

TO: Members of the Iowa Alzheimer's Disease Task Force
DATE: September 23, 2007
FROM: Linda A. Phillips, MS, NCC, NCCC
Alzheimer's Family Care Giver's Support Group Facilitator and
daughter of person with Alzheimer's Disease
RE: Needed Support Services

Both family exposure and volunteer experience have given me a close-up and first hand view of the devastating effects of Alzheimer's Disease and related dementia disorders. The devastation caused by Alzheimer's Disease is not only the physiological and psychological effects on the person with the disease, but also extends to the social and economic devastation wreaked upon the family of the person with Alzheimer's Disease.

Alzheimer's Disease is a socially isolating disease both for the person with the disease and the family care giver. There comes a time fairly early in the disease process where the person with Alzheimer's can no longer be left alone, even for as little as an hour, because that person cannot exercise proper judgment to keep self and property safe. Oftentimes, this is accompanied by reduced physical mobility caused by difficulty walking or balancing, making it impractical to take that person along on grocery shopping trips or other errands. This means someone has to actively care for the person with Alzheimer's Disease 24 hours a day, 7 days a week. In most cases, it is the person's spouse or an adult child who assumes the caregiver role, and that person becomes a prisoner in his or her own home by the demands of care giving.

The caregiver's forays out of the house, for precious few minutes at a time, are for unavoidable and essential errands: getting groceries, picking up medications, trips for medical care that have been put off several times already. Long gone are the days of going to church activities, volunteering in the community, attending lodge/sorority meetings or social events, lunching with friends, shopping excursions for anything other than the bare essentials, and other opportunities for connecting emotionally and physically with others to receive support and relief.

This caregiver isolation happens because one can call one's out-of-town son or daughter only so often to take a day off from work to come care for the parent with Alzheimer's Disease and allow the primary caregiver a much needed break. This caregiver isolation happens because friends and neighbors are afraid of the person with the disease and don't understand how to give support or deal with the challenging behaviors, and because one can tap the goodness of friends and neighbors only so often. This caregiver isolation happens because one can choose only so many times between paying for relatively expensive adult day care services and putting food in the belly or medication in the bloodstream or heat in the bedroom when one lives on a fixed and limited income.

Imagine, if you will, having to be at work every single day, every day of the week, no days off, no holidays, no vacation, with no more than 3 or 4 hours of sleep a day, for a period of 7 to 10 years. Under these sleep-deprived conditions, performing everyday tasks becomes dangerous. Cooking over a hot stove, driving a car, and using household chemicals hold an increased risk of injury for both you and the person with the disease. All the while, you must be keenly aware of your own well being and the well-being of a person totally

dependent upon you, while functioning safely under these conditions. This is what family caregivers do until they wear out and the only choices left are to accept defeat and put their loved one in a long term care facility, or die of exhaustion.

The medications to treat Alzheimer's Disease and its many co-morbid conditions are expensive. Even with the Part D Medicare coverage for prescriptions, there is still the "donut hole" in coverage to meet financially. That Part D coverage premium must be paid, just as any other supplemental insurance coverage premium must be paid. Adult Day Care services or in-home care services to provide a few hours of respite come with a steep price as well. These costs for medication and care have to be balanced against the costs of paying utilities, buying groceries, paying taxes, maintaining the care, making repairs to the home, and many other required expenses. The social security check and meager life savings are quickly drained by the absolute essentials. Adult day care, in-home and respite services are often little more than a wistful dream.

You, as members of the Alzheimer's Disease Task Force, are in a unique position to be able to effect a change in the lives of persons living with Alzheimer's Disease and their family caregivers, and to bring us some relief from this devastating and oppressive disease. The better and longer you can support the family caregivers who keeps their family member home, the lower the acute and long-term care costs will be for the person with Alzheimer's, and the healthier the caregiver will be. I ask you to please help us by providing the policy and regulatory structure, providing or encouraging the development of the physical facilities and services, and encouraging financial funding of the following:

- 1) Affordable, available and accessible Drop-In Adult Day Care Services, so that a person with Alzheimer's Disease has a safe and engaging place to be while the primary caregiver runs errands, has lunch with a friend, attends a meeting, receives medical care, or just spends time reconnecting with other human beings for care and support.
- 2) Affordable, available and accessible Respite Care Services, so that the primary caregiver can take a break for a few days to attend an out of town funeral, visit a grandchild, or just sleep.
- 3) Financial incentives for providers to develop and deliver Drop-In Adult Day Care Services (perhaps through Senior Citizen Centers) and Respite Services, and
- 4) Financial aid for families through both State/County/Community funds and insurance coverage to help the caregiver afford to participate in Drop-In Adult Day Care Services and Respite Care Services.

Thank you.

Linda A. Phillips
9005 Blue Street
Norwalk, Iowa 50211
Home (515) 285-3406 Work (515) 285-1240
e-mail: lap002@juno.com