



**Statement of  
THE ALZHEIMER'S ASSOCIATION**

**for the record**

**To  
COMMITTEE ON VETERANS AFFAIRS  
SUBCOMMITTEE ON HEALTH  
UNITED STATES HOUSE OF REPRESENTATIVES**

**May 22, 2003**

**“Oversight Hearing on Long-Term Care Programs in VA”**

Mr. Chairman and members of the Committee:

The Alzheimer's Association appreciates the opportunity to submit the following statement to the Committee on Veterans Affairs for the Oversight Hearing on Long-Term Care Programs in VA.

The Alzheimer's Association, a national network of chapters, is the largest national voluntary health organization dedicated to advancing Alzheimer's research and helping those affected by the disease. Having awarded \$136 million in research grants, the Association ranks as the top private funder of research into the causes, treatments, and prevention of Alzheimer's disease. The Association also provides education and support for people diagnosed with the condition, their families, and caregivers.

The purpose of our comments is to describe a successful, ongoing collaboration of the VA and the Alzheimer's Association. This collaboration began in 1997, when the Veterans Integrated Service Network in upstate New York (VISN 2) and four Alzheimer's Association chapters in the same geographic area applied and were selected to participate in Chronic Care Networks for Alzheimer's Disease (CCN/AD), a national demonstration project to improve care for people with Alzheimer's disease and other dementias. For more than five years now, VISN 2 and Alzheimer's Association chapter staff have worked together to create and implement the CCN/AD model of dementia care, with a particular focus on coordinating the medical and long-term care services available to veterans through the VA and supportive community services available to them through the chapters. Preliminary findings from an extensive evaluation show positive outcomes for the veterans and their family caregivers and enthusiastic responses from VA staff members who have been involved in the project.

Data collection for evaluation of the CCN/AD demonstration project ended in November 2002, but the close working relationship between the VA and the Alzheimer's Association continues in VISN 2. In addition, we are now finalizing a proposal for a project to implement the same model of care in other VA sites across the country. In this replication project, we will be using a more rigorous research design that will allow us to compare use of VA services, cost of care, and other outcomes for veterans with Alzheimer's disease and other dementias who are served through this model versus usual care. We will be seeking funding from the VA, other government agencies, and private foundations for the replication project.

### **Profile of VISN 2**

VISN 2 is an integrated health care delivery system composed of inpatient facilities, nursing homes, community clinics, and non-institutional long-term care programs and services provided through contracts and community agency referrals. VISN 2 provides acute inpatient and nursing home care services at five locations: Albany, Western New York, Syracuse, Bath, and Canandaigua. It also provides primary care at twenty-nine community-based outpatient clinics located throughout the region. The VISN serves an area of 42,925 square miles, encompassing 47 counties in New York State as well as two counties in northern Pennsylvania, with an estimated population of 573,546 veterans (17.7% of whom were treated in FY 2000).<sup>1</sup>

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<sup>1</sup> "Veteran Demographics". Department of Veterans Affairs Web site. Available at: [www.va.gov/visns/visn02/](http://www.va.gov/visns/visn02/). Accessed December 6, 2001.

Nationally, the rate at which the veteran population is aging surpasses the rate for the non-veteran population, and VISN 2 is serving large numbers of elderly veterans. In FY 2001, 52% of veterans who received VA services through VISN 2 were age 65 years and over, and nearly one-quarter were age 75 and over. Nationally and in VISN 2, the number of veterans age 85 and over is expected to nearly double in the next five years.

Historically, veterans age 65 and over have used health care services at a higher rate than younger veterans, but health care service use is much higher among those age 85 and over in all major care settings-acute inpatient, nursing home, and ambulatory care. While the overall veteran population is expected to decline by 20% in the next ten years, significant growth in the number of very old veterans will result in substantial ongoing demand for health care services.<sup>2</sup>

Prevalence of Alzheimer's disease increases rapidly with age, from about 3% of people age 65 to 74, to 19% of those age 75-84, and 47% of those age 85 and older.<sup>3</sup> Age-specific prevalence rates are not available for other diseases and conditions that can cause dementia, but rates are known to increase with age for most of these diseases and conditions. As a result, the total number of veterans with Alzheimer's disease and other dementias will grow significantly in coming years. Awareness of these demographic data and a desire to improve the care provided for veterans with Alzheimer's disease and other dementias were the primary reasons that VISN 2 leadership chose to participate in the CCN/AD demonstration project.

### **Overview of the CCN/AD Demonstration Project**

CCN/AD is a joint project of the Alzheimer's Association and the National Chronic Care Consortium (NCCC). In late 1996, these organizations sent out a request for proposals to all organizations that were members of NCCC and the Alzheimer's Association chapters in the same geographic areas, inviting them to apply jointly to participate in a national demonstration project to improve care for people with Alzheimer's disease and other dementias.

The VA is a member of NCCC, and VISN 2 is the designated VA representative to NCCC. When the request for proposals to participate in the national demonstration project was sent out, VISN 2 leadership decided to apply and was selected along with the four Alzheimer's Association chapters in its geographic area. Other organizations that participated in the demonstration project include non-VA health care systems and Alzheimer's Association chapters in San Francisco, Denver, Minneapolis, Philadelphia, and Albany, NY.

Once the project sites were selected, health care professionals and chapter staff from these sites worked together to develop detailed objectives and a model of care to be implemented and evaluated in the demonstration. The model they created consists of protocols and instruments to achieve four objectives: 1) identification of people with possible dementia; 2) diagnostic assessment; 3) ongoing medical and nonmedical care management; and 4) support for family caregivers.

Beginning in 1999, this model of care was put in place in all the demonstration sites. Training about Alzheimer's disease and dementia was provided for many health care

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<sup>2</sup> Ibid.

<sup>3</sup> Evans, D.A., Funkenstein, H.H., Albert, M.S., et al., "Prevalence of Alzheimer's Disease in a Community Population of Older Persons: Higher Than Previously Reported," Journal of the American Medical Association, 262(18):2551-2556, 1989.

professionals and other service providers. The project enrolled and provided services for more than 1,450 people with Alzheimer's disease and other dementias and 1,300 family caregivers. An extensive evaluation was conducted, and analysis of the resulting data is now underway. Preliminary findings are available about the characteristics and needs of the enrollees and their family caregivers, their responses to a telephone survey about the services they received, and the responses of health care professionals and chapter staff to a mailed survey about their observations and attitudes about the project model and the working partnership between the health care organization and the Alzheimer's Association chapter at their site.

### **The Upstate New York CCN/AD Site: Partners in Dementia Care**

Once selected to participate in the CCN/AD demonstration project, VISN 2 and its four Alzheimer's Association chapter partners began cross-training procedures to teach and learn about each other's organizational structure, programs, and services. At the same time, they participated in meetings and conference calls with other CCN/AD sites to develop the project model. Initial training about the model and about Alzheimer's and dementia care was provided for VISN 2 and chapter staff, and enrollment of veterans began in 1999. Over the next 3 years, more than 500 veterans were enrolled and served through the project, called "Partners in Dementia Care" in the Upstate New York site.

### **Dementia Care Managers**

For the demonstration project, VISN 2 created a new position, "Dementia Care Manager." In each of the five main locations in VISN 2, a nurse or social worker was hired for this new position. The Dementia Care Managers perform diverse functions, all intended to improve the care available for veterans with Alzheimer's disease and other dementias. They arrange and assist with training; help with the identification and assessment of the veterans and their family caregivers; respond to questions about the project model and tools; and work with VA primary care providers and chapter staff to coordinate care for the veteran and family and establish the necessary support system in the community. They serve as a portal of entry into the VA system and continuum of services and as a direct point of contact for chapter staff and project enrollees and their families

### **Training**

Training about Alzheimer's and dementia care was a major component of the project. Primary care providers were targeted for initial and ongoing training, and other VA and chapter staff were also trained in sessions specifically designed to meet their needs. A site-wide curriculum was developed that outlined a basic introductory presentation that was delivered (with CME credit) at each of the five main centers in VISN 2 and later at many of the community-based outpatient clinics. The purpose was to assure that each location started with the same basic information. Dementia Care Managers and chapter staff then identified ongoing educational needs for health care professionals and other providers at their locations. Faculty was recruited from within the VA, local universities, Alzheimer's Disease Centers, and Alzheimer's Disease Assistance Centers. In addition to dementia topics, VA and chapter staff were educated about the project objectives, protocols, and tools and about their roles in implementation. A milestone occurred when demands for training came from numerous VA staff themselves after hearing about or experiencing the quality of Alzheimer's Association chapter training sessions for direct care providers. Eventually, this led to use of Alzheimer's Association chapters for train-the-trainer programs and development of a plan to use those newly

trained as instructors and dementia resource individuals in their unit. The implementation of that plan was the culmination of efforts to reach our goal to train the full range of staff at VA facilities

### Preliminary Findings

- More than 500 veterans with Alzheimer's disease and other dementias were identified and enrolled in the project; these individuals were primarily male (94%) and married (79%); 64% had a diagnosis of Alzheimer's disease, and their mean age was 77.
- 500 family caregivers were also enrolled; these individuals were primarily female (89%); 78% were wives of the veteran; their mean age was 67, and 16% were employed full-time.
- More than 1,000 VA and chapter staff members received training about Alzheimer's and dementia care through the project. This training included formal group presentations as described above, formal and informal one-on-one meetings and case-based discussions, grand rounds, conference presentations, and written materials. Project data indicate that training was most effective when it was ongoing over the course of the project, when it was endorsed by a local "physician champion," and when it was supported and encouraged by VA supervisors.
- The CCN/AD protocols and instruments for identification of people with possible dementia were well received by VA staff. Training about these protocols and tools was used to raise awareness about dementia, and the tools were eventually incorporated into the VISN 2 computerized medical record.
- VA primary care providers used the CCN/AD protocols and instruments for diagnostic assessment despite concerns about the time required for their use. Providers who used the protocols and instruments most often also reported the most positive attitudes about their value for the veterans.
- The working relationship between the VA and the Alzheimer's Association chapters was effective in connecting veterans and their families to the chapters; 72% of veterans enrolled in the project received at least one chapter service.
- The working relationship between the VA and the Alzheimer's Association chapters was also effective in bringing chapter services into the VA; at each of the five main locations, a "resource room" was established with informational materials about Alzheimer's disease and dementia for veterans and their families; Alzheimer's support groups were also begun at the five main centers.
- In response to a 3-wave mailed survey, VA health care professionals and other providers reported positive attitudes about the partnership with the chapters; they agreed that the partnership improved outcomes for their patients and improved the quality of care they were able to provide.

- In response to a 3-wave telephone survey, family caregivers of veterans enrolled in the project (n = 270) reported that they had received extensive information about many important topics, including how to manage daily care for the veteran and how to access needed community services.
- In response to a 3-wave telephone survey, veterans enrolled in the project who were able to participate in a telephone interview (n = 85) reported that they had also received extensive information about topics important to them, including available treatments for Alzheimer's disease and other dementias, how to manage daily tasks, and how to coordinate help from family and friends.
- Veterans and their family caregivers generally reported high satisfaction with the care and services they received through the project.

### **Next Steps in the VA/Alzheimer's Association Collaboration**

In VISN 2, each of the five main centers has now signed a memorandum of understanding with the local Alzheimer's Association chapter, defining their agreement about details of their ongoing cooperation in the care of veterans with Alzheimer's disease and other dementias. Thus, the project functions will continue even though data collection and other aspects of the national demonstration have ended.

Using the evaluation findings and clinical knowledge obtained through the project, VA and Alzheimer's Association staff from the Upstate New York site, VA headquarters, and the Alzheimer's Association national office are now working together to develop a proposal to replicate the project in other VA medical centers across the country. A one-year planning grant to develop the proposal was provided by the Robert Wood Johnson Foundation, which also funded much of the work in VISN 2 over the past five years. We are currently refining the project model to incorporate findings from the Upstate New York site that would make it most appropriate for other VA sites. We are also investigating possible sources of funding for the replication.

### **Conclusion**

In upstate NY, the collaboration of the VA and the Alzheimer's Association in the CCN/AD project has been successful in demonstrating a model of care that can improve care for veterans with Alzheimer's disease and other dementias. This collaboration was based on the organizations' understanding that they have a common goal; that they serve a common population--individuals with dementia; and that neither organization has sufficient expertise and services to provide all the care needed by these individuals and their family caregivers. This understanding promoted pooling of experience, expertise and resources. The Alzheimer's Association chapters have extensive experience providing support and education for people with dementia and their families. VISN 2 brought to the partnership the clinical experience and expertise of its staff and an enviable array of medical and institutional and non-institutional long-term care services. The partnership worked, allowing both organizations to provide better care for their clients. The Alzheimer's Association is pleased and proud of the accomplishments of the CCN/AD project in VISN 2 and hopeful that these accomplishments can be sustained in VISN 2 and replicated in other VA medical centers across the country.