

Congress of the United States

Washington, DC 20515

October 7, 2004

Alzheimer's Care Givers Shoulder Huge Challenges

Take a Minute to Review This Landmark Alzheimer's Caregiver Survey

Dear Colleague:

As part of our ongoing commitment to raise awareness about the myriad aspects of Alzheimer's disease, the Congressional Task Force on Alzheimer's Disease would like to bring to your attention a new report: *Families Care: Alzheimer's Caregiving in the United States*, a collaborative effort of the Alzheimer's Association and the National Alliance for Caregiving. This report examines the personal sacrifices made by families caring for loved ones with Alzheimer's disease. Please take a minute to review the executive findings.

The report is based on a survey of 1,247 unpaid caregivers, 227 of whom have reported helping someone aged 50 or older with Alzheimer's or other dementia. It documents the very heavy burden shouldered by caregivers regardless of disease and level of disability. People who care for someone with Alzheimer's assist with difficult tasks such as bathing, feeding and dealing with incontinence. Furthermore, more than half of Alzheimer's caregivers pull "double shifts," caring for their loved ones in addition to working a full-time job. This lifestyle forces caregivers to sacrifice their own "down time" -- time that could be spent with their own families and friends, exercising, and relaxing. The study further indicates that because of the "double shift", seventy-four percent of the Alzheimer caregivers reported they had unmet needs of their own. The report also reveals that nearly half of dementia caregivers do not use any type of services to assist them with their caregiving responsibilities. Other results from the report showed that 23 percent of Alzheimer's caregivers surveyed provide 40 or more hours of care a week and that 71 percent provide care for more than one year. Thirty-two percent provided care for more than five years. Nearly one-third of the Alzheimer caregivers in the report say they need help managing challenging behaviors such as wandering and giving medications.

We hope that you find this report helpful and encourage you to contact the sponsoring organizations if you need additional information about Alzheimer's disease or the types of services that are available to help caregivers in your state.

In addition, we invite you to add your voice to the fight against Alzheimer's by joining the Congressional Task Force on Alzheimer's Disease. The purpose of the Task Force is to foster open bipartisan discussion about public policy solutions to help meet the long term care needs of people living with Alzheimer's. We hope that you are able to join this critically important group.

Finally, we invite you to cosponsor the Ronald Reagan Alzheimer's Breakthrough Act (H.R. 4595), legislation that will help alleviate some of the burdens placed on Alzheimer's caregivers. The recommendations to Congress contained in the report are directly addressed in our legislation. Please contact Nicole Encarnacao (Markey, 225-2836) or Andy Napoli (Smith, 5-3765) about any of these matters, or if you have questions.

Sincerely,



Edward J. Markey
Co-Chair



Christopher H. Smith
Co-Chair