

When Help Isn't There: Gaps in Attendant Care for Adults With Spinal Cord Injury

Attendant Care Overview

- > This fact sheet presents findings from 856 adults living with spinal cord injury (SCI). Of these, 257 people (30%) reported needing help getting out of bed. Participants were, on average, 57 years old and surveyed 28 years after injury.
- > Many people living with SCI depend on attendant care for essential daily activities such as getting in and out of bed safely.
- > Gaps in paid care can lead to missed daily care needs and increased reliance on family, friends, and unpaid support.
- > Financial barriers and caregiver shortages can make it difficult to maintain reliable support throughout the day and night.
- > Community resources, support networks, and planning ahead may help reduce interruptions in care and support independence.



AI-generated image created with DALL·E.

What is Attendant Care?

Attendant care refers to help at home, paid or unpaid, that supports people with SCI in doing basic and everyday activities. ¹

Help Turns Daily Needs Into Daily Living



AI-generated image created with DALL·E.

When attendant care is not available, people with spinal cord injury may be left without help for essential daily needs, such as getting out of bed or going to bed, which can put their health and safety at risk.

When Care Is Missing, Daily Life Stops

Stayed in Bed All Day

1 in 5



Among people who needed help with transfers, 1 in 5 (21%) stayed in bed all day for at least one day in the past 30 days because help was not available.

Spent the Night in a Wheelchair

1 in 20



Among people who needed help getting into bed, 1 in 20 (5%) spent at least one night in a wheelchair within the past 30 days because help was not available.

Among those affected, people spent about 5 days in bed or 4 nights in a wheelchair in a single month because help was not available.

Why Getting Help Matters ²

Spending long periods in bed or in a wheelchair can affect your health, increasing the risk of skin injuries, infections, and physical decline. Regular support can help protect your health and maintain independence.

Make a difference, **today!**

Family and Friends Become Essential Support

- Almost half (45%) of people who needed help getting out of bed relied on unpaid help because paid care was unavailable.
- About 2 in 5 (42%) people who needed help getting into bed reported relying on unpaid help because paid care was not available.
- More than half (55%) relied on unpaid family members or friends for caregiving.

1 in 2

Rely on unpaid help to get out of bed

2 in 5

Rely on unpaid help to get into bed

More than

1 in 2

Rely on unpaid family or friends for caregiving



Backup Support Matters

Family and friends often step in when paid care is not available, making backup support an important part of staying safe, active, and independent. Talking openly with your support network and planning ahead can help prevent being left without help.

Financial Resources Affect Access to Care

1 in 2

Can't afford night care



- Nearly half (45%) of people reported not having enough financial resources for night care.

1 in 2

Don't have backup support



- About 1 in 2 (46%) people reported not having enough financial resources for backup or respite care.



Community Support Can Make a Difference

Financial barriers can make it harder to maintain reliable support throughout the day and night. Community organizations, advocacy groups, churches, independent living centers, and state programs may offer support, funding guidance, respite resources, or caregiver assistance. Learning about available resources and talking with your care team or support network may help identify additional options for care.

What Can You Do If Help Is Not Available?

Build a Backup Contact List

1

Create a short list of trusted people who can help if paid care is delayed or unavailable, especially during important times like getting out of bed or nighttime care.

Helpful tools

[Caregiver Action Network](#)
[Lotsa Helping Hands](#)



Find Local Support

2

Independent Living Centers and SCI organizations may help connect you with attendant care resources, funding programs, peer mentors, or respite services.

Find resources near you [Independent Living Councils \(ILCs\)](#)
[United Spinal Association](#)
[Christopher & Dana Reeve Foundation](#)



Connect With the SCI Community

3

SCI peer groups and online communities may help you find caregiver referrals, practical advice, and emotional support from people with similar experiences.

[Peer Support Program](#)
[CareCure](#)



Explore Funding and Benefits Programs

4

Medicaid waivers, state disability programs, Veterans benefits, and nonprofit organizations may help cover attendant care or respite support.

Learn about benefits and assistance [Government Benefits](#)
[Eldercare Locator](#)



References

- 1 Smith EM, Boucher N, Miller WC. Caregiving services in spinal cord injury: a systematic review of the literature. *Spinal Cord*. 2016;54(8):562-569. doi:10.1038/sc.2016.8
- 2 Krause JS, Edles PA, Laursen-Roesler J, Jarnecke M. All day in bed, all night in the wheelchair: Unmet attendant care needs of people with spinal cord injury. *J Spinal Cord Med*. 2025;48(2):351-356. doi:10.1080/10790268.2024.2362505
- 3 Klebine P, Azuero C, Arthur K, Zanca J. Personal Care Attendants and Spinal Cord Injury. Model Systems Knowledge Translation Center (MSKTC); 2020. <https://msktc.org/sites/default/files/2022-06/PersonalCareAttendants-508.pdf>

About This Fact Sheet

This fact sheet was created using data from the Health, Employment, and Longevity Project (HELP) aging 50 database at the Center for Rehabilitation Research in Neurological Conditions (CRRNC). It is supported by the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR) grant 90DPCP0009. This fact sheet is not meant to replace the advice of your physician or other healthcare provider. You should always consult your physician or healthcare provider before making changes to behavior, treatment, or use of medicine.

CRRNC Director: James S. Krause, PhD

Authorship: When Help Isn't There: Gaps in Attendant Care for Adults With Spinal Cord Injury fact sheet was created by Ana Zeledon, MD, MPH, with feedback from Yue Cao, PhD, MSPH, and the CRRNC team at the Medical University of South Carolina.

Document Citation: Center for Rehabilitation Research in Neurological Conditions. When Help Isn't There: Gaps in Attendant Care for Adults With Spinal Cord Injury [fact sheet]. Medical University of South Carolina; 2026.

Contact: aust@muscd.edu

