

# Helping the Caregiver Stay Well

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*As a secondary caregiver your job is to support the primary caregiver.*

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Whether you are providing support from out of town or acting as a backup when your parent, sibling or friend needs time off, there are many ways you can provide love and support. Stepping into a secondary caregiver role can be a positive and rewarding experience, but it also comes with its own unique challenges. Here are some ways you can be helpful:

- **Call every week.** Set a designated day and time, and make the call faithfully. Inquire about both the person with Parkinson's 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 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 financial support no matter how dire the situation. Inquire tactfully 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 or pay for 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 or a gift card to buy something just for them. Be creative.
- **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. 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. During your visit, remember to ask about the health of the caregiver. Are regular check-ups and screenings being overlooked because of caregiving responsibilities?
- **Provide respite for the primary caregiver.** If you cannot fill in personally, locate other options and offer to cover the cost if possible. There may be free or low-cost services available in the primary caregiver's community. 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 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 rivalries or dwindling inheritances get in the way of doing what is best for the people whose lives are most affected.

NPF launched the CareMAP (Managing Advanced Parkinson's) website to provide practical suggestions for coping with the complex problems that arise as the disease progresses. It is your guide to managing advanced Parkinson's.

For more tips on caregiving, visit [www.caremap.parkinson.org](http://www.caremap.parkinson.org).