

**TESTIMONY OF
DONNA K. HARVEY
EXECUTIVE DIRECTOR
HAWKEYE VALLEY AREA AGENCY ON AGING
WATERLOO, IOWA**

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Each day, our agency receives calls from older individuals and their families requesting assistance to stay in their own homes. Many of these older individuals are embarrassed and frustrated that they have to turn to a public agency for assistance. They believed that they had worked hard, paid into a retirement plan, saved some monies, and prepared well for their later years. Fortunately, and unfortunately, persons are living longer than before and exercise their right to remain at home as long as possible. The unfortunate part is that funding for assistance is very limited and very few persons have purchased long term care plan or have adequate resources to purchase all the needed services to facilitate this continued independence.

The Medicaid Waivers available for frail elders in many states have allowed persons meeting all the guidelines to receive assistance with in-home services to provide the necessary assistance to maintain their independence. However, not everyone qualifies for the Waiver. Medicare is also limited, as you know, to persons who are homebound. While this offers limited services to a few more older persons, there is still a great number who do not meet either Medicaid or Medicare criteria.

Few persons purchased any type of private health insurance or long term care insurance that assists with the costs of in-home cares. Older persons attempting to purchase plans find them to be very expensive and limited due to their age at time of purchase.

Today, I would like to share with you about a 69 year old female who has and is facing challenges to staying in her own home due to lack of planning for the need for long term care services in order to stay in her own home.

Mr. and Mrs. L had planned to retire happily together and to live comfortably on Social Security and Mr. L's retirement from his teaching career. Mrs. L did not work outside the home while raising three children. In 1978, they purchased a small motel in a small community in northern Iowa which was managed by Mrs. L while Mr. L continued to teach in the Waterloo/Cedar Falls area. Mr. L passed away in 1985 before retirement. Mrs. L could not afford to maintain the motel without his income and was forced to sell the establishment and relocate to Waterloo to be near two of her children, Mrs. L was diagnosed with multiple sclerosis in 1978 but was in remission for 12 years and 9 days (1989).

In 1994, Mrs. L's doctor suggested it was time for her to seek assistance with her cares. At that time, she was receiving Beta Seron treatments which cost her approximately \$ 1,000 per month. By this time, Mrs. L was attempting to live on her Social Security income of \$593 per month. Mrs. L paid \$360 per month for her home which she rents. Her son had purchased a health care plan on her behalf, however, it was limited in its coverage. Her children attempted to assist with her cares and expenses but they had obligations with their own families. Mrs. L began placing some of her medical expenses on credit cards in order to maintain her treatments as this seemed to be her only option.

A hospital social worker began working with Mrs, L to identify services needed and funding to provide them. Mrs. L was very reluctant to accept assistance as she believed there were other who might need help more than she did. She also was not prepared to share the need for assistance as she and her

husband had felt they were prepared for retirement. She eventually agreed to receive home delivered meals and to have a visit from the Case Management for Frail Elders program administered through Hawkeye Valley Agency on Aging. After an assessment and intake process, Mrs. L was enrolled into the Project HOPE for Frail Elders which provided her Section 8 assistance and limited services on a participation basis (20% of the cost). Although Project HOPE assisted Mrs. L with rental costs and some of her services, she could not afford to pay the 20% co-pay. It was determined that she did meet the guidelines of the Medicaid Waiver and she began receiving that assistance in December, 1994.

Today, Mrs. L's income is \$702 per month and she is receiving nursing services, home care aide, chore services, home delivered meals, Section 8 assistance, her home has been modified to be more accessible, and equipment has been purchased to allow her to remain at home. Mrs. L is a wonderful, caring individual and loves to share stories about her husband and is proud of the fact that he served on Admiral Bird's last expedition to Alaska through the United States Navy. She has a burial plot in a military cemetery in Minnesota beside her husband. She has no life insurance due to her inability to keep the payments current and is concerned about how she will be buried.

This story is not unique or unusual. With time, we could tell more devastating and emotional stories. While attempting to identify someone to appear and share their stories themselves, there were several underlying issues: embarrassment about their inability to meet all obligations without assistance when they believed they had planned well for their retirement; emotional exhaustion with dealing with all the funding issues involved; and caregivers who were unable to leave their loved ones either due to their own declining health or their inability to locate someone to provide care in their absence.

Local organizations are working hard to locate funding and services to build and maintain a long term care system to allow older persons the ability to remain in their communities and, particularly, in their own homes. It is more apparent every day that education needs to occur with persons aged 20 and over on their responsibility to be aware of their future and what may lie ahead. While we know it is impossible to prepare for every crisis, we believe persons will always want to remain in their own homes and to maintain their independence. When the need arrives for extra assistance, a system to support these cares must be established and funded beyond Medicaid and Medicare. Most importantly, ongoing education of the needs and issues involved must be shared openly and frequently.