



**National  
Multiple Sclerosis  
Society**

**Greater Connecticut Chapter**

659 Tower Avenue, First Floor

Hartford, CT 06112-1269

Tel: 860.714.2300; Fax: 860.714.2301 [www.ctfightsms.org](http://www.ctfightsms.org)

**Western Connecticut Chapter**

One Selleck Street, Suite 500, Norwalk, CT 06855

Ph: 203.838.1033; Fax: 203.831.2973 [www.msswct.org](http://www.msswct.org)

1.800.FIGHTMS (800.344.4867)

**The Human Services Committee, March 13, 2007  
Testimony in support of HB 7323, An Act Concerning Long-Term Care**

To: The Honorable Jonathan Harris, Senate Co-Chair, Human Services Committee  
The Honorable Peter F. Villano, House Co-Chair – Human Services Committee  
The Honorable Eric D. Coleman, Senate Vice Chair, Human Services Committee  
The Honorable Catherine F. Abercrombie, House Vice Chair – Human Services Committee  
The Honorable John A. Kissel - Senate Ranking Member – Human Services Committee  
The Honorable Lile R. Gibbons - House Ranking Member – Human Services Committee  
and Distinguished Members of the Human Services Committee

**Thank you for the opportunity to submit testimony. The National Multiple Sclerosis Society supports HB 7323, An Act Concerning Long Term Care. We urge the Human Services Committee to pass this legislation which provides language for the development of a state funded pilot homecare program for people with disabilities between the ages of 18 – 64.**

My name is Susan Raimondo and I serve on the Long Term Care Advisory Council as the family caregiver representative. I also work for the National Multiple Sclerosis Society as the Community Programs Director. I have lived with multiple sclerosis in my family for over 30 years and worked at the MS Society for 20 years.

Many individuals with disabilities between the ages of 18-64 are not covered by current Medicaid Waivers or state-funded programs to receive homecare. They need help with activities of daily living and may have limited family support, have cognitive impairment, and/or have needs that change and progress over to those 65 and older. The Medicaid Personal Care Assistance (PCA) Waiver requires that individuals have the strength and ability to self-direct their care.

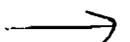
Who this can help

During state fiscal year 2003, 7,436 people under age 65 received care in a Connecticut nursing facility. Currently 10% of nursing home residents in Connecticut are younger than age 65. This proposal will also help individuals who are at risk of institutionalization. Many of these people, who have cognitive and other significant impairments, could live in the community with the right services, support and help managing their care. People with chronic illnesses and disabilities caused by such diseases as Huntington's Disease, Parkinson's Disease, Alzheimer's Disease, Multiple Sclerosis and HIV/AIDS are likely to be helped by this legislation.

The development of a state-funded pilot program for not more than 50 adults with disabilities aged 18 to 64 that would be similar to the current Connecticut Home Care Program for Elders (CHCPE). This pilot would include:

- Case assessment and monitoring (CAM).
- Services similar to those offered under CHCPE with the addition of personal care assistance.

**Case assessment and monitoring services are essential for a population which has cognitive or other significant impairments whose needs cannot be met by the self-directed care model. We need options and alternatives to nursing home care. This legislation offers hope and help**



**for many families.**

**I am one of those families....**

Every day of my life is impacted by family caregiving responsibilities and disability. I saw MS gradually rob my mother of her abilities and dignity. She spent the last eight years of her life in a nursing home because our family had no other options. In 1992 when she entered the nursing home there were no home and community based programs to provide long term care services at home for people in their 50's. My mother passed away in 1999.

I married my husband Tom in 1991 and knew that he had MS, yet never thought we would face a similar course of disability. My husband has secondary progressive multiple sclerosis. At the age of 34 he had his first stay in a nursing home. Tom, now 42 years old, is a quadriplegic and has partial use of one arm. He uses an electric wheelchair and often he becomes so weak that he cannot drive his wheelchair or he loses his voice and cannot speak. Over the past ten years he has been hospitalized many times and stayed in a nursing home three times. Each time, the care in these facilities gets worse and worse. My husband's needs exceed the level of care that he receives when he is in the nursing homes. Staffing is limited and they do not have the training to use the equipment to safely transfer him in and out of his wheelchair.

I am very fortunate because we have a strong support system and we have been able to bring him home after these stays in the nursing homes. We have an accessible home and an electric hoist lift for transferring him in and out of the wheelchair. Still, caring for my husband, as his disease progresses, is an ongoing challenge. We don't have insurance coverage that will pay for personal assistants or ongoing homecare. I rely on my 70 year old mother-in-law to care for my husband every day while I am at work. Weekends, mornings and evenings are my responsibility. Tom sits in his wheelchair all day, however if he needs to use the toilet, my mother in law must transfer him. My husband needs to be fed and often chokes on his food. He cannot be left alone.

My husband was a civil engineer before MS took over and he was forced to stop working. He does not qualify for the Medicaid Personal Care Assistance Waiver, like many individuals with MS and other acquired disabilities, his income from Long term Disability and Social Security Disability Insurance puts him about slightly over income for the program. We have not applied for the waiver because we both have very small retirement savings plan and we do not want to risk losing it.

I am fearful of the day when my mother-in-law can no longer help us. What is going to happen? I cannot quit my job to stay home with him. I work full-time and would need someone to manage his care, like a care manager to coordinate helpers and doctors appointments.

My story is not unique. Like many other family caregivers living with a person with disabilities, we are managing but are always living on the edge. We need help in order to continue to care for our family members.

Our loved ones are individuals who have acquired disabilities that change over time, people not eligible for Medicaid because of possessing a small savings or retirement account or who have incomes only slightly above the allowed amount, and people who are too sick or cognitively impaired to manage their own care. We could benefit from this pilot program that would provide home care including care management for people with disabilities between the ages of 18 -64.

**The National Multiple Sclerosis Society and I urge the Human Services Committee to pass HB 7323, An Act Concerning Long Term Care.**

**Thank you.**

Susan Raimondo, Community Programs Director Phone: 860.714.2300, [sraimondo@ctfightsms.org](mailto:sraimondo@ctfightsms.org)