

## Getting the Help You Need: Attendant Care Among Adults With Spinal Cord Injury in South Carolina

### Attendant Care Overview

- > This fact sheet presents findings from a self-report study of 770 individuals living with spinal cord injury (SCI) in South Carolina, who were on average 56 years old and surveyed 9 years after injury.
- > People living with SCI often need ongoing help with daily activities like bathing, dressing, transferring, and moving around.
- > Having reliable attendant care can improve independence, health, and quality of life.
- > **Attendant care is also called:**
  - Personal Care Assistance (PCA)
  - Personal Assistance Services (PAS)
  - Caregiving Services
  - Home-Based Support
  - Family Caregiver

### 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.<sup>1</sup>

#### Attendant Care Includes:

Bathing, dressing, grooming, eating, toileting, and transfers



**Personal Care**

**Household Tasks**



Cooking, shopping, light housekeeping, and managing medications.

Moving safely at home, attending work, recreation, or social events



**Community Participation**



Attendant care is more than just helping with personal tasks. It can also involve keeping you healthy, helping you move around safely, supporting you in staying active in your community, and can also be a trusted companion who supports shared experiences, fun, and meaningful activities.

### Who Needs Help With Daily Personal Care

1 in 3



Nearly 1 in 3 people with SCI (36%) said they need help with everyday personal activities like eating, bathing, dressing, toileting, and mobility

### Getting Help Moving In and Out of Bed

2 in 3



Among people who need attendant care, about 2 in 3 (66%) reported needing physical help to moving in and out of bed, into a wheelchair, or onto a scooter.



#### What This Means for You

Knowing your personal care and transfer needs helps you plan for the right support, stay safe, and maintain independence.

**Make a difference, today!**

## Days Spent in Bed Without Help

- About 1 in 3 (35%) people who need help getting in and out of bed reported that, at least once during the year, they had to stay in bed all day because no one was available to assist them.
- On average, those affected spent about 12 days per year in bed without help.

1 in 3

stayed in bed



12 days

in bed during the past year.



## Nights Spent in a Wheelchair

- 1 in 12 (8%) reported staying in their wheelchair one or more nights in the past year due to not having someone to help. Those affected usually spent about 5 nights per year in their wheelchair without help.

1 in 12

stayed in wheelchair



## ! Why Getting Help Matters <sup>2</sup>

Staying too long in bed or in your wheelchair can be dangerous for your health because it increases the risk of skin injuries like bedsores, which can lead to infections and hospital stays. It also contributes to a higher risk of depression, muscle loss, bone weakness, and overall health decline. Getting regular help can protect your health, keep you active, and support your independence.

## Who Provides the Help You Need? Paid vs. Unpaid Attendant Care



Half (51%) received some unpaid support each day, while 1 in 4 (26%) had 24-hour unpaid care, often from family or friends.



Half of SCI individuals (51%) had paid help with personal care. Of those, most (43%) received a few hours of help each day, while 1 in 12 (8%) had full-time, 24-hour support.

## Attendant Care by Race <sup>3</sup>

- Whites were more likely to receive daily care from a spouse and reported higher satisfaction with paid care.
- Blacks relied more on extended family, friends, and church, with differences largely explained by income and marital status.

## Who Has No Help at All



Among people with SCI who need assistance with personal care, 1 in 12 (8%) reported having no paid or unpaid help at all.



## Lessons Learned from the Pandemic <sup>4</sup>

Our team studied how COVID-19 disrupted attendant care for people with SCI, and we found:

- About 1 in 3 said the quality of their care got worse.
- More than 1 in 3 lost an attendant or had their hours cut back.
- Over half had to depend on family members more than usual for daily care.



## Lessons for the Future

### Plan for disruptions

Attendant care can break down quickly, so backup systems must be in place before the next crisis.

### Support families

Many families had to step in, showing the need for extra resources and relief for caregivers.

### Build reliable care networks

Stronger, more flexible attendant care systems are essential to keep SCI people safe during emergencies

## Tips for Finding a Personal Care Attendant (PCA)<sup>5</sup>

### Start local

Contact the South Carolina SCI Association (803-252-2198) or the ABLE Center for Independent Living (803-779-5152) for referrals and support.

### Use your network

Let friends, family, and support groups know you are looking. Include your church community and [SCI Breeze](#) support groups. Talking with people who already have a PCA can give you trusted referrals and real-life advice. Personal referrals are often the most reliable.

### Explore trusted agencies

Home health agencies can help match you with trained attendants. Always verify reviews and the services offered.

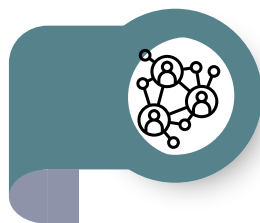


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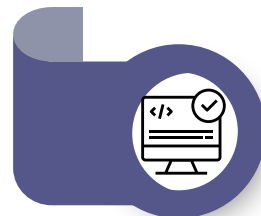


### Check your coverage

If you have a high-level SCI, contact the South Carolina Department of Disabilities and Special Needs at 1-866-867-3864 to ask about HASCI Medicaid waiver eligibility.



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### Search safely online

Use reputable caregiving platforms like Care.com and create a separate email to protect your privacy. Visit the [National Council on Aging's Caregiver Resources](#) for more options and guidance.



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## References

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## About This Fact Sheet

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CRRNC Director: James S. Krause, PhD

Authorship: Getting the Help You Need: Attendant Care Among Adults With Spinal Cord Injury in South Carolina fact sheet was created by Ana Zeledon, MPH, with feedback from Yue Cao, PhD, MSPH, and the CRRNC team at the Medical University of South Carolina.

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Contact: aust@musc.edu

