

CAREGIVING NEEDS OF THE SMA COMMUNITY



“In Their Words”

CAREGIVING CHALLENGES OF THE SMA COMMUNITY



Many individuals with spinal muscular atrophy (SMA)—a neuromuscular disease that significantly impacts physical strength—utilize personal care attendants (PCAs) or other in-home services to assist with their activities of daily living, such as getting out of bed and dressed in the morning so they can get to work or attend school.

I rely on PCAs to live independently and be a working, contributing member of society.

Unfortunately, individuals with SMA face significant and ongoing challenges in receiving adequate caregiving hours and in recruiting and retaining PCAs who provide these critical services. New investments, improvements, and flexibility in our nation's caregiving system are desperately needed to meet the unmet caregiving need and to promote independence and community living of the SMA community.

It is very difficult to find reliable assistance in my town.

Adults with SMA and parents of children with SMA describe the importance of and challenge in accessing PCAs and other home and community-based services...**in their own words.**



CALIFORNIA



WAYNE (ROSEVILLE, CA)

“PCAs are essential workers. They help keep the parents in the workforce, and give them a piece of mind while working, which can contribute to better health for all. They are essential workers, long before the pandemic. Will the circle be unbroken, it may be up to you.”

FLORIDA



ROBIN (TALLAHASSEE, FL)

“As a 65-year-old woman with SMA. I am no longer ambulatory. I do not have a lot of upper body strength. I need assistance with many activities of daily living, basically any part of my day that requires me to do something using the major muscles of my body. At a minimum, I need assistance two-times a day to get me up in the morning and situated and in bed for the evening. I currently rely on my husband since I am unable to access these caregiving services in my state. The need for caregiving services will continue to grow as SMA treatments prolong lifespans and as Baby Boomers, such as myself, start to need assistance as we age. It’s just going to be a huge problem, and it’s not getting smaller.”

ILLINOIS



AMBER (DIXON, IL)

“As a young adult with SMA, I need PCAs to help with daily activities, such as getting dressed, bathroom breaks, meal preparation and eating, transportation, and assistance in emergency situations such as fires. It is very difficult to find reliable assistance in my town to care for me while my husband is at work. Two caregivers quit in a short period, both without notice. For the few weeks they did work for me, they frequently cancelled shortly before their shift started that day. If I’m unable to find help while my husband is at work, I’m forced to not eat a meal and dehydrate myself so I will not need to use the restroom. A very important piece would be to allow customers the option of hiring their spouse as their care attendant. I’m urgently asking you to make a change to the spouse rule so that I and others in my situation can choose the person that will provide them with the highest quality care.”

SHANNON (DES PLAINES, IL)

“I rely on PCAs to live independently and be a working, contributing member of society. Almost every aspect of my daily routine would not happen without PCAs. Without them, I would not be able to get out of bed each morning, shower, and get dressed to go earn a living at my full-time job. Unfortunately, it is really difficult to find good PCAs because, in many states, they can make more money working in retail than they can taking care of me as a PCA. In addition to higher pay, these other jobs also provide health insurance and paid time off. For most individuals looking to provide for themselves, the obvious choice would be to take the job with higher pay and benefits rather than the PCA job. Please help me continue to live independently with the support of PCAs by expanding access to Medicaid services.”

LOUISIANA



ALYSSA (YOUNGSVILLE, LA)

“Investing in caregiving services will decrease unemployment by allowing people with disabilities to get to work using PCAs. Having caregivers is the only way I can remain employed and pay taxes. In addition to helping me get to work and complete work duties, my caregivers assist with meal prep, personal hygiene and grooming, transportation, overnight repositioning, and other daily activities. I struggle to keep caregivers long-term due to low pay and lack of healthcare and other benefits. At times, a lack of caregivers has limited my ability to work. Cuts in caregiving hours would also compromise my safety, potentially leading to injury or emergency when not assisted in daily living tasks. Please help me live independently by giving my current and future caregivers the compensation they deserve for helping ensure my safety and independence!”

MAINE



HEATHER (CUTLER, ME)

“I live in a rural place and am unable to access the caregiving services I need for dressing, medicine preparation, transportation, and grooming. My PCAs do not get paid enough or receive enough hours to be competitive with some fast food chains. They struggle to cover their housing and medical costs on their current wage. The only reason they stick around is because they truly do care about me. Caregiving is a huge market and field for employment. But it is not competitive. They get paid basically a poverty wage for caring for human life. In my opinion, PCAs should receive higher pay and be offered more training resources if they choose to access them to gain certificates.”

MARYLAND



JONATHAN (DERWOOD, MD)

“As a parent of a child with SMA, I am intimately acquainted with the burdens of caregiving. Due to the pandemic, my wife and I pulled non-stop caregiving shifts, 24/7 for over six months, without any additional home nursing support. Continual caregiver shifts, without respite, have taken a toll on our physical and mental health. With appropriate care, which includes medical and nighttime assistance and support at school, my son can grow, thrive, attend school, and participate in many daily activities. Without the care he needs, he will languish...not from his disease, but from lack of support. I want to believe in a future where my son will always get the support he needs, even as he grows into adulthood, when he will need a PCA or home health aide to live independently, attend school or work, and actively participate in and contribute to his community. Please treat home caregivers as a “first tier” of medical care by finding ways to maintain and increase compensation and licensing standards.”

MASSACHUSETTS



MICHAEL (PROVINCETOWN, MA)

“Thanks to PCAs provided through my state, I have sustained my independence for years. Now, however, due to the workforce shortage, I can no longer find PCAs. Not long ago, a part-time PCA opening drew about 20 applicants. Now, I don’t receive any applicants for jobs I have had open over the past few years. I thought that the PCA program would be the stability in my future. Now I fear that institutional care—which is far more costly to our state—is close, due only to housing and workforce issues. Please help.”

JOSEPH (NORWELL, MA)

“My niece has SMA and uses PCAs to assist with her daily needs. PCAs are critical to her independence and reducing the burden on other family members that must hold one or more jobs as well as providing for my niece.”



Investing in home and community-based services is SO important.



MINNESOTA



ADRIENNE (MINNEAPOLIS, MN)

“As an adult with SMA, I rely on PCAs for all of my activities of daily living, including bathing, transfers, grooming, cooking, dressing, transportation, and bathroom breaks. It is challenging to find and retain a solid crew of caregivers that are reliable, understand the job, and are compatible with me. I can’t tell you how upsetting it is to constantly be in the process of recruiting, hiring, and training new folks to assist me with my life, only to lose them a few months later to a job opportunity that pays more. As a human being, my right to live a normal life is not guaranteed and is constantly in jeopardy. That is absolutely unacceptable.”

MISSISSIPPI



BLAKE (BYRAM, MS)

“I am a working adult with SMA who uses PCAs for dressing, meals, feeding, positioning, and bathroom activities. The PCA pay rate is not competitive with similar positions in the area, so hiring has become more difficult, especially with the pandemic. I’ve been shorthanded for months as I’ve been unable to fill all my caregiving shifts. My mother helps me when I don’t have a PCA, but I worry about the toll it takes on her health given she is in her 60s. In addition, I worry about losing my PCA services if I am up for a promotion or a raise. In my opinion, we need a redesigned system that removes all income and means-testing and replaces it with a sliding scale premium—the more one makes, the larger one’s premium. We need to fix the system that pumps out talented, educated people with disabilities who are not able to realize their full potential for fear of losing the services they need to get out of bed in the morning.”

OHIO



MARGARET (URBANA, OH)

“Adults with SMA, like myself, utilize a PCA or home health aide to live independently and actively participate in and contribute to our communities. For me, it has been an incredibly difficult journey to find anyone who is willing to work due to the level of assistance required to help me get through an average day. Additional financial support would encourage more individuals to consider becoming PCAs or home health aides.”

OKLAHOMA



DONNA (STILLWATER, OK)

“I am a family caregiver for a disabled 40-year-old who has fought her whole life to be independent. She has her own business, lives in her own house, pays payments on her own car, and has a college degree. However, she requires help with routine daily activities such as getting up and ready for the day and putting her in bed at night. She is unable, for example, to even scratch her own nose without help. Unfortunately, she does not receive enough hours to move her during the night, so she lays in one place throughout the night because she is too weak to do anything on her own. Please support investments in home and community-based services, such as PCAs, to help those who cannot help themselves.”

TENNESSEE



JULIE (NASHVILLE, TN)

“My daughter lives with SMA. I need to be sure that she will be able to live a full, independent life into her adulthood. She deserves to live with dignity and the freedom to determine the course of her life. Investing in home and community-based services is SO important.”



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TEXAS



DANA (AUSTIN, TX)

“The reason I was able to successfully move out on my own and remain independent is because of Medicaid’s home and community-based services. This critical funding has allowed me to hire and train PCAs who assist me with literally everything. My attendants help me use the restroom, bathe, brush my teeth, get dressed, eat, transfer in and out of my wheelchair, and get to appointments and community events. Without these caregiving services, I would be forced into a nursing home...away from the apartment I have lived in for 15 years, away from my two cats and small dog, away from my neighbors and friends, away from my Independence and autonomy, away from my life. Over the last few years, however, I have seen a dramatic decline in the quantity and quality of people applying for my PCA positions. Until my newest caregiver joined my team, I’d been searching for over a year. In that year, I offered the job to 5 different people and all of them either turned it down or were never heard from again. I’m afraid for my independence if this trend continues! Invest in community care now or spend more on the institutional care we’d all be forced into when we can’t access PCAs and other community services.”

WEST VIRGINIA



VINCE (MOUNT CLARE, WV)

“I am from West Virginia, but I attend school out of state. When I was 2 years old, I was diagnosed with SMA Type II, which I have been living with throughout my life. I am currently on track to complete my bachelor’s degree and plan to go to law school and become an advocate for people like myself with disabilities. I have been unable to find enough employees for 24/7 services, especially during the summer when students who normally fill my PCA positions return home. My current PCAs work too many hours and are stressed. I am constantly worried that their stress could trigger a health issue where they would be gone long-term. How will I go to the bathroom? How will I get out of bed the next morning? Medicaid should cover every individual with SMA or other disability that requires 24/7 care or support for their life.”

WISCONSIN



BRIAN (HUDSON, WI)

“I am a 51-year-old man with SMA. I work full-time as a human resources executive at a large company. I have a good income, but with PCA cost of around \$6,000 a month I am not in a sustainable financial situation. As my disease has progressed, I have required increasingly more personal care assistance to get through the day. My insurance does not cover the cost of my personal care workers, and I continue to be in a situation where I cannot afford the care that I need. I have reduced the amount of help I receive to the point where I do not always feel safe; sometimes being home alone for 8 hours without the ability to eat, urinate, or reposition myself in my wheelchair.”

ACCESS TO CAREGIVING SERVICES MEANS INDEPENDENCE, EMPLOYMENT & COMMUNITY LIVING FOR INDIVIDUALS WITH SMA AND THEIR FAMILIES



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ABOUT SPINAL MUSCULAR ATROPHY

SMA is a degenerative neuromuscular disease that robs people of physical strength, taking away their ability to walk, eat, and breathe. SMA impacts 1 in 11,000 births in the United States and an estimated 1 in 50 people is a genetic carrier. If both parents are SMA carriers, every child they have together has a 25% chance of being diagnosed with SMA, regardless of race, ethnicity, and gender. With three effective U.S. Food and Drug Administration-approved SMA treatments and advances in SMA care, individuals with SMA are achieving unprecedented milestones and stopping or slowing the degenerative course of the disease. However, individuals with SMA, especially those who received treatment after symptoms appeared, may require lifelong medical care and caregiving support for their health and independent living.



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 and legislation that protect access to care, treatment, and services and that promote independence and community living for all individuals with SMA. Cure SMA also funds SMA research and supports the SMA community by hosting educational conferences and workshops and managing equipment pools and other support programs.



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