Preparing Paid Caregivers

Leaving the care of your loved one in someone else’s hands is not easy. But if you hire the right person and familiarize them with your loved one’s particular needs, it can be an invaluable help.

It is important for the people or agency you hire to understand Parkinson’s, so they can understand and better relate to your loved one. Even seasoned professionals might not know about Parkinson’s disease. You can provide the agency and/or worker with NPF’s free book What You and Your Family Should Know. The worksheet “Orienting a New Home Care Worker” at Parkinson.org/library will give you more information to help make sure that you and the worker get off to a good start.

Getting to Know the Person with Parkinson’s

Once they know about the disease, paid caregivers need to get to know the person. To provide the best possible care for the person with Parkinson’s, it is helpful for home care workers to understand your loved one’s history, personality and preferences as well as the family situation. Explain or provide a written document with insights on your loved one’s childhood, occupation, family stories, favorite hobbies, likes, dislikes and daily routines. Include information on relatives or friends who are involved in caring for the person with Parkinson’s.

Make a Care Plan

With this understanding in place, you, the person with Parkinson’s and the home care worker should collaborate to develop a care plan and checklist. It is important to identify and discuss the care and support needs of the person with Parkinson’s. These needs, and the steps that will be taken to address them, should be written down in a manner that is easily understood by all who are providing daily care and assistance. This document (referred to as a care plan) can help ensure that all necessary steps are taken to provide the best possible care on an ongoing basis.

Keep in Touch

If you are not living in the home with the care recipient, communication is key to better care. Make sure to check in regularly with the home care workers, particularly as your loved one’s needs change over time. The care plan will need to be updated to reflect the progression of Parkinson’s disease, so this is a good time to evaluate the caregiver relationship. Voice any concerns about the quality of care being provided. Stay calm and respectful during the conversation, but follow up to make sure that problems are addressed.
COMMUNICATION TIPS

» **Short sentences** that use everyday vocabulary lead to better understanding.

» **When correcting a worker, focus the discussion on the work.**
  Emphasize the actions and the behavior, not the person or the personality.

» **Avoid “you” statements and the words “always” and “never.”**
  Telling someone “you always” or “you never” is a set-up for an argument.

» **Provide frequent, meaningful and specific praise.**
  Include details of what was done and why you appreciated it.

» **Seek regular feedback from the care worker.**
  Ask how the job is going, what concerns he or she may have, suggestions for
  improving care and how you can be helpful. Remember to listen to the answers
  before formulating your response. If you hear something upsetting, ask for time
  to think about it before responding, but make sure you do respond.

**Know the Roles**

Paid caregivers are hired to keep the person with Parkinson’s safe and look after his
or her well-being. Caregiver and care recipient might form a bond over time, but it is
important that paid caregivers maintain professional boundaries. They should not
become involved in familial or financial conversations and decision-making. While your
role as a family caregiver is emotional and complex, remember that no matter how nice
the home care worker is or how much she or he likes you or the person with Parkinson’s,
it is a job.

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I needed to provide some training with every single aide that came in that was going to stay all night. I had to talk to them about Rogers’ personality, show them where things were and how he moves and what would help them move him, just a lot of logistics and little things about him.

— **LENNORE, CARED FOR HUSBAND, ROGER**

*For other tip sheets and caregiver support information, order the NPF book Caring and Coping.*

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