

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