



SUPPORT FAMILY CAREGIVERS OF INDIVIDUALS WITH SMA

Expand paid family caregiving opportunities and increase access to respite care

DID YOU KNOW?

- Family caregivers are family members who provide paid or unpaid assistance to a person with a chronic illness or disabling condition. ([Source: Centers for Medicaid and Medicare Services](#))
- Approximately 1 in 5 Americans (or about 53 million) have reported caring for an older adult or a person with a disability during the last year. ([National Alliance for Caregiving](#))
- Family caregiving can cause a heavy emotional, physical, and financial toll, with 65% of family caregivers of older adults and people with disabilities reporting that providing care interfered with their job and 75% saying short-term help, known as respite care, would allow them to care for their loved one longer. ([Source: U.S. Department of Health and Human Services](#))
- Many individuals with spinal muscular atrophy (SMA) have reported significant challenges in finding and retaining qualified caregivers. ([Source: Cure SMA](#))

CURE SMA POSITION

To help address the caregiving challenges and shortages in this country, Congress should help support family caregivers by:

- Fully funding the Lifespan Respite Program at the U.S. Department of Health and Human Services. These funds will help to expand the availability of respite care for family caregivers.
- Incentivizing states to pay family caregivers of children and adults with SMA and other disabilities.

WHY CONGRESS SHOULD ACT

Family members of individuals with SMA and other disabilities may take on caregiving duties to assist their loved one in their activities of daily living. Researchers have [studied](#) the emotional, physical, and financial toll caregiving can take on a family caregiver of an older adult or person with disabilities. Recognizing the enormous contributions family caregivers provide to their families and society, Congress [extended](#) respite care services through 2024. However, the [Lifespan Respite Care Program](#), which assists states in making respite care available to family caregivers, has been historically underfunded. In addition, some states [allow](#) Medicaid beneficiaries who manage their own long-term services through a [Medicaid Self-Directed Care program](#) to hire family members as caregivers. Unfortunately, not all states allow for paid family caregiving, which could help address the caregiving needs and direct care workers shortages that exist across the country.



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[Cure SMA](#) is a national organization that advocates for individuals with spinal muscular atrophy, a progressive neurodegenerative disease that robs people of physical strength, taking away their ability to walk, swallow, and breathe.