

**STATEMENT OF**

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on behalf of the**

**ALZHEIMER'S ASSOCIATION**

**presented to**

**Committee on Veterans Affairs  
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**9:30 a.m.**

Mr. Chairman and members of the Committee, thank you very much for giving me the opportunity to testify at this important hearing.

In my professional life I am the Director of the Geriatrics and Extended Care Line for the upstate New York Veterans Integrated Services Network (VISN 2). However, I am here this morning on behalf of the Alzheimer's Association and the views that I express do not necessarily reflect the views of the Department of Veterans Affairs.

The purpose of my appearance today is to explain how Veterans Integrated Service Network (VISN 2), located in upstate New York, was able to implement the Chronic Care Networks for Alzheimer's Disease (CCN/AD) project fully utilizing the continuum of VA institutional and non-institutional long-term care programs that are available to the Veterans.

In 1996, VISN 2 was the only VA Network that was a member of the National Chronic Care Consortium (NCCC). Membership in this organization reflects commitment on the part of VHA Central Office as well as executive support in VISN 2. As members of the NCCC, the Alzheimer's Association and VISN 2 leadership made a commitment to partner in the CCN/AD project because of our strong belief that chronic care takes many resources to work. There were seven sites selected from the NCCC applicants. VISN 2 and the upstate New York chapters of the Alzheimer's Association were among those selected. The importance of this project was recognized by the Robert Wood Johnson Foundation who heavily underwrote the evaluation component of the VISN 2/upstate New York Alzheimer's Association chapters site.

#### Background on CCN/AD Project

The following is a detailed description of the CCN/AD initiative and VISN 2 and the upstate Alzheimer's Association chapters participation. VISN 2 and the four upstate New York chapters of the Alzheimer's Association formed a community partnership to participate in the CCN/AD initiative, a national demonstration project. In Upstate New York the partners recognized that they had a common goal. They also served the same target population, individuals with dementia and their caregivers and families. The partners strove to provide their clients with the best quality care their agency resources allowed. This recognition of commonality promoted pooling of experience, expertise and resources. The Alzheimer's Association chapters have a history and extensive experience providing support and education to diagnosed individuals, their caregivers and families. The VA brought to the partnership their clinical experience and expertise in the provision of an enviable continuum of chronic care services. Both agencies have much to offer individuals with dementia and their caregivers. Both agencies also recognize, that no one organization, no matter how complete its array of services and programs, is sufficient to successfully manage the chronic and progressive illness of dementia throughout its course. Partnership is essential. Partnering in CCN/AD meant that both organizations could provide better access for their clients to a wider arrangement of services. Also as important, the partnership in the CCN/AD initiative would establish the foundation for development of a disease management model of care in VISN 2. This model serves as a guide for providing services and support throughout the course of the disease at all care sites within the Network.

## Demographic Profile of VISN 2

VISN 2 is an integrated health care delivery system composed of inpatient facilities, nursing homes, community clinics, non-institutional care programs 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, provides primary care at twenty-nine community-based clinics that are 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 in northern Pennsylvania, with an estimated 573,546 veterans (17.7% of those veterans were treated in FY 2000).<sup>1</sup> This is approximately the same area (minus counties in northern Pennsylvania) served by four Alzheimer's Association chapters. The chapters and VA Medical Centers formed the partnerships based upon shared service areas.

VISN 2 was strongly motivated to partner with a community organization, such as the Alzheimer's Association, to better serve an aging veteran population with a prevalence of chronic illness. Nationally, the rate at which the veteran population is aging surpasses the general population.

Highlights of veteran demographics for upstate NY:

- Over 52% of veterans treated in FY 2001 were 65 years of age or older, with nearly one-quarter over age 75.
- Perhaps equally significant is that while our total veteran population decreases, the number of veterans over age 85 will nearly double in the same five-year period.

While veterans over age 65 historically use health care services at a higher rate than younger veterans, greater demand is profoundly more significant among those 85 and over, in all major care settings-acute inpatient, ambulatory and nursing home care. The 20% reduction in the overall veteran population is offset by the significant growth of very elderly veterans, thereby maintaining significant demand for health care services over the next ten years.<sup>2</sup>

These demographic data provided VISN 2 an incentive to participate in the CCN/AD initiative addressing Alzheimer's disease, a chronic illness whose prevalence increases with age. A disease which if left undiagnosed could interfere with the management of their medical care and cause them to be labeled as non compliant patients, possibly leading to their death because they were not taking their medications as prescribed.

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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.

<sup>2</sup> Ibid.

In addition to the demographic challenges presented to us, VISN 2 was impelled by fiscal and budget realities to make effective changes, rapidly, and to look outside itself for agencies with whom to collaborate.

In VISN 2, Care Lines are structured along major program emphases. In my case, the major program emphasis is Geriatrics and Extended Care (GEC). In VISN 2, the Care Line Directors are given budgetary and operating authority over all relevant programs in this new organizational structure. Decisions about program operations are matrixed with the Directors of the major Medical Centers in upstate New York. This structure allows us to rapidly deploy and standardize the best, efficient and effective practices across all sites of care delivery within our Network. The Care Line organizational structure lets administrators in our Network focus and concentrate on all the pertinent issues and requirements relevant to aligning resources for efficient and effective service delivery. It also impacts the speed of implementation, in that, I can influence deployment across the entire Network catchment area, and not just at one Medical Center at a time. This structure allowed me to institute the CCN/AD initiative rapidly throughout all of upstate NY and hire and put in place Dementia Care Managers at each major site which I will talk about later.

### CCN/AD Project Goals

The CCN/AD project's primary goals are: identification of individuals in early stages of the condition, implementation of state of the art comprehensive care guidelines, creation of a dual track to support both the person with dementia and the family caregivers, over time and across the continuum of needed services, and modification of the care for coexisting conditions with recognition of the underlying dementia and its affect. As a selected CCN/AD site, VISN 2 was active in the development, piloting and demonstration of the CCN/AD model.

Chapters and VA partners quickly identified training as a major component of the intervention. Primary care clinicians were targeted for initial and ongoing training. Other staff in both partnering organizations, were also trained in sessions specifically designed to meet their needs. A site wide curriculum was developed that outlined a basic introductory presentation with CME credit that the VA clinical director of the Initiative delivered at each sub site. The purpose was to assure that each location started with the same basic information. During the clinical director's travels to the sub sites he met with key personnel and along with dementia care managers recruited physician "champions" who would participate in or support future sessions.

### The Role of the Dementia Care Manager

Recognizing the varied resources and needs of each sub site, Dementia Care Managers and chapter coordinators determine future educational needs for the staff at their facilities using the curriculum as a guideline to identify target audiences and use a variety of methods. Faculty was recruited from within the VA and more frequently from universities, Alzheimer's Disease Centers and Alzheimer's Disease Assistance Centers. Staff at both partnering organizations were educated about the goals, protocols and their role in addition to dementia topics. A milestone occurred when demands for

training came from numerous diverse staff themselves after hearing about or experiencing the quality of Alzheimer's Association chapter training sessions for direct care staff. 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.

Once the initial piece of the project was accomplished, the role of the Dementia Care Manager became more important. This is a unique staff role; unique both for this project and within the VA. These staff serve a variety of diverse functions all designed to advance the goals of the CCN/AD initiative. The Dementia Care Manager is there to respond to questions related to the tools after the education sessions and to collect the necessary data for the project. The other responsibility of the Dementia Care Manager is to work with the primary care provider to establish the psychosocial support system for the Alzheimer's patient in the community. Further these staff work with the family and the Alzheimer's Association to provide family/caregiver support.

The Dementia Care Managers like the other VISN 2 Geriatrics and Extended Care staff work diligently to insure that all veterans continue to have access to VHA resources and services when they need it. VISN 2 is one of the Networks nationally that met veteran resource, use reliance target levels for both our institutional Nursing Home programs as well as our non-institutional home care programs and services. But the needs, both in nature and kind of need, of patients with chronic illnesses and their families will always exceed the VHA's ability to directly provide for them.

### Partnership With the Alzheimer's Association

Faced then with increasing numbers of aging veterans in the upstate New York area and the competing healthcare budget needs previously mentioned, geriatric and extended care program planners in our Network factored in access to Alzheimer's Association community resources, as a necessary component to compliment services for veterans with dementia and their families. It is a good illustration of a model that strategically places VHA resources along side numerous community partners to work in concert to meeting the needs of chronically ill veterans.

### The Chronic Care Challenge

Treatment and management of chronic illnesses, such as dementia, fundamentally challenge the way healthcare service delivery systems are currently configured.

Medical care delivery within VHA, as is the case with most medical care systems, is well designed to manage health care problems of the general population. Typically care delivery centers around brief, episodic office visits with the primary care provider. The nature of the visit commonly focuses on the medical aspects of presenting problems. Patients are given prescriptions, advice on life style changes and follow up appointments if necessary to track progress of the condition for which they are being treated. At times, referrals may be made to specialty clinics and if warranted to treat

acute illness, hospitalization. In addition, providers in these settings are busy. They have high patient volume and are daily pressed to complete their scheduled visits. As would be expected, resources in most health care systems are aligned to meet this mission and model of healthcare delivery.

Chronic care management, however, presents a fundamentally different reality. Chronic progressive illness, such as Alzheimer's, needs to be addressed in clinic, over time rather than episodically. Also managing these patients, who are typically frail and elderly, takes time. Time to plan access to a full range of non-institutional resources such as Home Based Primary Care, Homemaker Home Health Aide, Adult Day Health Care and Respite Care, all services that the VA provides and/or coordinates. Providers are trained and trained well to assess and treat on the medical level and patients with chronic illness need this care. But often simultaneously, these patients and families need assessment and care on several other non-medical dimensions as well. These other domains that require attention and often intervention and care planning include functional, social, financial, psychological, behavioral and environmental dimensions. Further adding to the complexity is the work that needs to be done with the family caregivers. Caregivers often times are as old and sick as the identified patients they care for, yet they are so crucial to the success or failure of the management of the disease. Their needs must be accounted for in care planning. Finally, the nature of chronic progressive illness is such that it evolves, develops, and eventually deteriorates over time. Changes in condition and circumstance must not only be monitored but must be prepared for proactively. Patient's changes in physical, behavioral and functional needs require different mixes of supports, services and settings. Their caregivers' skills, aptitudes, as well as their own family and agency supports available to assist them need to be looked at as they progress through role changes and the changing demands that their loved ones chronic illness places on them. This is where the Dementia Care Managers come in and provide invaluable assessment, coordination and support.

To successfully address chronic illness management, the mindset, both clinically and in resource planning and deployment, needs to be fundamentally different than an uncritical reliance on a system of delivery designed to serve needs of a general population. The consequences of dependence on episodic care delivery as it's currently organized or premature reliance on costly institutional care for management of chronic illness is to squander precious resources that are and will be needed to treat the ever growing population of veterans with chronic illness.

### Replication of the CCN/AD Project

Given the complexity of what is described above, it is impractical to think that any one agency, no matter how vast its resources, can unilaterally provide all the care patients and their families with chronic progressive illness will need. To begin to think like this, and coordinate with community partners and monitor care over time outside of the clinic encounter, is nothing short of a cultural change in healthcare delivery. To actively change medical care delivery culture, the endorsement and commitment from top leadership is required. VISN 2 chose to use the CCN/AD model as the springboard to help change it's medical model and culture of primary care and to influence it over time to better accommodate the needs of patients with chronic illnesses and their

families. Over a five year period, the VISN deployed dedicated Dementia Care Managers to cover all the medical centers and major care sites within the VISN. These staff are able to take the time medical providers don't have to do detailed assessment of both patient and caregiver needs. They also are a direct contact point and portal of entry into the VA system and continuum of services. They are easily reached by their partners at the Alzheimer's Association and help sustain this inter-agency relationship. They collaborate with both VHA providers and Chapter staff and work to integrate into care planning relevant data about both patient and caregiver's current functioning.

### Conclusions

CCN/AD created in VISN 2, over time, the reality of viable partnerships with community agencies such as the Alzheimer's Association. It imparted to our providers the importance of addressing caregiver needs and supporting them as they struggled to cope with their loved ones illness on a day to day basis. It reaffirmed that chronic care had to be managed across settings and over time. It expanded the providers' appreciation as to where care was actually delivered in the majority of instances. It contributed to the provider's understanding that successful management of our patients with dementia means addressing the needs of the patient's family caregivers as well.

Our veteran patients, whom we correctly refer to as our nation's heroes, who now come to us with dementia, along with their family caregivers, who are quiet, unsung heroes in their own right, continue to teach us. They teach us that to be true to our mission and obligation to "serve him who has borne the battle and his widow and orphan", we must continue to maximize our resources to serve the extended care needs of our veterans as they age, become frail and more heavily rely upon us. They teach us that to be successful in our mission we cannot be solely focused on our identified patient, the veteran. We must also focus on those in our veterans' lives who are most intimately caught up in the provision of their extended care needs. And finally, they teach us not to come to rely solely on VHA resources to achieve our mission. They have taught us that we must reach out to our partners in the community, who have common missions, and work with them to offer our veterans and their family caregivers what they need, not just what we have.