Secondary Caregiving

If you are a secondary caregiver, your role will never be as demanding as the one played by the primary caregiver—who may be a spouse/partner, sibling, adult child, other relative or friend of the person with Parkinson’s. However, your role comes with its own unique rewards and challenges. Whether you are providing support from afar or act as back-up when the primary caregiver needs time off, there are many ways you can support both the person with PD and the primary caregiver. The following ideas will need to be adapted to your individual family and financial circumstances.

Call every week.
Set a designated day and time, and make the call faithfully. Inquire about both the person with PD and the caregiver. Make sure to include some topics not related to Parkinson’s or caregiving to stay connected on multiple levels. Consider setting up Skype or another video call service so you can see each other on the call. Just be there to listen.

Find out if financial help is needed.
Many people will not ask for monetary help no matter how dire the situation. Inquire tactfully but clearly if expenses are a problem, and then offer a plan that can work for everyone. You could provide a regular monthly subsidy, cover a specific expense such as a month’s supply of medications (especially important as long as the Medicare gap, or “doughnut hole,” exists) or pay for a service that relieves the caregiver of one or more chores (e.g., housecleaning or yard services).

Send a care package once a month.
Try to tailor the surprise to the individual to make it more special. It might be a bouquet of favorite flowers, a magazine subscription for a personal interest or a gift card to buy something just for them. Be creative. Never underestimate how much a personally written thank-you note can mean to a caregiver whose work goes mostly unrecognized.
Visit the person with Parkinson's.
Budget time and funds for regular visits. Find your own way from the airport, and book a hotel room if quarters are cramped. Your trip should not add to the responsibilities and strain of the primary caregiver. Make the goal of your visit to provide a listening ear and a helping hand. Spending time with the caregiver and the person with Parkinson's will give you a firsthand look at specific challenges and issues and help you think about how to be involved.

Try to schedule at least one of your visits when your loved one has an appointment with the neurologist. This will allow you to better understand your loved one's medical status, see how the doctor, patient and caregiver interact and add your own valuable observations. During your visit, remember to ask about the health of the caregiver. Are regular check-ups and screenings being overlooked because of caregiving responsibilities? Consider coordinating a visit so the caregiver can schedule doctor, dentist and optometrist visits while you stay with the person with Parkinson’s.

Provide respite for the primary caregiver.
If you cannot fill in personally, locate other options and offer to cover the costs if possible. There may be free or low-cost services available that the primary caregiver just hasn’t had the energy to locate. Many people who care for someone with Parkinson’s say that their role started much earlier in the course of the disease than anyone else realized. If your loved one is able to travel, invite him or her for a visit. This allows the person with Parkinson’s to get all your attention and enjoy a change of scenery while the primary caregiver enjoys a welcome break in familiar surroundings.

Support the health care team's and primary caregiver’s decisions.
Express vocal support to your loved one for the health care team’s care and safety recommendations, such as using a walker, not driving, accepting additional help with personal care or wearing a medical identification bracelet. Similarly, if and when the time comes, affirm the difficult decision to place your loved one in a care facility. Be respectful of the fact that you are not the person providing day-to-day care. You may not fully recognize how caregiving responsibilities have grown. It is a mistake to let worries about cash flow, sibling rivalry or dwindling inheritances get in the way of doing what is best for the people whose lives are most affected.
TIP SHEET

What Not to Do

It might feel like you need permission to help, like the primary caregiver cannot or will not delegate responsibilities. This can be frustrating and emotional. Use the strategies on the previous pages to support from afar, and avoid these common mistakes:

**Not understanding the severity of day-to-day symptoms.**
Many caregivers will say that the person with Parkinson’s is at his or her best when at a doctor’s appointment or having visitors. What you see when you visit may be quite different from the daily reality. Research found that people who care for someone with Parkinson’s provided an average of 14 hours of care daily and had greater levels of physical and emotional strain than people caring for someone with Alzheimer’s disease.

**Offering too much unsolicited advice.**
Friends and relatives who do not provide daily care often have a valuable ability to “see the forest instead of the trees.” However, this objective wisdom must be expressed with great care and without criticism for family members who live close by and carry the greater responsibility of caregiving.

**Not honoring the historical relationship of the caregiver and the person with Parkinson’s.**
In most cases, the caregiver and the person with Parkinson’s will have had a long and intimate relationship with one another. A caregiving wife once said to her daughter, “My relationship with your father may be dysfunctional, but it's OUR dysfunctional relationship.” Trying to make fundamental changes in a relationship of many years can result in frustration and hurt feelings for everyone involved.
COMMUNICATION TIPS

» When talking with the caregiver or the person with Parkinson’s, **always listen to what is being said** instead of thinking about what you are going to say next.

» **Be especially careful when sending email or text messages.** Without the benefit of eye contact and body language, messages can be misunderstood and feelings can be hurt.

» **Do not expect any of your loved one’s health care team to speak with you** unless the person with Parkinson's has signed a release giving his or her permission.

» **Remember to ask the primary caregiver what he or she would find helpful.** It may be that paying the bills and balancing the checkbook is more important than a cleaning service.

» **Not all problems can be solved.** Sometimes the caregiver needs a patient, understanding ear rather than a quick solution.

There’s guilt when you are away from your loved one. The primary caregiver is at home when you’re not. You love the person as much as they do, but for whatever reason you can’t be there every day. There’s sadness that goes along with that because you want to be there.

– KAREN, CARED FOR FATHER, JOSEPH

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