



National
Multiple Sclerosis
Society

Please Support the Lifespan Respite Care Program

What is multiple sclerosis (MS)?

- MS is an unpredictable, often disabling disease of the central nervous system.
- MS interrupts the flow of information within the brain, and between the brain and body.
- Symptoms range from numbness and tingling to blindness and paralysis.
- The progress, severity and specific symptoms of MS in any one person cannot yet be predicted.

MS and Long-term Services and Supports

- Up to **25% of people living with MS** will require long-term care services at some point.
- A 2012 National Alliance for Caregiving (NAC) survey of individuals providing care to people living with MS shows that :
 - On average, caregivers spend **24 hours a week** providing care.
 - 64% of caregivers were emotionally drained, 32% suffered from depression, 25% could not focus at work, and 22% have lost a job due to caregiving responsibilities.
 - 66% said respite care would allow their care recipient to live at home longer.

Respite Care

- Respite care offers professional short-term help to give caregivers a break from the stress of providing care.
- Respite is the most frequently requested support service among family caregivers, yet a 2009 NAC-AARP report revealed that nearly 90% receive no respite.
- Respite has been shown to provide family caregivers with the relief necessary to maintain their own health and bolster family stability.

Request

The National Multiple Sclerosis Society urges Congress to provide **\$2.5 million for the Lifespan Respite Care Program in Fiscal Year 2014** and to reauthorize the program.

Background on the Lifespan Respite Care Act

- In 2006, President Bush signed the Lifespan Respite Care Act into law (P.L. 109-442).
- According to a 2011 AARP report, 61.6 million family caregivers provided care at some point during 2009 and the **value of their uncompensated services was approximately \$450 billion a year.**
- The Lifespan Respite Care Program (LRCP) provides grants to state agencies to maximize existing resources and ensure that respite is available and accessible to family caregivers by establishing or enhancing statewide respite systems.
- States are mandated to: provide planned and emergency respite services, train and recruit workers and volunteers, offer information to caregivers about support services, and assist caregivers in gaining access to services.
- Unlike much existing respite care, the LRCP serves families regardless of special need or age.
 - Currently more than half of care recipients (56%) are under age 75, and almost one-third (28%) are under age 50 reflecting the need to offer respite across the lifespan.
- Despite modest funding, state grantees have made significant steps such as identifying and coordinating available respite services, building respite capacity, and raising awareness about respite.