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Representing the Clark County Alzheimer's Action Network (CCAAN)

In September 2011, a diverse group of stakeholders from government, the private sector, nonprofit, academia, and advocacy organizations assembled at the Cleveland Clinic Lou Ruvo Center for Brain Health. Sponsored by Pfizer, participants include the Alzheimer's Association, the Nevada Department of Aging and Disability Services, UNLV, Nevada Senior Services, the Nevada Primary Care Association, the American Cancer Society, St. Rose Hospital, the Southern Nevada Health District, HealthInsight, the Lou Ruvo Center for Brain Health and our own internationally renowned Alzheimer's expert Dr. Jeffrey Cummings.

The purpose was to address Alzheimer's disease in Southern Nevada, and explore ways to improve the quality of care and of life for patients and their caregivers who are affected by this cruel disease. By forging cooperative relationships and developing joint projects with a diverse array of service providers, we sought to create an inclusive strategy to address the overwhelming need for an Alzheimer's disease-focused continuum of care.

Clark County is particularly vulnerable to the health, emotional, and financial toll that Alzheimer's disease will render since it leads the state in population growth including older adults. One in eight people over the age of 65 have Alzheimer's disease, and the incidence doubles every five years thereafter. These risks reach nearly 50% after age 85. Moreover, Clark County leads the state in several modifiable risk factors that can cause Alzheimer's disease: it has the highest incidence of diabetes and an increased risk for cardiovascular disease caused by smoking, drinking and obesity.

The mission of CCAAN seeks to make Alzheimer's disease and other dementias a community priority by:

1. Driving awareness of Alzheimer's disease to increase community focus and actions.
2. Empowering Alzheimer's providers to recognize and deliver an Alzheimer's-centered continuum of care.
3. Serving as a catalyst to create a robust, interconnected Alzheimer's providers community, and strengthen the health professional network to ensure that Clark County residents impacted by Alzheimer's receive the best care, support, and access to research.

During the course of our meetings, we had the opportunity to listen to the heartfelt stories of Mayor Carolyn Goodman and County Commissioner Susan Brager as they told us how Alzheimer's disease stole away cherished family members.

Like Larry Ruvo, who lost his father to Alzheimer's disease in 1994, these were not individuals without resources or contacts, however, they all found themselves adrift by the confounding and

insidious nature of this dreadful disease. So this begs the question ... how are the rest of Nevadans coping with Alzheimer's disease? How can CCAAN, and this task force, make it better?

After 10 months of meetings, we were able to develop action steps around two primary challenges:

The 1st Challenge: Public Awareness

1. Alzheimer's disease is under diagnosed.

Published studies cite that these "missed" diagnoses can be a result of several factors:

- A physician's lack of knowledge of what constitutes "normal" changes of aging.
- Physicians' fear that a dementia diagnosis would stigmatize a patient or that an early Alzheimer's diagnosis is futile since there are limited treatment options.
- Some cited problems with testing for dementia as a factor, including a lack of assessment tools and protocols, or a lack of tools perceived as helpful.

2. People are unclear about the warning signs. Not all forgetfulness should be considered "senior moments". The warning signs of Alzheimer's disease should be prominently and consistently posted in public health locations and physicians' offices. Many sources including the Alzheimer's Association identify the warning signs for this disease..

Knowledge can help patients and their caregivers become their own advocates for diagnosis and ongoing care. For example, if you or your loved one is getting lost in a once familiar location, or is asking the same question over and over, you should request a cognitive assessment for Alzheimer's disease.

The early diagnosis of dementia offers many benefits:

1. Detection can prompt evaluation of the patient for reversible causes of memory loss.
2. When the course of the disease is determined to be progressive, pharmacologic intervention may slow cognitive decline.
3. Early diagnosis provides time for patients and families to prepare for future care and maximizes patients' opportunities to contribute to the care planning process.
4. A proactive approach to diagnosis and intervention may improve the well being of both persons with dementia and family members involved in their care, and ultimately delay institutional placement.

Moreover, once an individual learns he or she has Alzheimer's disease, they should strongly be encouraged by their healthcare providers, public service announcements, or whatever means available to seek out the community resources that can help them learn about and navigate through their disease.

The 2nd Challenge: Navigating the system once a diagnosis has been made

Primary care physicians might be more comfortable diagnosing Alzheimer's if they knew there was a comprehensive network of resources to support their patients. Physicians want to diagnose and treat their patients effectively, but they don't have time to be the psychologist and social worker as well. An effective, affordable community-based service system would include screening and diagnosis options,, specialized healthcare services, caregiver support programs including support groups, counseling, community living arrangements, social work, legal and financial planning for care, short-term stay options, education and information and assistance.

For the patient/caregiver, providing a roadmap of resources to support them throughout the course of their disease is priceless. It can help them plan for the future with confidence rather than flounder in a bewildering abyss.

For example, an individual who has just been diagnosed with Alzheimer's disease could be encouraged to determine who will make financial and healthcare decisions for them when they are no longer able to do so. For this service, they might be referred to the Senior Citizens Law Project. It is important for AD patients and their families to consider identifying services that offer support at each stage the disease such as transportation services when safe driving is no longer possible and meal preparation, in-home support services and adult day care as capacities decline.

These services do exist in our community, but the overall system is fragmented, costly and inaccessible; there is no organized, consistent, or corroboratory method by which to deliver or advertise these services to the individuals who need them.

Members of CCAAN tasked with developing strategies to address this challenge discussed the possibility of a dedicated Alzheimer's Disease Patient Navigator who would work along with physicians to support the family and individuals with AD to educate, answer questions, increase awareness of services, and facilitate access to community resources. The Navigator would work to help overcome barriers including clinical obstacles (like scheduling conflicts), social and spiritual support barriers, financial concerns and other considerations like legal and transportation issues.

CCAAN also created an Alzheimer's disease compass; a handy chart of resources printed on a card listing the available community resources and important considerations for the Alzheimer's patient, to be distributed through physicians' offices at the time of diagnosis.

The members of CCAAN have wrestled with the challenge of identifying and creating implementable and effective ways to assist individuals impacted by Alzheimer's disease. As service providers, we witness first-hand the devastating circumstances these individuals and their families will confront throughout the disease course. Happily, the state of Nevada and this task force are now charged with this same mission.