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 **Service Sites**

Boca Raton  
Boynton Beach (2)  
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A United Way Member Agency



United States Senate  
Special Committee on Aging  
Wednesday, March 25, 2009

Testimony Presented By

Larry Butcher, Chair

Prepared By

Mary M. Barnes, President and CEO

Alzheimer's Community Care, Inc.

Thank you, Senator Herb Kohl, Senator Mel Martinez, and your distinguished committee and panel of caregivers. As an American I could not be prouder that we are discussing the growing crisis that Alzheimer's disease poses to our nation.

It has only been these past 15 years that Alzheimer's disease and the related disorders have been acknowledged as debilitating diseases that affect two people – the caregiver and the person who is diagnosed.

In the state of Florida, which is my family's home, it is projected that there are in excess of 500,000 patients diagnosed with Alzheimer's disease. When the other related disorders are factored, in such as Lewy Body Disease, Pick's Disease, Vascular Disease and Parkinson's, that number climbs to over 800,000. In our service area that encompasses Palm Beach, Martin, and St. Lucie counties, the projected number of patients suffering with Alzheimer's disease or a related disorder is over 107,000. For every person diagnosed 19 people in the community are affected.

When my loving wife of 35 years, Jeannette, was diagnosed with a strain of Alzheimer's disease at age 55, it quickly made her a different person. Before the affects of the disease took hold, she thrived on being a mother and an active community leader. She turned into someone who was angry, belligerent, had no sense of judgment, and was resentful of me. This was heartbreaking at the time, because I was not aware of all the emotional aspects of the disease process. I continued to believe it was my fault that she was acting out the way she was. Her doctor gave me very little support. She progressed quickly and we both became very depressed. At the lowest ebb of my life, by accident I found Alzheimer's Community Care and immediately became enveloped by their "model of care."

The Family Nurse Consultant became my best friend; the study calls her a care manager nurse. As a registered nurse certified in dementia specific care, she is well aware of when a disease is evident and is the integrator of specialized care that administers support, guidance, and advocacy throughout all stages of the disease. Every service and resource, including

support groups, was instrumental in providing me with the knowledge, strength and stamina to make the hard decisions when it was necessary, such as taking away the car keys early; 60% of patients will wander at least once during the disease process. Removing the keys was for her safety. These resources also taught me the importance of taking care of myself; 63% of Alzheimer's disease and related disorders caregivers are at risk of death before other caregivers. Because of their commitment and services to me I became a volunteer and an advocate for the organization and now proudly serve as the Chair of the Board of Directors.

Alzheimer's Community Care is unique and unlike any other organization in the country. The mission of Alzheimer's Community Care is to promote and provide specialized quality compassionate care to Alzheimer's disease and related disorders patients and caregivers within a community-based environment. They are where "the rubber hits the road" and innovation is their hallmark.

Traditional funding for services under the Older Americans Act is for persons 60 years of age or older which is limiting to the point that it is not disease specific nor is this considered a resource for patients diagnosed at a younger age. As diagnostic capabilities become more sophisticated, and with an estimated 10 million baby boomers developing the disease in their lifetime, the impact of Alzheimer's disease is of significant concern and one which Alzheimer's Community Care is prepared to embrace.

Alzheimer's Community Care is one such organization that works with both the patients and caregivers, from the initial indication of dementia, referrals for appropriate medical diagnosis, and planning and assisting with the patients and caregivers every step of the way. Patients are being diagnosed at a younger age and caregivers have had to adapt to their changing roles and relationships without forewarning or preparation. All staff of Alzheimer's Community Care is trained and receives dementia certification. Community resources used in the provider network and through information and referral must meet standards of practice for dementia care. Alzheimer's Community Care has included cognitive screenings and measurements in their assessment tools recognizing that assessment forms used in aging programs generally concentrate only on the physical deficits in the aging process. The cognitive assessment includes the Mini Mental State Examination, safety concerns - wandering and Alzheimer's proofing the home, financial planning, specialized disaster preparedness, and legal issues, such as living will and advanced directives. Also used during the assessment process is the Caregiver Strain Index that assists both the Family Nurse Consultant and the caregiver to determine the level of caregiver burden and the appropriate mode of service to assist with caregiver relief.

Alzheimer's Community Care's "Model of Care" provides therapeutic interventions targeted at community-based services by well trained staff during the continuum of the disease process. Community partnerships and collaborations have been beneficial with successful outcomes. Training with law enforcement for appropriate recognition of signs of Alzheimer's disease diminishes inappropriate interpretations of behavior and prevents unsuitable incarceration. The specialized Alzheimer's day services provided by Alzheimer's Community Care have been proven to reduce health care costs by providing health care monitoring, preventative health care, and timely provision of primary care.

The findings in an independent evaluation conducted by the University of South Florida regarding the Florida Medicaid Alzheimer's Home and Community-Based Waiver Program, which Alzheimer's Community Care is one of three participants in the state, reported the

program is an effective resource for caregivers to Medicaid recipients, improved their personal quality of life and delays institutionalization for the patient. The report concluded that overall the Medicaid Alzheimer's Program represents a multi-service intervention that targets not only the problems of the Medicaid recipient with Alzheimer's disease (e.g., medication use, wandering, provision of stimulation and social contact), but also the problems and issues faced by the caregiver (need for general assistance in care provision, respite, information about the provision of care to an individual with Alzheimer's disease, etc.). The results demonstrate that a specialty program such as the Alzheimer's waiver program can have a positive impact on the well-being and trajectories of enrollees with Alzheimer's disease and their caregivers.

Caregivers and families express a high satisfaction with service provision. Service providers are trained and resourceful on dementia specific needs and their delivery of those services and resources applies to the ever changing needs driven by stages of the disease's progression.

Alzheimer's Community Care has established 11 specialized Alzheimer's day care service sites, 8 of which operate in church fellowship halls and 3 in other community based settings. We sponsor an annual Alzheimer's educational conference that brings national, state, and local presenters to speak on research, care techniques, legal, and safety issues. Last year, of the 534 attendees half were caregivers. We are projecting over 600 attendees this year.

In our service area, over 167 cultures are represented, all of whom have needs for our services. Hispanics will exhibit the symptoms of Alzheimer's disease 5 to 8 years sooner than Caucasians. Recognizing this need, Alzheimer's Community Care has operated a Spanish speaking specialized Alzheimer's day care center for six years. African Americans will suffer longer with vascular dementia because of complications from co-morbid illnesses, such as hypertension and diabetes. 55% of all caregivers who have their loved ones in our 11 specialized service sites are employed. On average the day care centers operate for 10 hours each day to accommodate working caregivers. We provide a staff to patient ratio of 1 to 5. With volunteers it is 1 to 3. The longevity of caregivers has increased and both caregiver and patient hospital stays are far less than other traditional government funded models of care. Institutionalization is delayed for 2 to 4 years and many never require placement.

The average cost of this service is under \$1,500 monthly. Institutional care is \$4,000 to \$5,000 monthly.

Alzheimer's Community Care is our community's stakeholder.

I am a living testament of this model of care provided by Alzheimer's Community Care. It is not the retirement years that I had envisioned for myself and the love of my life, Jeannette, but I now have a quality of life that allows me to live in dignity as well as oversee and be a part of her care with the knowledge that I am doing the right thing each step of the way. I have not been relieved of my pain, but it is being shared with those who truly care, who understand, who are knowledgeable and compassionate so I am not isolated or ever alone.

Thank you for allowing me to give my personal testimony on behalf of a model of care that needs to be made available to the millions of others that cope every day with Alzheimer's disease and the related disorders throughout our great country.