



Make today a breakthrough.

September 7, 2022

Chiquita Brooks-LaSure
Administrator
Centers for Medicare and Medicaid Services (CMS)
7500 Security Blvd
Baltimore, MD 21244

Re: Comments on reconsidering the national coverage determination related to seat elevation in power wheelchairs

Dear Administrator Brooks-LaSure:

As the leading national organization that supports and advocates for individuals with a rare disease known as spinal muscular atrophy (SMA), **Cure SMA is pleased to share the SMA community views on the national coverage determination (NCD) for seat elevation in power wheelchairs.** Cure SMA joined more than 50 other disability and health-related organizations in urging CMS to reconsider its NCD policies that prohibits Medicare from covering power seat elevation in power wheelchairs as well as power standing systems.ⁱ These systems are critical for many individuals with SMA in improving mental and physical health, increasing quality of life, and maintaining independence.

Many children and adults with SMA, a degenerative neuromuscular disease that robs individuals of physical strength, use power wheelchairs due to loss of ambulation and fine motor skills. Most power wheelchair users with SMA spend *at least 7 hours* daily in their chairs, including 47% who spend *more than 12 hours per day*, according to a recent Cure SMA survey on seat elevation and standing systems.ⁱⁱ *“Wheelchairs are our legs. Wheelchairs are a lifeline. Wheelchairs are independence,”* said a **Florida woman with SMA.** Individuals with SMA tailor their wheelchairs to address their individual needs associated with SMA. In addition to posterior tilt, power recline, and leg rest elevation, most power wheelchair users with SMA also require seat elevation to access surfaces and objects, improve mental and physical health, and increase independence. *“Seat elevation is an absolute necessity for me,”* said an **adult with SMA from Texas.**

The CMS NCD policy prohibiting Medicare coverage of seat elevation and standing systems jeopardizes access to these necessary features. The CMS policy was the rationale a private insurer used for denying a seat elevation request of a **northern California woman with SMA.** *“My insurance utilizes Medicare guidelines and has denied this feature stating it is not medically necessary,”* she said. An **Illinois woman with SMA** described her seat elevation denial process as *“frustrating and degrading”* and noted that *“others need to put themselves in my shoes to understand how it would feel to be denied something that would enhance my already limited abilities. It is hard enough to have a major disability and then to be denied this opportunity for a better quality of life.”* The NCD policy has forced individuals with SMA to live without or find other means to obtain this necessary wheelchair option.

The SMA community overwhelmingly views seat elevation as being medically necessary.

More than 70% of individuals with SMA who responded to Cure SMA's recent survey said that seat elevation improved their health and well-being. A **young adult with SMA from the Midwest** said, *"I challenge anyone who says that seat elevation and standing systems are not medically necessary to live a day in a wheelchair without these features as your arms and legs are tied to the chair."* A **woman with SMA from the West Coast** similarly questioned the notion that seat elevation and standing systems are not medical necessary. *"Clearly insurance people have never been in a wheelchair because otherwise this wouldn't be an issue."* The SMA community identified three primary reasons why seat elevation is a medical necessity: to reduce pain, improve overall well-being, and prevent injuries.

Seat Elevation Reduces Pain

Individuals with SMA said seat elevation reduces pain, particularly related to neck kinks and contractures. A **woman with SMA** said *"raising up with a seat elevator helps me engage with others at a peer level without hurting my neck since I have neck contractures and can't look up."* A **young man with SMA from the West Coast** and a **California woman with SMA** agreed by saying their seat elevation *"makes you eye level and not hurt your neck to talk to someone"* and *"seat elevation reduces neck pain and eye strain from being short in an ambulatory world."* Parents of children with SMA also pointed to pain relief as a benefit of their child's seat elevation. A **Nevada mother of a child with SMA** said *"being able to adjust the seat helps with joint pain for my daughter."* A **Kentucky mother of a child with SMA** said *"it allows my son to sit at variable height tables and counters, he can speak to people eye to eye, he can avoid having to look up and see people which is hard on his neck."* Pain relief was a top reason a **central Florida woman with SMA** requires the use of a seat elevator: *"I utilize my seat elevator for everything from pain relief to reaching counters to reaching elevator buttons and access buttons at work."*

Seat Elevation Improves Well-Being

Individuals with SMA said seat elevation greatly improves their overall health, safety, and well-being, from being able to eat, use the bathroom, and reach doors in an emergency to greatly improving mental health. A **man with SMA from Washington** said *"before I had the elevator, I would skip meals and sometimes not eat because I couldn't. Malnutrition has no limit on the health complications it may result in. I am now able to eat and feed myself because I can raise my wheelchair to a position where I can use the limited strength in my arms to feed myself."* A **California woman with SMA** said *"it reduces my anxiety and depression from being constantly looked down on and isolated."* A **Texas man with SMA** said *"I can raise up to be level with my peers contributing to my mental health."* A **Tennessee man with SMA** pointed to his own personal safety by noting that *"I can reach for doors and elevator buttons in an emergency, when I am alone."* Several individuals with SMA commented about how seat elevation was critical to bathroom use, from *"something as simple as washing my hands in the sink after using the restroom"* to safely transferring to use the bathroom. *"Toilets are different heights all over. Even in accessible bathrooms, the toilet can be 6 inches lower than wheelchair,"* said one survey respondent with SMA.

Seat Elevation Prevents Injuries

Individuals with SMA said seat elevation also prevents wheelchair transfer injuries that can lead to other significant health challenges. A **Massachusetts man with SMA** said *“not having seat-height variability, I have experienced physical injury while being transferred from my chair.”* An **Illinois woman with SMA** said *“seat elevators are essential for the safety of both parties during transfers, and these transfers happen multiple times per day. It reduces injuries caused by drops or other transfer challenges.”* A **Nevada man with SMA** said *“I transfer from a bed that requires a seat height and or bed height adjustment to safely use a transfer board.”* An **individual with SMA from Wisconsin** said because of seat elevation *“I can transfer to and from the toilet, chairs, and bed as well as maneuver during doctor’s visits to access elevators and exam tables.”*

Final Comments from the SMA Community

Several individuals and families with SMA who responded to Cure SMA’s seat elevation survey described how the feature increases independence, which in turns improves health. *“Why is it not medically necessary to be able to get a cup and a glass of water in the sink without somebody’s help when you need it? Why should I have to wait on someone to wait hand and foot on me when I need something right away and I can’t reach it? Why is it medically necessary not to have the world accessible to me?”* ask an **adult with SMA**. A **man with SMA from the Pacific Northwest** described seat elevation as being *“transformative”* because he can adjust his seat to fit under any size table or participate in any situation. *“I cannot overestimate the improvement this has given to my quality of life,”* he added. A **woman with SMA from southern California** emphasized how increased independence and ability impacts all aspects of her life, including her well-being. *“Seat elevation and standing systems provide independence and access. These functions are not only critical for physical health but psychosocial well-being and self-determination.”* A **Virginia man with SMA** described how seat elevation allows him to maintain employment, which is the source of his vital health insurance. *“Without the ability to reach an elevator button, I literally would not be independent enough to keep my current job,”* he said.

While the current CMS comment opportunity is specific to seat elevation, Cure SMA also urges CMS to reconsider its coverage policy related to standing systems in power wheelchairs. Individuals with SMA said standing systems are equally important and medically necessary, helping with everything from improving digestion and bone density to reducing pressure sores and urinary tract infections. A **father of a child with SMA** said *“the standing system has helped with my son’s circulation. It helps his bowel movements, and he doesn’t have the intestinal pain or issues he gets when he isn’t able to stand. His knee and hip contractures loosen up the more he stands. He can participate more with his friends, at their level, which has greatly affected his overall happiness and well-being.”* He added, *“what hasn’t it improved?”* A **Nebraska woman with SMA** said *“the standing feature decreases the risk for pressure wounds, joint tightness that could result in needed surgeries, improved lung function, reduces the need for additional therapy services due to continued stretching in the joints, and also provides improved mental status for settings that the standing position provides opportunities to feel included.”* **Cure SMA**



respectfully asks CMS to reconsider its NCD related to standing systems by opening a public written comment opportunity.

Thank you again for the opportunity to share the SMA community's views on seat elevation in power wheelchairs. We are hopeful that our comments will help inform your team about the medical nature of seat elevation and the importance of full Medicare coverage. For more information, please contact Maynard Friesz, Vice President for Policy and Advocacy at Cure SMA, at maynard.friesz@curesma.org or 202-871-8004.

Sincerely,

A handwritten signature in black ink that reads "K. Hobby".

Kenneth Hobby
President
Cure SMA

A handwritten signature in black ink that reads "Maynard Friesz".

Maynard Friesz
Vice President of Policy & Advocacy
Cure SMA

ⁱ ITEM Coalition Letter, September 15, 2020; <https://itemcoalition.files.wordpress.com/2020/09/letter-to-cms-re-request-for-reconsideration-of-ncd-for-mae.pdf>

ⁱⁱ Online Survey on Seat Elevation and Standing Systems in Power Wheelchairs; Cure SMA, August 2022