National Alliance for Caregiving

A National Resource for Caregivers

Testimony for a Joint Hearing
of the

THE UNITED STATES SENATE
SPECIAL COMMITTEE ON AGING

and the

HEALTH, EDUCATION, LABOR, AND PENSIONS
SUBCOMMITTEE ON AGING

February 6, 2002

By

Gail Gibson Hunt, Executive Director
National Alliance for Caregiving
4720 Montgomery Lane, Suite 642
Bethesda, MD 20814
(301) 718-8444
www.caregiving.org

Mr. Chairman and Members of the Committee:

Thank you for the opportunity to speak to you regarding women and long-term care. My name is Gail Gibson Hunt; I am Executive Director of the National Alliance for Caregiving, a nonprofit coalition of 30-some national organizations that have come together around the issues of family caregiving. We conduct research; develop national programs to support family caregivers, such as our Internet clearinghouse of consumer materials; analyze policy; and work to increase public awareness of caregiver needs and concerns.

In this hearing, we are looking at the role of women as participants in our nation's long-term care system. Long-term care has a female face. Women represent the vast majority of those being cared for as well as those, both paid and unpaid, providing the care. Women have higher levels of chronic illness and disability than men as we age. We have a higher incidence of Alzheimer's disease, for example. And because we live longer than men, more of us will now and in the future require long-term care at home, in community settings and in nursing homes.

And who provides that care? Again, the ranks of paid and unpaid caregivers are filled with women. Data from the Paraprofessional Health Care Institute estimate that 86 percent of paid caregivers are women--those providing hands-on care for the sick and frail--bathing, dressing, and feeding them--through home health agencies, as independent self-employed personal care workers, and in the whole array of nursing homes, assisted living facilities, and board and care homes.

But I would like to talk mostly about the family caregiver, who provides 80 percent of the long-term care in this country. The value of this unpaid family care is estimated by the United Hospital Fund at nearly $200 billion per year--more than the cost of nursing home and home health care combined. Make no mistake: family caregivers are the unpaid extension of our country's healthcare system. Without them, the long-term care system would collapse.

Who are these family caregivers? The national profile of the family caregiver from the national caregiver survey published in 1997 by the Alliance and AARP is a 46-year-old Baby Boomer woman, who works AND spends an average of 18 hours per week caring for her 77-year-old mother. Approximately one-quarter of US households contain someone caring for an elderly relative or friend, and nearly 73 percent of these caregivers are women--our mothers and sisters, daughters and granddaughters.

What else do we know about these women? Nearly one-third are caring for more than one person; more than 40 percent also have children under 18 living at home. They are married, working outside the home, and make considerable sacrifices to be caregivers.
We also know that half of these women are providing at least one Activity of Daily Living--bathing, dressing, feeding, toileting--and nearly a third are providing hands-on personal care for three or more of these activities. When we conducted a factor analysis of Caregiver Level of Burden (that is, hours spent caregiving by the more intense hands-on tasks), more than three-quarters of the Level 4 and 5 caregiving, the most intensive caregiving, is done by women.

What is the impact of caregiving on these women's lives? First of all, we need to remember that most people view caregiving positively--as difficult and frustrating and isolating as it can be. When asked for a single word that defines caregiving for them, most caregivers will pick a

positive term, such as "loving," "rewarding," or "helpful." The biggest reward is seeing that their loved one is getting good care. Nonetheless, caregiving often carries emotional, physical and financial burdens, especially if the caregiver is by herself without other family members to share the burden, if she lives with the older person, and/or if the care recipient is very ill or has dementia. One in four caregivers experience emotional stress and about 15 percent of women report physical strain or physical problems due to caregiving. Financial stress is another matter: on average, caregivers spend $171 per month on out-of-pocket expenses--or approximately $1.5 billion per month--for groceries, medications, home modifications, and the like, for their family member. This is the equivalent of an IRA each year for many women who may not have a pension through their workplace.

In terms of caregiving and work, we see another dramatic impact on women. Three-quarters of caregivers work full or part-time, and half of those who work are making some sort of work-related adjustment. Those workplace accommodations break out as follows:

Go in late, leave early, take time off from work	49%
Take leave of absence	11
Drop back to part-time, take less demanding job	7
Lost job benefits	4
Turned down promotion	3
Chose early retirement	4
Give up work entirely	6

In the MetLife study of the cost of caregiving to US employers, the estimate of annual cost in terms of lost productivity is between $11.4 and $29 billion per year. The MetLife Juggling Act study, which we conducted with Brandeis University, indicated that the cost to "intense" caregivers over a caregiving and working "career" was nearly $600,000 in lost pensions, wages and Social Security.

So, what can be done to help these women who are holding up the long-term care system with their unpaid labor? First of all, they need recognition that their efforts are appreciated and meaningful. The National Family Caregiver Support Program is a step in that direction, but needs to be increased substantially and be given much more visibility to allow the aging network to offer the volume and variety of caregiver support programs needed. Another form of recognition could be a White House Conference on Caregiving and a national public awareness campaign. Second, caregivers need financial support, such as S.627 begins to offer in the form of a tax credit. Third, they need information--about resources; their loved one's illness, treatment, and prognosis; and services for themselves as well as the family member--and training in the hands-on skills necessary to do personal care. Lastly, they need services, whether in the form of respite or counseling or support groups, or in the form of assistance from paid and volunteer caregivers to help with those numerous tasks of personal care.

This past July the Alliance and Partnership for Caring convened a Caregiver Empowerment Summit to develop a National Caregiving Agenda for empowering family caregivers. The Summit participants agreed on a three-point action plan:

1. Strengthen the national coalition of groups engaged in addressing the problems of caregivers.

2. Develop a national public awareness campaign.
3. Develop a grassroots plan to promote activism among caregivers.

Each Congressional office has received a copy of the agenda, and we encourage you to take a look at the agenda and join the Alliance and the other Summit participants in implementing these steps. Congress can play a vital role in accomplishing these goals, not only through legislation, but also by encouraging the administration to develop a White House Conference on Caregiving and calling for a Surgeon General's report on caregiving.

In closing, the Chinese have a saying that "women hold up half the sky." In the case of long-term care, women hold up most of the sky and we need them to continue doing so. Let's give them the support they need.