

Testimony of Raye Mutcherson in support of the Alzheimer's Statewide Respite Program

Senator Toni Harp and Representative Toni Walker, and members of the Appropriations Committee, My name is Raye Mutcherson, and the following is a brief description of the many ways my family cares for my grandmother, Gladys Sutton, and proactively giving care/relief to my grandfather, Clifton Sutton.

Speaking directly to the care for my grandmother who was diagnosed as an early onset dementia patient approximately 15 years ago, there are three primary areas the family highlights. 1) Medical decisions, 2) financial care and 3) direct time spent with my grandmother. My family is extremely lucky to have the support and care for my grandmother.

As an African-American scientist and training clinician my concern is directed at diagnosis, treatment and outcomes for ethnic minorities. "African Americans stand a greater chance of being misdiagnosed and mistreated by the very people who are supposed to help them, including physicians, nursing homes, and community services providers." Understanding this and addressing this possibility will lead to tackling health care disparities and the continued disproportionate medical attention to ethnic minorities. Like most diseases and disorders early detection and diagnosis increases health outcomes. Some experts agree that early recognition of Alzheimer's has become a vital component to the course of care and outcomes for the patient and the families involved. At present, available drugs are useful only in the early stages of the disease, and new agents being developed are considered far more likely to arrest or slow disease progression than to reverse damage that has already occurred. Additionally interventions, such as adult day care programs that help support caregivers and stimulate patients, also are aimed at those early in the disease progression. Moreover, neuropsychological tests used to screen for Alzheimer's often fail to detect early dementia, so pursuing the lengthy investigation that may lead to early diagnosis often depends on investigating 1. red flags raised by the patient, 2. a family member, and 3. An astute primary care physician, Vicki T. Lampley-Dallas MD, MPH University of Oklahoma pointed out.

Research has suggested that ethnic minorities with dementia, Alzheimer's and associated diseases receive less formal treatment than their white counterparts, and the treatment they do receive often comes later in the disease course. Early detection has to be an area of tremendous focus by the patient, family and clinicians if we hope to slow the progression of this disease. With that said there are many hurdles that need to be addressed and crushed to reach this beginning point in care. I point to racial and ethnic disparities, access to care revolving around health insurance and continued minority fear of the medical field. Medical fear by ethnic groups is well documented in cases like The Tuskegee syphilis experiment and plays role in the inability to reach these groups not only for basic care but when attempting implement early detection protocols.

It takes a village to care for an individual with Alzheimer's. Tasks have been split largely between my mother and my aunts. My mother is the primary conduit to the physicians that care for my grandmother, particularly in the areas of monitoring progress, bringing information to the family and the spokes person for any medical decisions that need to be made. My aunt is the primary financial directors helping my grandfather maintain the daily house and medical

expenses. Finally, due to the progression of the disease my grandmother can no longer be left alone. Here is where the family picks up the baton in care for my grandmother and subsequently my grandfather.

My mother, who is the medical conduit for the family, also developed a schedule for the women in the family to spend designated time throughout each month with my grandmother in order to give my grandfather some relief. It can never be overstated the burden emotionally on the primary care giver of a patient with dementia, Alzheimer's or associated diseases. Our family ensures that my grandfather has time to himself, be it time caring for his yard or simply meeting his friends for morning coffee. My mother takes this very serious and is the person hiring, managing payroll, and schedules for the several Personal Care Assistant Nurses we have coming in to assist us. This requires, doing background checks, interviewing and making sure they can work with an Alzheimer patient and understand what is important for the family. Additionally, with an increase in health service's there are now three PCA's working with the family on rotating schedules throughout the day.

My Grandmother was going to Adult Day Care for a period of five years. At the onset of her attending adult day care it was costing my grandfather, \$400 per week for 3 days and her medications were in the neighborhood of \$200 per month. Through many conversations and paperwork, we were able to get part of the Adult Day Care paid for. As My Grandmother progressed and we were able to get documentation from the Doctors and her being reevaluated Adult Day Care was provided for a full week, and she was eligible for state sponsored health care so her medication was drastically reduced.

My aunt handles all to the financial aspects of care for my grandmother and the daily expenses for both my grandparents. For example she was instrumental in establishing direct deposit for her retirement pension and social security disbursements. To stream line everything in the house she is also involved in managing my grandfather's accounts. My aunt also manages and ensures basic needs are met regarding food, toiletries, and any other items my grandfather may request. All clothing purchases are handled by my aunt. Something as simple as planning her attire based on the weather and time of year has been designated as a task. This highlights at a simple level how the disease progression forces the family to constantly be aware of things we take for granted like what type of socks to wear.

The physician that works with my grandmother has been fantastic in their approach and obvious investment in the care and progress of my grandmother's health. With this dedication and family network my grandmother is evaluated regularly leading to adjustments in medication and additional services. The services and care we are able to provide are attributed to 1) the families' willingness to care for our grandmother, 2) the physicians' openness to give quality sensitive care and 3) the community services available to assist in care.

Not only is Alzheimer's currently the 6th leading cause of death, in some communities throughout the nation the mortality rates associated with the disease have displayed even larger increases relative to diseases such as Cancer and Cardiovascular disease. The more frightening thing here is there is no cure and the cost to the health care system will be felt by all. Remember the Village analogy, this needs to be elevated to a national effort. The affects of Alzheimer's and

associated diseases will undoubtedly reach every individual in this nation leading to the necessity to implement support groups, train clinicians, recruit social services and educators to battle this disease.

Connecticut is a leader with its Alzheimer's State Respite Program in keeping individuals like my Grandmother in the community with supports. I ask for your support in retaining funding for this program.

Thank you for allowing me to provide this testimony.