alzheimer's % association

Testimony of Joanne Vidinsky

San Francisco, California Before the Senate Committee on Aging March 9, 2006

Good morning Chairman Smith and members of the Committee. It is an honor to be here before you this morning, representing the Alzheimer's Association and its views on the role of private insurance in long term care financing. My family's experiences with Alzheimer's disease and the enormous cost of long term care illustrate the need for a comprehensive solution to the long term care challenges created by an aging population and increasing numbers of people of all ages with disabilities.

I am in Washington today to tell you the story of my in-laws and their heroic efforts to cope with the ravages of Alzheimer's disease and the effect of their experience on my brother and me as we helped our mother cope with her desire to avoid becoming a burden on her family.

In 1993, my mother-in-law Velma, then aged 78, showed the initial signs of confusion and memory loss that began her battle with Alzheimer's disease. Over the next 6 years, my father-in-law Joe cared for her at home in Ohio. It was hard for me and my husband to help Joe with the care, both because we were living in California and because he disguised the difficulty of the situation to spare us pain.

Two years after the initial signs of the disease, Velma developed significant cognitive impairment that affected her judgment and ability to take care of herself and her home. At age 83, Velma began behaving irrationally and could not take care of even her most basic daily needs. It was a matter of honor for Joe to take care of Velma himself. However, like many other Alzheimer's families, after years of caring for her, Joe could not do it alone. He had to place Velma in the best nursing home he could find and he paid for her care himself at a cost of approximately \$60,000 a year. In 2001, Velma died after 2 years in the facility, visited every day by her devoted husband.

Joe had been a coal miner and chemical plant supervisor, he was not wealthy. But, he was able to pay for all of Velma's nursing home care because of his savings, Social Security, and retiree benefits. He started working in the mines in 8th grade, and he and Velma lived simply and saved money from every paycheck during their marriage of 63 years. In addition to their savings, Joe had excellent pension and retiree health benefits from his membership in the United Mine Workers union. Joe, at age 91, now lives with Alzheimer's disease in an assisted living facility in San Francisco; his remaining savings pay for his care.

My in-laws' story has had a profound effect on my mother. She wants to avoid becoming a burden to me and my brother. Although she and my father worked hard in sales positions all their lives, their incomes were never high enough for them to save much for their retirement. And, as is common in the service industry, my parents did not retire with pensions or health benefits. My mother lives modestly on her Social Security benefits and a small amount of savings that came from a life insurance policy that my father had when he died from cancer 18 years ago. My mother is typical of most elderly women who live alone; should she become disabled she does not have a spouse to help her remain at home and her financial resources would be drained after only a few months in a nursing home. Despite working her whole life and raising her two children, she would face impoverishment, if it were not for the help she receives from my brother and me.

At age 78, my mother heard about long term care insurance from friends of hers who were buying it to preserve their independence and ability to remain at home. We respected my mother's desire to avoid becoming a burden and remain at home as long as possible and helped her buy a long term care insurance policy. We knew that she could not afford the annual premiums herself. Nor could she have waded through the complicated information available about long term care insurance to arrive at a good decision about which policy to purchase.

So my brother and I took on the responsibility of finding and paying for a policy. We received a brochure in the mail from the government that described the need for long term care insurance and visited several governmental and non-governmental websites that only had general information available. Most of what we learned about specific policy options came from insurance agents.

Luckily, my mother was in good health at age 79. If she already were experiencing symptoms of Alzheimer's disease or another chronic illness, we could not have purchased the policy for her. The policy costs \$10,000 a year and covers the care at home that my mother wants. We also made sure that the policy would pay benefits if my mother had problems with two or more daily activities or the equivalent in cognitive impairment. We decided not to purchase inflation protection or non-forfeiture benefits because of my mother's age and our certainty that we would be able to continue paying premiums or supplement the long term care expenses if necessary. For us, placing \$10,000 a year in other investments might have been more prudent economically, but the trade off is that our mother will not view herself as a burden to us with the long term care insurance policy she has.

My in-laws represent the end of the long term care financing spectrum that can self-insure for long term care, due to prudent budgeting and good retiree benefits. My mother represents the other end of the spectrum. If she did not have children with the financial resources to care for her, she would have to rely on Medicaid if she acquired a disability.

Unfortunately, most older people in this country cannot afford the average annual cost of \$76,219 for nursing home care (*Genworth Cost of Care Study*, 2006) out of their own savings, nor do they have children who can afford to buy long term care insurance for them. The majority of older people must rely on the governmental Medicaid benefits to help them meet their long term care needs, when informal caregiving is no longer enough. This program requires impoverishment of its beneficiaries. There are very few options for those who cannot pay their way, other than to rely on Medicaid.

As a nation, we are only beginning to wake up to the Long Term Care crisis that is brewing. Our Association is pleased that the government is addressing the issue through public education and expansion of the Long Term Care Partnership programs. The Deficit Reduction Act has two important new provisions. The Act creates a National Clearinghouse for Long Term Care Information that will educate consumers about the limitations of Medicaid and provide information that will help consumers choose among private long term care financing options. The Act also allows all states to implement Long Term Care Partnership programs. These programs, which have been piloted in five states for more than a decade, permit people who are able to buy qualified long term care insurance to keep some of their assets, if at some future time they must rely on Medicaid for help with long term care expenses. Creative solutions like the partnership program and education to help people plan for their long term care needs are an essential part of any solution to the challenge of long term care financing. It is important that states and the federal government move as quickly as possible to implement these programs nationwide.

While education and incentives to purchase insurance are important steps, we need to think beyond the current long term care system because it does not work for millions of people who cannot access or afford insurance or are forced into poverty in order to get any help from the government. We believe that the crisis in long term care, fueled by a large and rapidly aging population, requires action now. We should initiate a national dialogue immediately to reach consensus on a viable solution to the long term care financing problem. The exact form of the solution is not clear, though it is clear that current budgetary constraints make it difficult to discuss additional governmental expenditures at this time.

The Alzheimer's Association envisions a public/private partnership for long term care financing that assists people before they are broken by the costs and consequences of their long term care needs. The partnership should ensure that those with few financial resources have access to a means-tested safety net, that people who can plan ahead for their long term care costs are encouraged to do so, and that there is a public sector program that provides a stable base of support and wraps around private benefits. It is important for private sector and public sector benefits to complement one another, with proper incentives and regulations to ensure affordable, meaningful protection.

In the meantime, Congress could take some incremental steps toward meeting families' long term care needs. Simple caregiver interventions, such as respite, counseling, and supportive services can have a major impact on health care costs by delaying nursing home placement. Providing care management for Medicare beneficiaries with multiple, chronic conditions would save hospital and home health costs, and delay the need for institutionalization. In addition, requiring health and long term care plans and providers to identify people with dementia would improve care and treatment for this population. Increased efforts to educate the public about the financial risk of long term care and financial incentives may induce those who can afford it, to do the necessary planning or purchase private insurance.

Chairman Smith, thank you for holding this hearing on private long term care insurance and giving me an opportunity to testify. While it may seem slightly off the point, I am compelled to plead with you and your colleagues to support funding for Alzheimer's research through the National Institutes of Health. I am a grandmother of an adorable toddler, David with another grandbaby due this summer. This is a photo of David on the cover of the Alzheimer's Association Annual Report. To think that this beautiful child may become a victim of Alzheimer's disease and travel the same journey as his great-grandmother Velma overwhelms me with sadness. If we could prevent Alzheimer's disease, or even just slow its progression and delay its onset a few years, we could take a huge step toward relieving a staggering burden on our families and our health and long term care systems. That, perhaps more than anything else, could help us address the looming long term care crisis.

On behalf of the Alzheimer's Association and all the individuals and families we represent, I thank you again for your commitment to these issues and for giving me the opportunity to be here today. I am happy to answer any questions you may have.