



the compassion to care, the leadership to conquer

CONTACT:

Erin Heintz
312-355-5796
Erin.Heintz@alz.org

**NEW STATEMENT TO MEDICAL COMMUNITY DEMANDS A
DIGNIFIED DIAGNOSIS OF DEMENTIA**

*Principles for a Dignified Diagnosis are First Statement of its Kind Written by
People with Alzheimer's Disease*

(CHICAGO) February 12, 2009 – In recognition of the changing landscape of Alzheimer's, the Alzheimer's Association hosted four regional town hall meetings with more than 800 participants, including 300 people living with the disease. The 2008 report *Voices of Alzheimer's Disease* examined the rich dialogue at these town halls and identified diagnostic challenges and dissatisfying interactions with the medical community as two major challenges articulated by people living with the disease. The new, innovative *Principles for a Dignified Diagnosis* are insights from people living with the disease on how to improve that experience.

"Patients with Alzheimer's disease face many challenges as they strive to maintain a normal life, and physicians are committed to helping ease the burden with high quality health care," said American Medical Association President Nancy Nielsen, M.D. "The AMA applauds the Alzheimer's Association for bringing forward the patients' perspective on compassionate care, as Alzheimer's patients, their families and their physicians battle the disease together."

Dr. Steve Hume, a member of the Alzheimer's Association Early Stage Advisory Group and a co-author of the *Principles for a Dignified Diagnosis*, was diagnosed with younger-onset Alzheimer's disease in May of 2007 at the age of 61. Prior to his diagnosis, Steve was a clinician, consultant and senior manager in the behavioral health field. Despite his professional health background, Steve struggled to secure a complete diagnosis. In fact, the first neurologist he visited told him he'd be fine if he just lost weight.

"The face of Alzheimer's has changed in recent years and the *Principles for a Dignified Diagnosis* adds a voice to that face," said Dr. Hume. "It is important that we not only tell clinicians we want a dignified diagnosis, but also teach them what that means. There is a lot we can learn from each other."

The *Principles for a Dignified Diagnosis* include the following:

- **Talk to me directly, the person with dementia.** I am the person with the disease, and though my loved ones will also be affected, I am the person who needs to know first.

- **Tell the truth.** Even if you don't have all the answers, be honest about what you do know and why you believe it to be so.
- **Test early.** Helping me get an accurate diagnosis as soon as possible gives me more time to cope and live to my fullest potential and to get information about appropriate clinical trials.
- **Take my concerns seriously, regardless of my age.** Age may be the biggest risk factor for Alzheimer's, but Alzheimer's is not a normal part of aging. Don't discount my concerns because I am old. At the same time, don't forget that Alzheimer's can also affect people in their 40s, 50s and 60s.
- **Deliver the news in plain but sensitive language.** This may be one of the most important things I ever hear. Please use language that I can understand and is sensitive to how this may make me feel.
- **Coordinate with other care providers.** I may be seeing more than one specialist — it is important that you talk to my other providers to ensure you all have the information so that changes can be identified early on and that I don't have to unnecessarily repeat any tests.
- **Explain the purpose of different tests and what you hope to learn.** Testing can be very physically and emotionally challenging. It would help me to know what the purpose of the test is, how long it will take and what you expect to learn from the process. I would also appreciate the option of breaks during longer tests and an opportunity to ask questions.
- **Give me tools for living with this disease.** Please don't give me my diagnosis and then leave me alone to confront it. I need to know what will happen to me, and I need to know not only about medical treatment options but also what support is available through the Alzheimer's Association and other resources in my community.
- **Work with me on a plan for healthy living.** Medication may help modify some of my neurological symptoms, but I am also interested in other recommendations for keeping myself as healthy as possible through diet, exercise and social engagement.
- **Recognize that I am an individual and the way I experience this disease is unique.** This disease affects each person in different ways and at a different pace. Please be sure to couch your explanation of how this disease may change my life with this in mind.
- **Alzheimer's is a journey, not a destination.** Treatment doesn't end with the writing of a prescription. Please continue to be an advocate — not just for my medical care but for my quality of life as I continue to live with Alzheimer's.

“The *Principles for a Dignified Diagnosis* will build greater understanding of Alzheimer’s disease in the medical community,” said Dr. Laurel Coleman, Alzheimer’s Association national board member. “Since Alzheimer’s is a progressive brain disease, the physical, emotional and social implications of the diagnosis need to be considered throughout the journey.”

For more information on the *Principles for a Dignified Diagnosis* or Alzheimer’s disease, visit www.alz.org.

The Alzheimer’s Association

The Alzheimer’s Association is the 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. For more information, visit www.alz.org.

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