

**STATEMENT OF**

**Bill Kays  
(Vienna, Virginia)**

**on behalf of the**

**ALZHEIMER'S ASSOCIATION**

**presented to**

**United States Senate Finance Committee  
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**10:00 a.m.**

Thank you Chairman Grassley and members of the Committee:

It is a true honor to have the opportunity to address you today. I was quite surprised when I received the invitation to testify. However, I have to say that the greatest surprise I have ever had was when I was told ten years ago that my beautiful 60 year old wife, Pearl, had Alzheimer's disease. Her diagnosis came just one year after I had retired from Bell Atlantic with great expectations of travel and all the other wonderful plans we had postponed and saved for our entire married life. It was now too late for any of those plans.

When Pearl was diagnosed, I didn't know how to spell Alzheimer's but I quickly learned that there was no cure, effective treatment or prevention for it. I was devastated.

I cared for Pearl at home alone for six years because I didn't want to interfere with the lives of my children and their careers. I joined an Alzheimer's support group, thank goodness, and they told me that I should start looking for someplace to put Pearl because it was never going to get any better. I put her in day care so that she could get the benefit of a therapeutic program, and so I could have some respite and could start looking at different places and facilities. The day care cost me about \$1,000 a month. At the time, it seemed like a huge expense. But I didn't know how lucky I was to have that option.

Senators, when I started visiting homes where Pearl could be cared for properly, that's when the real shock came. When I found that it would cost between \$4,000 to \$6,000 per month to keep Pearl in a long term care home, I nearly fainted. You see, Pearl needed help with everything at that point – bathing, feeding, dressing and toileting. She would wander away if you took your eyes off her. The title of the Alzheimer's book, *The 36-Hour Day*, couldn't be more accurate. A caregiver's day seems that long.

I had to do something. I was running out of time and choices because Pearl's needs were increasing. After a lengthy search, I finally found a place. It was 57 miles away from our home but it was perfect for Pearl. It is called Royal Haven, Inc. and it is in Front Royal, Virginia. The cost was much more reasonable than anything in the Northern Virginia area and the care matched exactly what Pearl needed.

Pearl went to live at Royal Haven four years ago and it was without a doubt the most difficult decision I have ever made. Three months after she moved there I had a heart attack and quadruple bypass surgery. My doctor told me that the heart attack was caused by all of the stress I endured as a caregiver.

Senators, I am one of the lucky ones. Pearl and I had saved and planned and put off a lot of expenses until my retirement. It is true that we never got to spend it as we had hoped but now we are just barely able to afford her care. Medicare doesn't cover the cost of the home and we're above the Medicaid level. We have no long term care insurance and my pension doesn't have a cost of living (COLA) adjustment each year like many retirees. My out-of-pocket expenses are running over \$25,000 per year, not counting the cost of gas to go visit her twice a week.

I often think about the folks who are less fortunate than I am. I have met many who have had to spend themselves into poverty in order to qualify for Medicaid. My heart goes out to them.

Senators, as you know, the situation is getting worse. The fastest growing population is the group over 65 and they are the ones who will need help. I just read in the *Fauquier Democrat* up in Warrenton where Pearl and I grew up together that according to the 2000 Census, the total population of the county went up by 13 percent but the over 65 population went up by 40 percent. I realize that I am preaching to the converted but as the baby boomers reach their golden years the problem is going to skyrocket.

I would like to thank Chairman Grassley, Senator Graham and others on their proposal for a \$3,000 caregiver tax credit. It would be a tremendous help but it will not begin to cover the cost of care for Pearl and me and millions like us. It is certainly true that we all have to take some responsibility for our care. And the proposed tax incentive for long term care insurance will help some people make better plans for the future.

But the problem cannot be fixed by long term care insurance alone. When Pearl and I were planning for our retirement, long term care insurance really wasn't available. Lord knows, I wish it had been. But even if I had bought a policy, we would have exhausted the benefits by now because of the length of Pearl's illness. Every once in awhile I'll get a telephone call at home from someone who wants to sell me a long term care insurance policy. When I tell them that I am 69 years old, that I have a heart condition and that my wife has Alzheimer's disease and is in a nursing home, the callers quickly hang up.

Senators, I ask that you and your colleagues walk in our shoes for just a short distance. I pray that you will give favorable consideration to the proposed tax credit. But we are going to have to do a lot more to make sure that a family that is unlucky enough to get hit with something like Alzheimer's disease is not financially devastated. We have to develop a better combination of public and private insurance that will fairly share the risk of long term care and will meet everyone's needs in a way that families and the nation can afford.

Before I close, I want to remind you that long term care is about more than just helping families pay for care. It is about assuring the quality of that care. And the biggest single factor that determines quality is staffing. Pearl is getting wonderful care at Royal Haven because the staff is great, and they have been there a long time. But I know from people in my support group, and from what I read in the papers, that this is not always the case.

Taking care of a person is some of the hardest and most important work we ask people to do. We need to recognize them for that work, pay them enough to support their own families, give them a manageable work load, and make sure they have the training it takes to understand how to care for a person with dementia.

Senator Grassley, on behalf of Pearl and every other person who needs long term care, thank you for all that you are doing to improve staffing and quality. Thank you, for your efforts to help ease the financial burden of long term care. And thank you for holding this hearing to remind your colleagues and the country of this urgent national problem.

