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ALZHEIMER'S ASSOCIATION RELEASES DEMENTIA CARE PRACTICE RECOMMENDATIONS FOR END-OF-LIFE CARE

- New Document Captures Consensus of More than 30 National Care Organizations -

CHICAGO, Tuesday, August 28, 2007 – The Alzheimer's Association today released its third set of *Dementia Care Practice Recommendations for Assisted Living Residences and Nursing Homes*. The Recommendations focus on improving the end of life experience for people with Alzheimer's and other dementias by offering concrete suggestions for addressing issues unique to people with dementia at the end of life.

The Recommendations were released at the Alzheimer's Association's 15th annual Dementia Care Conference, held in Chicago.

More than 50 percent of residents in assisted living and nursing homes have some form of dementia or cognitive impairment, including Alzheimer's. Available research indicates that about 67 percent of dementia-related deaths occur in nursing homes. The number of people with Alzheimer's is projected to sharply increase from more than 5 million today to as many as 16 million by 2050, as the 78 million Baby Boomers mature and reach the age of highest risk.

“Underlying the end-of-life care practice recommendations is a person-centered approach to dementia care, which involves tailoring care to the abilities and changing needs of each resident,” said Peter Reed, PhD, Senior Director of Programs for the Alzheimer's Association.

The recommended care practices for end-of-life cover:

- Communication and decision-making strategies, including residents and family members.
- Assessment and care of behavioral and physical symptoms, including pain.
- Psychosocial and spiritual support of residents and family.
- Care provision, coordination and communication when residents choose hospice services.
- Acknowledgment of resident death and bereavement services.
- Staff training.

Key aspects of the wide ranging report include:

- The need for advance planning for end of life as soon as possible after diagnosis of dementia. This includes documenting the person’s wishes regarding medical treatments in advanced stages of dementia and designation of a proxy decision-maker.
- Provision of person-centered palliative care to people with advanced dementia. Care should follow residents’ wishes regarding end of life as closely as possible.
- The importance of dementia-specific training for residential care workers on end of life issues – for example, signs of dying, pain management issues, and communicating with families.

The recommendations emphasize the importance of consistency in individualized and person-centered care approaches; development of relationships between staff and residents; and increasing staff knowledge of individual resident needs, abilities and preferences.

“Our highly collaborative, consensus-based process ensures that the Recommendations represent the best dementia care practices and, at the same time, are practical so that nursing homes and assisted living residences can incorporate them into the daily care routines of their residents,” said Jane Tilly, DrPH, Director of Quality Care Advocacy for the Alzheimer’s Association.

Two primary sources of research evidence were used to develop the Phase 3 Recommendations on end-of-life care. An Association-sponsored literature review, *End-of-life Care for People with Dementia in Residential Care Settings*, by Ladislav Volicer, MD, PhD, summarizes current peer-reviewed research relevant to end-of-life care for residents with severe dementia. To extend the knowledge gained through this literature review, Dr. Tilly, with Abel Fok, wrote *Quality End-of-life Care for Individuals with Dementia in Assisted Living and Nursing Homes and Public Policy Barriers to Delivering This Care*, which describes what practitioners, providers, professionals and researchers believe constitutes high quality end-of-life care for residents with dementia.

Dementia care experts and professional staff from the Alzheimer’s Association, representatives of more than 30 national associations and other experts used the evidence in a consensus-building process to translate the research into specific suggestions illustrated by “real world” examples based on the experience of the contributors.

To support implementation of the Recommendations and help ensure that staff is adequately trained, the Alzheimer’s Association is developing classroom-style and online training programs based on the recommendations for all levels of care staff in assisted living residences and nursing homes. The Association is also advocating with direct care providers and working with federal and state policy makers to incorporate the recommendations into their quality assurance systems.

Alzheimer’s Association Quality Care Campaign

In 2005, the Alzheimer’s Association launched its Quality Care Campaign to improve the quality of care for residents with dementia in assisted living and nursing homes. To better respond to residents’ needs, the Association joined with leaders in dementia care to develop the evidence-based Dementia Care Practice Recommendations for Assisted Living Residences and Nursing Homes. Phase 1 of the recommendations focuses on the basics of good dementia care, food and fluid consumption, pain management and social engagement. Phase 2 covers wandering, falls and physical restraints. Now, Phase 3 covers end-of-life care practices and issues.

All aspects of the Quality Care Campaign are based on the best available evidence on effective dementia care in residential settings. To date, more than 30 leading health and senior care organizations have expressed their support and acceptance of one or more phases of the Dementia Care Practice Recommendations.

Alzheimer's Association

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

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**Organizations Supporting the Alzheimer’s Association, Quality Care Campaign,
Dementia Care Practice Recommendations, Phase 3**

- AARP
- American Academy of Hospice and Palliative Medicine
- American Assisted Living Nurses Association
- American Association for Geriatric Psychiatry
- American Association of Homes and Services for the Aging
- American Association of Nurse Assessment Coordinators
- American College of Health Care Administrators
- American Dietetic Association
- American Health Care Association
- American Medical Directors Association
- American Occupational Therapy Association
- American Pain Foundation
- American Physical Therapy Association
- American Seniors Housing Association
- American Society of Consultant Pharmacists
- American Therapeutic Recreation Association
- Assisted Living Federation of America
- Catholic Health Association of the United States
- Consumer Consortium on Assisted Living
- Hospice and Palliative Nurses Association
- National Association of Activity Professionals
- National Association of Directors of Nursing Administration/Long Term Care
- National Association of Social Workers
- National Center for Assisted Living
- National Citizens’ Coalition for Nursing Home Reform
- National Conference of Gerontological Nurse Practitioners
- National Gerontological Nursing Association
- National Hospice and Palliative Care Organization
- Paralyzed Veterans of America
- Service Employees International Union
- Supportive Care Coalition
- The American Speech Language Hearing Association accepts the recommendations.
- The American Bar Association’s Commission on Law and Aging and the American Health Lawyers Association provided invaluable legal expertise during the development of the Alzheimer’s Association practice recommendations on end-of-life care for residents with dementia.

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