National
Multiple Sclerosis
Society

Family caregivers need relief now: Cosponsor the Credit for Caring Act

Caregiving and families impacted by MS

- While breakthroughs in MS research have helped the estimated 1 million Americans diagnosed with MS live more independently, up to 58% receive informal (non-professional) care from family members.
- Family caregiver responsibilities may include emotional support as well as hands-on assistance with daily activities (e.g., transportation/mobility, coordination of in-home care, medication management)—which are time-consuming and often necessitate time away from work, and loss of income.
- The unpredictable nature of MS – from relapses and disease progression – further complicate the demands of caregiving, as day-to-day responsibilities can widely vary.

There are significant financial challenges to caring for loved ones

- An estimated **40 million family caregivers** in the U.S. provide **$470 billion per year in unpaid care,** with 7 in 10 using their own money to cover care expenses.[1]
- Recent reports suggest family caregivers spend an average of **20% of their income** – nearly $7,000 per year – on caregiving costs.[2]
- **39% report financial strain**, including forgoing savings or dipping into retirement funds to cover expenses, with the highest burden falling on younger caregivers and those who are Black or Hispanic/Latinx .[3]
- Caregivers of people living with MS spend an average of **6.5 hours a day** dedicated to caregiving responsibilities.[4]
- Nearly 45% of family caregivers report negative financial impacts such as debt, and **86% indicate needing funding assistance to pay for in-home care.**

The Society proudly supports the Credit for Caring Act (S. 1670/H.R. 3321)

- Creates a new, non-refundable federal tax credit of up to $5,000 for 30% of long-term care expenses to help relieve the financial burden placed on family caregivers.
- The credit would count towards qualified, documented expenses paid by the caregiver above $2,000 to help defray the cost of home health care, adult day care, transportation and travel costs, respite care and other support - helping family caregivers continue to work.
- Could enable more people living with MS to receive care at home from loved ones, saving taxpayer dollars by preventing premature and expensive nursing home care and avoidable hospitalizations.

What is multiple sclerosis (MS)?

- MS is an unpredictable, often disabling disease of the central nervous system.
- The progress, severity and specific symptoms of MS in any one person cannot yet be predicted.
- Nearly 1 million people in the United States live with MS.

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[1] https://www.aarp.org/research/topics/care/info-2015/national-survey-family-caregivers.html
[2] https://www.aarp.org/research/topics/care/info-2015/national-survey-family-caregivers.html
[3] https://highlandcountypress.com/Content/In-The-News/Headlines/Article/AARP-research-shows-family-caregivers-face-significant-financial-strain-spend-on-average-7-242-each-year/2/73/69893
[4] https://pubmed.ncbi.nlm.nih.gov/26078487/

Cosponsor the Credit for Caring Act Now

Michael Olex, Virginia

We were diagnosed with MS about 15 years ago. I use the term "we" because while I live with the disease, MS has significantly impacted my wife, Amy. In addition to working full-time as a senior bioinformatics specialist at a major medical university, Amy has become the caregiver for our family due to the significant progression of my MS. MS is unpredictable – through the years, I have had facial paralysis, deafness, and used a walker, cane and scooter. **Currently, I use a power wheelchair, as I am no longer able to walk or stand without assistance.** In addition to the normal, motherly duties she does for our two 13- and 11-year-old kids, Amy has to help me with everyday tasks, like getting dressed and cooking. **Amy is invaluable to my survival** – I cannot go through this journey without her. She supports me, and I support her, but caregiving can be exhausting – and **the financial costs of caregiving only add to the stress of everyday life for Amy.**

We had to add a handicapped accessible addition onto the back of house so that I can move around as independently as I can. If I have even a minor infection, **Amy has to take off work to help me**, which happens about once a month. My legs don't pick up anymore, so we needed to purchase a wheelchair van with hand controls – this was approximately **$25,000.** Traveling to and from appointments together regularly costs us over **$200** in gas and tolls. For the bedroom, we purchased a power bed so I can sit up, a ladder to be able to pull myself up and a bed railing. This was probably **$800.** Incontinence supplies can cost up to **$100 monthly.**

> "Because of services and equipment needed, **MS has become a line item in our monthly budget.** The disease has become a part of the family, regardless of how welcome it is."

As Amy helps me sit up on the bed, she does not need to be worrying about how much the bed railing costs to help her with this essential task. She does not need to be burdened by the cost of caregiving.

Stand by my family and the millions of caregivers who are navigating this crucial role without the financial support they need. **Cosponsor the Credit for Caring Act now.**