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Multiple Sclerosis
Society

The National Multiple Sclerosis Society appreciates the opportunity to provide testimony to the Commission on Long-term Care. The Society works in strong partnership with the Leadership Council of Aging Organizations (LCAO) and the Consortium for Citizens with Disabilities (CCD), as well as Advance CLASS, Inc. and hereby supports all principles and cornerstones submitted by those entities.

Because people living with multiple sclerosis have unique and varied needs, the Society submits this additional information for the Commission's consideration to help ensure that the long-term services and support needs of people with MS are met. Should you have any questions, please contact Laura Weidner, Director of Federal Government Relations at laura.weidner@nmss.org or 202-408-1500.

What is Multiple Sclerosis?

Multiple sclerosis (MS), an unpredictable, often disabling disease of the central nervous system, interrupts the flow of information within the brain, and between the brain and body. Symptoms may be mild, such as numbness in the limbs, or severe, such as paralysis or loss of vision. One of the most unique aspects of MS is that the progress, severity, and specific symptoms of MS are unpredictable and vary from one person to another. While there are cases of pediatric MS, most people with MS are diagnosed between the ages of 20 and 50 which leads to another unique quality of MS—that once diagnosed, the unpredictable physical and emotional effects are life-long.

Types of MS: For most people with MS, the disease is initially characterized by periods when symptoms intensify (relapses) and quiet periods (remissions). As time goes along, many individuals will transition into a more progressive course with continuously increasing disability. The future is uncertain, regardless of the initial disease course. For a smaller percentage of people with MS, the disease is progressive from the time of diagnosis.

Treatment of MS: The cause of multiple sclerosis is unknown and there is currently no cure for the disease. There are now ten FDA-approved drugs for people with relapsing MS that slow disease progression and may forestall disability, as well as drugs that help manage the symptoms of MS. There are no treatments available for people with the most severe form of the disease—primary-progressive.

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People with MS and Employment: Approximately 60% of people living with MS are working when they are diagnosed. Several years down the road, the percentage remaining in the workplace drops to around 40%. The number of people with MS working declines over time for a variety of reasons: increased disability and inability to work; lack of awareness of rights afforded to them in the workplace; employers becoming unsympathetic to needs of workers, particularly because of the hidden symptoms and sporadic nature of MS; or leaving the workplace voluntarily to prioritize their well-being.

Long-term Services and Supports Needs of People with MS

Approximately 20-25% of individuals with MS need long-term care (LTC) services and approximately 5-10% will require residential care. People with MS often require assistance with activities of daily living (ADLs) such as bathing, dressing, eating, walking, and toileting and/or instrumental activities of daily living (IADLs) such as housekeeping and managing finances. While some require assistance for a few hours a week, others need full-time assistance.

MS is a family affair. Family members are usually the primary providers of care and assistance to their loved ones with MS. They also carry most of the financial burden for long-term care since third party insurance and community social services don't usually underwrite on-going, chronic care services. Stress and tension in households often arise as family members must adapt to new roles and responsibilities. Breakdown of families struggling with daily care issues and financial concerns is common.

Community support. Since Medicare does not pay for ongoing home care services, when the personal care needs of the individual with MS exceed the resources of the family, access to Medicaid home and community-based services becomes critical. Home health care workers and personal care attendants are often the gateway to independence for people with MS. However, these workers are typically underpaid and often lack benefits such as sick time and health insurance. Adult day centers provide excellent support for the person with MS while also giving his/her family caregivers much needed respite—but more adult day centers that specialize in the MS population—particularly young adults with MS—are needed. Assistive technology, accessible transportation and housing are other key elements in the promotion of independence of people with MS.

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Residential Care. When community life is no longer feasible and 24 hour skilled care is required, quality, age-appropriate assisted living and nursing home programs must be available. Most nursing homes are currently not equipped for a younger disabled population who use power wheelchairs and have complex care needs.

Long-term Care Principles Important to People with MS

In addition to the principles submitted by LCAO-CCD and Advance CLASS, Inc., the National MS Society finds the following LTC principles of utmost importance:

Consumer choice: People with MS must be free to choose from a full range of age appropriate and affordable home, community-based, and facility-based health and social service options to meet individual needs and preferences.

Promotion of the least restrictive setting: People with MS should be supported to remain at home and in the community for as long as possible. Nursing home residents should be able to transition back to community living when appropriate and feasible. At the same time, quality, age-appropriate assisted adult day, living and nursing home options must be available.

Access to appropriate and coordinated MS clinical care: People with MS must have affordable access to MS specialists, durable medical equipment, rehabilitation, and treatments. Clinical services must be physically accessible, of high quality, comprehensive in nature, and coordinated among providers.

Support for the caregiver: The role of families in providing long-term care must be recognized and supported, the Society suggests through refundable tax credits for family caregivers and increased access to quality respite care.

Decreased financial burden on families: Tax benefits and other sources of services, and financial assistance not requiring impoverishment for eligibility, must be available to at least partially offset the high costs of long-term care.

Wider range of housing choices: A wide range of accessible and affordable housing options including financial assistance for home

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accessibility and modifications for individuals and families must be available.

Enhanced use and access to assistive technology: There must be greater awareness of the role that assistive technology can play to keep people with MS independent. Options must be available to ensure that people with MS have access to this technology when needed.

Personal Stories of People with MS with LTSS Needs

Michael Ogg, New Jersey Resident who Lives with Primary Progressive MS, Age 58

Michael Ogg was diagnosed with primary progressive multiple sclerosis in 1997 at age 42. He was in the prime of his life, working as a physics and software engineering professor at major Universities. Within eight years, Michael couldn't move his legs or left arm. Now, the 58-year old is functionally quadriplegic, retaining only partial use in one arm. Although technologies such as speech-to-text software and the iPad allow Michael to communicate with others and to control the lights, heat, and locks to his house, he is essentially completely dependent on others for all daily activities.

Michael is divorced and lives alone. He must rely on his two home aides for everything from getting out of bed to bathing to emptying his catheter of the urine that collects over the course of a day. In the hours between his morning aide's departure and his night aide's arrival, Michael's MS has rendered him helpless if something goes wrong: once, while heating up his dinner, Michael spilled it, scalding his flesh and leaving him helplessly burned until EMTs could arrive. Michael's aides don't just help him through his days--without them, he could not stay at home and would have to move into institutional living.

In terms of life planning, Michael was incredibly conscientious and "did everything right." After disability stopped him from working at age fifty, he spent most of his savings on a one-story, ranch-style house. He spent over \$150,000 out of pocket to make his new home as accessible as possible. Knowing he has a progressive disease, thinking ahead, Michael also purchased long-term care (LTC) insurance from his last employer. Because his LTC policy has a lifetime cap, however, his coverage will run out in four short years. Michael set up a Special Needs Trust (SNT) and has been trying to qualify for Medicaid, but as someone who worked and smartly saved throughout his life—even with the high cost of treating MS

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and paying out of pocket to make his home accessible—he cannot meet Medicaid’s incredibly low income eligibility requirements.

Despite his planning, Michael’s likely future is this: he will use up the remaining funds in his LTC policy, use the remainder of his savings for LTC, and when he runs out of money, Michael will finally qualify for Medicaid. Spending down into Medicaid will make supporting his daughters (ages 16 and 13) very difficult. Medicaid will have a lien on Michael’s SNT, and if he is not bankrupt before he dies, the lien has to repay what was spent on his care, leaving his daughters little to no inheritance despite his careful lifelong financial planning.

Michael was fortunate enough to be able to obtain and afford long-term care insurance, but it falls vastly short of meeting his needs. The significant and long-term impact of his disease make the out-of-pocket costs of LTSS cost-prohibitive, leaving people like Michael with a choice between bankruptcy or having to leave home and enter a nursing home prematurely--where Medicaid will eventually become the payer. As our population ages and more and more people need long term services and supports, Michael urges Congress to address the lack of accessibility to LTSS and to create more affordable and flexible LTSS options.

Kathryn Romig, New Mexico Resident who Lives with Primary Progressive MS, Age 44

After experiencing numbness in her hands for a few years, Kathryn Romig was diagnosed with primary progressive MS the same month she turned 30 years old. Kathryn managed to continue working in state government until her benefits vested and then retired on disability. Now, at age 44, Kathryn’s MS has progressed to the point that she requires total assistance for all activities of daily living. Kathryn’s mother Edith Powers provides full-time emotional, physical, financial support whether Kathryn is at home, hospitalized or in nursing facility. Adding complexity, Kathryn recently found out that she has Stage 4 lung cancer.

As they continue coping with MS and fighting lung cancer, of most importance to Kathryn and her mother is that America and its government realize that affordable, flexible long-term supports and services are not just needed by older adults, but also younger adults with disabilities or chronic conditions like Kathryn. Supportive housing, nursing home facilities and adult day programs that better understand and serve younger adults are particularly important. Kathryn and Edith also stress the need for better support for family caregivers—as they are the backbone of our

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nation's long-term care system—particularly in terms of the financial consequences of family caregiving.

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