REMARKS BY BILL KAYS
ALZHEIMER'S ASSOCIATION
TOWN HALL MEETING ON CAREGIVING
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Thank you Secretary Thompson, Assistant Secretary Carbonell and other distinguished panelists. It is a true honor to have the opportunity to address you today. I applaud the Department of Health and Human Services and the Administration on Aging for holding such a critical forum.

The importance of ensuring the health and wellness of family caregivers cannot be overlooked. It is a lesson that I learned all too well as a caregiver for my beautiful wife Pearl. I lost Pearl to Alzheimer's disease almost two years ago but it still feels like yesterday. She is in my heart and on my mind constantly.

I will never forget when I knew that Pearl and I needed help. Pearl got in the care out in Vienna, Virginia where we lived. I said, "Darling, where are you going?" She said, "I'm going to Safeway, I'll be right back." It was only five blocks away, but three hours later she still wasn't back. I was frantic. Finally she pulled in to the driveway and parked the car without getting out. I walked up and said, "Darling, where have you been?" She looked at me with tears running down those beautiful cheeks and said, "I've been lost." We went in the house, had a good cry together and concluded that we needed professional help. Shortly after, Pearl was diagnosed with Alzheimer's disease. She was 60 years old. 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. 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.

Like so many other caregivers, I made the decision to care for Pearl at home. I cared for her alone for six years alone because I didn't want to interfere with my children's lives and careers. They called each evening asking - "How did Mom do today?" Regardless of how horrible my day had been, I invariably replied - "She did pretty well." My motto was if you're not happy - fake it. I know a lot of caregivers do that and keep things pinned up inside themselves. Therein lies a major cause of health problems for us. I thought that no one could care for my wonderful wife better than I could. As Pearl's disease progressed and her needs grew, my caregiving responsibilities became more intense. My children, seeing how exhausted I was and how much stress I was under, begged me to get help. They researched services available in Northern Virginia, gave me the phone number for the local area agency on aging and even volunteered to make calls to agencies for me. I told them I didn't need help, that I could do it on my own and that I was fine. They pushed and nagged me until I finally agreed to call the Alzheimer's Association. I called the local chapter and they got me into an Alzheimer's support group. The people in the support group knew what I was going through and offered many helpful solutions to the difficulties I experienced taking care of Pearl. The support group helped me realize that I couldn't do it on my own. 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 support group 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 I could have a break from caregiving. Having Pearl in a day care program also allowed me to start looking at different long term care facilities.

After a lengthy search, I finally found Royal Haven, a facility in Front Royal, Virginia, 57 miles away from our home but it was perfect for her. The cost was much more reasonable than anything in the Northern Virginia area and the care matched exactly what Pearl needed. The day I moved Pearl to Royal Haven was the most difficult day of my life. But it probably saved my life. Three months after she moved to Royal Haven I had a heart attack and wound up having quadruple bypass surgery. My doctor told me that the heart attack was caused by all of the stress I endured as a caregiver and the consequences of neglecting my own health for many years.

The whole time I was caring for Pearl at home I didn't go to the doctor because I couldn't leave Pearl alone. I couldn't go for a walk because I had to look out for Pearl. Even when I put Pearl in day care and had a little time to myself, I concentrated on finding a place that could take care of her, rather than seeing my doctor or getting some exercise or just sitting down for an hour to have a healthy, relaxing meal.

My heart attack and bypass surgery was a wake-up call. When I got out of the hospital I made changes in my lifestyle, started exercising more and began to look out for other caregivers I knew. As a support group facilitator, I made sure I told the caregivers I counseled to take a break, go to the doctor, reach out for help. I give talks all over Northern Virginia and I tell people about what happened to me. I hear a lot of excuses from caregivers - I don't have time or there's no one to watch my husband if I go to an exercise class. I ask these caregivers what would happen to their loved one if they had to be in the hospital for a few days or broke their arm and couldn't even dress themselves, not to mention the person they were caring for.

Caregivers today have a lot of resources to turn to. I was lucky to get help from the Alzheimer's Association and other organizations like the area agency on aging. There is so much more awareness about caregiving now and the toll that stress takes on the caregiver. Even the federal government has increased its commitment to family caregivers through the National Family Caregiver Support Program. The National Family Caregiver Support Program ensures that caregivers in every state can get information, counseling, caregiver training, respite care and other services they need to help take care of their loved ones. The Alzheimer's Association also offers programs on managing caregiver stress, promoting caregiver health and supervising nutrition for persons with Alzheimer's. Local chapters offer respite care to enable caregivers to take a break, go to the gym or spend an afternoon with friends. Funding from the National Family Caregiver Support Program has allowed a number of Association chapters to expand their respite care programs. The Association is also funding a study to evaluate the impact of an in-home exercise program on the health of persons with Alzheimer's disease and their caregivers. And because caregiving is a 24-hour a day job, the Administration on Aging recently awarded nearly one million dollars to the Alzheimer's Association to operate a National Call Center so that caregivers and people living with Alzheimer's can have access to information, counseling and support around-the-clock. The Association is looking forward to expanding its collaboration with AoA and others in the aging services network.

Secretary Thompson, Assistant Secretary Carbonell, thank you again for inviting me to speak today and for your steadfast leadership in supporting our nation's family caregivers. You are to be commended for your dedication and commitment to helping such a critical part of our long term care system.