

Personal Care Attendants and Spinal Cord Injury

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SCI Factsheet

This fact sheet offers suggestions on finding, interviewing, funding, and managing a personal care attendant.

What is a personal care attendant?

A personal care attendant, or PCA, is someone paid to help you with some or all of your self-care and other activities that you need for daily living after spinal cord injury (SCI).

- “Personal Assistant” and “Personal Assistant Service” are other terms that refer to similar personal care services.

Do I need a PCA?

You may benefit from a PCA if you need help with daily needs. A few ways a PCA might help you include:

- Meeting basic daily care needs.
- Making the best use of your time and energy to get through a full day of activities. For many people with higher levels of SCI, a PCA can make it easier to work or go to school.
- Helping to minimize pain or fatigue that you have when doing daily activities without help.
- Adapting to any decline in your abilities to do daily activities as you age.

What help does a PCA provide?

- Self-care. This often includes help with bathing, grooming, dressing, feeding, and bladder and bowel management. It may also include help with other tasks, like keeping your lungs clear of secretions.
- Mobility. This may include help with transfers, pressure relief movements, using a wheelchair, and driving.
- Set-up. This may include help with setting up assistive devices or other items around you, such as a computer, so that you can do activities by yourself.
- Light housework. This may include help with tasks like preparing food, washing dishes, doing laundry, and cleaning.

Is it better to rely on care from a PCA or a family member?

Each person's situation is different. It is common to get help from family members. You may also prefer to have family help with ongoing daily needs because it works best for your situation or you simply feel more comfortable getting help from someone in your family.

- Some states pay a family member if you prefer a family member to a PCA.

Getting help from family for some or all of your daily needs can have benefits, but there may also be downsides. It is important to consider your needs as well as the needs of your family members when making a plan for your care.

The Spinal Cord Injury Model System Program is sponsored by the National Institute on Disability, Independent Living, and Rehabilitation Research, Administration for Community Living, U.S. Department of Health and Human Services. (See <http://www.msktc.org/sci/model-system-centers> for more information).

If a family member is providing your daily care, it is a good idea for you and your family member to talk with a psychologist, counselor, or social worker for guidance. Here are some topics you might discuss:

- Managing stress.
- Keeping family roles separate from caregiver roles.
- Reducing the burden on your family member, such as arranging time off from caregiving duties.

Some of the benefits of relying on a PCA rather than a family member include:

- It may help to avoid blurring the roles of caregiver and family member.
- It may help reduce stress on the relationship, especially if the caregiver is a partner or spouse.
- It may give you and your family member more independence. This may give you both more opportunities to live active, productive lives.
- It may help prevent a partner or spouse from becoming resentful, depressed, or upset if they are having difficulty meeting your needs.

How do I find a PCA?

- Contact your state Department of Rehabilitation Services. Many states offer programs that can help you find a PCA. Some states will also help to pay for a PCA.
- Contact your local Center for Independent Living (CIL). Each state has at least one CIL. Your local CIL offers many services, and CILs can often provide you with information and referrals related to any personal care services in your area.
- If you have private insurance or workers' compensation insurance, contact customer service to find out if your coverage includes PCA services. Your insurance provider may have a service to help find a PCA.
- Use social media and the web. Social media posts let friends and family know you are looking for a PCA. Someone in your social network may be interested, or they may know someone. Also, some websites let you place ads for help.
 - Be careful when you are online. Avoid giving out personal information until after you are comfortable with the person receiving it. You might create a separate email account or web-based voicemail box so that you can connect with people without sharing your personal information.
- Post a flyer in places where people in the personal assistance field may see it. For instance, you might put a flyer on a hospital or skilled nursing facility bulletin board. You might post a flyer at a local college that offers nursing, occupational therapy, or physical therapy courses.
- Put a classified ad in your local newspaper. If you place an ad, do it on weekends because that is your best chance to reach the most people.
- Contact a local agency or business that offers personal assistance services. You can search online using terms like "personal assistant," "personal care," "caregiver," or "home health services."
 - Always check reviews and take other steps to find out if the agency or business is trustworthy.
 - Some agencies limit the types of services offered. This may include limits on "medical" services, such as bowel and bladder management.



What is the first step in hiring a PCA?

The first step is to know your needs so that you can clearly explain them to people who are interested in the job. Make a list of all activities that you expect your PCA to help you do. List the time it usually takes to do each activity along with the total time it usually takes to complete all activities.

What do I do when someone is interested?

Talk to the person on the phone. Give the person a brief overview of the type of help you need. Then, schedule an interview if both of you are still interested.

What do I need to know about interviewing?

Have a plan

Prepare a list of questions to ask before you set up any interviews. Think of questions that will help you find the best match to meet your personal needs. Ask each person the same questions so you can judge everyone on equal terms. Here are only a few examples:

- What work experience do you have?
- Do you have references?
- Are you able to lift, push or pull things?
- Do you cook and do housework?
- Do you have a driver's license and reliable transportation?

Hints for interviewing

- You may prefer to conduct your first interview at home, but you can also do it over the phone or in a public location where you can talk privately.
- Clearly explain in detail every task that you need your PCA to do. Consider providing a written list as a visual aid during the interview.
- Explain your schedule and the importance of staying on schedule.
 - You may need a PCA in the morning, in the evening, or both. If both, make sure you talk about what tasks you do at specific times. You may need to decide if you want different PCAs for morning and evening or if you prefer a PCA who can work split shifts.
- Outline the education and training you will provide.
- Explain any rules you want them to follow. This might include not allowing smoking or limiting personal calls and texting. Also, explain what they should do if they are running late or cannot come to work.
- Describe the work environment. Make sure the person knows if you have pets or if you need the room to be a certain temperature.
- Talk about vacation and time off.
- Explain how you manage situations and payment when you need unscheduled services outside normal times.
- Invite the person to ask questions. Some tasks can be very personal. Answering questions can help them understand what is needed and feel more at ease with doing these tasks.
- Get to know each other. Questions and answers are only one part of an interview. Interviews are also a good way to find out if you feel comfortable with each other and get along well.



Making your choice

Choose the person who best fits your needs. If you are having a hard time deciding, make a checklist of your needs and then list the person that you think will best fit each need. You also want to think about the qualities of a “good” employee in any job.

- Do you think the person provided good references?
- Do you think the person is dependable and will be on time?
- Do you think the person is trustworthy and honest?
- Do you think the person can follow instructions?
- Do you think the person is friendly and someone you want to spend time with?

Do a background check

It is important to do a background check to find out if the person has a criminal history before making a job offer. The simplest way is to pay a service to do a background check. You can find many background check agencies online. You might also ask your local law enforcement for advice on how to best do a background check.

What education and training do I need to provide?

Most PCA education and training is done through hands-on work with you, even if you find a PCA with a lot of experience. This means it is up to you to work with your PCA through each task to provide the education and training needed to meet your daily needs.

- The Model Systems Knowledge Translation Center offers educational factsheets and other resources on many SCI topics. You might use them to help educate and train your PCA to meet your needs.

How do I pay for a PCA?

PCAs are usually paid by the hour. The cost per hour varies depending on the cost of living in your area.

Few people can pay out-of-pocket for PCA services, so you might brainstorm options to help offset or supplement your PCA’s pay. For example, a trusted PCA might be offered room and board or use of a vehicle in exchange for PCA services.

- Make sure you plan your budget carefully if you intend to pay out-of-pocket for some or all of the cost of a PCA.
- Talk with an accountant about tax-related questions about out-of-pocket costs.

Suggestions for getting help to pay for PCA

- Some states help pay for PCAs through medical assistance programs or with funds from the state’s Department of Rehabilitation Services.
- Some Area Agencies on Aging help pay for PCAs. Check with your local agency to find out what resources are available.
- In some cases, private insurance and workers’ compensation insurance will pay for a PCA. Most insurance cards include a customer service number that you can call to ask about PCA coverage.
- Contact a local social worker to find out if any options are available in your area.



What can I do to help keep a PCA?

It can be hard to keep a good PCA even under the best conditions, but you can make sure that your PCA is working in a pleasant environment. Here are a few suggestions.

- Develop a professional, pleasant relationship. Humor can help create a more relaxed work environment.
- Be polite and show appreciation. Say “thank you” and “please.” Pay raises or small bonuses are always welcome.
- When making requests for a task to be done a certain way, explain the reasons for that request. For example, you may need an object placed in a specific location so you can reach it when your PCA is away, or you may ask for strict handwashing to prevent you from getting infections that will send you to the hospital. Sharing the reasons for your requests can prevent you from being thought of as “picky” and provides an opportunity to show how much you value your PCA’s efforts. This may increase the likelihood of your requests being fulfilled.
- Do as much for yourself as you can. This shows your PCA that you are partners in your care.
- Be assertive without being rude. Although you are in charge of your personal care, treat your PCA like a person and not like a servant.
- Avoid major changes in your routine that disrupt the work schedule or waste time.
- Respect your PCA’s views, opinions, and personal life. Avoid talking about “hot topics” that may cause conflict such as religion and politics.
- Be honest about the hours worked and pay on time.
- Do not ask for special favors or expect your PCA to work for free.
- Avoid overworking your PCA. When possible, use more than one PCA. If you rely on one PCA, find ways to give your PCA time off.
- Be flexible and understanding. Do not be too strict. Understand that mistakes happen. Also, keep in mind that sometimes people cannot avoid being late or sick.

What do I do if I experience abuse?

No form of abuse is acceptable. This includes you abusing others or others abusing you.

Anyone can be an abuser. It might be a health care provider, a friend, or a family member. Here are a few types of abuse experienced by some people with SCI.

- Verbal or emotional abuse includes non-physical behaviors. This may include insults, threats, or excessive yelling or screaming as a way to control you.
- Physical abuse is any intentional use of physical touch to cause fear, pain, injury, or trauma. This may include shoving, hitting, or strangling.
- Sexual abuse is any unwanted or improper sexual advances or activity. This may include unwanted sexual touch or sexual assault (rape).
- Abandonment is being intentionally left alone without making sure that your basic needs are met. This may include being left in the bed with no way to get out and with no access to food, drink, or the bathroom.



- Financial abuse is when there is money stolen or someone takes control over another person's money for his or her own personal benefit.
- Neglect is withholding necessary services to maintain your health and wellbeing. This may include being denied access to proper food choices, hygiene care, necessary assistive devices, medication, or healthcare.

It is very important to have a plan in place to act quickly if you experience abuse. Here are some potential action steps to take if you are experiencing any form of abuse:

1. Call 9-1-1 anytime you have an emergency or feel in danger of harm.
2. To report abuse and get advice on actions to take, contact local entities like your local Adult Protective Services, Social Security office, Agency on Aging, Department of Social Services, or law enforcement.
 - You can also get support and advice from the National Domestic Violence Hotline (1-800-799-7233).
3. Tell a family member or someone else you trust. You might also set up a "safe word" that secretly tells the person you trust that you need help.
4. You might set up smart home devices like cameras, locks, and smart speakers to help prevent crime and offer you added home security when needed.
 - A touch pad combination lock with changeable codes may be another option in place of smart locks.

Additional Resources

Links to online resources can change, but you can search online for these recommended resources on finding and managing a PCA.

- How to Successfully Hire and Manage a Personal Care Assistant for People with Spinal Cord Injury – published by Shepherd Center.
- Managing Personal Assistants: A Consumer Guide – published by the Paralyzed Veterans of America.
- A Step-by-Step Guide to Training and Managing Personal Assistants: Consumer Guide – published by the Research and Training Center on Independent Living (University of Kansas)
- Personal Care Assistants: How to Find, Hire & Keep - published by Craig Hospital
- Personal Care Assistance: How Much Help Should I Hire? - published by Craig Hospital

Authorship

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