

Primary Caregiving from Afar

Many primary long-distance caregivers enter into this relationship because their loved ones do not want to leave their home or environment. This is understandable. But Parkinson's is a progressive, degenerative illness. At some point, your loved one may need in-home care or relocation to an assisted living or skilled nursing facility.

Unless you are able to make frequent visits, have friends or other relatives who can visit often and report back to you or have the finances to hire a geriatric care manager, you may need to move the person with Parkinson's closer to you to assure that he or she receives consistent and adequate care. Since travel can become more difficult as the disease progresses, a move should be discussed sooner rather than later.

If the person lives alone, consider daily well-being calls or checks by a neighbor. The call should be set for a specific time every day when the person is most likely to be home. If there is a neighbor that is willing to do so, you can alternate calls and visits. You might also want to consider an emergency alert system, especially since falls are so prevalent in advancing Parkinson's.

Educate Yourself

Learn all about Parkinson's, including motor and non-motor symptoms, the drugs used to treat the disease and other available forms of treatment. You must be well-versed in the needs and functional status of the person with Parkinson's. You may wish to hire a geriatric care manager to conduct a functional assessment every six months. These assessments determine how well the individual is able to perform activities of daily living such as bathing and dressing and instrumental activities of daily living such as taking medications properly and preparing meals.

Learn about your loved one's general health and all medications taken including dosages, regimes and possible side effects. Keep a list of your loved one's doctors, specialists, pharmacist, care providers and neighbors along with contact information. Keep all financial and legal documents easily accessible and make sure bills are paid in a timely manner. Parkinson's disease and some of the medications used to treat it can result in compulsive behaviors. Try to find a discrete way to monitor any gambling activities as well as excessive spending or eating.

Keep in Touch

If for whatever reason you cannot move your loved one closer to you, communicate regularly with the person with Parkinson's and his or her local care providers, whether that means an in-home aide or the staff at a care facility. If your loved one's needs change, you need to know what that will mean for him or her – more skilled in-home care, visits with a different medical specialist, additional prescriptions, new diet regimens – as well as what it will mean for you – more visits, higher costs for care, etc. You can help assess changing needs during each visit.

Work with a Geriatric Care Manager

A geriatric care manager can provide a number of useful services for a fee. These services include regular wellbeing checks, ongoing communication with family members and arranging financial, legal and medical services, in-home care providers and transportation. Fees vary depending on what services are needed. You should personally interview the prospective care manager, ideally during one of your visits, before engaging his or her services.

The Aging Life Care Association offers a Certified Geriatric Care Manager designation to those who have been certified by one of three certifying bodies and who have completed the Association's necessary education and work experience requirements. Make sure to obtain proof of certification before hiring someone.

Be Kind to Yourself

Caregiving from a distance can be emotionally taxing, so make sure you have a support system in place.

Visit the "Caring for You" section at [Parkinson.org/caregivers](https://www.parkinson.org/caregivers) to find tips and tools for self-care.

COMMUNICATION TIPS

- » Make sure the person with Parkinson's has **signed the necessary forms** with all of the medical personnel providing care.
- » **Include other topics in your conversation** with your loved one so that every call is not always just about Parkinson's.
- » **Remember to show appreciation often** to everyone involved in the care of the person with Parkinson's – neighbors, volunteers, friends and paid personnel.
- » **If moving your loved one closer is an eventual goal, start talking about this early and gently.** It is always preferable to reach a mutual agreement rather than imposing your will.
- » **Try to offer care solutions that provide as much autonomy as possible.** Remember that a mentally competent adult has the right to make choices for himself or herself as long as those choices do not put others at risk. This ability to make choices comes with responsibility for the consequences of those choices.