



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 Program

- 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.



In more than 15 years of providing day-and-night care for his wife, Pam, Ray Heron has never looked back. Pam was diagnosed with multiple sclerosis (MS) in her mid-30s, after bouts of double-vision. Pam disclosed her diagnosis to her employer, which, after a few years, asked her to go on medical leave but covered Pam's first power wheelchair and provided long-term disability benefits. Ray's employer was not so supportive; within three years he was encouraged to leave (he believes in order to get Pam's growing expenses off his employer's health insurance policy). Pam had become completely dependent on her wheelchair by 1995 and has needed round-the-clock care since the late 1990s. Pam wants to remain at home and is able to do so with in-home care and Ray, her husband and family caregiver.

"Medicare kicked in, and then Social Security Disability," remembers Ray who took temporary work where he could for a few years. The couple has three sons (one of whom has since been diagnosed with MS) who had all moved out of the house by this time. Since 1999, Ray has worked at a small furniture store while Medicaid covers nine hours of certified nurse assistant (CNA) care for Pam each day. Ray, now 62, hasn't had health insurance for himself in nearly two decades.

Ray gets up each morning at 6:00 a.m. "I get Pam out of bed with the lift, take care of her bladder and bowel needs, then wash her and get her into her wheelchair. Then the CNA arrives so I can leave for work." Pam's CNA feeds her breakfast, lunch and dinner, and manages her other needs including positioning to avoid pressure sores. Pam can be in her wheelchair for four hours at a time, then she must be on the alternating-air mattress on her hospital bed. "After I get home," says Ray, "we watch TV and talk. I scratch her nose for her or smooth her hair until bedtime."

When Ray heard about Virginia's Lifespan Respite Voucher Program in the course of his volunteer activism with the National MS Society, he called the agency that provides Pam's care and discovered that the vouchers would fill the gaps in Pam's Medicaid-paid care for up to three days. Due to his caregiving responsibilities, Ray hasn't been able to visit his parents – a six-hour drive away – for years and will use the voucher for much-needed respite to visit them soon.

After nearly 39 years of marriage and extreme challenges caused by MS, Ray considers the couple to be "extremely lucky if you're going to have MS. Pam's unable to do anything physically, but has very little cognitive disability." Ray is proud to call himself a family caregiver and happily points out a priceless benefit: "I still get to spend every day with Pam."

Since 2009, Lifespan Respite grants have supported better coordination and delivery of services to family caregivers like Ray in 30 states and the District of Columbia. Vouchers to help family caregivers pay for respite are or will soon be made available in a few other states, and the program needs ongoing funding. Our nation's more than 60 million family caregivers save our government \$450 billion annually and – perhaps more importantly – enable loved ones to stay at home surrounded by their support networks and connected to their communities. Ray and Pam wouldn't have it any other way.