

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, FaceTime 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 "donut 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 the person with Parkinson's 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 healthcare team's and primary caregiver's decisions.

Express vocal support to your loved one for the healthcare 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.