



STUCK INSIDE: A NATIONAL REPORT ON CAREGIVING FOR INDIVIDUALS WITH SMA

Key Findings from Cure SMA's *Stuck Inside* Report

- Individuals with SMA, on average, require **1 to 3 caregivers** to cover 100 or more caregiving hours a week. Top caregiving needs include wheelchair transfers, bathroom support, and household duties, such as laundry, shopping, and light housekeeping.
- **37 percent** of individuals with SMA receive fewer paid caregiving hours from their state than what they need to maintain their health and independence. About one-third of individuals with SMA who sought additional paid caregiving hours from their state through an appeal were denied.
- **86 percent** of individuals with SMA and their families struggled to find caregivers and **62 percent** reported difficulty retaining caregivers. The SMA community's most difficult caregiving shifts to fill were for nights and weekends.
- **79 percent** of individuals with SMA relied on a non-paid caregiver (i.e., parent, partner, relative, or friend) to assist with their activities of daily living. Many individuals with SMA fear for their own safety and independence if their family caregivers become unavailable due to health, injury, or other reasons.
- **41 percent** of individuals with SMA said they declined a job or school opportunity that was out of state for fear of losing their caregiving services.
- **27 percent** of adults with SMA said they do not work or work only part-time to maintain their eligibility for caregiving services. Another **30 percent** said their earnings or savings made them ineligible for caregiving services through their state.
- **47 percent** of individuals with SMA and their families struggled to find information about paid caregiving options in their state.

Stuck Inside: A National Report on Caregiving for Individuals with Spinal Muscular Atrophy chronicles the caregiving challenges experienced by individuals with SMA and recommends state and federal actions to help address their caregiver needs. The report, which was released by Cure SMA, features numerous first-person experiences and quotes highlighting the essential role caregivers play in the lives of children and adults with SMA.

For more information, contact Cure SMA at advocacy@curesma.org.



Cure SMA Advocacy | 800-866-1762 | advocacy@curesma.org | cureSMA.org

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.

ABOUT CURE SMA

Cure SMA is the leading national organization that represents individuals with SMA and their families across the United States. Cure SMA educates and advocates for policies that protect access to care, treatment, and services and legislation that promotes independence and community living for all individuals with SMA. Cure SMA also funds SMA research, promotes healthcare best practices, and supports the SMA community through educational events, independence packages, and equipment pools.

ABOUT SMA

Spinal muscular atrophy is a progressive neurodegenerative disease that causes severe muscle weakness and motor function loss and impacts a person with SMA's ability to walk, lift their arms, and independently perform key functions of everyday life. Due to the physical effects of SMA, most individuals with SMA rely on personal care attendants or other in-home supports to assist with their daily living activities.

Key State and Federal Recommendations from Cure SMA's *Stuck Inside* Report

- Strengthen the direct care workforce through increased wages, benefits, training, and career mobility.
- Improve online information about caregiving options in each state so residents can find searchable, consumer-friendly, plain language information about available in-home caregiving supports through Medicaid and other programs.
- Update eligibility requirements to access caregivers and other in-home support services by eliminating or significantly increasing the asset and income limits in Medicaid waiver and Medicaid Buy-In for Workers with Disabilities programs.
- Incentivize Medicaid waiver best practices, including paying family caregivers and offering caregiving services for individuals with disabilities who work and earn above traditional Medicaid levels.
- Promote Medicaid coverage portability or fast track eligibility for waiver beneficiaries who relocate to another state.
- Ensure fair, independent oversight of the state appeals process within Medicaid.

Key SMA Community Quotes from Cure SMA's *Stuck Inside* Report

- *"Caregivers allow me to get up and out of bed each morning and ready to work. Without caregivers I would not be able to live independently or successfully employed."*
- *"Without caregivers and caregiving hours, I would not be able to live independently, be successfully employed, or enjoy anything fun as I would be stuck at home in bed."*
- *"I have not been 'fully staffed' in about a year and supplement my needs with assistance from my parents and partner."*
- *"I would love to move out and be on my own, just like any other 25-year-old wants to be. However, because I can't get enough care hours, I do not see a future where I would be able to be independent and live on my own."*
- *"In my appeal letter, I pointed out that no human goes to the restroom only morning and night. I was able to get a mid-day shift. Now I can use the restroom a whopping 3 times a day!"*
- *"I have had to rely on my aging parents who are increasingly unable to provide my care."*
- *"Disabled people will remain poor and at the mercy of government benefits until the rules are dramatically changed. The point of government disability benefits should be to support disabled people in staying healthy, doing work that is the most lucrative and matches their skills and education."*



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