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Good morning and thank you Mr. Chairman and members of the House of Representatives. We are privileged to be here today on behalf of the Alzheimer's Association.

From the moment a patient receives a diagnosis of Alzheimer's disease or related dementia, a spouse, a daughter, son or other family member will embark on a new, perhaps unfamiliar journey as he or she gradually assumes the role of caregiver.

As the disease progresses, it robs its victims of memory, judgment, and the ability to reason until they cannot care for themselves any longer or engage in normal daily activities such as cooking, dressing or bathing.

According to a 1996 survey conducted by the national Alzheimer's Association, seven in ten people with Alzheimer's disease and related dementias are cared for at home. Most caregivers are spouses or adult children who spend an average of 69-100 hours per week caring for their loved ones, surpassing the equivalent of two full-time jobs. Fifty percent of all caregivers actually live with their loved ones and assume responsibility of care 24 hours a day.

Unfortunately, caregivers are often the second victims of Alzheimer's. Caregivers all too often sacrifice their own health and well being to ensure their loved one is receiving the best possible care. Consequently, more than 1 in 10 caregivers become physically ill or injured and anywhere from 43% to 46% suffer from depression.

In addition, more than 80 percent of Alzheimer caregivers report they frequently experience high levels of stress. Among the many causes of stress and depression are feelings of guilt, anger and resentment toward a loved one who no longer comprehends the world around him, as well as concerns about future care and finances. The level of stress caregivers experience often escalates as the disease progresses.

A study published in the *Proceedings of the National Academy of Sciences* recently concluded that the stress of caring for an Alzheimer's patient at home can prematurely

age the immune system, putting caregivers at risk of developing a raft of age-related diseases.

These problems exacerbate state medical expenditures as well as impact businesses. Presently, Pennsylvania businesses spend nearly \$2.6 billion annually on Alzheimer's disease. These costs account for the business share of health and long-term care expenditures for people with Alzheimer's disease and related dementias and also the cost of family caregiving – absenteeism, productivity losses and replacement costs.

As evidenced above the family caregiver is a comprehensive piece of the continuum of long-term care. Families provide 75 percent of care at no cost to the state. In effect, saving the state \$4.6 billion per year. Therefore, it is in the best interest of Pennsylvania to provide substantive support for programs that not only maintain people with Alzheimer's in a community setting, but also sustain the network of family caregivers.

One significant way in which this can be done is through the support and continuation of the federal Administration on Aging Memory Loss Screening Program.

You will later hear about the specific programs and services of the Memory Loss Screening Program. Now, however, we would like to emphasize the importance of respite services, particularly to families experiencing Alzheimer's disease. Chiefly because respite services are the keystone of the Memory Loss Screening Program.

While there is general consensus that respite means “an interval of temporary relief,” there is almost no agreement as to the composition of the services that are to provide this relief. Respite programs have ranged from volunteers providing short periods of companionship to short stays in institutions. Services can be provided in a client's home, (in-home services), in a group or institutional setting, (out-of-home service), or in multiple settings, also referred to as combination programs.

Within the three general types of respite settings, there are a number of possible variations depending on the level of care, the types of activities available to participants, and the duration and frequency of respite episodes. Programs may vary along a continuum from low to high levels of care, and respite episodes may range from short periods of a few hours to long stays of up to six weeks or as frequently or infrequently as needed.

Currently there is overwhelming consensus that respite services are the most desired and needed support for families caring for persons with Alzheimer's disease or related dementia. Research suggests that respite care relieves the burdens of caregiving, helping to maintain the physical and mental well being of the caregiver. As a direct result, families can care for relatives who otherwise might have been institutionalized, reducing the state and federal costs associated with long-term care.

Moreover, individuals with dementia benefit indirectly from respite when the reduction in caregivers' stress and burden leads to enhanced quality of interactions between the

caregiver and the care recipient. Those individuals attending day care centers also benefit directly from increased opportunities for socialization and stimulation.

It is for these reasons, Chairman and Representatives, that we urge you to support the endeavors of the Alzheimer's Association. Through their statewide network, the Alzheimer's Association provides needed services to the citizens of this Commonwealth. They truly are an ally and aid to the Pennsylvania Department of Aging who is working equally hard to service all older Pennsylvanians, including those with dementia. However, as you are likely aware, the demand on the local Area Agencies on Aging has increased and resulted in the denial of services to many who need them.

The Alzheimer's Association is able to pick up these individuals through a broad range of core programs and services for people with dementia, their families and their caregivers. Moreover, through the special Memory Loss Screening Program, Pennsylvanians are for the first-time provided with an opportunity to receive direct services free of charge. It would be a disservice to those in the program, those waiting to be placed, and those who could potentially be placed, if it was indeed completely halted.

Thank you for your time today.