s Disease, the bill would:

- Provide Medicare coverage for a package of services, including:
  - clinical diagnosis of Alzheimer’s disease;
  - care planning to provide those with the disease and their caregivers information about medical and non-medical options for treatment and support services.

- Require documentation of the diagnostic evaluation and any care planning provided in an individual’s primary medical record.